

**Understanding resistance to childhood vaccination in  
the UK: Radicals, Reformists and the discourses of  
risk, trust and science**

**Pru Hobson-West, M.A. Hons.**

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## Abstract

Vaccination is regarded by the medical profession as one of the greatest public health success stories, and recent opposition, for example over the MMR (measles, mumps and rubella) vaccine, as a failure of understanding. Relatively little social scientific analysis exists on vaccination opposition. However, risk, trust and science are dominant themes within literature on public resistance to technology, and in contemporary theories such as risk society. This thesis therefore evaluates the relevance of these themes for an understanding of vaccination resistance in the UK. The empirical research primarily involves a discourse analysis of interview, document and website data generated from ten parental organisations, established to campaign against aspects of vaccination policy. The study defines these organisations as ‘Vaccine Critical groups’ and further classifies them into Radical and Reformist categories.

In contrast to smallpox vaccination in nineteenth century England, vaccination is no longer compulsory in the UK. Nevertheless, from a governmentality perspective, the individual is still subjected to, what can be termed, the ‘imperative of vaccination’. This thesis argues that the Vaccine Critical groups resist this imperative: first, by reframing risk as unknown, non-objective and individual specific; second, by demonstrating an ambivalent relationship with science; and third, by challenging faith in professional expertise and constructing the parent as the potential vaccine expert. These discourses create another type of moral imperative, which actually conforms to developments in the new public health that are encouraged by the state and the medical profession.

The findings demonstrate the limits of a realist approach to risk, challenge existing theories of risk society and complicate assumptions about a public crisis of trust in expertise or science. Policy implications include the need to engage with vaccine resisters and their critical discourses, and to reassess the value of risk communication strategies.

# Chapter 1: Introduction

Under the heading ‘the benefits of immunization’, a World Health Organisation fact-sheet claims that vaccines are ‘widely and routinely administered around the world based on the common-sense principle that it is better to keep people from falling ill than to treat them once they are ill. Suffering, disability, and death are avoided’ (WHO, 2005). Using similarly positive language, the UK Department of Health argues that ‘With safe, effective vaccines, lives are saved and the risks of serious illness are reduced’ (Department of Health, 2005). Given this image of vaccines as safe, effective and justified by ‘common-sense’ thinking, why would anyone resist the use of vaccine technology? This research started with the puzzle of resistance to vaccination policies.

The thesis investigates the arguments of organised groups that have been set up to campaign against, or challenge aspects of, current childhood vaccination policy. The title of the thesis is ‘*Understanding resistance to childhood vaccination in the UK: Radicals, Reformists and the discourses of risk, trust and science*’. This introductory chapter clarifies the meaning of the title, justifies why a greater understanding is necessary, spells out the main research questions, and explains the structure of the thesis. The main argument is that vaccination resistance involves a reframing of risk, a challenge to faith in professional expertise, and demonstrates ambivalence about the role of science in society.

## **Mass childhood vaccination in the UK**

For the public health profession, vaccination is regarded as a ‘a cornerstone of preventive medicine’ (Streefland 2001) and ‘one of the greatest public health success stories’ (Poland and Jacobson 2001). It is widely claimed to be responsible for a dramatic decline in morbidity and mortality from infectious disease. The aim of *mass* vaccination is to achieve high population uptake in order to promote herd immunity. Herd immunity is defined as a situation where disease circulation is blocked, thus protecting all in the community, including those who are not fully immune (McGuire,

1998). Vaccination in the UK<sup>1</sup> is organised by the state and administered and supported by the medical profession.

Vaccination against smallpox was compulsory in England in the nineteenth century, and dissenters could be fined or even imprisoned (McGuire, 1998). Although vaccination in the UK has not been subject to this type of state sanction since the early twentieth century, this thesis argues that the individual is still subjected to a wider ‘imperative of vaccination’. Building on the work of Foucault, Lupton (1994; 1995) uses the notion of the ‘imperative of health’ to discuss historical and contemporary public health. As chapter four argues, this approach can be adapted in order to identify an imperative of vaccination. This imperative is created and articulated through a combination of mechanisms and social relationships. Vaccination continues to represent an important symbol of success, and hope, for modern science. In turn, science is the system of knowledge used to justify and legitimate vaccination policy. As the primary language of health promotion, risk is also a crucial part of the imperative of vaccination: risk constructs vaccination as the normal and rational behaviour for the ‘good parent’. And finally, vaccination relies heavily on the relationship between individuals and professional experts and expertise, namely on relationships between the doctor and the patient, and the citizen and the state. These relationships are partially built on notions of trust. Trust and expertise therefore form part of the social context in which vaccination takes place. The themes of risk, trust and science constitute the framework used to examine both vaccination and vaccination resistance.

This study looks at *childhood* vaccination, as opposed to vaccination in general, for three main reasons. First, some mechanism was needed to focus the project in order to promote a more in-depth understanding and analysis. Second, childhood vaccination<sup>2</sup> is a good example of mass vaccination, a strategy of vaccination which arguably throws up a greater number of social, ethical and political issues than, for example, travel

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<sup>1</sup> The thesis is specifically concerned with vaccination and vaccination resistance in the UK. As stressed in chapters three and eight, this means that the findings cannot be generalised internationally without further research. It is recognised that the context of vaccination in developing countries is significantly different, in terms of mortality, access issues and uptake rates. For an example of social scientific work on vaccination in a developing country see Birungi, 2002.

<sup>2</sup> It is recognised that vaccinating children and babies, as opposed to adults, also carries with it additional social and ethical issues. Literature on the sociology of childhood sees the way childhood is constructed as a category (meaning, for example, innocence and vulnerability) as significant (see Murcott, 1980). In order to concentrate on other aspects, this thesis has not looked at vaccination from this perspective.

vaccines. As is discussed in chapter four, this is partly due to the fact that the state has a greater involvement and investment in mass vaccination strategies. And finally, preliminary literature review and monitoring of news reports confirmed that childhood vaccines are most associated with public controversy. In particular, the measles, mumps and rubella (MMR) vaccine has come to dominate recent media debate on vaccination in the UK. Public concern with the MMR vaccine is often assumed to be a response to the publication of a paper by Wakefield and colleagues (1998), which suggested the possibility of a link between MMR and forms of bowel disease and autism. Despite statements in support of MMR from the Royal Colleges and the Chief Medical Officer, episodes of intense media coverage continued throughout the study period, 2001-2005. At times, this looked like the public humiliation of the leaders of the medical profession (Dingwall and Hobson-West, forthcoming). Focussing on resistance to childhood vaccination thus enables this debate to be captured, although MMR is not the primary concern of this research.

The term 'vaccination', rather than 'immunisation', is adopted throughout the thesis. Strictly speaking, vaccination and immunisation refer to different procedures - the former originally referred only to the smallpox vaccine. In this sense, immunisation is more accurate in referring to the current recommended schedule which includes vaccines against several diseases. However, in everyday usage, and, according to the Health Protection Agency, 'vaccination is now used to refer to all procedures for immunisation' (HPA, undated). Some critics of vaccination argue that given vaccines do not necessarily create full immunity in all individuals, the term immunisation is misleading and vaccination is more neutral. For these reasons this thesis uses the term 'vaccine' to refer to the technology and 'vaccination' to refer to the process of receiving a vaccine and the policy that surrounds the technology.

### **Vaccination resistance in the UK**

As already argued, the existence of public concern or outright opposition to vaccination has been regarded as a public health puzzle, given the scientific evidence for the success of vaccination strategies. For those who manage and promote vaccination, resistance is not only regarded as puzzling but also potentially dangerous, in threatening herd

immunity<sup>3</sup>. In general, mass vaccination in the UK is characterised by high levels of uptake (Department of Health, 2004c). However, even relatively low levels of resistance or non-compliance are treated as extremely serious. The aim of this research is to contribute to a greater understanding of the discursive ways in which childhood vaccination is currently resisted.

Chapter two argues that the term ‘resistance’ carries many different connotations. Following Streefland (2001), the phrase ‘vaccination resistance’ is used in a specific way to mean organised, collective opposition, as opposed to individual refusal. In his book on resistance to new technology, Bauer identifies individual and collective resistance as a key distinction in the literature (Bauer, 1995a, p16). Resistance is also helpful in carrying connotations of ‘active’, as opposed to passive or unintentional action. More theoretically, resistance carries Foucauldian overtones. These overtones are appropriate, given the governmentality approach used in order to identify an imperative of vaccination. The term vaccination resistance was therefore chosen as the best way of capturing the empirical focus of the research which is on deliberate, organised opposition. This thesis defines vaccination resistance as groups set up specifically to campaign about childhood vaccines, or groups who spend a significant amount of time dealing with the issue of childhood vaccination and adopt a critical perspective.

Organised resistance to vaccination was identified as the empirical focus of the research for several reasons. The literature review in chapter four reveals very little research on public attitudes to vaccination in general, but even less reference to organised groups of opposition. This focus therefore is empirically original. Preliminary research also confirmed that the leaders of oppositional groups are used by journalists as spokespeople for a critical point of view. In addition, several of the groups have their own websites. The implication is that the public are exposed to the views of the groups: an understanding of the reasons for vaccine resistance may therefore potentially be useful for gaining a greater understanding of parental attitudes to vaccination in general. This is of great importance for public health disciplines and those who are concerned with promoting and maintaining public support for vaccination. For the social sciences,

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<sup>3</sup> Herd immunity refers to the situation where a high vaccination coverage can reduce the overall circulation of disease in the community. This concept is discussed further in chapter four.

a study of vaccination resistance represents a contemporary case study which can contribute to broad debates about public resistance to technology and expert advice.

### **Social scientific understandings of resistance to technology**

Literature searches on contemporary resistance to vaccination uncovered very little existing research. Wider social scientific literatures which aim to understand public opposition to technology were therefore accessed. Three primary themes were identified that are central to existing accounts: risk, trust and science. These ideas were then applied to vaccination and used as a framework to deconstruct the imperative of vaccination.

Risk has undoubtedly become an important topic within social science. Debates have been given added fuel since the publication of work by Ulrich Beck (1992) on risk society. For Beck and his many followers, risk is one of the key motifs of contemporary social life which, rather than being organised around the production and distribution of goods, is now said to be about bads or ‘risks’. In terms of resistance to technology, theories of risk perception have been widely adopted by different disciplines to explain why attitudes or responses are not always in line with risk advice and information. More and more complex explanations are offered to explain the difference between actual risk and risk perception (e.g Spier, 2001; Slovic, 2002). As will be explained in chapter two, these explanations have been challenged on several grounds by those adopting more social constructionist approaches (e.g. Lupton, 1999; Wynne, 1992).

Although the idea of trust is visible in the classic political philosophical texts (Miztal, 1996), the concept has received more direct and widespread attention within social science in the past few decades. In part this is down to the development of the notion of a ‘crisis of trust’ which, like risk society, is an attempt to capture something new about contemporary social relationships. The literature review reveals that there are serious problems with attempts to measure trust (O’Neill, 2002; O’Hara 2004) and demonstrates that there is a lack of clarity when talking about different types of trust.

And finally, science and technology are also arguably now subject to a greater degree of sustained sociological analysis. This can be linked to the theoretical and empirical work

carried out under the broad headings of science and technology studies and the sociology of scientific knowledge, areas of study that attempt to open the ‘black box’ of science and technology (e.g. Sismondo, 2004). More specifically, social science has attempted to investigate public attitudes to science and technology and much work has been associated with trying to make links between understanding of science and attitudes or behaviour.

The purpose of reviewing these literatures is to investigate the existing explanations that aim to account for public opposition to technology and identify those that can be usefully applied to an understanding of vaccination resistance. The literature review in chapter two confirms the importance of risk, trust and science as themes by which to investigate contemporary social life. These three broad concepts are then taken forward as a framework for the interrogation of the data.

### **Research questions, design and process**

This research did not start from a definite hypothesis to be empirically tested, and nor did it proceed via the adoption of a particular theoretical perspective. The relevance of a Foucauldian perspective was thus not decided upon at the start. Rather, the research design gradually developed in response to the critical observation of vaccination resistance as a significant but under-researched social phenomenon. The approach is therefore more inductive than deductive.

The thesis is guided by an over-arching question:

- *How is resistance to childhood vaccination best understood?*

This is then operationalised into two more specific research questions:

- *How is resistance to childhood vaccination organised in the UK?*
- *How do discourses of risk, trust and science contribute to an understanding of vaccination resistance in the UK?*

The decision to concentrate on organised resistance reflects the ontological assumption that institutions and other organisations are key components of the social reality and that, epistemologically, knowledge is structured through discourses. In-depth qualitative interviews were planned using an interview schedule (see appendix 4), designed with sufficient flexibility to ensure that informants had enough time and space to discuss vaccination in their own terms. This design was partially informed by critical reflections on the literature review, including claims about the unsuitability of more quantitative methods for investigating knowledge and understanding, and in particular by the arguments of the PABE report on ‘Public perceptions of Agricultural Biotechnology in Europe’ (Marris *et al*, 2001).

Representatives of 30 organisations were approached and 23 interviews conducted. Full analysis was carried out on 10 of the critical organisations, in order to achieve a sufficiently detailed level of investigation. (This strategic decision is discussed and justified in chapter three.) A form of discourse analysis was used to analyse the interview transcripts, and on other data generated from document and website searches. Through this analysis, the category ‘Vaccine Critical group’ was developed and the sub-categories of ‘Radical’ and ‘Reformist’ were constructed in order to better differentiate between the groups. This categorisation is new and is presented as an advance in understanding of the nature of vaccination resistance, and an important contribution to the limited amount of existing literature.

### **The structure of the thesis**

Following on from this introduction, chapter two begins by suggesting the competing ways in which resistance in general can be theorised. A social constructionist, and Foucauldian perspective in particular, is shown to have advantages for this type of research. The primary aim of the chapter, however, is to review the existing literature (of all perspectives) which sees risk, trust and science as important themes for understanding public resistance to technology. The chapter also discusses the major social scientific debates that utilise these concepts to understand social relations in late capitalist society. In summary, empirical and theoretical work problematises the assumption that public resistance to technology or expert advice represents a failure of

risk perception which needs to be 'corrected'. Some evidence does exist for a crisis of public trust in the institutions of medicine, politics and science. However, such conclusions are challenged on methodological and other grounds. The literature also demonstrates that despite significant social and cultural changes brought about by technological advances, examples of resistance to technology are not necessarily explicable as anti-science or a misunderstanding of science. This literature review provides the conceptual tools that are used to construct the second research question: *How do discourses of risk, trust and science contribute to an understanding of vaccination resistance in the UK?* Overall, the chapter demonstrates that resistance must be subject to detailed empirical investigation.

Chapter three explains how this detailed empirical investigation was carried out. The chapter is written as a kind of political history of the research by justifying the strategic decisions required at each stage of planning, process and analysis. These decisions are related to broader debates in the methodological literature. In addition, the discussion also includes a more critical, reflexive analysis of the unanticipated aspects of the research. These include the role of emotion in the interview encounter (Bondi 2003; Bondi, forthcoming) and the ethical decisions involved in publication (Murphy and Dingwall, 2001). Limitations of the research, and issues of generalisability are addressed. The primary limitation is the inability automatically to extend the findings on resistance to an understanding of individual vaccination refusal. In terms of the research questions, the contribution of the chapter is in demonstrating how the empirical work helps an understanding of the nature and organisation of contemporary resistance to vaccination.

The fourth chapter on vaccination and vaccination resistance fulfils a variety of functions and uses a combination of existing literature and new empirical data. The main elements of vaccination in the UK are introduced by focusing on the position of the parent, the medical profession, and the role of the state in relation to vaccination and public health. A more critical perspective, which sees an imperative of vaccination is explained and defended. The chapter discusses historical opposition to the smallpox vaccine, as well as the more contemporary examples of controversy over DTP (Diphtheria, Tetanus and Pertussis) in the 1970s and MMR from 1990s. The chapter demonstrates the relative lack of published literature on the topic of vaccination

resistance but identifies the main themes within the small amount of existing research and commentary. Finally, empirical data are used to provide a focussed introduction to the groups under study. Following Eyerman and Jamison (1991), the main organisational, strategic and cognitive aspects of the Vaccine Critical groups are discussed. Preliminary analysis of the data on these aspects is achieved through links made to existing studies. In doing so, the chapter begins to answer the first research question: *How is resistance to childhood vaccination organised in the UK?*

Chapters five to seven form the core empirical chapters of the thesis and present the data that deals with risk, trust and science respectively. These chapters demonstrate what relevance these themes have for an understanding of vaccination resistance. What is revealed is the way that the groups use different kinds of claims and examples that challenge the standard success narrative of mass childhood vaccination and resist the imperative of vaccination. Chapter five demonstrates that the groups do not engage in direct 'risk talk' but instead reframe risk as not objective, neutral or reliable. Discourses of unknowns are particularly important, as anticipated by Wynne (1992). Risk is constructed as individual specific: ironically, this conforms to, rather than resists, developments in what Lupton refers to as the 'new public health' approach (Lupton, 1995; Peterson and Lupton, 1996).

Chapter six shows how trust in those who provide and promote mass vaccination is undermined. This is achieved through identifying a systemic conflict of interest, identifying instances of spin and secrecy, and by highlighting past policy mistakes. Faith or deference to professional expertise is constructed in highly negative terms and contrasted with personal responsibility and empowerment. This discourse bears similarity with the Department of Health's (2001) vision of the expert patient. The empirical research also confirms the multifaceted nature of the concept of trust (Bennett, 1999).

Chapter seven discusses science, technology and medicine and demonstrates significant differences between Reformist and Radical discourses. The former is concerned with the direction and type of science in relation to vaccination but exemplifies continued belief in science (cf. Epstein, 1996). The latter provides a deeper critique of the relationship between science and progress. Surprisingly, a minority of the Vaccine

Critical groups are also engaged in the production of new 'evidence' in relation to the health impacts of childhood vaccination. Following Brown, this is best analysed as popular epidemiology (Brown, 1995). In contrast to a strong critique of medicine, overall the data suggests a high degree of ambivalence in relation to science.

The concluding chapter brings together all previous elements to answer the two main research questions. The organisation of vaccination resistance is explained and the usefulness of the distinction between Radical and Reformist groups is reassessed. The role of discourses related to risk, trust and science in contributing to vaccination resistance is clarified. Finally, wider theoretical and policy related implications are drawn out.

## **Chapter 2: Understanding resistance to technology: the role of risk, trust and science**

Researching resistance to childhood vaccination provides an opportunity to consider, and contribute to, some of the key debates in contemporary social science. The introductory chapter explained the research questions that guide the thesis. As will be demonstrated in chapter four, very little empirical research on vaccination resistance exists. A wide range of social scientific literature was therefore accessed in order to analyse how public resistance to technology, or resistance to expert advice associated with technology, has been previously understood. This literature relies heavily on three themes: *risk*, *trust* and *science*. As this chapter demonstrates, these themes are used to explain specific examples of resistance, such as public scepticism about GM (Genetically Modified) food, but are also used in theoretical attempts to capture what is new about contemporary social relations. In later chapters, risk, trust and science are combined to form a conceptual framework which is used to interrogate the empirical data on vaccination resistance.

The discussion begins with a concise introduction to competing theoretical traditions in relation to power and resistance. Lupton's (1995) Foucauldian perspective is helpful in providing a multidimensional, diffuse view of power. In particular, Lupton's critical discussion of the discourses and practices of public health as an 'imperative of health' is used later as a basis on which to argue for a new concept of the 'imperative of vaccination'. This is discussed in chapter four and sets up the remaining chapters which aim to investigate empirically whether, and in what ways, this imperative is resisted.

### **THEORISING RESISTANCE**

The term 'resistance' is used in many different contexts and carries contradictory associations. In his discussion of resistance to new technology, Martin Bauer demonstrates that the term often carries positive connotations. In moral philosophy resistance retains a kind of moral dignity. In the 20<sup>th</sup> century, resistance carries an aura of heroism associated with resistance struggles against the forces of totalitarianism and

colonialism. In contrast, resistance is also associated with opposition to modernisation: a managerial and technocratic discourse constructs resistance as a structural or personal deficit. In this account, 'resistance is irrational, morally bad, or at best understandable but futile' (Bauer, 1995a, p2).

Different views of resistance depend on competing understandings of power. In the field of sociology of health and medicine, for example, Lupton has defined three dominant perspectives. The choice of perspective tends to influence what type of research is carried out. A functionalist perspective builds on Parsons classic work on the sick role. Parsons conceptualised ill health as 'deviance', given that the consequence of illness is that the individual cannot fulfil their social roles. To ensure the functioning of society, the patient is therefore obliged to get better and return to normality, using medical help. This perspective has been criticised for assuming a 'harmonious and consensual' model of society and the doctor-patient relationship. According to this model, resistance to expert medical advice would be regarded in negative terms as 'malingering' and a failure to conform to the sick role (Lupton, 1994, p7). Research in this tradition tends to assume the need for compliance and is directed towards investigating how the doctor can do their job more efficiently (Lupton, 1994, p107).

In contrast, a political economic perspective has conflict at its heart. This Marxist inspired approach analyses the institution of medicine in far more critical terms. There are several different strands to this critique, some focusing on processes such as medicalisation and the increasing power of medicine (see Zola 1981 cited in Lupton, 1994, p8), and others on the failure of medicine to recognise the socio-economic causes of ill-health. Some of these issues will be returned to later in the chapter when the question of trust in the relationship between patient and doctor is discussed. For present purposes, what is important is the way this approach is criticised for failing to question the 'neutrality and objective validity of medicine itself' (Lupton, 1994, p10). In addition, some proponents of this approach see mass social movement as the only possible way of resisting dependency on medicine (Lupton, 1994, p9-10). For others, this remains an unrealistic view of resistance.

Lupton herself is committed to the third approach, namely social constructionism, and, in particular, a governmentality perspective inspired by Foucault (Lupton, 1994;

Lupton, 1995; Peterson and Lupton, 1996). This approach sees knowledge and power as closely related and all knowledge, including medical, as the result of social processes that are subject to change. In this model, power is not necessarily wielded from above or from powerful institutions but is more diffuse and is productive as well as repressive, operating through gratification as well as punishment. Power is therefore decentralised and individuals play an active role in self-governance. Foucault called this power 'disciplinary power', a form of surveillance which is internalised.

In considering modern public health, Lupton builds on Foucault's notion of the 'imperative of health' (Foucault, 1984, p277 cited in Lupton, 1995, p1). The imperative implies that health is not simply the existence or absence of disease but is also a moral category. The individual is expected to follow medical expert advice and maintain health, 'for the sake of their own interests' (Lupton, 1995, p9). Lupton argues: 'It is clear that public health and health promotion may be conceptualized as governmental apparatuses. The institution of public health has served as a network of expert advice, embodied in professionals such as doctors and health promoters, who have dispensed wisdom directed at improving individuals' health through self regulation' (Lupton, 1995, p10). Crucially, these expert knowledges 'serve to channel or constrain thinking and action' (Peterson and Lupton, 1996, pxii). However, expert advice is unlikely to be seen as coercive because it appeals to the shared value of health.

For the researcher interested in resistance to technology or to expert advice from this perspective, part of the task is to make this diffuse power visible, and to describe the processes by which subjects are controlled and disciplined, without assuming that technology is 'benign' or separate from these processes. This perspective tries to explain the complex ways in which moral categories such as 'non-compliant' are created and maintained (Dew, 1999, p384). A constructionist governmentality perspective is also useful in allowing the researcher to apply the same type of critical analysis to expert knowledge, as to examples of lay opposition or resistance.

Whilst a full review of this perspective is beyond the scope of the chapter it is recognised that the Foucauldian view of resistance is not without its critics. McNay, for example, criticises Foucault's early work for conceptualising the individual body as docile: If power is everywhere and diffuse then it becomes hard to dislodge. Although

Foucault's later work was more concerned with how individuals can practically resist the effects of power through 'techniques of the self', McNay still criticises Foucault for failing to elaborate on resistance in practice and for an insufficient recognition of the wider socio-cultural influences on the individual (cited in Annandale, 1998, p39-41). Dew, in contrast, found Foucault's approach attractive in implying that wherever there are new forms of power there will also be new forms of resistance (Dew, 1999, p387).

This research on vaccination resistance is not primarily designed to evaluate these different approaches to resistance. As will be explained in chapter three, the usefulness or otherwise of a governmentality perspective was not decided upon in advance of the empirical stage of the project. However, this brief discussion introduces and theoretically situates the concept of the imperative for health, a concept that is returned to in chapter four, in order to provide a critical reading of vaccination policy and practice. This chapter now moves on to consider the wider theoretical and empirical literature that is relevant for an understanding of public resistance to technology or expert advice. These literatures were found to rely heavily on the themes of risk, trust and science. These themes are used to structure the rest of the chapter. How each theme relates to resistance is clarified at the end of each section.

## **RISK**

In a recent review, Lupton argues that the meaning of risk has evolved over the centuries. In the pre-modern period the term was associated with acts of God or nature, over which humans had no control. The modernist conception of risk, in contrast, assumes that risk can also be the consequence of human action. Modernity and Enlightenment thought rely on the notion that science, rationality, probability and statistics can be used to bring disorder under control (Lupton, 1999, p5-6). Luhmann has identified this shift semantically, from cosmology to technology (Luhmann, 2000, p96). Risk is now used to refer to the mathematical probability of something bad happening, but is also used simply to refer to the hazard itself.

The literature using the concept of risk or about risk is vast. This review therefore concentrates on two major contributions within social science that are most relevant for

an understanding of risk, health and resistance. The first is the distinction between realist and constructionist approaches and the second is the identification of risk as one of the key principles of late-capitalist society. These contributions are now reviewed, in order to lay the groundwork for an articulation of the relationship between risk and resistance.

### **Realist accounts of risk**

Realist understandings of risk are dominant in scientific and technical approaches, such as epidemiology. The risk of certain events is measured and compared with the risk and benefits of other courses of action. Realist assumptions are also influential in theory and research in psychology and other social sciences in the form of the ‘cognitive science’ approach (Lupton, 1999). This approach is primarily concerned with offering explanations of how humans respond to risk, both cognitively and behaviourally. Much of the work aims to explain the difference between the ‘actual’, ‘objective’ or ‘real’ risk, and the ‘perceived’ or ‘subjective’ risk. Martin Bauer summarises this approach critically; ‘empirical risks (objective risks) are compared with perceived risks and deviations between the two are diagnosed as deficits in non-expert reasoning’ (Bauer, 1995b, p396). Reference to ‘deficits’ in reasoning alludes to the deficit model of the public understanding of science, which is discussed later in the chapter.

In the realist view, risk communication refers to the last stage in the process and follows the identification of a hazard, assessment of risk, and risk management. This traditional model assumes a rational actor who is expected to respond to risk communication messages and alter behaviour to avoid or minimise risk. However, the recognition that the public do not always respond ‘rationally’ has led to detailed and increasingly complex attempts to explain the factors that contribute to risk perception. For example, research in the so-called ‘psychometric’ tradition (Bennett, 1999, p6) has identified ‘media triggers’ and ‘fright factors’ (see also Spier, 2001) which explain why risk perception is ‘amplified’ in certain circumstances (Pidgeon *et al*, 2003). This perspective predicts that events or technologies will cause more anxiety and a heightened view of risk if the individual does not have control of the outcome, if damage is potentially long term or fatal, or if the risk affects the vulnerable, such as children or pregnant women. Such observations also contribute to the ‘health belief

model' which dominates ideas about risk perception in health promotion (Lupton, 1999, p21).

Problems or limitations with the psychometric paradigm have become widely recognised and discussed in recent years. For example, there are methodological problems with measuring risk perception. This is because, as Lynn Frewer summarises, 'the results are dependent upon the set of hazards studied, the questions asked about these hazards, the types of persons questioned, and the data analysis methods' (Frewer, 1999, p20). These methodological concerns, and how they impact on the design of this research project, will be returned to in the following chapter.

A more recent development within psychology which aims to advance approaches to risk perception has been to focus on how emotion or *affect* impacts on decision-making (e.g. see Slovic *et al*, 2002). Such a focus may initially be welcomed by some critics as a move away from a rational-actor model of behaviour and decision-making. Considering the role of emotion could be claimed to represent a shift to focus on the social, in the sense that emotions are partially socially determined. Work that uses the social amplification of risk framework (Kasperson *et al* cited in Pidgeon *et al* 1999, p65) also represents an attempt to combine social, institutional and cultural (as well as individual and psychological) factors. However, from a more constructionist perspective, such work can still be criticised for assuming a fundamental difference between real or objective and perceived risk. To talk about affect, therefore, is just to 'add-on' yet another factor for explaining the deviation between risk and risk perception.

Assuming that there is a distinction between actual and perceived risk, the task for health promotion is to investigate the various factors that contribute to risk perception, so that information campaigns can be targeted more effectively. These information campaigns can then hopefully correct the 'misperception'. A more nuanced argument has been made by Bennett in relation to risk perception and health. Rather than claiming a public misperception, Bennett claims that there are differences between lay and scientific perspectives on risk but that these are explicable by the fact that scientists usually define risk in terms of the population whereas the lay audience is concerned with effects on individuals (Bennett, 1999, p14). This has particular relevance for later

discussion of public health and vaccination, and the relationship between individual and social risks and benefits.

Before moving on to more constructionist approaches, it should be clarified that not all academic reference to 'risk perception' necessarily means that the deficit model has been uncritically adopted or that perceptions are seen as in need of correction. For example, some authors argue for the complexity of lay risk perception, stressing that it is not explicable by reference to tables of fright factors or rules of thumb. Researchers at the University of East Anglia put this elegantly; 'risk perception is a collage of outlooks, predispositions, relationships, and structures all relating to each other in complex ways, like stars in a rotating galaxy' (Langford *et al*, 1999). Others have discussed the difference between lay and expert risk perception, not to bemoan a public misperception, but in order to demonstrate that 'it is less a case of misunderstanding, as of understanding and reacting to information in a different, but no less valid, way' (Green *et al.*, 1999, p52). This is part of wider debate which remains very active, particularly within medical sociology, about the difference between lay and professional expertise (e.g. Stacey, 1994; Shaw, 2002). Nevertheless, the way that the term 'perception' is often used in relation to risk still does carry associations with psychometric realist approaches.

### **Social constructionist accounts of risk**

The so-called constructionist turn in social science is visible in theories of risk<sup>1</sup>. Alternative accounts of risk vary in the extent to which they embrace a weak or strong version of constructionism. Broadly speaking, however, social constructionist approaches stress the social and cultural context of risk, and also the constructed nature of risk itself. The contention is that risk is not an objective fact that is out there and waiting to be measured by science. Rather, 'what we measure, identify and manage as risks are always constituted via pre-existing knowledges and discourses' (Lupton, 1999, p29). What follows from this argument is that expert risk judgements are socially constructed, just as lay ones are, and that knowledge, even scientific or medical knowledge, is therefore always partial or incomplete. To draw a distinction between real

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<sup>1</sup> This is not to imply that constructionist approaches are not challenged within social science. Abraham (2002), for example calls for an objectivist realism.

risk and risk perception therefore misses the point. For researchers using a social constructionist approach, the research question is then less about what factors, cognitive or affectual, influence risk perceptions, and more about what types of claims are used to construct particular ideas of risk and about the social consequences of these claims.

Social scientific work that is part of this tradition, or has been adapted by others to support this theoretical position, includes work which focuses on the idea of uncertainty or unknowns. In the realist account, uncertainty and unknowns may well be recognised but are normally framed as temporary phases that are overcome by means of more (scientific) research. In contrast, Brian Wynne, amongst others, has offered a typology of risk which aims to expand on and problematise this framing. He distinguishes between risk (when you know the odds), uncertainty (when you don't know the odds but may know the main parameters of the problem), ignorance (where you don't know what you don't know) and indeterminacy (where causal chains or networks are open) (Wynne, 1992). For the discussion here what is important is the potential to use such distinctions to argue that public concern about a technology, or non-compliance with risk advice, may not be due to a misunderstanding of risk, but rather due to a recognition of inherent uncertainty or ignorance that has not been taken into account in the calculation of risk statistics.

To take an empirical example, recent European research on public attitudes to biotechnology supports the importance of uncertainty. In relation to GM agriculture, the PABE report argues that it is important not to assume to know the meaning of the debate to the public, and not to assume that we are talking about public perception of *risk*. It may be, in fact, more accurate to talk about 'public perception of uncertainty' (Marris *et al.*, 2001, p59). Furthermore, the study found that the denial of inherent uncertainties, especially about long term or chronic impacts, was directly related to a public mistrust of the technology (Marris *et al.*, 2001, p87). Research on GM has also been used to argue for the political nature of risk assessment. Levidow and Carr argue that risk assessment only understands a certain type of evidence, which depends on 'worldviews about nature and society...in seeking and organising more facts about risk, we make socio-political choices' (Levidow and Carr, 2000, p260) and that 'risk debates express contending visions of how society should be organised' (Levidow *et al.*, 2000, p190). The implication of this argument is that resistance to technology or arguments

over risk reflect political or value disagreements or 'clashes of political, moral and aesthetic judgements' (Lupton, 1999). This is very different to the conclusion, encouraged by cognitive science approaches, of the need to explain the psychological reasons for the difference between actual and perceived risk.

Another social constructionist tradition not only challenges the assumption that risks are known and calculable, but also provides a way of questioning the aura of objectivity that surrounds risk. Lupton's governmentality perspective, introduced above in relation to power and resistance, is useful in this regard. Her approach, and other cultural perspectives, are powerful in their capacity for reinterpreting risk. Far from an objective or neutral result of scientific inquiry, risk assessment facilitates 'government at a distance' (Peterson and Lupton, 1996, p19). Risk is therefore a key mechanism which ensures that health promotion is not seen as direct intervention, coercion or punishment by the state. For example, after investigating the public health literature around AIDS in the UK, Tim Brown argues that risk serves to draw the discursive boundary between normal and abnormal behavioural practice, or between normal and 'Other' (Brown, 2000). The impact of this boundary drawing is the stigmatisation of certain groups, the fragmentation of society and the further extension of medical authority into the population. Brown does not focus on resistance but does imply that this was achieved, by resisting stereotyping or deliberately using this for identity purposes. Overall, the implication of adopting a social constructionist perspective is that risk is not objective or neutral but is the result of social and cultural processes. Resistance is therefore likely to represent a critical response to these processes.

Lupton claims that a risk society perspective wavers between a realist and a weak constructionist approach (Lupton, 1999, p28). Whatever its epistemology, this body of literature has undoubtedly had a significant influence on social science. This chapter will now review the more macro perspective on risk attributed to work by Ulrich Beck and Anthony Giddens.

### **Risk in a risk society**

Beck argues that we are currently living in a period of transition from industrial society to 'risk society'. This society is primarily concerned, not with the production and

distribution of goods, but with the regulation and management of bads (risks). For Beck and those who have adopted his thesis, risk is therefore a key principle of modern society, rather than simply one element of it and 'debates and conflicts over risks have begun to dominate public, political and private realms' (Lupton, 1999, p59). There is debate about whether or not the thesis assumes risks have quantitatively increased, but Beck undoubtedly sees a qualitative shift towards risks that are *not* tied to place, class or gender. According to the risk society thesis, the nature of risks has changed so that risks are potentially catastrophic and global, making them both hard to quantify and hard to prevent: 'The ecological and high-tech risks that have upset the public for some years now...have a new quality. In the afflictions they produce they are no longer tied to their place or origin...By their nature they endanger all forms of life on this planet' (Beck, 1992, p22).

One consequence of this supposed transition to risk society and of the difficulty of 'quantifying' risk is that science and traditional experts lose some of their authority. This is explained as resulting from the recognition that all knowledges are open to revision and that science is therefore eternally incomplete (Giddens, 1991). Furthermore, science itself is recognised as having produced some of the risks that we are now struggling to cope with. These risks are therefore seen as 'the side-effects of the quest for dominating nature' (Raman, 2004). Such recognitions about risk are understood by Beck and Giddens as coming about through a process of reflexivity. This process is claimed to go hand in hand with individualization, where traditional norms no longer hold. This results in a considerable amount of anxiety, as 'the individual increasingly stands alone, looking for security in the face of uncertainty and an implosion of knowledge-systems' (Annandale, 1998 p19).

Beck's work on risk society has been subject to much debate and criticism from within sociology and other disciplines. For example, Beck has been criticised for failing to recognise the importance of low level non-catastrophic everyday risks (Cottle, 1998), perhaps due to his over-reliance on nuclear power as an important example of risk in risk society. Beck and Giddens' view of reflexivity has also been criticised for adopting rational actor model assumptions which fail to appreciate the role of habit in explaining decision-making (Lupton, 1999, p120). Other critics argue that Beck plays down the continuing importance of class and gender, and the difficulty of exercising reflexivity in

practice (Lupton, 1999, p113). Wynne in particular is associated with the critique that the risk society thesis focuses too much on expert knowledge and ignores how individuals create their own knowledges, as well as using and responding to expert ones (Wynne, 1996). In doing so, Wynne argues, Beck is guilty of reproducing the lay/expert dichotomy and holding onto an uncritical, realist view of science and knowledge. This results in a one-dimensional understanding of risk (Wynne, 1996, p45). Overall, what these critiques share is the argument that the risk society thesis pays insufficient attention to the ways in which risks are actually experienced and constructed in everyday life.

Such critiques have led to several responses from Beck and Giddens and much lively academic debate. However, the idea of risk society, like risk itself, remains highly influential for social science. For a study of resistance to technology, the most important point to take forward from the risk society thesis is the argument that science and technology act as sources of risk, as well as the mechanisms by which risks are calculated and, ideally, managed. Even more important, perhaps, is what is implied about trust in expertise, a question which will be returned to in the next section.

### **Risk and resistance**

As argued earlier in the chapter, risk communication strategies and studies of risk communication often contain elements of a realist understanding of risk. This approach is associated with the argument that resistance to a technology (or to expert advice related to technology) results from a failure of risk understanding. Whilst increasingly sophisticated research identifies increasingly complex factors affecting risk perceptions, at its root such research still assumes a stark difference between actual risk and risk perception, where the former is calculable and fixed and the latter is variable and determined by social factors. One aim of health promotion, in the realist view, is to correct the misperception. Research in this tradition bears comparison with the functionalist approach to power and resistance as discussed at the start of the chapter, where research into resistance is mainly designed to understand sources of opposition in order to counter them.

Research influenced by a social constructionist approach also sees risk as an important dimension of attitudes and behaviour. However, the advantage of this approach is that public resistance is revealed as a criticism of those who calculate, communicate and seek to manage risk. This criticism may be due to an inability to recognise the importance of uncertainties or unknowns, or may represent disagreements over the assumptions that underlie the processes of risk calculation and management. Despite much social scientific critique, a narrow focus on risk perception continues to exert influence in some academic and policy circles. Beck's risk society thesis was discussed as a macro example of the ascendancy of risk in social science, which assumes that risks are increasingly important in contemporary social life and increasingly difficult to measure and control. This is one explanation for why experts lose some of their authority. The critique of the realist approach to risk has also been directed at the risk society thesis. Overall, however, risk has become an extremely dominant explanatory tool for understanding resistance to technology.

## **TRUST**

Trust is an important concept for a variety of literatures including civil society and social capital (Putman, 2000), democracy and political participation (Warren 1999a), and within medical sociology's consideration of the doctor-patient relationship (e.g. Ogden *et al*, 2002; Jackson *et al*, 2004). This section draws on these literatures where appropriate but structures the discussion around the different definitions of trust that are drawn upon, either explicitly or implicitly. Clarifying the different meanings of trust is a necessary starting point before considering the more macro empirical and theoretical debates about a contemporary 'crisis of public trust'. In terms of the thesis, the overall aim of the section is to reveal the ways in which a lack of trust can be said to account for resistance to technology or expert advice.

### **Multiple understandings of trust**

Trust, like risk, is a term of widespread everyday use. Partly because of this, trust is often talked about as if its meaning is self-evident and fixed. As Frewer and Miles (2003) argue, one of the problems is that trust is often discussed in the academic

literature but rarely defined. At a minimum, what is clear is that trust has several dimensions and a review of the literature reveals fundamental differences over meaning.

In his summary of trust in sociology, Marshall claims that ‘arguably trust is a neglected and underdeveloped notion in sociological analysis’ (Marshall, 1998, p675). Luhmann, himself often cited in relation to trust, claims that ‘trust has never been a topic of mainstream sociology’ (Luhmann, 2000, p94). However, Misztal argues that the idea of trust is often implicit in classic sociological texts and more modern writings. In her chapter on ‘Defining Trust’, several understandings of trust are introduced. These include trust as faith, confidence, exchange, expectation, role performance, co-operation, and gift giving (Misztal, 1996, p12-32). This list is unwieldy as an analytical tool and some of the distinctions can be fairly easily collapsed. In the context of this research, three broad definitions are particularly relevant: trust as *interest promotion*, trust as *role performance* and trust as *faith*.

Trust is firstly defined as an expectation that interests will be promoted. In other words, this assumes that I trust another person to both know what my interests are and to promote them. On this model of trust, resistance to technology could be a result of a perceived conflict of interest in those individuals or institutions who are promoting or managing the technology. The idea of interest promotion is implicit in classic debates about the meaning of political representation, for example, about whether representation is about the voter’s interests or the public interests (see Birch, 1993, p69). Lack of trust in this context is usefully understood as a failure of representation. One critique of this reading of trust comes from those who suggest that trust is a moral concept (Mansbridge, 1999). Such an argument dates back to Weber (Stevenson *et al*, 2002) and contradicts the idea of trust as purely interest driven. The implication of this argument is that resistance to advice or a lack of trust should also be understood as a moral, as well as a ‘rational’ judgement.

Trust as interest promotion can be analysed as one dimension of a broader issue of *role performance*, where the individual is trusted to carry out their duty (Barber 1983 cited in Misztal, 1996, p23). This definition of trust is drawn from Barber’s influential understanding of trust as expectation (Barber, 1983 cited in Misztal, 1996, p23). Depending on what individual or institution one is referring to, part of the criteria for

satisfactory role performance may include the demonstration of objectivity, openness and independence. Where this is seen to be lacking, trust is withheld. This definition helps explain why past mistakes, or events considered to represent a failure, undermine present and future trust, as the fulfilment of expected role is disrupted. For example, in the case of public attitudes to GM, 'failure to acknowledge past errors and learn from past mistakes' was identified as related to public mistrust in health policy-makers (Marris *et al.*, 2001, p87). The BSE affair is often quoted in this regard as the most important 'trigger' for a decline in public trust in government advice in the UK, a hypothesis that will be critically discussed below.

The third definition sees trust as involving a kind of *leap of faith*. This understanding has been credited to Simmel and is developed more recently by Möllering (Brownlie and Howson, 2005). This leap may itself be defined as a risk, and suffers the negative associations of the idea of 'blind faith'. However, Luhmann and others who share a functional view of trust define faith as positive and rational in allowing individuals to cope with complexity (cited in Misztal, 1996, p95), by deferring to someone else (usually an expert) who has assimilated the knowledge and weighed up the arguments. Indeed, Giddens has argued that this kind of trust is absolutely vital for our psychological or ontological security (Lupton, 1999, p78) in enabling us to deal with the panoply of risks in modernity that would otherwise paralyse us.

Implicit in the idea of faith is that trust is placed in another individual because of another attribute – for example medical training or professional status (see the discussion of medicine taking by Stevenson and colleagues, 2002). This suggests that faith is often encouraged by the demonstration of competence. However, this assumption is complicated by O'Hara's critique of the standard model of trust. Instead of assuming that trust is bestowed after careful monitoring of behaviour, as is assumed by the rational actor model, O'Hara asks whether in some instances trust is better understood as a *cause* of good behaviour rather than the *outcome* of trustworthy actions (O'Hara, 2004, p268). In other words, is trust the result of satisfactory role performance or is trust a pre-requisite for it? Recent work on biotechnology by Brown and Michael (2002) also moves beyond the idea of competence to suggest that in contemporary society, trust is encouraged by the demonstration of authenticity (and the 'performance

of suffering') rather than authority derived from knowledge. More broadly this is characterised as a shift from a 'trust me to a show me' society.

All three types of trust just discussed are highly inter-related and all could be said to express both the relationship between individuals and between individuals and institutions. Another key distinction in the literature is made between *personalised* and *generalised* trust or trust in 'abstract systems'. Such a distinction is usually credited to Giddens (1990) but the explication of face-to-face personalised confidence versus generalised trust is linked to earlier work by Luhmann (1979, cited in Luhmann, 2000) and is identified as a key signifier of the shift from pre-industrial to modern society. The distinction between personalised and generalised trust is visible in explanations of resistance which attempt to argue that there is an important difference between, for example, the trust I have in my own GP and the trust I have (or don't have) in 'the medical system' (Mechanic, 2004). Luhmann claims that 'many empirical studies' have confirmed that a negative view of a system is not necessarily incompatible with positive experiences in individual cases (Luhmann, 2000, p104).

In common with the structure of the first section on risk, this discussion now considers how the concept of trust has been used on a macro level. The section will consider the claim that contemporary society is currently suffering from some sort of widespread 'crisis of trust' in professional expertise. Once again, this review functions as a necessary background to the subsequent discussion of the nature of public resistance to technology or expert advice.

### **The 'crisis of trust'?**

In the last decade there has been much media talk of a general crisis of public trust in expert authority (e.g. Moore, 2002). That there is a crisis is also assumed by the oft cited House of Lords Select Committee report on Science and Society (Great Britain, 2000). This section will introduce the main empirical, methodological and theoretical debates that relate to this issue.

A crisis of public trust is assumed to be visible in political life. Sometimes the language of crisis is not used directly but the general discourse of decline is implied<sup>2</sup>. For example, Coote and Franklin discuss risks to public health and argue that ‘Trust was never strong between people and politicians, but it is decomposing in new ways’ (Coote and Franklin, 1999, p185). As discussed above, BSE, or rather the government’s handling of the BSE affair, is often cited one of the triggers for the crisis, in both popular and academic accounts. To take just one example, an article in the *Readers Digest* magazine concluded; ‘A recent succession of food-safety disasters and imbroglios, from BSE to dioxin, and even troubles with HIV-tainted transfusion blood, have seriously decreased public confidence in the ability of authorities to protect public health’ (Harriss, 2000). Even the government’s Phillips report into BSE says that ‘confidence in public pronouncements about risk was a further casualty of BSE’ (cited in Irwin and Michael, 2003, p54). In contrast, Marris and colleagues argue that BSE should not be regarded as the starting point of some sort of crisis. According to their empirical research on public attitudes to GM, BSE is regarded by the public as the rule, rather than the exception, in conceptualising a problematic relationship between government and science (Marris *et al*, 2001, p84).

The relationship between doctor and patient is one that has been analysed in detail by medical sociology (Blaxter, 2000) and one that has traditionally been seen to epitomise a relationship of trust. Many commentators have argued that this characterisation of the doctor-patient relationship has become less accurate than it once was (Ham and Alberti, 2002) as we live in a less deferent society, where expertise or status is not deferred to, automatically<sup>3</sup>. Empirical evidence for this is mixed: large scale international surveys claim to show that trust in key actors is low and falling (O’Hara, 2004, p239). However,

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<sup>2</sup> Whilst not directly evidence of a crisis of trust a related argument is made about challenges to politics or democracy including falling voting numbers, the rise of direct action, and the development of new social movements, (A. Scott, 1990; Dalton and Keuchler, 1990).

<sup>3</sup> This is part of wider debates about current challenges to medicine including the rising use of complementary and alternative medicine (Coward, 1989; Saks, 2003), the rise in patient associations and self-help groups (Wood, 2000; Kelleher, 1994), and the increasing availability of health information from a wide variety of sources on the internet (Nettleton, 2004; Abbott, 2002). These developments could be analysed as undercutting the dominant role of the medical profession and contributing to a crisis of trust in healthcare. However, as discussed at the start of the chapter, different theoretical perspectives would conceptualise the doctor-patient relationship differently. For example, Gabe and Calnan (1989) refer to a ‘deferential dialectic’ (cited in Lupton, 1994, p115), rather than simple trust or deference. A detailed review of the sociological literature on the doctor-patient relationship is beyond the scope of this discussion.

other polls have complicated this picture by claiming to show that trust in doctors remains high, despite negative media headlines (MORI, 2002).

There are several problems with such polls, or social scientific research that is constructed using polls or surveys as research evidence. For example, Frewer and Miles consider the psychological determinants of trust and argue that ‘it is important to examine trust in the context of specific issues’, in their case food risks (Frewer and Miles, 2003, p261). Whilst this advice is no doubt sound, their work still relies heavily on questionnaires that ask respondents to rank sources (such as NGOs or the Department of Health) as more or less trustworthy. However, as argued recently by Onora O’Neill (2002), in order to understand trust we need to look at what people *do* rather than what people *say*, and in practice trust is regularly placed in individuals and institutions. A broader problem is that in trying to measure trust you inevitably deal with proxies of trust (O’Hara, 2004, p257). If this is the case then attempts to restore trust may not succeed. Such arguments are related to warnings by Brown and Michael (2002) that in trying to restore public trust in authority you will simply end up creating other problems such as a ‘crisis of transparency’. Interestingly, some of these arguments find resonance with methodological and theoretical critiques of the psychometric approach to risk discussed in the previous section.

As well as empirical and methodological debates, the notion of a crisis of trust is related to broader theoretical debates about whether or not society has moved beyond modernity, into a different stage, such as risk society or postmodernity. Warren links the argument about a declining respect for authority to Inglehart’s classic text on post-materialist culture, and the claim that we no longer worry about basic survival so have less need to cling to those in authority (Warren, 1999, p7-8). Klein (1995) links the birth of the modern NHS to the post-war consensus and widespread optimism in the progress of medical science. A postmodern perspective would identify a breakdown in this consensus and a corresponding breakdown of trust in legitimised authority (Kelleher *et al.*, 1994 pxxii). What these arguments share is the assumption that current changes or crises should be understood as part of fundamental transformations in the nature of society. As Misztal argues, ‘the recent increase in the visibility of the issue of trust can be attributed to the emergence of a widespread consciousness that existing bases for social co-operation, solidarity and consensus have been eroded’ (Misztal, 1996, p3).

One of the most influential theorists who have written on trust is Giddens. Whilst not directly diagnosing a 'crisis' of trust, Giddens' work does offer an explanation for changing relationships of trust. He distinguishes between simple modernity, where trust in experts and expert systems was more or less taken for granted, and reflexive modernity, where 'trust must be won and continually negotiated' (Lupton, 1999, p78). Wynne (1996) argues that Giddens' analysis has been increasingly influenced by Beck. However, according to Lupton, key differences remain: for Giddens, the reflexivity that characterises risk society takes place through expert systems, so some level of trust is still required or assumed. For Beck, reflexivity flows from a critique of and *distrust* in expert systems (Lupton, 1999, p81-83).

As with their approach to risk, Wynne has been strongly critical of the way that Beck and Giddens conceptualise relationships of trust. In particular he claims that they have uncritically adopted a rational choice model, where trust is invested or not invested in particular experts as a recognised choice between alternatives. Wynne also complains that Giddens assumes that public mistrust has only arisen because of increasingly open expert dissent (Wynne, 1996, p48). Citing empirical studies, Wynne argues that Giddens and others are wrong in assuming that a lack of public opposition necessarily equates to trust (Wynne, 1996, pp48-49). This latter argument is particularly important for a consideration of vaccine uptake and will be returned to in later chapters.

Irwin and Michael's (2003) reading of Beck and Giddens on this topic is more sympathetic. They argue that the image constructed by Beck (1992) and Giddens (1991) in relation to trust is actually better described as ambivalence. In terms of scientific institutions they argue that there are 'cross-cutting and sometimes contradictory patterns of trust' which includes routine dependence on institutions coupled with virulent distrust when things go wrong, and provisional trust when things go right (Irwin and Michael, 2003, p74). The implication of this argument is that trust is complex and closely related to issues of dependence and agency. Ambivalence may be a more accurate term than crisis.

## Trust and resistance

The key literature reviewed above confirms that trust is a multifaceted concept, rather than one dimensional (Bennett, 1999, p5). Using this literature, trust was defined in different ways as interest promotion, role performance and as a leap of faith. Trust as interest promotion bears similarity with the political economy approach to power and resistance, discussed at the start of the chapter, which sees economic interest as an important motivation for behaviour. An understanding of the different dimensions of trust is necessary before evaluating claims for the existence or otherwise of a 'crisis of trust'. Trust and risk are closely inter-related on several different levels (Luhmann 2000; Brownlie and Howson, 2005). Theoretically, what talk of a crisis of trust and the risk society thesis share is the attempt to describe some sort of fundamental shift in contemporary social relations. This shift is then used to explain resistance to technological change and expert advice. Some evidence exists for a crisis of public trust in the institutions of medicine and politics. However, such conclusions are challenged on methodological and other grounds, and there is a tendency to simply refer to high profile examples, such as BSE, without careful consideration of precisely how such episodes are supposed to have precipitated a loss of trust. Furthermore, an apparent lack of controversy does not necessarily equate to the existence of trust.

In the field of risk communication and healthcare, the relationship between risk and trust is also crucially important. Even within the mainstream risk communication literature has come the recognition that 'messages are judged primarily not by content but by source – *who is telling me this and can I trust them?*' (Bennett, 1999, p4, original emphasis). The implication is that public response to risk information is partly a function of where the information is seen as coming from, and whether that authority is 'trusted'. From a realist model, this would be seen as a source of frustration and further evidence of the difference between real and perceived risk. However, Wynne argues that judging risk messages by source is a wholly rational strategy as it recognises that some risks are unknown and the public need to be confident that those in charge will be able to deal with any 'surprises' (Wynne, 2001, pp. 455-456).

Acknowledgment of the importance of trust in understanding how risk messages are received, and Wynne's contribution in highlighting public rationality in this respect, should not be underestimated. However, some accounts are in danger of conceptualising trust as simply another 'factor' that streams into the process of risk perception. If this approach is taken, then the research task is simply to understand who is and who is not trusted in order to design better risk communication strategies (Marris *et al*, 2001). A social constructionist perspective is useful in highlighting the constructed and political nature of risk, even when risks are not classified as 'unknowns'. The implication for resistance is that non-compliance with risk information may not be a failure of risk understanding, nor a simple response to a lack of trust in the individual or organisation that is providing the risk information. Rather, resistance is reframed as a possible response to the constructed and contingent nature of risk itself, and a judgement on the epistemological processes involved in constructing a technology or risk advice.

## **SCIENCE AND TECHNOLOGY**

According to Wynne, 'science is an icon of modern society' (Wynne, 1991, p112). Literature within social history looks at the birth of modern biomedicine and argues that medicine has benefited from the 'badge of empiricism' it borrows from science (Weatherall, 1996). In other words, science is used to give medicine its cultural authority and legitimacy. Arguably policy-making also uses science for this purpose, although how the relationship between science and policy should be conceptualised, and how it has changed over time, is disputed (e.g. see Weingart, 1999 and responses; and Coles, 1999). This section will consider the main debates in the literature about the extent to which public resistance to technology, or non-compliance with advice about technology, is explicable as concern about science or a lack of scientific knowledge and understanding.

### **Science and 'anti-science'**

The argument that a crisis of trust is visible in contemporary society, for example in the medical and political domains, can also be applied to science, and the relationship between science and society. This section discusses the hypothesis that public resistance

to a technology is a result of *anti-scientific attitudes*. In order to appreciate this hypothesis it is also necessary to consider the nature of science itself, and how science has been considered from within sociology. The oft-quoted Mertonian vision of science is of a profession guided by norms or 'institutional imperatives' of universalism, communism, disinterestedness and organised scepticism that combine to produce scientific knowledge (Merton, 1942 cited in Bucci, 2004, p17).

Merton's norms have been much criticised and questions asked about whether scientists actually follow these in practice, their applicability to areas outside science, and about the importance of the social and political context within which Merton wrote (Sismondo, 2004, p24-32). Critics have argued that Merton's norms are best understood not as working definitions of science but as 'ideological resources' (Sismondo, 2004, p32). More broadly, as Wynne points out, there is no clear consensus even what science is, even among scientists (Wynne, 1991, p112). Much more could be said about the influence of Robert K. Merton. However, for the purposes of the thesis, Merton's imperatives are used to represent a traditional, idealised image of science, where technological innovation is seen as a kind of fortunate by-product, and the rational result of the application of science. According to Sismondo, this view is found in both popular and academic accounts (Sismondo, 2004, p8).

Various social, cultural and academic developments since the 1960s have been assumed to act as a challenge to this positivist vision of science and technology. For example, the environmentalist movement, arising in response to nuclear power and concerns about environmental degradation, has questioned the beneficence and truth claims of medical science (Elston, 2004, p225). In common with the feminist movement, it has also expressed a serious interest in the meaning of *nature* and its relationship to culture. Indeed, nature remains a key symbolic battleground for current debates over GM food (Sismondo, 2004, p159-160; Marris *et al*, 2001), GM animals (Macnaughten, 2004) and animal genomics (ESRC 2004). If modernity is understood as 'the separation of nature and humankind', then concern over nature may be explained as a rejection of modernity (Touraine, 1995 p52). In the medical field, Illich's call in the 1970s for an appreciation of the 'limits to medicine' and warnings of iatrogenic disease (Illich, 1976), and public scandals like thalidomide, may also be analysed as contributing to the uncoupling of the assumed relationship between science, medicine and progress.

Academic developments since the 1970s also include the growth of science and technology studies (STS). Whilst not necessarily normatively critical of science, STS has succeeded in opening the ‘black-box’ of science and technology. The result is empirical and theoretical evidence against the assumed close relationship between science and technology (Sismondo, 2004, p158) and analysis of science as work, rather than simply a method of objective knowledge or truth gathering<sup>4</sup>. This latter point helps explain why STS scholars are often identified as adopting a constructionist approach to scientific knowledge which sees science, like any system of knowledge as partly constructed, as ‘researchers transform disorderly nature into artifacts’, rather than revealing a deeper order of reality (Sismondo, 2004, p161). Science is therefore also inherently social, involving claims that result from social processes (Sismondo, 2004, p162). More broadly, postmodern sociology has, according to Annandale, thrown the modernist assumption that science and reason provide an objective foundation for knowledge, into doubt (Annandale, 1998, p45).

To return to the question of public resistance to technology, some of these arguments are drawn upon in order to claim that resistance to technology is a result of ‘anti-science’ attitudes. For example, opposition to water fluoridation (see Reilly, 2004 for a critical discussion) and animal experimentation (Broida *et al*, 1993) has been explained in these terms. More broadly, Hagendijk and Kallerud (2003) offer a ‘typology of governance’ comprising six types. Within this they suggest that the assumption that public resistance to technology is ‘anti-science’ is widely visible in ‘educational models’ of governance<sup>5</sup>. However, work within social science has challenged the anti-science hypothesis on both empirical and theoretical levels.

Empirically, work by Strickland on organised opposition to GM agriculture concludes that opponents are not in fact ‘anti-science’ (Strickland 2000). Research on public

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<sup>4</sup> Looking at science as work was also part of Merton’s aims. Sismondo concludes that ‘Merton can be seen as asking what science needs to be like, as a social activity, in order for it to best provide certified knowledge’ (Sismondo, 2004, p32).

<sup>5</sup> The six models are; discretionary, educational, deliberative, corporatist, market and agonistic. Unlike discretionary governance, some resistance or public non-compliance is recognised in the educational model. However, some of this resistance is excluded as ‘anti-science’ or ‘anti-technology’. The authors link this type of governance to the ‘deficit model’. Vaccination currently fits most closely with this educational model. A full discussion of the literature on governance is beyond the scope of this chapter.

attitudes to GM across Europe also came to the same conclusion (Marris *et al*, 2001). In investigating opposition to water fluoridation, Brian Martin also found that campaigners have not rejected science but on the contrary make reference to science in order to gain support (Martin, 1989). Epstein's (1996) work on AIDS activists in the US has had a significant impact on these debates. Whilst being critical of some aspects of the way science and technology were being applied to the problem of AIDS, activists were actually identified as 'believers in science' (p343), some even going on to pursue medical careers. In terms of social movements, Mike Michael points out that 'those who are critical of technoscientific innovations rely upon other (counter-) scientific experts' (Michael, 2001, p209). This was indeed the case with Epstein's activists. Writing with Irwin, Michael has also argued that social movements use a combination of scientific, local, economic and legal knowledge to make their case (Irwin and Michael, 2003, p94). Taken as a whole, what these empirical studies suggest is the need to delve into the different meanings of science, beyond the Mertonian image. They also tend towards the conclusion that the act of questioning particular technologies is not achieved through a wholesale rejection of science. This challenges the logic of trying to identify groups or individuals as 'pro' or 'anti' science.

Theoretical work has also complicated the assumption that resistance to technology can be accurately labelled as anti-scientific. In analysing contemporary society Lyotard (1984) argues that there is indeed a generalised disillusionment with science. This is explained as resulting from the realisation that science has become the servant of industry, rather than being engaged in the progression towards freedom or equality (cited in Irwin and Michael, 2003, p70). In a similar vein, Alan Touraine has argued that 'we still believe in science, but no longer in progress' (Touraine, 1995, p45). What is meant by this, he explains, is a questioning of the assumption that science and technology will automatically produce welfare, freedom and happiness. This questioning has emerged as a result of 'big science' and 'technocracy' that have combined to challenge the traditional (Mertonian) image of science as pure and disinterested, and through an awareness that 'science is no longer a small community of distinguished minds. It is part of the economic and of the political system and decisions about science are not entirely scientific' (Touraine, 1995, p49). However, for Touraine, such questions represent a challenge to the management of science and technology, rather than science itself. For social science, this implies the need to adopt careful

research strategies to ensure that this kind of political economic critique would be revealed, and to avoid the assumption that resistance to technology is necessarily the same as anti-science.

### **Public understanding of science**

The second hypothesis, often intimately related to and difficult to untangle from the first, is that public concern or resistance to technology can be explained by a *lack of* scientific knowledge or understanding. In other words, this hypothesis makes a definite association between knowledge levels and attitudes. Early survey research in the UK in the 1980s appeared to confirm this relationship by revealing that those with a higher degree of scientific knowledge were more likely to be positive about science and technology (Durant *et al* 1989). This assumption is also said to be commonly held by science policy-makers (Irwin and Michael, 2003, p23). On this analysis, resistance is partly a function of knowledge levels.

Such research and commentary on scientific literacy contributed to what subsequently became known as the deficit model of public understanding of science (PUS) which assumes, first, that non-experts suffer from a lack of knowledge and second, that attitudes can be changed by filling the knowledge or information gap. In other words, this perspective assumes that: ‘Protests, fears, criticism or resistance are a *pure problem of information*’ (Beck, 1992, p58 original emphasis). According to Michael, this model assumes that scientific literacy is ‘a good thing’ for several reasons (Michael, 2001). In short, it renders one: more practically competent in everyday life, more able to make informed decisions, more employable, a more rounded member of western civilisation, and a better citizen. According to versions of the deficit model, ‘more likely to be supportive of technology’ could also be added to this list. This bears some resemblance to the functionalist view of power which was considered at the start of the chapter. Despite social science research that complicates the picture, elements of the traditional deficit model, it has been argued, continue to ‘retain something of a foothold in academic, public and policy debates’ (Miller and Macintyre, 1999).

This ‘foothold’ appears particularly secure in attempts to explain public attitudes to new technologies. For example, whilst claiming to advocate a move from public

*understanding* of science to public *engagement*, in his 2005 Reith Lecture, the engineer Lord Broers still criticised the public for ranking the bicycle as more important than other inventions, including vaccination and the discovery of the structure of DNA. His explanation of the poll results is a 'profound misunderstanding of the contribution of advanced technologies to our lives'. Related to this is the theory that 'modern technologies are too complex to be understood by anyone but the experts' (Broers, 2005). In addition, the deficit model is implicit in attempts to explain public concern over the new genetics (Kerr and Amos, 1998). In 2001, the European PABE report also found that policy-makers still hold onto the 'myth' that the main cause of concern about GM agriculture is because lay people are ignorant of the scientific facts (Marris *et al*, 2001). At a recent ESRC meeting on animal genomics, some delegates argued that 'the public outlandishly misinterprets biotechnology and that this is why they tend to resist it' (ESRC, 2004). This deficit model finds a parallel in traditional approaches to risk communication that were discussed earlier in the chapter. Both models see a lack of understanding as the problem and information as the solution, and see the role of experts as crucial mediators who 'translate' evidence for the public.

This traditional model of PUS has been widely criticised from several perspectives, even from within political institutions such as the Department of Health (Bennett, 1999)<sup>6</sup>. Other survey research has found far less correlation between knowledge and attitudes or has found that the relationship differs depending on which technology you are talking about (Evans and Durant, 1995 cited in Irwin and Michael, 2003, p23). International survey research has gone further to indicate that increasing knowledge actually polarises existing views (Bauer, Durant and Evans, 1994 cited in Bauer, 1995b, p406). Still others have argued that the more information people have the more sceptical they become (Martin and Tate, 1992 cited in Marris *et al*, 2001, p79). At best, survey research offers a mixed picture about the relationship between knowledge and attitudes.

The methodology of such research that attempts to measure understanding in a 'standardized way' (Wynne, 2001, p113) has also been critiqued by those who argue

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<sup>6</sup> The author is based at the Department of Health and identifies a progressive change in the literature on risk: 'from an emphasis on 'public misperceptions', with a tendency to treat all deviations from expert estimates as products of ignorance or stupidity *via* empirical investigation of what actually concerns people and why *to* approaches which stress that public reactions to risk often have a rationality of their own, and that 'expert' and 'lay' perspectives should inform each other as part of a two way process' (Bennett, 1999, p3, original emphasis).

that the questions used to measure knowledge are highly problematic: most quantitative work is designed for 'quizzing' the public about 'scientific facts'. This design allows results to be coded by researchers but only allows responses in a certain format and does not allow space for the respondent to express the way in which knowledge plays a role in their everyday life. Furthermore, in allowing 'yes/no' answers about technologies, some quantitative research assumes the 'intellectual unity of technologies' (Irwin and Michael, 2003, p24-25). Behind this work are realist assumptions about the ability to distinguish between public knowledge and real, objective scientific facts. This relates back to the distinction made between realist and constructionist approaches to risk. Methodological arguments about the difficulty of measuring knowledge or understanding also find resonance in debates, discussed earlier in the chapter, about whether it is possible to measure trust. Taken together, this suggests the difficulty of using survey methodologies to assess either knowledge or attitudes.

Qualitative and ethnographic research has been used to construct a more 'critical' model of PUS. In his highly influential case study of Cumbrian sheep farmers, Brian Wynne suggests that the farmers had a more useful knowledge of the causes, effects and solutions to radiation than did scientists, based on their intimate knowledge of the local farming conditions (Wynne, 1992, 1996). This finding bears some similarity with work by Phil Brown (1995) who looked at local toxic waste activists and argued that they were engaged in a form of 'popular epidemiology', where relationships between events were identified through local knowledge. The implication of these empirical studies is that knowledge is complex and is highly contextual, and that scientific knowledge is evaluated using many different frames of reference. They also suggest the value of alternative forms of expertise that may not be strictly considered 'expert' or 'scientific'.

Mike Michael agrees that the significant contribution of a critical PUS is to show that understanding is embedded in a cultural context. This can then allow a charting of 'the clash between expert and lay cultures' (Michael, 2001, p208 following Wynne). One important element of this 'clash' is the tendency for science or experts not to appreciate the uncertainty of knowledge that is recognised by the public. According to the Mertonian image, science is supposed to be eternally sceptical, implying openness to the possibility of new evidence and theories. However, Dew (1999) cites Feyerabend's claim that in practice new ideas are treated as taboo. Similarly Wynne argues that

despite claims to reflexivity, science is actually the opposite – and that its lack of openness has encouraged ‘public scepticism, alienation and mistrust’ (Wynne, 1993, p329). This links back to the previous discussion of the relationship between risk and uncertainty and about the requirements of trust.

One unfortunate impact of work in the sociology of scientific knowledge, according to Michael, is that research tends to assume that looking at context means looking at the *local* level and local identities (as was the case with Wynne’s local sheep farmers). However, some technologies, such as the new genetic technologies, are global in scope, and so a different focus is required. For example, the ability to ‘technologically bespoke’ animals disrupts our identity about what it means to be human (Michael, 2001). Taken together with existing critical PUS studies, what this argument implies is that concern about a technology or resistance to expert advice may be less about a lack of understanding and more about alternative, experiential understandings, or a concern about the potential for disruption to both local and global identities.

Writing with Irwin, (Irwin and Michael, 2003, p56) Michael also claims there is evidence, including the House of Lords report on Science and Society (Great Britain, 2000), that some of the insights from these studies are beginning to be adopted by government. The result is a move from deficit to dialogue, and a move from government to governance. A critical discussion of this shift, and whether it is only ‘partial’ (Irwin and Michael, 2003, p57), is beyond the scope of the chapter. What is important is the general observation that issues of engagement, dialogue, and participation have recently become watchwords of policy-making on issues of science and technology. The question of whether the same can also be said for vaccination will be addressed in chapter eight.

### **Science and resistance**

This chapter has considered the hypothesis that resistance to technology or scientific expert advice is a reflection of ‘anti-science’ attitudes. The rise of new social movements, such as feminism and environmentalism, could be cited as evidence of a challenge to the assumed relationship between science, technology and human progress. However, empirical social scientific data are useful in interrogating this claim and

demonstrating that even for those groups who question technology, science may still be 'believed in'. Theoretical work also distinguishes between science and progress. Overall, the discussion confirms the value of detailed work which not only deconstructs science but also promotes scepticism about 'pro' and 'anti-science' labels.

The deficit model of the 'public understanding of science' has proved influential in explaining resistance to science or technology, particularly in the domain of new technologies. The adequacy of this model is challenged by other empirical studies and by those who question the largely quantitative methodologies used to measure public knowledge and attitudes. A more critical PUS has developed which destabilises the basic assumptions of the traditional model. This has implications for how resistance is understood: if not a lack of understanding of science, resistance could instead be about a failure of science to recognise inherent uncertainty or, more broadly, a reaction to the disruption of local and global identity. Once the diagnosis of a lack of scientific knowledge or understanding is removed, new and fundamentally more interesting questions emerge about the nature of expertise. This then opens the door to debates about the similarities and differences between expert and lay knowledge(s) and the practical and theoretical challenges of the inclusion of non-professionals in policy-making on science and technology.

## **CONCLUSION**

This chapter has provided a review of the literature that refers to risk, trust and science. The review has been deliberately focused in order to demonstrate how claims about these three themes are used to give meaning to public resistance to technology or expert advice. For the purposes of the rest of the thesis, three broad sets of arguments are worth clarifying.

First, the literature review demonstrates that the distinction between realist and constructionist approaches is visible in competing accounts of resistance to technology. The remaining chapters take the social constructionist approach forward. A functionalist approach would be less suitable, given its tendency to assume that medical dominance is necessary. From the functionalist approach, research is designed to identify why

resistance occurs, principally in order to counter it. This finds echoes in the realist models, where the sources of misperception are located in order to design better risk communication strategies. A political economy perspective at least encourages research which investigates conflict, by prioritising the importance of competing interests. However, by looking at the reproduction rather than construction of power, this approach does not allow consideration of how wider social assumptions and values are embedded in, and created by, medical knowledge. The following chapter explains the rationale behind the adoption of a 'symmetrical' research approach. A social constructionist approach remains the most attractive in that it also allows claims in favour of vaccination to be subjected to critical analysis.

Second, the chapter has started to develop alternative interpretations of resistance to technology or expert advice. Resistance does not necessarily represent a failure of risk perception, a lack of scientific literacy or a rejection of science, and nor is there conclusive evidence for a broad crisis of trust in professional expertise. Despite much constructionist social scientific analysis, a narrow focus on risk perception continues to exert dominance in some academic and policy circles. Detailed empirical work is needed to investigate whether and in what ways trust is a more useful perspective. For this research project, the most important question is not whether or not there is a crisis of public trust, but more about the interrelationship between risk and trust, and about how expertise is conceptualised. Theoretical work reviewed in this chapter suggests an important distinction between science and progress. Existing empirical research indicates that resistance to technology may represent an evaluation of the ability of science to capture uncertainty, or in the ability of technology to lead to human progress. In summary, this review has investigated the key debates in social science about risk, trust and science. As expressed in the second research question, the task is to evaluate the relevance of these ideas for an understanding of vaccination resistance, and, in doing so, contribute to these debates.

And finally, the literature confirms the value of methodologies that are sufficiently flexible to allow consideration of the different meanings of, and interplays between, risk, trust and science. If the aim of the research is to take a constructionist approach to understand the meaning of resistance then this aim will not be met by quantitative techniques, or by assuming to know which ideas are most relevant. An assumption that

risk is the most important framework, for example, would miss the importance of other dimensions. Furthermore, as argued by Bauer, we must avoid the tendency to assume that the object of resistance is technology: ‘What is being resisted is normally complex and requires empirical analysis’ (Bauer, 1995a, p19). These arguments are what guide the rest of the thesis. How the empirical work was designed and carried out is the subject of the next chapter.

## Chapter 3: Research design and process

Part of the reason for some of the disagreements in the literature on resistance to technology is that researchers adopt different research methodologies. As demonstrated in the previous chapter, quantitative attempts at measuring public attitudes or understanding have been much criticised by those advocating more qualitative or ethnographic approaches. Serious questions have been asked about the ability of highly structured questionnaires to measure complex phenomenon, particularly when the aim of the research is precisely to try and understand how that phenomenon is conceptualised by a certain actor. These critical reflections on the literature have informed the way the empirical research was planned and carried out. In terms of the broader thesis, this chapter is necessary to explain why this research design is the most appropriate way of addressing the main research questions.

The chapter details the rationale behind the research and explains the thinking behind the key strategic decisions. The structure of the chapter is broadly chronological, although the issues raised often refer to more than one stage of the research. What results is a kind of political history of the research process. The discussion is divided into four sections. Section one discusses project definition and design, and includes an explanation of case selection. Section two considers the interview process, from access negotiations to managing consent. Section three looks at analysis and explains the kind of discourse analysis adopted. And finally, section four changes tack to provide a more critical, reflexive commentary on the research process and some of the unanticipated issues arising. In doing so, the strengths and the limitations of the study will be considered. The aim is not to provide a simple checklist of the research progress but to illuminate and reflect on the sometimes difficult strategic decisions necessary for completion of each stage of the project. The chapter also makes explicit some of the theoretical assumptions that have guided these decisions, and how these relate to debates in the methodological literature. As Irwin and Michael argue in the context of research on public understanding of science, ‘methods embody assumptions about both society and individuals, even if these are rarely expressed or even acknowledged’ (Irwin and Michael, 2003, p9).

## **THE PROCESS OF PROJECT DESIGN**

This section explains how the research evolved and how the approach moved from a broad interest in the topic to a defined set of research questions and methods.

### **Early ideas and actor mapping**

The research started with a keen interest in exploring the dimensions of, and understanding the reasons for, opposition to vaccination. Literature review confirmed two important early hunches; one, that opposition to vaccination is regarded as very serious by the medical profession and two, that there was relatively little social scientific research on any aspect of vaccination. In order to address the original interest in understanding why, it was first necessary to understand who was involved in questioning vaccination, to enable the project to be operationalised into a piece of manageable empirical research. The first stage therefore involved a process of 'mapping' out the main actors involved. The original map included the following actors: children, parents, vaccine manufacturers, health professionals, national and international policy-makers, scientists, the media, alternative health practitioners and religious groups. This mapping was partly achieved through literature and website searches, and critical reflection upon these. For example, research by New and Senior (1991) found that homeopathy was one of the principal 'reasons' for vaccination refusal. However, how exactly this operates as a 'reason' is left frustratingly unarticulated. What this finding does is indicate that alternative health may be a focus for vaccination critique.

The next stage was to decide which actors to concentrate on for empirical study. Two categories of actors were identified; organisations making up what I temporarily called the 'anti-vaccination movement' and vaccination 'policy-makers'. The decision to concentrate on the former was made for several reasons. Firstly, literature review suggested that very little research had been carried out looking at 'groups' or organised opposition to vaccination and I was genuinely excited about the opportunity for empirical 'originality' that this afforded. Secondly, a focus on groups reflects a personal theoretical orientation towards the collective; I am less interested in the motivations of individuals and how individuals explain their behaviour, and more interested in the role

of groups in society. What is being described is an ontological perspective (open to challenge), which sees institutions, social movements, and groups as key components of the social reality. The epistemological assumption, that knowledge is structured as discourses, and that these discourses are accessible through investigation of such groups, is returned to in the later section on discourse analysis. Once the decision had been taken to concentrate on organised opposition, this could then be classified as 'resistance' using Streefland's (2001) distinction, mentioned in chapter one, between refusal and resistance.

The second category of actors was vaccination 'policy-makers'. Once again, this strategic focus was established for several reasons. First, it was recognised that carrying out research with those responsible for promoting vaccination would promote a greater understanding of what exactly is being opposed, and for whom opposition represents a serious problem. This would then help my credibility and sensitivity to the arguments of groups critical of vaccination. Second, I was aware from early on in the project of the intense policy interest in the issue of vaccination. Carrying out research on these actors would therefore encourage a heightened awareness of the policy implications of the research findings. Third, and more theoretically, I was impressed by arguments made by authors writing in the tradition of the sociology of scientific knowledge about the value of 'symmetrical' research approach to studying science or controversies (Bloor 1991 [1976] cited in Sismondo, 2004, p42). This principle is about more than hearing 'both sides of the story' but reflects a theoretical commitment to the idea that the analyst should not simply problematise one side of a debate, and represents 'a reaction against an unsymmetrical pattern or style of explanation, in which true beliefs require internal, rationalist explanations, whereas false beliefs require external or social explanations'(Sismondo, 2004, p43). Such an approach is in line with the constructionist approach to resistance that emerged out of the discussion in chapter two.

The decision to adopt a symmetrical approach and focus on policy-makers was made for legitimate practical and theoretical reasons. In retrospect, this was perhaps over-ambitious and represents an underestimation of the time involved in planning, conducting and analysing complex interview data. As will be discussed in the following section, subsequent decisions were required in order to further narrow down the data for empirical analysis.

## Case selection

Having decided to focus on the ‘anti-vaccination movement’ and policy-making institutions, the next stage was to identify the groups or organisations that make up each category. The thirty organisations and individuals contacted are listed in appendix 1. This section will explain the selection criteria and the stages of ‘sampling’.

The first stage of case selection involved the identification of organisations that could be described as part of a broad ‘anti-vaccination movement’. At this point, the selection criteria was to include all organisations or groups located in the UK who expressed critical views towards vaccination, and childhood vaccination in particular. Identifying groups within the ‘anti-vaccination movement’ (Category 1) was far from straightforward. Sources utilised include news reports, websites, CD Roms, online databases and local library guides such as ‘Self Help Groups: Nottingham and district’ (Self Help Nottingham, 2003) and ‘Help!: A comprehensive guide to over 800 national self help groups’ (Anon, 2004). These library sources were deliberately used as a way of countering the potential bias towards web-based groups. Groups were also deliberately identified to ‘represent’ a perspective that the original mapping process had identified with vaccination opposition: groups representing alternative health (homeopathy, naturopathy, anthroposophy), and religion (Catholic doctors, Christian Scientists, Jehovah’s Witnesses) were located. Legal firms involved in the case against the MMR manufacturers were also included because of their significant involvement in the vaccine debate and the inclusion on their website of vaccine policy criticisms. This clearly represents a purposive or theoretical, rather than a representative sampling strategy.

A list of organisations involved in some capacity in vaccine-policy making in the UK was made and labelled as ‘Category 2’. Once again, this list was constructed through a variety of methods. News reports and web searches helped establish the key players involved. One source which proved particularly useful was a joint statement released by organisations supporting the government’s policy on MMR (Faculty of Public Health Medicine *et al.*, 2001). This letter was signed by groups such as the Royal College of General Practitioners and proved to be an efficient way of identifying the organisations

and individuals seen as key players in promoting vaccination. The selection criteria was once again very broad; organisations were targeted if they had an impact on or interest in vaccine policy in the UK.

For both categories a small amount of ‘snowball sampling’ was used, where contact with one group enables the identification of others to target. This strategy proved particularly valuable for identifying those groups in Category 1. It also functioned as an informal method of ‘triangulation’; by discussing with informants my intended target organisations, coverage could be confirmed or potential gaps filled. A lack of existing research on the anti-vaccination movement meant that working out exactly what the population was proved a significant part of the research – and the only way to do this (i.e. understand the dimensions or nature of the ‘anti-vaccination movement’) was to actually carry out research with groups and investigate the existence of other sources of opposition during the interviews. This explains the formulation of the first research question: *How is resistance to childhood vaccination organised in the UK?*

Once the data collection stage was complete, the strategic decision was made not to analyse data from all groups but instead to concentrate on data from 10 opposition groups. These groups were later labelled Vaccine Critical groups and sub-divided into Radical and Reformist groups, terms that are explained and justified in the following chapter. The construction of these terms was far from straightforward and represents a significant advance on existing understandings of the nature of vaccination resistance. The ten groups were selected from those in Category 1 as having a direct, rather than indirect interest in vaccination. They include groups specifically set up to campaign about vaccines, or groups who spend a significant amount of time dealing with the childhood vaccination issue. This could be regarded as the third form of sampling.

There are three main explanations for the decision to focus the empirical research in this way. After collating the data it became clear that exciting themes were emerging but that a detailed analysis, of the type planned, would not be possible given the time available. A way to achieve a more satisfying in-depth analysis was therefore sought. Second, regular monitoring of the literature confirmed the continued lack of published research on groups established specifically to criticise vaccination. I was confident that research focused on these actors would be of wide interest and originality. Finally, the

realisation dawned that research with policy-makers and with organisations expressing some criticism of vaccination had still been worthwhile in sensitising me to the political nature of vaccination, and the types of discourses that may be drawn on in vaccine critiques. In other words, in order to construct the 'Vaccine Critical group' identifier and be confident that the main players in the UK had been identified, the other interviews with a wider range of actors needed to have taken place. All interviews were therefore necessary to enable final definition of the world under study. Whilst disappointed to be unable to adopt the envisaged symmetrical approach in its entirety in the empirical part of the study, the strategic decision was taken in order to promote a more detailed and rigorous analysis. In the end, a more limited symmetrical approach was indeed adopted for the writing up: this was achieved by adopting an explicitly critical perspective to discuss vaccination policy. As argued in chapter four, there exists a powerful imperative of vaccination.

### **Choice of data collection methods**

Whilst quantitative data on, for example, numbers of sceptical parents or what proportion of non-vaccination is due to active refusal versus problems of access would be of interest to policy-makers, this is not the focus of the research. The original interest in understanding, in detail, the dimensions of opposition to vaccination strongly suggested the need for a qualitative approach. As Bryman (1988) has argued, one defining characteristic of qualitative research is the commitment to viewing meaning from the informants' perspective.

Qualitative research can be achieved through a variety of data gathering techniques. The main technique adopted for this research, for pragmatic and theoretical reasons, was semi-structured qualitative interviews. Interviews were chosen as a way of ensuring that data could be generated from those oppositional groups who do not have websites or readily available documents. In addition, the literature review revealed the existence of previous empirical research based wholly on the websites of oppositional groups. Carrying out interviews therefore represented an opportunity for methodological originality. Interviews with policy-makers were chosen as the research method, partly to ensure that similar methods were used for both 'sides' (consistent with a symmetrical approach) but also in order to provide an opportunity to probe on some issues and gain

an understanding of the assumptions underpinning government policy and communication strategies.

Semi-structured interviews were adopted in preference to more structured methods for very deliberate reasons. My theoretical perspective bears similarity with the grounded theory approach of Glaser and Strauss (1967). One of the dangers of some readings of this approach is in assuming that it is possible for the researcher to act as a blank canvas, without prior commitments of any kind. This is clearly unrealistic and naïve: in my case a large amount of literature had already been accessed and this had contributed to the development of certain ideas and priorities. What is useful to be taken from the Glaser and Strauss approach is that research can itself generate theoretical frameworks. The rest of the thesis is structured around the notions of risk, trust and science. Although these form part of the second research question, these were not originally hypotheses to be tested but have emerged and solidified throughout the entire research process, including the on-going review of the literature and data analysis.

Crucially, this process of solidification also occurred in relation to an understanding of vaccination itself: the next chapter takes a governmentality perspective in order to argue for the existence of a powerful ‘imperative of vaccination’. Once again, this was not assumed prior to undertaking the research but instead emerged, partly in response to some surprising empirical findings. In other words, the research did not start with the aim of applying a governmentality perspective to the vaccination domain; such an aim would have led to a very different research methodology and literature review. Although, as argued by Hammersley (2003), most research involves both, this description more closely conforms to an inductive, rather than deductive approach. In these circumstances, semi-structured qualitative interviews provided the desired level of flexibility. The aim was to give the interviewees sufficient time and space in order that they could discuss vaccination, and the problems with vaccine policy, in their own terms. This was a methodological requirement, given the over-arching question of investigating how vaccination resistance should be best understood.

Qualitative interviews form the major research strategy but the analysis is also supplemented by the use of documents and web-based material. A significant amount of webpages had already been collected through the process of actor mapping and using

this as a data source in its own right seemed a sensible decision. Key documents, such as government reports, press releases and information leaflets were discussed and, sometimes offered by the informant, during the interview. A discourse analytic approach (discussed below) is useful in allowing these different types of data to be treated as text for analysis, notwithstanding the awareness that the text was produced for different audiences and reasons.

## **THE PROCESS OF INTERVIEWING**

The previous section discussed the identification of groups to be targeted. This section moves on to consider the practical and theoretical aspects of the interview process, from the starting point of planning the interview agenda, through to accessing informants and securing consent.

### **Interview planning and access**

Having decided on the benefits of semi-structured qualitative interviewing, the next task was to design the interview schedule. This design process involved numerous drafts. The main difficulty was in striking the balance between the need for sufficient detail, in order to function as a reference guide, and the desire to provide enough space for different, and unexpected themes to emerge. Drafts were piloted twice and small changes in structure were made. The final interview agenda (see appendix 4) is deliberately structured around very meta-level themes, such as ‘institutional relationships and governance’ and ‘perception of the public’, rather than around case-specific themes such as ‘MMR’ or ‘vaccine damage compensation’. This was done in order that vaccine policy examples would emerge, rather than assuming their relevance to informants beforehand. Of course, the meta-level themes that guide the interview agenda did not emerge from nowhere but were influenced by my reading of the existing literature, and through early document and website analysis.

The first question under each thematic heading is very broad in nature. This was deliberately designed in order to provide the informant with maximum space to pursue several issues; subsequent questions were then only necessary in some cases. The

themes were not read out to the interviewees but instead functioned as structure and prompts, where necessary. This represents a form of guided interviewing (Murphy and Dingwall, 2003, p77). In line with my sympathies towards a symmetrical research approach, the interview schedule was designed in such a way as to be used for both Category 1 and Category 2 interviews.

The design of the interview schedule was significantly influenced by the PABE study, a European report on attitudes to GM food (Marris *et al* 2001) cited in the previous chapter. This report is attractive, both for its conclusions and for its methodology. Although the research relied on focus groups as well as interviews, the overall research strategy is impressive in not assuming '*a priori* what kind of knowledge or information is relevant for the shaping of public perceptions' (Marris *et al*, 2001, p29). In my research this was played out through the decision not to specifically ask about vaccine risk or trust, but to leave open the space for these concepts to be introduced by the interviewees. This then allows for an analysis, not just of what claims or arguments are made in relation to vaccination, but in the way these contested concepts are used in making claims. This strategy has helped answer the overarching question of how vaccination resistance is best understood. This strategy could be interpreted as a positive response to the demand by Frewer, in her case in relation to risk research in psychology, for methods that 'enable individuals to describe their concerns using their own terminology, to avoid the problems associated with the imposition of risk characteristics upon individuals by the researchers conducting the experiment' (Frewer, 1999, p21). This also chimes with those who warn of the danger of closing off other analytical possibilities by assuming that risk is the dominant framework (Gofton and Haines, 1999).

The PABE report influenced the research methodology in another more direct respect; section five of the interview agenda (see appendix 4) was inspired by the focus on how the public, as opposed to the substantive issue (of GM or vaccination), is constructed by both sides. This is part of a broader tradition in social science aimed at assessing the different ways 'the public' or 'the people' are represented (Irwin and Michael, 2003, p10). This proved useful later in allowing the argument to be made that in some respects Vaccine Critical groups adopt a deficit model of public understanding of science and themselves create another type of moral imperative (see chapter eight).

Once satisfied with the interview schedule, the next stage involved the identification of the individual to approach for consent to interview. This identification proved more straightforward with Category 1 than for Category 2 organisations. The names and addresses of the leaders of many of the groups in Category 1 are provided on their websites, which made identification straightforward. For other organisations such as the Faculty of Homeopaths, named individuals were identified through monitoring of media reports (to see who was the spokesperson on vaccination issues) or through initial inquiries made by telephone to the organisation. A letter requesting interview (see appendix 2 for an example) was then sent to these named individuals, following this up with phone-calls and emails where necessary. The letter was altered slightly for each organisation. Overall, agreement for interview proved to be relatively straightforward: the leaders or spokespeople for the groups seemed genuinely interested in the research and happy to take part. Only four organisations identified as part of Category 1 were not interviewed. Rather than a result of a specific refusal, these did not take place due to the inability to identify a mutually convenient time within the data collection period.

A similar access strategy was adopted for Category 2. As well as media and websites, the professional literature also proved to be a useful resource. Several of the vaccine policy-makers write regularly in publications such as the *British Medical Journal* and this enabled the identification of those individuals most attuned to vaccination debates and most influential for vaccination policy in the UK. Once identified, these individuals were sent a letter, designed slightly differently to stress the potential policy relevance of the research (see appendix 3). In most cases, an email version of this letter was resent to individuals, and several phone conversations with secretaries or other ‘gate-keepers’ proved necessary for interview agreement. In one case, access was greatly helped through informal meeting at a professional conference. As detailed in appendix 3, the majority of those targeted agreed to take part. Hazel Blears MP, Minister for Public Health at the time, was the only individual who specifically declined to take part, citing time pressures and directing me to the Head of Immunisation at the Department of Health (whom I had already targeted for interview). Attempts at accessing two other ‘policy-maker’ organisations (Community Practitioners and Health Visitors Association and Faculty of Public Health) were eventually abandoned after several phone-calls and emails failed to establish an interview date. Overall, the response rate (or rate of

agreement) of 23 out of 30 was considered highly satisfactory and sufficient to produce enough data for analysis.

The 23 interviews took place in a variety of settings. Interviews with groups in Category 1 were mainly carried out in the leaders' homes and these were located all over the UK (a table including Vaccine Critical group locations is provided in chapter 4). Two of these interviews were conducted over the telephone. The interviews varied in length from 33 minutes (a telephone interview) to 2 hrs 27 minutes. The average length for Category 1 was 1 hr 25 minutes. Two interviews with groups in Category 2 were carried out over the telephone but the majority took place in person at the workplace of interviewees; these were predominately in London. The interview times for Category 2 ranged from 53 minutes to 1 hour 47, with an average length of 1 hour and 3 minutes. My initial assumption that interviews in person are preferable to telephone interviews was confirmed in practice. Whilst happy to conduct telephone interviews where this suited the informant, the interviews that took place in person were generally longer (reflecting the greater comfort than speaking on the telephone, and greater opportunities for rapport building), allowed the collection of key documents and allowed some observation to take place. Observation field-notes taken at the time later proved particularly useful for writing chapter 4, which includes discussion of the organisational and strategic aspects of the Vaccine Critical groups.

### **Managing consent**

Although this research did not require formal ethical approval, issues of ethics and consent are still paramount. Even after consenting to be interviewed, consent to be tape recorded also needed to be negotiated. After considering and deciding against the use of written consent forms, an interview protocol was established which involved the careful explanation at the start of every interview that the interviewee could request that the recording device be switched off at any time, and that any discussion during these periods would not be used and would not be attributed to them. Confidentiality or anonymity was not offered; all who took part were contacted and interviewed in their capacity to represent their group or organisation.

In practice, the vast majority of those interviewed appeared unconcerned by the use of the tape recorder. Some asked general questions at the start or end about which other organisations would be interviewed, when the research would be finished, and how the research was being funded. I was asked to switch the tape recorder off only a handful of times by those in Category 1 and 2, often when names of individuals were mentioned. Consent only became a tricky issue in a few instances. Following interview at the Health Protection Agency, the interviewee made clear the expectation that they would be contacted prior to use of any direct quotation. Whilst I foresaw some difficulties with this, I did agree following her insistence. Another issue of consent arose with UVIG, the organisation representing vaccine manufacturers. As a condition of agreement to tape the interview, the informant wanted to be emailed a copy of the transcript to be checked by members of his organisation. In recognition of the sensitivities involved, and mindful of the length of time access negotiations had taken, I agreed to this before the interview began.

Although I remain satisfied that consent was given for interview and the use of interview data, the process of writing up generated some unexpected ethical concerns. This issue will be returned to later in the section on ‘Critical Reflections’.

## **THE PROCESS OF ANALYSIS**

Having explained the rationale behind the research methodology and the process of planning and conducting semi-structured qualitative interviews, this section will explain and justify the type of analytical approach adopted, and the assumptions about the status of the data upon which this relies. All interviews were transcribed in full, in order that they could be subject to a discourse analysis. What kind of discourse analysis adopted is also explained in this section.

### **The status of the data**

How one views the ‘status’ of research data depends on theoretical commitments but also impacts in a very practical way on how data are gathered and, in particular, how that data are subsequently treated. The first point to clarify is that interviews themselves

do not constitute data: the interview is 'transformed' into data, often through the process of transcription. This brief summary helps explain the significance of transcription and why it is an important process to be regarded as the first stage of analysis.

A Conversation Analyst (CA) would record features such as pauses and false starts, as these are seen as relevant for analysis and as a route to understanding what social interactions are going on in the interview. Reflecting my research aims and interest in discourse such minute linguistic details were not transcribed. Instead, transcription recorded the words which were said, plus some key notes of context – such as when someone left the room or asked for the tape machine to be switched off. Despite the serious time commitment involved, all interviews were fully transcribed, with the justification that I was unable to judge the importance of topics at this stage. In practice, the process of transcription proved to be an important and useful method of data familiarisation.

Once transcription is complete, the question of the status of interview data arises again. As David Silverman asks when discussing interviews, do they give direct access to experience or are they actively constructed 'narratives?' (Silverman, 2000). Interviews, unlike other data gathering techniques, involve an exchange. As will be discussed in a later section on the role of emotion, there is a great deal going on in the interview encounter, and a high degree of impression management on both sides. This is eloquently summarised by Dingwall as a 'dance of expectations' (Dingwall 1997 cited in Murphy and Dingwall, 2003, p85).

For some of a positivist persuasion, this 'dance' is one of the root causes of the limitations of interviews as a method of data collection as it reveals that the context of the interview, including the behaviour of the interviewer, has an impact on the data gathered. For others, the dance implies the need for careful consideration of the role of the interviewer and serious reflexivity about the extent to which they are involved in the co-construction of their data. However, I would argue that although documents and websites are produced without direct input from the researcher, they are nevertheless also 'constructed' for a certain purpose with some audience in mind. The question of what status to give data is therefore relevant beyond interviews. As Scott argues,

following Giddens, all texts should be regarded as ‘socially situated products’ (J. Scott, 1990, p34).

The literature provides several dichotomies that are used to capture the different approaches to reading text. On the one side, text can be read in a literal way, as representation of something else (attitude or belief or fact). In this case the analyst is usually interested in analysing content. This approach has been claimed to adopt modernist, positivist assumptions and as being particularly suited to the task of explaining or naturalism. On the other side, text can be given an interpretative (or even reflexive) reading, where both form and content are important in analysing meaning. This approach has been more associated with postmodernism, constructivism and a hermeneutic aim of understanding (see J.Scott, 1990; Mason, 2002; Silverman, 2000).

In practice, such dichotomies are themselves analytical constructs and most research combines elements from both approaches in different ways. This helps to explain why empirical research can often be justly criticised from multiple angles. For example, this research started out with an interest in understanding, rather than explaining, the kinds of arguments made against mass childhood vaccination. Early thinking was also influenced by constructionist approaches in the literature, and this is reflected in the previous chapter, for example in distinguishing between realist and constructivist accounts of risk. The desire to use empirical research to understand the meaning of resistance from the point of view of those actors involved in the debate finds support with the postmodern recognition that there are multiple versions of reality.

However, the eventual analysis took a more literal turn than was expected. As introduced in chapter one, the research is presented in order to answer the overarching research question: *How is resistance to childhood vaccination best understood?* Through the process of analysis I therefore retained a sensitivity as to how ideas, such as risk, were used by informants. However, the subsequent chapters also reflect an interest in what my informants said about, for example, trust in society, and about what it is then possible to conclude about wider relationships between trust, risk and attitude to science. In other words, the data has been treated as a vehicle to access meaning located outside the interview encounter or the document. As will now be highlighted,

for some commentators this treatment of the data undermines my claim to discourse analysis.

### **Discourse analysis**

As explained in the section above on ‘case selection’, ten groups were identified for analysis. Interview transcripts, documents and websites were then treated as data and analysed. An early decision was made not to use a computer package such as NVivo; previous experience suggested the tendency to encourage the creation of category after category, without leaving enough space and time for critical thinking and in-depth analysis. Whilst the use of software is no doubt useful for some studies, (particular research with more than one investigator), a more ‘manual’ approach was successfully adopted.

Instead of creating trees and nodes on NVivo, ten separate ‘analysis’ electronic files (one for each group) were created. These files include observational notes made after each interview, notes from initial analysis of document and webpages, some of them very rough and speculative, and also some direct quotes cut and pasted from the interview transcripts. Next, these ten files were compared and contrasted. Several ‘themes’ or ‘topics’ reoccurred within and between the groups. Themes identified included those related to various actors (the media, doctors, the government, parents, other Vaccine Critical groups), processes (setting up, campaigning activities, membership) and conceptual dichotomies (such as health and disease, the natural and the unnatural). The three ideas of risk, trust and science emerged as primary themes, although these were used in very different ways and so necessitated the construction of several sub-headings. A personal system of signs and symbols was also used at this stage as a way of indicating potential relationships between themes or empirical examples. All original transcripts and documents were then reviewed again to check whether the themes and subheadings sufficiently captured the arguments made by the groups. The subheadings were then expanded, added to, collapsed or refined (see coding frame in appendix 6). Overall, what is essentially being described is data interrogation and the construction and validation of analytical categories. But what kind of analysis does this represent?

The stated aim of the research was to carry out a type of discourse analysis (DA). This approach was initially attractive for several reasons: because of the desire to discuss arguments and claims, rather than perceptions or variables such as gender or class, the concept of discourse seemed a good fit. In addition, discourse includes the idea of imaginaries – how things could or should be (Chiapello and Fairclough, 2002) - and this chimed with an early observation about the importance of claims about alternative futures and histories for those involved in critiquing vaccination. Whilst aware of the arguments claiming a differences in status between interview and website or document data (the former being more co-constructed, see Bondi, forthcoming), DA is useful in allowing the treatment of all documents as text or discourse, for the purposes of analysis. I was also comfortable with the associated epistemological position that knowledges are generated and circulate in society as discourses (Chiapello and Fairclough, 2002). The term discourse is also closely associated with Foucaudian approaches and his description of ‘discursive formations’ (Marshall, 1998, p162-163). Using this term therefore represents a level of consistency, given that a kind of governmentality approach is taken in order to discuss vaccination policy (see chapter 4).

However, as became clear from reading the wider methods literature, the term discourse or discourse analysis is used in numerous ways and passionate debate continues in pages of journals like *Discourse and Society*. For some, discourse has a very narrow meaning referring to a specific activity; for others it is about a whole social system (Howarth, 2000). Others have debated whether or not it is a method or a paradigm of research (Hammersley, 2003). Whilst reviewing the whole literature on discourse is not possible here, some reflections are required in order to situate this research.

On one understanding of DA, the strategies just described and the way the data are discussed in the chapters that follow does not constitute DA. For example, Martyn Hammersley argues that one of the things that DA and CA share is ‘a refusal to treat what the people studied say about the social world as a source of information about it’ (Hammersley, 2003, p752). In elaborating on Potter and Weatherall’s model of DA, Hammersley stresses that they have a central concern with discourse as action and ‘on this basis they specifically reject the representational model of language, whereby statements are held to correspond to phenomena that exist independently of them’ (Hammersley, 2003, p756). Elsewhere Potter himself has made clear that DA should not

be used for accessing accounts (Potter, 1996). In other words, this vision of DA requires that the analyst does not aim to uncover things about the social world but rather aims to demonstrate how language strategies are used to make arguments. In the chapters that follow interview and document data *are* used as a way of accessing arguments and as evidence of certain understandings of concepts like trust, concepts that are separate to the interview encounter. On this reading, my analysis thus bears more similarity with a thematic content (Burnard, 1991) rather than discourse analysis.

However, Potter and Weatherall's model of DA is one example, albeit an influential one, that has been taken up by many analysts beyond its origins in social psychology. Outside the methods literature there are examples of DA in use that correspond more closely to the type of analysis eventually adopted for this research. Michael and Birke (1994), for example, claim to have investigated discourses in their analysis of scientists' accounts of animal experimentation. Their aim, in particular, is to assess the response to the 1986 Animal in Scientific Procedures Act. To this end they claim that scientists are 'drawing upon a shared discourse that is articulated in terms of the legislation. Here, we seek to interpret these shared assumptions and representations' (Michael and Birke, 1994, p192-193). Michael and Birke cite all the classic references, such as Potter and Weatherall and Foucault, but explain that they 'employ a representational approach focussing explicitly on the content of discourse rather on its interactive deployment' (Michael and Birke, 1994, p192). This bears more similarity with the approach adopted in the chapters that follow and allows the location of the work within other published research that does claim to adopt a discursive analytical perspective.

## **CRITICAL REFLECTIONS ON THE RESEARCH PROCESS**

The chapter so far has explained and justified the methodological approach adopted and detailed the strategic decisions required. Throughout, the way in which the decisions relate to the original research questions has been made explicit. In the process of justifying decisions, key methodological debates within the literature have been alluded to and referenced. This allows potential criticisms of my approach to be placed within wider and ongoing academic debates. This final section will take a more explicitly reflexive approach by considering some of the more unanticipated dimensions of the

research process - the 'role of emotion' and the 'ethics of publication' - before going on to formally consider some of the limitations of the empirical research.

### **The role of emotion**

In general the interview process was tiring, but extremely rewarding, and the interview agenda worked very well in practice. I was also successful in creating the atmosphere of a purposeful conversation, rather than an interrogative situation (Burgess 1984). In retrospect, the interviews were sometimes highly emotionally charged. There are several possible explanations or understandings of this that relate to the broader question of the relationship between the researcher and the researched. Insights from literature inspired by feminist theory on the role of empathy, identification and emotion are relevant for accounting for some elements of my interview experience (Bondi, 2003; Bondi, forthcoming).

First, the emotional charge experienced could be a result of the emotional nature of the topic: some of the leaders of the Vaccine Critical groups were parents visibly struggling to cope with severely disabled children with suspected vaccine damage (precisely which groups this refers to is clarified in the following chapter). During the interview, other group leaders recounted quite poignant stories of how they were 'woken up' to the problems of vaccination and related episodes where their negative views on vaccination led to being treated badly by health professionals. Whilst aware of these issues in advance of the interviews I was perhaps not prepared for how graphically these were expressed. Focussing on understanding the arguments of groups had encouraged an insufficient appreciation that the interviews were with individuals with very personal experiences as parents. Whilst deciding not to pursue this thought as far as the analysis stage and treat the interviews as examples of story-telling or narration, this experience has aroused my interest in literature which looks at the interview encounter in these terms (e.g. Bulow, 2004).

Second, emotion could be seen as a result of the status characteristics of who I was interviewing. Given those in Category 1 were either 'lay' parents or representatives of religious or alternative groups, emotion could be seen as flowing from the relatively marginal position of these informants, where the interview becomes an opportunity for

‘unburdening’ and a momentary experience of power. As Kleinman and Copp (1993) have argued, researchers may provide legitimacy for informants’ concerns by providing an opportunity for expression (cited in Jarzabkowski, 2001). However, if defined as passion, commitment or frustration, emotion was demonstrated by *all* informants, including policy-making professionals. All seemed genuinely convinced that their position reflected the best thing for children, and at times demonstrated frustration that their arguments were not seen to be heeded. For all informants, then, the interview encounter allowed for the display of emotion. This leads on to the third possible understanding of emotion: that it is partly a function of the method adopted.

During the interview, all informants were engaged in conveying information but also in persuading the interviewer of the rationality of their arguments and in demonstrating competence. This is part of the broader identification of interviews as opportunities for the display of ‘moral adequacy’ (Murphy and Dingwall, 2003, p98). This is no doubt an element of all interview situations but is perhaps felt as particularly heightened by those studying an issue that has a high media or policy profile. Scott and colleagues describe this graphically in their phrase ‘captive of controversy’, used to describe what happens to the researcher when they find themselves being co-opted into the (scientific) controversy they are trying to study (see Scott *et al* 1990). On this reading, the interview encounter becomes a way for the informant, not just to influence the researcher, but to directly influence a controversy in a certain direction.

This literature does help to explain some aspects of my interview experience. At times the interviewees appeared not only to want to persuade me of their rationality, but also to believe that if only they could just convince me of the logic of their position, then my research would echo this and impact positively on the vaccine controversy. In reflecting on her own doctoral experiences, Liz Bondi also recounts such feelings, and the difficulties in expressing these at the time (Bondi, forthcoming). In her discussion of ethnography with primary school teachers, Lucy Jarzabkowski explains the ways in which her participants tried to use her research as a ‘vehicle’ and as an ‘agent of expression’ for views that would otherwise not be heard or acted upon (Jarzabkowski, 2001).

The role of emotion, and the multiple aims of the informants during the interview encounter, could be seen to represent a form of ‘bias’ in the research, or a challenge to the validity of the findings. However, this is not the case for this research, given that the aim is precisely to understand how concepts and arguments are used to defend a particular position. Whether the audience is the interviewer or the parent who accesses their website, the aim is still to persuade. Such a potential criticism is also countered more broadly by arguing that emotion is a key part of the research process itself, regardless of topic, the status of the informant or method adopted. Bondi argues that this also holds true for natural science – moments of inspiration such as Archimedes’ Eureka moment entails intense emotions<sup>1</sup>. More theoretically, Bondi suggests that the traditional call for ‘detachment’ itself reflects a particular emotional commitment. Such arguments are part of a post-structuralist turn which challenges the binaries of emotion and reason, objectivity and subjectivity.

Arguments from this kind of feminist literature did not contribute to the overall process of project planning and definition. However, insights from this literature on emotion have proved useful as a way of making sense of some aspects of the interview encounter, aspects that were not fully appreciated in advance. This may be partly related to a lack of discussion of these issues in the main methods textbooks.

### **The ethics of publication**

As previously indicated, interview informants were not offered and did not request confidentiality or anonymity. However, during the latter stages of the research I did revisit this issue and reflect on the wisdom of this strategy. Once the analysis had been written up, it became easier to see the potential for harm, particularly for the groups in Category 1. As will be demonstrated in the following chapter some of the groups do not have, and do not seek, a high media profile, so would not necessarily appreciate attention as an indirect consequence of the research. Even for those groups who would welcome more ‘publicity’, some would undoubtedly express disagreement with the ways that their quotes have been used and the arguments made on the basis of them.

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<sup>1</sup> The different definitions of science were touched on in the previous chapter and will be returned to in chapters seven and eight.

Some researchers have tried to address these issues by allowing informants to give their feedback on final reports. Such strategies, however well intentioned, do not solve the underlying ethical issues that strike the heart of the research enterprise. To put it crudely, who 'owns' the products of research? If we do then what do we 'owe' our informants? And, more narrowly, who is in the best position to predict harm or judge what is in the informants' interests: the researcher or the researched? This final point is related to an issue, much discussed in the literature, about the meaning and nature of consent and of informed consent.

After carefully considering these issues it was decided to use the name of the groups or organisations, but remove the names of individuals (such as the names of children) where these were provided. As promised before the interview, quotes were not used where the informant requested it or requested that the tape recorder be turned off. Names of the groups were included after the recognition that their removal would not necessarily have removed the ability for groups and individuals to be identified, especially in a relatively small world (Jarzabkowski, 2001) of vaccination policy-making or vaccine campaign groups. Given that part of the aim of research is to characterise the groups in order to understand the nature of vaccination resistance, identifying characteristics of each group and naming them is a fundamental step in the analysis process. In addition, due to the availability of websites for most of the groups, the use of pseudonyms made little sense.

Murphy and Dingwall contrast biomedical with ethnographic research and cite other studies that claim that for the latter, the greatest risk 'arises at the time of publication' (2001, p341). This argument is useful in contrasting the different types of research. However, my experiences challenge the assumption that difficult ethical decisions come at the end of the research process.

First, for those committed to an academic career, the increasing pressure to publish earlier in the PhD process is likely to result in increasing numbers of students who have published some aspects of their research, whilst access negotiations are still going on. In my case this meant that some informants had read some of my work before the interview. Whilst this actually helped access in some cases, particularly with policy-makers, this also gave the informants the chance to quiz me before and during the

interview on my arguments, and challenge the way in which I had previously referred to their organisations. This is, of course, entirely legitimate behaviour. For more established researchers, being judged on one's publication record, is to be expected. The point is that such issues can also apply to doctoral students and that caution is merited before publication, whenever this takes place, and may impact on access or interview processes in unanticipated ways.

Secondly, some of these issues are relevant for those without formal publication. Three informants indicated that they had searched for my name online after receiving the request for interview letter, and found information on the research through University web-pages and various conference papers and abstracts. What this experience brought into focus was the capacity of those being researched to carry out research of their own, just as I had carried out research on them prior to the interview encounter. Whilst one could object that these experiences are specific to studying highly controversial topics, this could also be taken as evidence for the way in which the internet does not just provide more opportunities for research sampling, access and dissemination, but also carries various risks and increases the likelihood that the researcher will themselves be researched.

### **Research limitations**

The section on 'case selection' in the first part of the chapter explained the decision to only carry out in-depth analysis on the data collected from the ten Vaccine Critical groups. This decision was made for practical and theoretical reasons in allowing me to approach the analysis with enough depth, and overcome the early underestimation of the time needed for interviewing, transcription, and discourse analysis. One of the ways in which the study could be strengthened would be to continue the process of analysis on this original data in order to capitalise on the benefits of the symmetrical research approach as first envisaged. The thesis has relied on documentary and website sources at times in order to summarise a policy or public health position. A more sustained analysis of the interview data would be helpful in this regard. Similarly, analysis of interview data from religious and alternative health groups would help to clarify the position of the ten Vaccine Critical groups, by investigating the extent to which shared

discourses are used. Further analysis and publication of this wider data set is planned following the thesis write-up period.

Chapter one made clear that the focus of the research is on vaccination resistance in the UK. Although the discussion on risk, trust and science is relevant to other areas of social science, caution should be exercised in assuming that the particular case study is generalisable internationally. One of the difficulties is a relative lack of empirical research from other countries, and therefore an inability to compare and contrast UK data with other countries. However, the literature review of the existing research suggests that there would be significant differences between countries. For example, the next chapter makes clear that childhood vaccination is currently voluntary in the UK. This is in contrast to the US where a discourse of rights is expected to be more important to vaccination resistance.

And finally, one of the key limitations of this study is that it is derived from data from vaccine campaign groups and does not include empirical research on individual mothers or parents making vaccine decisions. In other words, the research questions are about vaccination resistance, as a social phenomenon, rather than individual vaccine decisions. This focus is one of the strengths of the study and one of the reasons why the research is an original contribution to the literature. However, this means that findings from this study cannot be automatically generalised to a wider population of parents without further research. This research is thus limited in its claims to be able to account for individual or 'public' views on vaccination. Using a discourse approach, what can be hypothesised, however, is that the discourses drawn upon by the groups under study may well be shared by those outside the groups. After all, individuals draw on culturally and socially embedded narratives and concepts, just as groups do. The next chapter touches on this issue in explaining the kind of approach to social movements adopted by this research.

## **CONCLUSION**

The research is designed to answer the over-arching question: *How is resistance to childhood vaccination best understood?* This chapter has explained how this question

has guided the stages of the research project but how, at the same time, the specific research questions have evolved and been clarified throughout the research process. Rather than a simple chronology, the discussion is perhaps more accurately described as a 'political history' which illuminates some of the reasoning behind the strategic decisions made, and how these relate to broader debates in the methodological literature.

The chapter described how an original interest in opposition to vaccination was first broadened through literature review and actor mapping, and then narrowed by focusing on policy-makers and the 'anti-vaccination movement'. Once interviews were completed with these actors, further sampling was required to narrow down the data, define vaccination resistance, and promote a more in-depth analysis. This additional focussing partly represents an initial underestimation of the time needed to carry out a detailed discourse analysis but also reflects the nature of the topic; because little had been written about organised resistance, scoping research was first necessary in order to more confidently map out the empirical world to be studied. This explains the rationale behind the first research question which requires an investigation of the *organisation of* vaccination resistance. The type of analysis was labelled as a form of discourse analysis, although the approach does not fully reflect the understanding of discourse as action that some proponents demand. What a version of discourse analysis allowed was a focus on arguments, including imaginaries, and the ability to treat all sources as text to be analysed.

The chapter also provided some critical reflections on the personal experiences of organising and carrying out interviews. Drawing on existing research influenced by feminist theories, it was argued that the interviews were highly emotionally charged and that this can be understood in several ways. Rather than explained as a problem for the researcher, the status of the interview data or as evidence of bias, emotion is instead evidence of the multiple functions of interviews. It is therefore a key part of the research process, whether this is recognised or not.

Ethical issues were discussed throughout the chapter, including the contested notion of consent and informed consent. Strategies such as the use of written consent forms or allowing informants to check transcripts were not used, and fail to solve the underlying

questions over, for example, the ownership of data. Publication was argued to represent a critical moment for the researcher in terms of ethics. This research experience demonstrates how this can apply earlier in the research process and career than may have been assumed, and can affect access to, and relationships with, interviewees in positive, negative and unanticipated ways. The chapter also referred to the limitations of the research, in terms of generalisability. In short, this research was not designed to offer firm conclusions about the reasons for individual vaccination refusal, and nor can the results be automatically generalised cross-culturally. This issue will be returned to in the concluding chapter when the prospects for further research are considered.

As stated, ethical issues were referred to throughout the chapter, rather than in one defined section. This also applies to the theoretical framework. This structure was consciously chosen in recognition of the embedded nature of ethics and theory within research, and the observation that these are relevant in different ways at different stages of the project. In summary, this chapter has explained that the research reflects an ontological assumption about the importance of institutions and groups as social actors. Epistemologically, knowledges are assumed to be constructed as discourses that can be accessed through a type of discourse analysis. The research is guided by a more inductive approach and the rejection of *a priori* assumptions about the meaning of the debate for actors involved; this in turn encouraged a methodological design which allows significant space for informants to define the issue in their own terms. This explains why the second research question, and the importance of risk, trust and science, only emerged gradually throughout the research process. This approach is particularly appropriate, given the relative lack of existing empirical data on vaccination resistance from which to build, and given the advantages of more qualitative and ethnographic research on resistance to technology, discussed in the previous chapter.

The remainder of the thesis moves away from theoretical and methodological issues to look in detail at the arguments used by the Vaccine Critical groups and how notions of risk, trust and science are relevant for an understanding resistance. Before considering these in turn, the next chapter discusses vaccination and vaccination resistance. The individual, it is argued, is subject to an imperative of vaccination. The chapter also introduces the groups themselves, combining both published literature on historical and

current developments, and new empirical evidence based on interviews, observation, and website and document analysis.

## Chapter 4: Vaccination and vaccination resistance

Vaccination is often held up as one of the greatest success stories of modern medicine, as stated in chapter one. Such claims to dramatic benefits are common in the scientific and medical literature and it is easy to become acclimatised to these statements. However, in order to understand vaccination resistance, these success narratives need to be taken seriously. Recognising the power of such narratives is crucially important as a first step to understanding vaccination and for anticipating the vaccination critique. This chapter therefore proceeds from the assumption that in order to appreciate the significance of resistance to vaccination it is necessary to understand critically vaccination policy and practice.

The chapter is divided into three sections and makes reference to both existing literature and new evidence from the empirical study. The first section introduces the topic of vaccination by focusing on the main actors: the state, the medical profession, and the parent. The discussion confirms the importance of risk, trust and science for vaccination but concludes that, overall, vaccination promotion is best understood in terms of an ‘imperative of vaccination’. In essence, the function of this discussion is to answer the first research question: *How is resistance to childhood vaccination organised in the UK?* The objective of the following three chapters is then to reveal how mass vaccination is challenged or undermined.

Section two demonstrates the relative lack of empirical research on public opposition to vaccination, particularly on organised resistance, but reviews the small amount of existing literature and commentary that tries to explain vaccination concerns. Rather than a micro analysis of each group under study, the objective of the third and most substantive section is to provide a broad introduction to the ‘Vaccine Critical groups’ as the empirical focus of the research, and to justify the analytical categories used throughout the rest of the thesis. In doing so, this final section directly contributes to the answering the second research question, by starting to reveal the nature of vaccination resistance in the UK.

## VACCINATION IN THE UK

In order to understand the meaning and significance of resistance to vaccination it is first necessary to develop an understanding of vaccination itself. As indicated in chapter three, vaccination involves several actors. For the purposes of this discussion, this will be simplified to the state, the medical profession, and the parent. In order to provide the necessary background, the chapter begins by summarising the scientific theories that underpin vaccination strategies. Building on Lupton's (1995) discussion of the imperative of health, the section concludes by arguing that the individual is subjected to an 'imperative of vaccination'.

### Science and vaccination

In the medical and scientific literature, vaccination is usually referred to in glowing terms. For example, the global eradication of smallpox in 1979 has been labelled as 'one of humankind's greatest triumphs' (Spier, 2001, p82). Vaccination in general is claimed to be responsible for a dramatic decline in disease and mortality from infectious disease, although this has been challenged by McKeown who argued that measures other than vaccination should be credited (McKeown 2001 [1976]; Szreter, 1995; Garratt, 2000; Illich 1976). As highlighted in chapter one, vaccination has also been described as 'a cornerstone of preventive medicine' (Streefland 2001) and 'one of the greatest public health success stories' (Poland and Jacobson 2001). It is also claimed to be 'unquestionably one of the most cost-effective public health measures available' (Ehreth, 2003, p599). For example, supporters claim that for every \$1 spent in the US on the MMR vaccine, \$21 are saved in direct medical care costs (Ehreth, 2003, p598).

This great success story relies on a strong historical narrative which dates back to the experiments of Edward Jenner. In a presentation to the Royal Society in 1786, Jenner explained that he was able to prevent smallpox by inoculating people with the scabs of those infected with cowpox. The inoculation induced cowpox, a mild viral disease, but succeeded in preventing smallpox. The term vaccine is derived from *vacca*, the Latin for cow (Wolfe and Sharp, 2002) and was used by Louis Pasteur in retrospect to describe Jenner's invention. Apart from smallpox, the majority of the vaccines now in

use were developed in the twentieth century, including polio in the 1950s and measles in the 1960s. A recent review of vaccination science calculated that there are now 26 'vaccine preventable' infectious diseases (André, 2003). ✕

Vaccination is not only a symbol of historical success for modern science and public health but also functions as a symbol of future hope and medical progress. The scientific literature talks enthusiastically about possible advances in 'vaccinology'<sup>1</sup> including live vectored vaccines (where foreign DNA is inserted into a virus), chemical synthesis (to produce synthetic vaccines) and new ways of delivering vaccines, such as in foodstuffs (Blume and Geesink 2000, pp52-53). Vaccines against chronic (rather than infectious) illnesses, such as cancer, heart disease and Alzheimer's disease are seen as 'the next great frontier for vaccine development' (Levine *et al*, 2002, p7). ✕ Vaccination also frequently appears in popular, as well as scientific discussion of public health. For example, the recent outbreak of SARS saw the media debate shift almost immediately from containment strategies to the search for an effective vaccine (BBC news 31/3/04). ✕

The aim of vaccination is disease prevention and, in some cases, like smallpox, the ultimate eradication of the disease<sup>2</sup>. Vaccines work by stimulating the immune system to produce specific antibodies to a particular disease (Bedford and Elliman, 1998). The scientific principle behind vaccination is the germ theory of disease, linked to the laboratory work of Koch and Pasteur who saw that 'the origin of many diseases is in the morbid influence of certain fungi, which are introduced into the organism by means of their germs or spores' (Oxford English Dictionary, 1989). The germ theory remains important to modern clinical healthcare (Peterson and Lupton, 1996, p32) but should be understood as representing a break with previous understandings of disease causation, such as that popularised by Edwin Chadwick, for which odour played a central role. Until the rise of the germ theory, the public health movement was not regarded as scientific and was more concerned with the containment of epidemic diseases such as plague, through quarantining individuals, rather than the prevention of endemic ones through surveillance and intervention at the population level (Lupton 1995; Peterson

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<sup>1</sup> Vaccinology refers to the development, production and use of vaccines. This term is credited to Jonas Salk in the 1970s as discussed in Blume and Geesink, 2000, p53.

<sup>2</sup> Eradication is not possible for those diseases that live outside the body, such as tetanus (Department of Health, 2004b)

and Lupton, 1996). Dew cites Tesh's (1988, p38) claim that the germ theory is now 'virtually synonymous with science' and argues that 'vaccines, along with antibiotics, symbolically represent the medical profession's ability to battle against these germs' (Dew, 1999, p383).

As well as the germ theory, mass vaccination (such as childhood vaccination) relies on the theory of herd immunity. This describes a situation when 'a sufficiently large number of individuals are immunised [so] transmission becomes less likely as there is less disease in the community as a whole' (McGuire, 1998, p12). Achieving herd immunity means that those who cannot be vaccinated for medical reasons (such as those with a compromised immune system), those who are not vaccinated (for whatever reason), and those who are vaccinated but do not become fully immune, are still protected from the disease. The percentage of a population required to be vaccinated to achieve herd immunity varies by disease. Measles, which is highly contagious, is estimated to require 95% coverage. Ironically, if vaccination levels fall below the target then mass vaccination can actually have a detrimental effect, as this may increase the age at which those who do so catch the disease, thereby increasing the chance of medical complications (McGuire, 1998, p12). The scientific theory of herd immunity thus creates a very strong incentive for high vaccination rates.

In summary, vaccination functions as a crucial symbol of historical success and hope for modern science. In claiming to be responsible for disease reduction and eradication, vaccination also serves as an example of the 'undisputable benefits' of modernity (Wikipedia, 2005). In turn, science is the system of knowledge that is used to justify vaccination. In other words, vaccination both borrows legitimacy from, and bestows legitimacy on, science. This links back to the argument made in chapter two, about science as an icon of modernity, and about the relationship between science and medicine and the 'badge of empiricism' that science provides (Weatherall, 1996). An awareness of the scientific development of vaccination is a prerequisite for understanding the current relationship between science and vaccination. However, this summary does not sufficiently explain the political nature of vaccination. Without the support of the modern state, vaccine technology would not have achieved its dominant role in preventive healthcare.

## The state and vaccination

The story of the development of public health and vaccination, and the development of the modern state, are intertwined. The widespread use of vaccination in England began in the mid-nineteenth century with the introduction of the smallpox vaccine. This locates vaccination firmly in the post-Enlightenment period<sup>3</sup>, characterised by the emergence of the dual ideologies of statism and scientism. Statism assumes that the state has responsibility for the protection of the population. This ideology was in line with the economic desire to promote a healthy workforce. Scientism assumes that rational thought and the scientific method comprise the route to human progress (Lupton, 1995, p22).

In this historical context of statism and scientism, the public health profession emerged as an important mechanism for the surveillance of the population and was vested with the authority of the state. As well as surveillance, this authority allowed for and continues to justify quite drastic intervention. Indeed, one of the only purposes for which an individual can still be legally detained against their will or quarantined, where no crime has been committed or suspected, is in the name of public health (Martin, 2004).

In terms of vaccination, the introduction of state sanctions should be seen as part of this broader public health picture. By the 1840s, legislation had been introduced to enable vaccination at public expense (Howard, 2003). The Vaccination Act of 1853 made vaccination compulsory for all infants under three months and introduced measures to fine or imprison those parents who refused (McGuire, 1998). This was enforced through the appointment of special vaccination officers. The 1853 measures were extended in 1867 to cover those up to age fourteen (Wolfe and Sharp, 2002), making it a criminal offence for a parent to deny vaccination to a child under this age (Howard, 2003). Historically, vaccination was therefore associated with a high degree of state intervention, including coercion.

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<sup>3</sup> Building on the work of Armstrong (1993) Lupton (1995) discusses different periods in the history of public health: Pre-Enlightenment; Enlightenment; modern public health; and the new public health. As she argues, these periods are complex and characterised by a number of continuities and discontinuities (p46). A full discussion of these is beyond the scope of this chapter.

One of the most significant shifts in the social and political management of vaccination in the UK was the shift from compulsory to voluntary vaccination<sup>4</sup>. In 1898 'conscientious objection' was allowed (the first time such a concept had been used in English law (Wolfe and Sharp, 2002) and a precursor to its use in relation to military service (Durbach, 2002 p82) ). This was followed by the eventual abandonment of all enforcement measures by 1948 and the birth of the National Health Service. There are interesting debates within the ethical literature about whether and in what circumstances compulsory vaccination becomes justifiable (Spier, 1998; Bradley, 1999; Vermeersch, 1999). There is also occasional discussion of re-introducing compulsion into the UK (Rogers and Pilgrim, 1995; BMA 2002), although the Department of Health has stated they have 'no plans' for this (Griffith, 2003). The question of why direct state sanction still seems 'politically untenable' in the UK (Baker, 2003, p4009) is an interesting one and may be related to the level of public dissent in the nineteenth century. The extent to which compulsion accounts for historical resistance is discussed later in the chapter.

Current vaccination policy in the UK is highly centralised. Policy is guided by the Joint Committee on Vaccination and Immunisation (JCVI), an expert advisory committee set up in 1963. Its website explains its remit is to 'advise the Secretaries of State for Health, Scotland, Wales and Northern Ireland on matters relating to communicable diseases, preventable and potentially preventable through immunisation' (Department of Health 2002). The committee is currently chaired by Professor Michael Langman and is comprised of scientific and medical experts, as well as one 'lay member'. A significant proportion of those attending are from the Department of Health. Part of the task of the JCVI is to advise on the recommended childhood schedule (discussed below).

Despite the scientific narrative of success, vaccines are recognised as causing mild and serious adverse reactions in some individuals. However, these risks are seen as tolerated because of the benefits accrued to the majority through the principle of herd immunity. This demonstrates the utilitarianism that is at the heart of mass vaccination strategies. The recognition of the possibility of serious vaccine damage is institutionalised in the

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<sup>4</sup>This contrasts with the situation in some other countries which continue to use degrees of overt sanction: in contemporary France parents must provide proof of vaccination in order to claim child benefit. Parents in the US who want to refuse childhood vaccines must claim exemption certificates, otherwise they will encounter problems in registering their child into a school or nursery. A full comparative analysis requires further research (see chapter eight).

UK as the Vaccine Damage Payment Act 1979. Interestingly, the Department of Health does not deal directly with vaccine damage. Rather, the Department of Work and Pensions oversees the Vaccine Damage Payment Unit (VDPU) which deals with individual claims. The Act allows for a one-off payment to those who suffer serious vaccine damage following a recommended vaccine. Nine hundred and seventeen payments have been made since the Act was introduced (BBC news 16/03/05). However, this body only recognises certain symptoms as linked to vaccination (Dingwall and Hobson-West, forthcoming) and has therefore become a target for some campaigners. The VDPU, and the JCVI are both closely related to their relevant government departments. Arguably, however, their legitimacy is gained, not directly through the ballot box, but through their position as 'experts'. This claim to expertise is, in turn, justified by reference to science (Peterson and Lupton, 1996, pxii). This demonstrates the close relationship between the elements of the discussion so far: vaccination benefits from a strong narrative of scientific success; the political management of vaccination is justified by reference to science.

In summary, this section has detailed the role of the state in public health and vaccination. Implicit in the discussion are several explanations for why the state continues to define itself as the key protector of public health and why vaccination is central to this. Explanations include the economic desire to promote a healthy and productive workforce coupled with scientific claims to cost effectiveness; the utilitarianism of vaccination, which fits well with the collective aims of the liberal state; and, more symbolically, the desire to share the success narrative of vaccination and the hopeful view of modernity it represents.

### **The medical profession and vaccination**

The Department of Health produces a 'green book' (Department of Health, 1996) which is regularly updated and issued to healthcare workers in Britain. This book includes detailed information about individual vaccines and their contraindications<sup>5</sup>, together with the 'recommended vaccine schedule' (Rogers and Pilgrim, 1995, p75-76). The schedule is similar to other developed countries, although the exact timing of

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<sup>5</sup> Contraindications refers to those conditions which, if present, means that vaccination is not recommended or is delayed.

immunisations does differ. As at November 2004, it includes the following vaccines and timescales:

Age	Vaccine(s)	Method
2, 3 and 4 months	Diphtheria, Tetanus, Pertussis, polio and Hib (DtaP/ IPV/ Hib)	One injection
	Meningitis C	One injection
Around 13 months	Measles, Mumps and Rubella (MMR)	One injection
3 years and 4 months to 5 years	Diphtheria, Tetanus, Pertussis and polio (dTAP/IPV or DtaP/IPV)	One injection
	MMR	One injection
10-14 years	BCG (against tuberculosis)	Skin test then one injection if necessary
13-18 years	Diphtheria, tetanus, polio (Td/IPV)	One injection

Table 1: Current recommended childhood vaccination schedule  
Source: Department of Health (2004a)

One of the key roles of the medical profession is the delivery and promotion of this schedule to individual parents. It is these professionals who are the link between the state and the individual, and the actors who are most directly involved in responding to queries about vaccination. The vaccinations are usually carried out by nurses based at GP practices, although there is a debate in the professional literature about the potential for more 'opportunistic immunisation' in locations such as schools and hospitals (McGuire, 1998, p22-23). Since 1990, GP practices have been offered an economic incentive to promote high uptake of the recommended vaccines (Bedford and Elliman, 1998; Rogers and Pilgrim, 1995).

The policy of setting targets for vaccine uptake has arguably proved effective but has become controversial, even within the medical profession. In 2002 the British Medical Association conference heard a motion proposing the abolition of target payments because of the 'detrimental effect on the doctor/patient relationship resulting from the perceived link between medical advice and pecuniary interest' (BMA 2002). In other words, doctors themselves are worried about the possibility of damaging the relationship between doctor and patient. As demonstrated in chapter two, this relationship is traditionally characterised by trust or, more accurately by trust as faith or

deference. The BMA quotation exemplifies how a conflict of interest can be seen to damage this relationship.

The policy of GP payments represents a form of professional incentive. Overall it should be seen as symbolic of the importance attached to vaccination and high uptake by the state, and also a recognition of the central importance of the doctor-patient relationship as the key social context for childhood vaccination. Rogers and Pilgrim argued in 1995 that it signals 'that spontaneous parental compliance was not considered sufficient, in itself, to ensure targets being met' (Rogers and Pilgrim, 1995, p73). More critically, it is also evidence of a professional failure to achieve sufficient vaccination uptake, using existing norms and practices.

Finally, it should be recognised that many healthcare professionals involved in the delivery and promotion of vaccination are themselves parents. Furthermore, they are used to dealing with families on a regular basis and may therefore feel torn between their triple role as parent, as carer for an individual patient, and as the deliverer of national healthcare policy. As such, they have a complex self-identity and are located at the 'interface between official state endorsed, immunisation policy and the immediacy of the reactions of the dissenting recipients of such a policy' (Rogers and Pilgrim, 1995, p82).

### **The parent and vaccination**

Compliance with the recommended schedule and the maintenance of high uptake is crucially reliant on the behaviour of parents; namely in presenting their child for vaccination. Given that childhood vaccination is no longer compulsory, this is encouraged through the use of reminders sent via GP practices, and health promotion material made available through health visitors, GPs and practice nurses. Parental adherence to this schedule is also encouraged through the use of national advertising campaigns. These are sometimes concerned with specific vaccines, such as the £3 million MMR TV campaign launched in 2001 (BBC news, 22/01/01). In short, 'Parents are there to be persuaded' (Rogers and Pilgrim, 1995, p77).

The health promotion literature made available to parents does include limited reference to the risks posed by vaccination, but these are claimed to be vastly outweighed by the benefits, and by the risks associated with contracting the natural disease. For example, a key leaflet that is part of the MMR promotion campaign contains the following table of comparative risks, although the term ‘risk’ is not used. Such figures are calculated through scientific epidemiological research which estimates the risk or chance of an adverse event, such as convulsions.

<b>Condition</b>	<b>Children affected after the natural disease</b>	<b>Children affected after the first dose of MMR</b>
Convulsions	1 in 200	1 in 1000
Meningitis/Encephalitis	1 in 200 to 1 in 5000	Less than 1 in a million
Conditions affecting blood clotting	1 in 3000 (rubella) 1 in 6000 (measles)	1 in 22, 300
SSPE (a delayed complication of measles that causes brain damage and death)	1 in 8000 (children under 2)	0
Deaths	1 in 2500 to 1 in 5000 (depending on age)	0

Table 2: Comparative risk of MMR vaccination. Source: NHS (2001)

The use of such risk communication is built on the assumption that by providing this information the parent will infer that vaccination is the less risky option and duly present their child for vaccination, in accordance with the recommended schedule. Elements of the deficit model of the public understanding of science, critically discussed in chapter two, are therefore visible in strategies to promote vaccination. The next section will argue that this use of risk statistics contributes significantly to the ‘imperative of vaccination’ to which individual parents are subjected.

### **The ‘imperative of vaccination’**

The chapter so far has introduced the topic of vaccination by discussing the role of the key actors. However, a more critical perspective is required in order to indicate how the discourses and practices of vaccination relate to each other and impact on the individual parent. Chapter two referred to Lupton’s (1995) use of the ‘imperative of health’ concept. This governmentality perspective can also be usefully applied to vaccination to

identify, what I have termed, an 'imperative of vaccination'. This imperative is manifested and sustained in several ways.

Firstly, the withdrawal of state sanction should not be seen as the cessation of power in relation to vaccination. Indeed, the concept of governmentality anticipates this move from direct coercion to more indirect forms of power. By monitoring levels of vaccine uptake and local disease outbreaks, the state remains involved in the close surveillance of individuals and populations. The information that this surveillance provides is fed back to the policy-making institutions who then design further interventions, such as targeted vaccine campaigns in certain areas. By justifying this surveillance, and vaccination policy in general, by reference to science, the state promotes 'government at a distance'. This enables the continual management of disease and populations without the need for direct government sanction.

Secondly, the importance of professional experts in vaccination is also anticipated by a governmentality perspective. As argued by Miller and Rose, experts are involved in 'shaping conduct not through compulsion but through the power of truth, the potency of rationality and the alluring promise of effectivity' (1993, p93 cited in Lupton, 1995, p10). As discussed in chapter two, experts and expertise are unlikely to be recognised as coercive because of their appeal to shared norms, such as the desirability of health. In the vaccination domain, this is achieved by reference to scientific 'truths' of safety, need and efficacy. However, experts do serve to constrain individual action. As has been demonstrated, health professionals are closely involved in the surveillance that is an integral part of mass childhood vaccination. There are anecdotal reports of parents being struck off GP lists if vaccination is refused (Rogers and Pilgrim, 1995). This is one example of the practical difficulty of resisting the imperative of vaccination, and going against expert advice. More indirectly, what is being created in the healthcare encounter is the moral distinction between the 'good' parent, who follows expert advice and accepts vaccination for their child, and the 'bad' parent who refuses. This dichotomy has the potential to have a significant impact on individual subjectivity; childhood disease prevention and vaccination acceptance become defined as a marker for the 'good parent'.

And thirdly, risk information is also significant in terms of governmentality. The way that risk information is presented to parents should not be regarded as neutral. Rather, risk creates a particular rationality which encourages and normalises one form of behaviour. This rationality is based on a realist model, dominant in risk communication and health promotion, of the individual as the calculating, rational actor who aims to reduce risk. As argued in chapter two, this realist model has been criticised for failing to admit the importance of uncertainty or unknowns. The use of figures and tables, such as the one reproduced above from the MMR leaflet, does not leave room for any doubt or uncertainty (Peterson and Lupton, 1996, p38). Once these risks have been calculated and advertised to individuals, through the use of devices such as risk tables, it then becomes the responsibility of the individual to avoid or reduce risk.

In summary, the chapter so far has discussed the policy and practice of vaccination in the UK. The aim was not to offer an exhaustive description of the details of vaccines or vaccination but instead to promote a critical perspective. This perspective has revealed that although the state does not use direct force in childhood vaccination, several discourses and practices combine to create an imperative for the individual. Vaccination is intricately linked with science and relies on science for its legitimating and strong historical narrative. Risk is the language of health promotion and is also the language used to construct vaccination as the rational option. Finally, trust or, more accurately, professions and professional expertise, also contribute to the imperative of vaccination. The outcome of this is that the individual parent (on behalf of the child) volunteers for vaccination, not because they are forced by the direct threat of sanction, but as a result of disciplinary power, where each person disciplines him or herself (Shawver, 1999). The next section moves away from the theory and practice of vaccination to a consideration of existing literature on historical and contemporary opposition.

## **EXPLANATIONS OF OPPOSITION TO VACCINATION**

The purpose of this section is twofold: first, to demonstrate that opposition and resistance to vaccination have existed as long as the technology itself. Recent debates about MMR should not therefore only be discussed in their own terms but seen as part of a wider social and historical context. And second, that relatively little empirical

research exists on this topic, particularly in relation to collective or organised resistance. Little is therefore known about the organisation of contemporary vaccination resistance: this explains the formulation of the first research question.

### **Historical opposition to vaccination**

As argued above, vaccination in nineteenth century England was subject to increasing sanction as the state became more closely involved in public health. There is a small but fascinating social history literature which documents opposition to vaccination during this time and looks at the birth of organised opposition in the form of groups like the Leicester Anti-Vaccination League and critical publications like the *Vaccination Inquirer*. Several of the accounts demonstrate the successes of organised campaigns which inspired marches of up to 100,000 people, riots, burning of effigies of Edward Jenner, and the celebration of martyrs (Beck, 1960; Porter and Porter 1988; Durbach 2000). Wolfe and Sharp also credit the anti-vaccination movement with changes in the law in 1898 allowing ‘conscientious objection’ (2002). Other accounts have stressed the impressive ability of the ‘anti-vaccinators’ to harness the power of the press (Howard, 2003, p22) and the important role of key individuals in pushing forward the movement (Porter and Porter, 1988). Organised resistance may also have had a part to play in reducing vaccine uptake: Howard documents the fall in vaccination rates to 3% in 1890 in Leicester, a town labelled the ‘home of resistance to vaccination’. Nationally the figures fell from 96% in England and Wales in 1875 to 78% in 1889 (2003, p24).

So how has historical resistance to smallpox vaccination been understood? Howard’s explanation is centred around parental apathy due to the steady decline in disease, ‘coupled with the Victorian strength of feeling that government should advise, persuade and provide rather than coerce’ (Howard, 2003, p24). Other accounts also focus on the compulsory nature of vaccination as a source of discontent. Porter and Porter have labelled vaccination opposition as an expression of the desire to maintain the boundary between public and private life and to restrict state interference (Porter and Porter, 1988). Gladstone himself spoke of vaccination as an attack on ‘private liberty’ (Beck, 1960, p316).

Dubach's approach differs to most of the social history accounts by claiming that the majority of historians have looked at middle-class resistance, which may indeed have been concerned with the violations of libertarian principles. In contrast, her analysis suggests that compulsory vaccination was perceived as targeting working class infants and that 'working people claimed they were pathologised as filthy and contagious' (Durbach, 2000, p49). This was partly to do with the close relationship between vaccination and administration of the Poor Law, seen as a symbol of class oppression (Baker, 2003). On this reading of history, vaccine resistance was also about resisting negative class identities and the regulation of the working class body.

These political dimensions are important. However, an alternative reading of the literature suggests that opposition should not be solely understood as about liberty, freedom or class and other discourses were also vitally important, both before and after the 1853 Act. These other reasons include the belief that vaccines cause idiopathic (Illich, 1976) illnesses. For example, the 1878 National Anti-Compulsory Vaccination Reporter argued that 'dangerous illnesses' such as diphtheria, abscesses and bronchitis follow the vaccination process (cited in Wolfe and Sharpe, 2002, data box A). Today this would be analysed in terms of risk.

Porter and Porter discuss the 'ideology of anti-vaccinationism' and cite MacLeod's contention that resistance was also about resisting 'new science' and a public distrust of scientific medicine (Porter and Porter, 1988, p236). As argued above, vaccination rests on the germ theory of disease which sees illness as a result of a chance encounter with a germ. This contradicts religious views about the meaning of illness, which were dominant in early discourses of public health and may account for some of the resistance (Porter and Porter 1998; Spier 2001). Elston (1994) also reminds us that the germ theory would have been seen as quite radical at the time and in contradiction to other understandings of health and disease. Chadwickian understandings of health and disease still prevailed to some extent so that 'the germ theory of infection, when first presented, found lukewarm reception' (Beck, 1960, p313). This scepticism was not confined to the lay public but also included medical experts who were suspicious of contagion theories and the claims made for vaccination. In other words, dimensions of trust and claims to expertise are also relevant to an understanding of historical

vaccination debates. Similarly, vaccination was contested on scientific terms, in relation to prevailing paradigms and medical models of illness.

This brief historical perspective establishes that concerns about vaccination are as old as the technology itself. Concerns did not suddenly emerge in 1990s with media interest in the MMR vaccine. Multiple explanations for resistance have been identified: parental apathy due to declining disease rates; libertarian objections to compulsion; and resistance to working class identities. Concepts of risk and science can also be used to help an understanding of historical resistance. Overall this summary confirms that ‘objection to vaccination has never just been about disease levels *per se*, but a complex set of social and political responses to a political issue’ (Hobson-West, 2004, p90). Some interesting parallels can be drawn between the interweaving of concerns in the 19<sup>th</sup> century and more contemporary debates.

### **Contemporary opposition to vaccination**

Since the birth of the NHS and the widespread use of childhood vaccinations there have been two prominent examples of falling vaccine uptake; DTP (Diphtheria, Tetanus and Pertussis) in the 1970s, and MMR from the late 1990s. This section does not provide a detailed political history or chronology of events (see Baker 2003; Fitzpatrick, 2004; Horton, 2004). The main aim is to provide an outline of the main points that is sufficient to allow consideration of the explanations that have been offered for resistance.

In the 1970s, national uptake of the DTP vaccine fell from 80 to 30 percent. Notifications of whooping cough went up, and by 1988 the number of deaths was calculated at ‘over 70’ (Nicoll *et al* 1998). The impact of the controversy was also felt internationally, including in Japan and the US (Baker, 2003). This crisis is usually blamed on publication of a 1974 article by Kulenkampff and colleagues in the journal *Archives of Disease in Childhood* which was based on a study of 36 children admitted to hospital suffering from neurological complications following the DTP vaccination (cited in Fitzpatrick, 2004, p23).

This episode has frequently been identified as the precursor to current concerns over MMR, and limited attempts have been made to compare and contrast the events (Baker,

2003). The case against the pertussis (whooping cough) part of the vaccine was taken up by Gordon Stewart, a Glasgow University medical professor, and his enthusiastic campaigning, publicised by the media, is blamed for the subsequent fall in uptake (André 2003; Fitzpatrick 2004). Indeed, André claims that unsubstantiated vaccine hypotheses are usually the origin of 'one zealous champion' (André, 2003, p594). A parent group called The Association of Parents of Vaccine Damaged Children (APVDC), founded in 1974, was a key player during the 1970s in campaigning for a safer pertussis vaccine and agitating for the introduction of the 1979 compensation legislation<sup>6</sup>. According to Baker, the APVDC 'countered the media's natural short attention span, and succeeded in sustaining the national spotlight on the alleged dangers of vaccination' (Baker, 2003, p4007). Baker's analysis is also useful in stressing that concerns were expressed within the medical profession, as well as amongst the lay public. Reflecting this uncertainty, no major campaign was launched 'to restore public confidence' until a large epidemiological study found only a small increased risk of neurological damage (Baker, 2003, p4004). Vaccine rates and professional confidence eventually began to rise following failed court cases led by families associated with APVDC. According to Baker, 'by the late 1980s the long whooping cough vaccine controversy was finally losing momentum' (Baker, 2003, p4006).

The most recent fall in vaccination uptake concerns the MMR vaccine. MMR was introduced into the recommended schedule in 1988. National uptake has fallen about 10% from a high of 92% in 1995, and uptake has dropped as low as 62% in some areas of London (BBC news 23/09/04). Like the experience in the 1970s, this fall is usually dated to the publication of one paper, in this case a 1998 *Lancet* article by Dr Andrew Wakefield and colleagues (Wakefield *et al*, 1998). Again like the 1970s, this research was a small-scale preliminary study. Wakefield's research is based on clinical examination of twelve children displaying both autism like symptoms and severe bowel problems. The paper suggested that the two problems may be linked, and reported the view of some of the parents that onset of illness was associated with the MMR vaccine. At a subsequent press conference, Wakefield suggested that it may better to give the

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<sup>6</sup> The topic of vaccine compensation legislation is an important one which cannot be fully dealt with here. For a critical discussion of the current Vaccine Damage Payment Act 1979 see Pywell, (2002). For a detailed political history of the role of legislation in vaccine policy and practice see Geier and Geier (2002).

vaccines singly, until further research was completed. It is this suggestion that is claimed to have resulted in a sharp decline in MMR uptake.

The government continue to recommend the combined MMR vaccine<sup>7</sup>. In defending the decision not to offer single measles, mumps and rubella vaccines on the NHS, a 2002 factsheet states: 'Choice is often an important part of NHS policy and practice. But the NHS cannot provide a vaccination programme that increases the risks to children and unborn babies' (NHS 2002)<sup>8</sup>. They continue to maintain that 'the overwhelming weight of evidence proves that MMR is safe, and the number of studies demonstrating this is growing' (NHS, 2004). The methods of Wakefield's paper have also been attacked as 'clinical anecdote' in comparison to research that rests on an 'epidemiologically sound base'. This same contrast is also made for the 1970s and pertussis concerns based on 'anecdotal case reports' (Nicholl *et al*, 1998). Wakefield himself has also been criticised for a conflict of interest related to way in which aspects of his research were funded and his failure to disclose these at the time of publication (Deer, 2004). Wakefield resigned from his post in 2001 but stated that 'I have been asked to go because my research results are unpopular'. He is now working in Florida (BBC news, 23/02/04).

At the start of this research project in 2001, remarkably little qualitative research was available which looked at public attitudes to, and experience of, mass childhood vaccination (Vernon, 2003). This situation is slowly beginning to change, following sustained media interest in the MMR vaccine (see Poltorak *et al*, 2005 for a rare example of recent ethnographic research on MMR narratives<sup>9</sup>). For present purposes,

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<sup>7</sup> One dimension of the MMR controversy is that vaccination became, to some extent, a party political issue. For example, in 2004 the Conservative leader Michael Howard expressed support for the introduction of single MMR jabs on the NHS, at a time when the government was under increasing media pressure to do so. The opposition also capitalised on Blair's refusal to say whether or not his son, Leo, has received the MMR vaccine. This contrasts with the vaccination of Prince William with DTP amid great publicity in 1982 (Baker, 2003, p4005). Party politics and vaccines also became linked via stories about a contract for the production of a smallpox vaccine being awarded to a large labour party donor (BBC news 13/4/02) Overall, however, it still remains the case that most aspects of vaccine policy are supported by all the main parties.

<sup>8</sup> The controversy over the combined and separate jabs is an important issue, particularly for media discussion of MMR. The issue is not treated as central in this research which explicitly aims to focus on discourses relating to all childhood vaccination and not just MMR. However, the issue is briefly discussed in the concluding chapter in the context of consumerism in healthcare.

<sup>9</sup> This very recent research is based on narrative analysis and interviews with mothers in Brighton. The study concludes that engagement with MMR was as much about issues around personal histories and birth events, as it was around understandings of vaccination (Poltorak *et al*, 2005, p712).

four main types of explanation are visible, several of which relate back to the competing explanations for resistance to technology discussed in chapter two.

First is the argument that it is the media coverage of MMR, described by critics as a ‘feeding frenzy’ (Spier, 2002, p2847) that is responsible for negative public attitudes and falling uptake (Leask 2002). A recent analysis blamed one newspaper – the *Daily Mail* – for continuing to drive the issue (Cricher, 2004). Various high profile reports have been produced to look at the impact and style of journalistic coverage of MMR (Harrabin *et al*, 2003). A recent report by the Science Media Centre entitled ‘MMR: learning lessons’ is explicitly critical of reporting; ‘The overall goal of the Centre is to help renew public trust in science by promoting a more balanced, accurate and rational coverage of the controversial science stories that now regularly hit the headlines’ (Science Media Centre, 2002, p3). The role of the media in relation to vaccination might be assumed to be a contemporary phenomenon. However, as demonstrated in the previous sections, the press was also claimed to be an important actor during the 1970s and even during 19<sup>th</sup> century smallpox campaigns.)

The way in which the media is assumed to impact on attitudes is by concentrating on the dangers of vaccines. This leads on to the second set of explanations which focus on risk. For example, David Salisbury, head of the immunisation programme in the UK writes that ‘the greatest threat comes not from new or re-emerging infectious diseases, but from public loss of confidence in vaccine safety’ (Salisbury *et al* 2002). This suggests that it is concerns over risk or safety that explains attitudes and uptake<sup>10</sup>. A version of this argument, popular in public health, is that the public underestimate the risks from the disease, as they now have less direct experience of such diseases, and overestimate the risks of vaccine adverse reactions (Bedford and Elliman 1998, p1). Paradoxically, therefore, historical vaccination success is seen as undermining itself. What such statements have at their core is the assumption that non-vaccination reflects misinformation or ignorance (Poltorak *et al.*, 2005, p710). In other words, this assumes a deficit model of the public understanding of science. In drawing a distinction between actual risk and the public misperception of risk, a realist model of risk is also being assumed.

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<sup>10</sup> Reference to ‘loss of confidence’ also implies that trust is seen as a key requirement of successful vaccination, an issue that is returned to below.

The third set of explanations concerns the relationship between individuals and the community and utilises the concept of individualism. The argument is that opponents of vaccination are guilty of an individualistic approach to risk. Writing about school vaccination requirements in the US, Hodge and Gostin (2003) state that 'Antivaccinonists tend to view the consequences of mass vaccination on an individualistic basis'. During an interview on BBC Radio 4, a local director of public health complained of 'rampant individualism' as a threat to MMR uptake in the UK (see Taylor, 2004). The director of the UK Public Health Association also argued in *The Guardian* that public panic could partly be down to 'the decline in collectivism. The shift towards individualism means that more people are happy to have a 'free ride' from other people's immunity, thus avoiding the albeit limited risk of side effects' (Rayner, 2002).

This danger of individual free riding is also discussed in the ethical literature on vaccination (e.g. Euro Elsav, 2002). In the context of mass vaccination, the term 'free riding' clearly carries negative connotations, but Rogers and Pilgrim (1995) argue that it is mass vaccination itself, rather than individual behaviour that should be regarded as the anomaly in the current social and political context of healthcare which stresses individual lifestyle. This stress on individual lifestyle is *one* strand of the 'new public health' that has risen in prominence since the 1970s, for which discourses of freedom, responsibility and empowerment are particularly important (Lupton, 1995, p76). This issue is returned to in greater detail in chapter eight.

And finally, the issue of trust is implicitly or explicitly visible in explanations of MMR decision-making. In brief, a lack of trust or crisis of trust is assumed to explain parental non-compliance with governmental and health professional advice on MMR. This assumption is the driving rationale behind research which focuses on assessing health professionals' attitudes, in order to explain different levels of uptake (Bedford and Kendall, 1998; Chen, 1999). This is because health professionals are expected to act as 'champions of vaccines' (Poland and Jacobson, 2001, p2441) and are charged with maintaining levels of MMR uptake (Ramsay *et al*, 2002). This assumes a relationship of trust between doctor and patient. A recent focus group study reported that parents felt unwelcome pressure from healthcare providers to vaccinate (Evans *et al*, 2001) and a

large scale interview study found parental doubts about the financial and political partiality of health workers, doubts that the authors identify as particularly damaging (McMurray *et al.*, 2004). The potential seriousness of perceptions of ‘partiality’ is related to the concept of ‘trust as interest promotion’, as discussed in chapter two. This concept states that trust is placed under conditions where an individual’s interests are expected to be promoted. Financial or political partiality would therefore damage this type of trust.

However, existing literature reveals some disagreement about the role of trust in explaining the MMR issue. Writing recently in the BMJ, Bellaby claims that the idea that the public has lost faith in health professionals and scientists is actually a ‘mistaken belief’, contradicted by survey research (Bellaby, 2005). Brownlie and Howson (2005) carried out a re-analysis of Scottish data looking at how trust is relevant to the MMR issue. They argue that it is important to look beyond trust at this interpersonal level to look at trust in systems, a distinction credited to Giddens (1990) in chapter two. Their findings suggest that a general lack of parental trust in government is expressed. Poltorak and colleagues stress that it is important not to assume that compliance with MMR necessarily equates to trust (Poltorak, *et al* 2005). According to Taylor-Gooby (2002) and others, more research is needed which focuses on the socio-cultural concept of trust as a way of understanding the vaccine debate.

This section has looked at contemporary concerns over DTP and MMR and uncovered some of the key themes that underpin existing literature and commentary. So far the majority of the discussion relates to the role of actors such as the media, health professionals and parents. As indicated in the introductory chapter there is a striking lack of discussion of the role of organised resistance to vaccination. The remainder of this chapter concentrates on this under-researched social phenomenon.

### **Organised resistance to vaccination**

[Rogers and Pilgrim’s 1995 paper identifies the emergence of campaign groups as one of the potential threats to the hegemony of mass childhood vaccination.] However, a literature search suggests that vaccination resistance has not been subject to detailed empirical analysis. The research that does exist is dominated by survey methods or

media content analysis, so that results appear as 'lists' of concerns or lists of medical conditions blamed on vaccination. Much of the commentary does not go much beyond their portrayal as dangerous. For example Crowcroft and Gibbons (2003, p150) describe a 'vociferous collection of anti-vaccination pressure groups [who] maintain constant vigil and take advantage of any opportunity to get their message across'. This section provides an interrogation of the small amount of existing literature which focuses, almost exclusively, on the websites of groups and the press reporting of vaccine critical arguments.

Published in the prestigious *Journal of the American Medical Association*, Wolfe *et al*'s 2002 article is a frequently cited analysis of the websites of organised groups. Using ten internet search engines the authors sampled 22 websites, the majority of which were from organisations based in the US. The article is useful in highlighting some of the key themes that reappear across many of the sites. These include concerns about vaccine safety, government abuses, and a discourse of alternative health (Wolfe *et al*, 2002). As well as analysing content of the sites, the article also includes 'design attributes', listing the characteristics of the sites such as the inclusion of personal stories about vaccine-damaged children. Nasir (2000) has also carried out a review of vaccine critical websites using standard search engines to identify different strands of critique that approximate to the three broad themes identified by Wolfe and colleagues.

The tone of this and similar research, often published in medical journals, is critical, even fearful, of the internet and its increasing availability to non-experts. For example, Halperin (2000) worries about the increasingly professional appearance of vaccine critical websites and Nasir (2000) cites Till's vision of the internet as a 'pandora's box' of misinformation. Several authors have commented on the high number of vaccine critical websites that result from a simple web search (Poland and Jacobson, 2001; Gallager, 2003) and the way that groups can communicate with each other to create an 'emergent anti-vaccine diaspora' (André, 2003, p594).

The second dimension highlighted by existing research focuses on the press reporting of vaccine critical arguments. Cookson (2001) argues that a textual analysis demonstrates conclusively that vaccination, and anti-vaccination views, are becoming more and more discussed by the media. Organised groups are occasionally mentioned in this context as

the sources responsible for negative media coverage. For example, Poland and Jacobson (2001) claim that anti-vaccine groups use the media 'skillfully' (with negative connotations), a claim that has also been made by Howard (2003) in relation to organised opposition to smallpox in the nineteenth century. Streefland (2001) argues that collective resistance to vaccines follow similar paths in different countries and that groups use the media and the internet to spread news around, once initial scientific discussion has been translated into a popular risk discourse. Poland and Jacobson, amongst others, criticise the media's role in this; 'the media and the anti-vaccine groups engage one another without regard to scientific knowledge, facts or credentials'. They describe this graphically as 'scientific terrorism' (Poland and Jacobson, 2001, p2442).

A more detailed analysis by Leask and Chapman (1998) of the Australian print media found eight key themes recur. These are: 'cover-up'; 'excavation of the facts'; 'unholy alliance for profit'; 'towards totalitarianism'; 'us and them', 'vaccines as poisonous chemical cocktails'; 'vaccines as sources of idiopathic ills'; and 'back to nature'. Journalists are criticised for being unqualified in science or medicine and therefore incapable of judging whether 'quasi-scientific claims made by anti-immunizationists have any substance' (Leask and Chapman. 2000, p5). The themes identified by the authors are useful but their main aim is not to critically reflect on these, but to discuss how public health officials should respond to such media stories.

Taken together, such research and commentary is important and could be seen as a contribution to wider social scientific debate about the role of the internet as a source of health information (e.g. Nettleton, 2004; Abbott, 2002; and see BMJ, 2002), and on the role of the media in influencing vaccine and health care decision-making (Harrabin *et al* 2003; Hargreaves *et al*, 2003; Crowcroft and Gibbons, 2003; Kitzinger, 1999). However, such research does not represent a sustained analysis of the organised groups themselves.

There is one notable exception to this general finding in the very recent work of Robert Johnston (2004). His analysis is broad in scope but primarily describes the emergence and activities of the National Vaccine Information Centre (NVIC), the largest vaccine campaign group in the US, led by Barbara Loe Fisher. The chapter is presented as a kind of historical commentary rather than a social scientific analysis. Unsurprisingly,

therefore, a formal methods section is absent but the acknowledgements section makes clear that several detailed interviews were carried out with Fisher and other key activists and vaccine policy-makers. What results is a highly detailed and unusually sympathetic account of the successes that can be attributed to the work of the NVIC, particularly in terms of US legislation and compensation, and of the 'remarkable legitimacy' achieved in the eyes of the media (Johnston, 2004, p260).

Johnston's work is useful in several respects. He confirms the importance of the media and the internet as locations where vaccine critical ideas are expressed, but his analysis goes further. After discussing whether vaccine activism should be understood as left or right wing, he concludes that it cannot easily be labelled as either (p278). For Johnston, becoming a vaccine activist is 'not about ideology but about thoughtful parenting' (p275). He also makes reference to the 'fringes' and the 'mainstream' of the movement (p271) and problematises labels like 'anti-vaccination' and 'anti-science'. Such arguments about science and expertise are explored further in subsequent chapters. The main point is that such a detailed analysis of organised groups in the UK was absent from the social science literature. The final section of this chapter reports those findings from the empirical research which are relevant for an understanding of these actors.

## **THE VACCINE CRITICAL GROUPS**

There is a vast amount of social scientific literature which looks at the study of social movements, and there is growing interest in the analysis and classification of movements that relate to health (e.g. Brown *et al*, 2004; Jones, 2003). This literature will not be reviewed or critiqued here. Rather, the aim of this section is to introduce the key subjects of the empirical research, to allow their claims and discourses to be fully discussed in the following three chapters. This discussion therefore helps answer the first research question: *How is resistance to childhood vaccination organised in the UK?*

In order to provide structure, a conceptual framework is loosely applied which is adapted from Eyerman and Jamison's (1991) approach to social movement studies. They provide a model of cognitive praxis that distinguishes between organisational,

technological and cosmological dimensions. This reflexive approach is particularly attractive in seeing social movements as a 'cognitive territory' and as 'bearers of new ideas' (Eyerman and Jamison, 1991, p3). Eyerman and Jamison's model does not focus on why individuals take part in movements, but rather is aimed at uncovering their core assumptions. In theoretical terms, social movements are analysed as 'symbolic challenges' that upset dominant cultural codes (Eyerman and Jamison, 1991, p48)<sup>11</sup>. This perspective fits well with the approach to discourse that has been adopted and was discussed in detail in the previous chapter.

Taking inspiration from Eyerman and Jamison, this section will first consider the key organisational aspects of the groups under study, highlighting their size and chronology in particular. Second, the strategic dimensions of the groups will be considered. As well as the importance of the media and the web as strategic resources, the groups are also found to fulfil lobbying and support group roles. These roles are not anticipated by the existing literature. Finally, the main cognitive dimensions of the groups are considered. This is done by introducing and explaining the 'Vaccine Critical group' category and in formulating the distinction between 'Radical' and 'Reformist'. These distinctions are used to guide the analysis throughout the rest of the thesis. The key dimensions are summarised in tabular form at the start of each section and collated at the end of the chapter.

### **Organisational aspects**

The following table summarises the organisational aspects of the groups under study. The groups are listed in chronological order (their full names are spelt out below in the final section on cognitive aspects).

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<sup>11</sup> See chapter 2, Eyerman and Jamison, 1991, for a critical review of existing approaches to social movement studies. Also see Strickland, 2000 for a concise review.

Name of group	Date established	Location	Charity status	Approximate number of members/subscribers
APVDC	1974	Warwickshire	No	N/A
JFAVDC	1981	Bristol	No	N/A
AiA	1987	Peterborough	Yes	2000
Vaccination Information	1988	Hull	No	60 <sup>12</sup>
Informed Parent	1992	Worthing	No	1,000
JABS	1994	Warrington	No	2000
vaccination.co.uk	1995	London	No	N/A
Vaccine Victims	1997	Birmingham	No	600
AAA	2000	Glasgow	Yes	Not given <sup>13</sup>
VAN	2002	Derby	Yes	300

Table 3: Key organisational features of the Vaccine Critical groups

As indicated in the table, the groups were started at various times from 1974 to 2002. It is immediately striking that eight of the groups pre-date the publication of Wakefield's controversial paper in 1998 and four pre-date the widespread use of MMR after 1988. As will be discussed, MMR remains an important topic for most of the groups. However, this chronology confirms that organised opposition did not primarily emerge as a response to the MMR-autism hypothesis articulated by Wakefield. The chronological emergence of the groups, and other key vaccine events since 1970 are illustrated graphically in appendix 5.

The table also shows that the groups are not concentrated in one geographical area. Organised vaccination resistance can thus be seen as a national phenomenon. However, as the next section which looks at strategy will demonstrate, a high proportion of the groups use the internet as a means of communication. To some extent, therefore, geographical location becomes less relevant.

Three of the Vaccine Critical groups (AiA, AAA, VAN) are registered charities. This label carries with it various requirements as detailed by the Charity Commission, for example in terms of record keeping and administration (Charity Commission, 2004). The remaining seven groups vary in their organisational type but can all be classified as having a relatively informal structure. During the interview several of the groups

<sup>12</sup> This figure refers to the number of subscribers to Vaccination Information's magazine 'Life-force' but pre-dates the scaling down of activity as a result of the leader working full time.

<sup>13</sup> The group preferred that this remain confidential.

explained their decision not to seek charitable status as being in order to avoid bureaucracy. For example, APVDC stressed:

I said straight off we are not going to be a formal group, we are not going to have rules, regulations and constitutions and all this kind of nonsense, it will take us all our time to campaign and provided all the parents are kept informed of what's going on...We don't get involved in outside nonsense if you like, so we remained...informal (APVDC)<sup>14</sup>.

A very similar argument was made by the Informed Parent during the interview:

Some charities I haven't been impressed with how many people are working within those charities and don't seem to be doing much. Flapping bits of paper around and having meetings about meetings about meetings (Informed Parent).

Table 3 also aims to give an indication of size by stating how many members each group has. The groups differ in size according to this criteria. However, caution is needed before interpreting this as evidence of relative importance, given that some of the groups are more concerned with activities other than securing membership. (This relates to their different strategic functions, to be discussed in the following section). Furthermore, some of the groups do not offer membership at all: [vaccination.co.uk](http://vaccination.co.uk), as the name suggests, functions more like a website providing advice and information. APVDC and JFAVDC, the two oldest groups, are far less involved in campaigning now and are more likely to direct parents with inquiries to other more active groups.

Overall the most important quantitative point is that the Vaccine Critical groups do not have a large membership base. This is one explanation for the groups not having a large number of staff or formalised structure. On the contrary, all the groups were set up and continue to be managed by one or two individuals. This description conforms to Wood's (2000) image of patient groups in the UK which are more likely to be small and run from people's living room and kitchen, in contrast to organisations in the US. The next section moves on to consider the strategic aspects of the groups.

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<sup>14</sup> Text from interview transcripts is signified throughout by indentation and the name of the group in brackets. Text from other sources, such as documents or websites, is specifically labelled as such.

## Strategic aspects

The small amount of existing literature on vaccination resistance was reviewed earlier in the chapter and suggested the importance of the internet and the media as mechanisms by which groups make their arguments. Data from this empirical research confirms the importance of these as strategic resources. However, the data analysis also suggests the importance of other roles and activities, more closely associated with pressure groups and support groups.

The following table summarises the main strategic aspects. The groups are listed according to whether or not they make strategic use of the internet.

Name of group	Web features					Media
	Web-site	Links to other UK and international groups	Message board	Form to report vaccine reactions	Books/ leaflets for sale	High media profile <sup>15</sup>
AAA	Yes	Yes	No	No	Yes	Yes
AiA	Yes	Yes	Yes	No	No	No
Informed Parent	Yes	Yes	No	No	Yes	Yes
JABS	Yes	No	Yes	Yes	No	Yes
Vaccination Info.	Yes	Yes	No	Yes	Yes	No
VAN	Yes	Yes	Yes	Yes	Yes	No
vaccination.co.uk	Yes	Yes	Yes	No	Yes	No
APVDC	No	N/A	N/A	N/A	N/A	No
JFAVDC	No	N/A	N/A	N/A	N/A	No
Vaccine Victims	No	N/A	N/A	N/A	N/A	No

Table 4: Key strategic features of the Vaccine Critical groups

Table 4 shows that seven out of the ten groups have a website, although during the interviews it became clear that some of the groups use this more than others. Of the three who do not, two (JFAVDC and APVDC) were set up at a time which predates the widespread use of the technology. In addition these groups are far less active now so would see little need for this today. Vaccine Victims, the other group without a website, explained this in interview as ‘we are not that kind of group’. This was elaborated to

<sup>15</sup> Assessment of media profile is based on news monitoring from 2001-2005. It is also partially based on interview data which included discussion of contact with journalists and news organisations.

indicate that the group see themselves as having a supporting, rather than campaigning, role, so that their contact with individuals tends to be more person-to-person.

The table also illustrates that the groups' websites have a variety of features. One particularly interesting feature is that, apart from JABS, all the websites carry links to other groups in the UK and internationally, in particular to those based in the US, Australia and New Zealand. This suggests that the groups do have a high awareness of each other. The existence of linked websites could be seen as evidence of 'globalization of a non-economic sort' (Lindenbaum, 2005, p752). Whilst electronic links are not necessarily evidence of substantive agreement, this does explain why commentators refer to an anti-vaccine 'movement'. The use of this term, and its potential problems, will be discussed shortly.

The other web features are less consistently evident for all groups. Several of the websites contain a message board where web users or members can post messages, comments and questions. Three of the groups' websites also specifically allow for and encourage the reporting of vaccine reactions. (This function is analysed in greater detail in chapter seven which considers the role of the groups vis-à-vis science). Together with the availability of books and leaflets for sale, these website features suggest a significant level of interactivity. In other words, the websites are not simply additional fora by which the groups provide information to the public. Instead, the websites and email addresses are practical ways in which the groups receive communication from individuals. This type of interaction is difficult to measure quantitatively and is one reason why only limited implications should be drawn from membership statistics.

As well as confirming the importance of the internet as a strategic resource, the empirical work also confirms the importance of the media in two respects. First, the media is seen as an important resource by all groups, and those with websites have links to news stories, along with critical commentary. News articles are also often the source for articles in magazines and leaflets produced by the groups. Secondly, as indicated in Table 4, some of the groups themselves have become important actors for the media. JABS, for example, is frequently contacted by television, radio and print journalists for their response to various vaccine policy or research developments. As the following section will highlight, JABS is particularly concerned with the MMR vaccine. For this

reason, amongst others, JABS has emerged as the main media target. The profile of Jackie Fletcher, as leader of JABS, bears comparison with the profile of Barbara Loe Fisher, founder of the NVIC in the US, as analysed by Johnston (2004). As well as arguing persuasively that the NVIC are very 'media savvy', Johnston also identifies Fisher as 'the movement's media icon' (p266-267). The same can also be said of the leader of JABS in the UK.

This analysis should not be taken to imply that the groups have a wholly positive and straightforward relationship with the media. Whilst the media may indeed be an important channel through which critical views are expressed, this research suggests that the groups have a more *ambivalent* attitude to the media. During the interviews several groups voiced appreciation for the media, particularly certain journalists, in that they were the first institution to listen to them. AAA for example explained that, in contrast to doctors, politicians and the Joint Committee on Vaccination and Immunisation:

The media, and I've got to say, some of the people in the media are so intelligent, these are not dumbos. These are gifted intelligent people who suddenly could smell a rat because they sat down and listened to the story which nobody else is willing to do and that's why this [the MMR issue] has run and run (AAA).

A few groups, however, also expressed the difficulty they feel in having to condense an argument into a couple of sentences, and some recounted horror stories of being misquoted. Other groups voiced a deeper critique of the media for their lack of interest in reporting the wider issues of vaccination, preferring instead to concentrate on the relationship between MMR and autism or the relative merits of the single or combined jabs.

The documentary and interview data also suggest that the groups engage in other activities, not captured by a narrow focus on the websites or media reporting, that would be difficult to express in tabular form.

First, some of the groups engage in what can be identified as traditional 'lobbying' activities. During the interviews several of the groups gave examples of instances where

they had written to MPs or key figures at the Department of Health. This sometimes led to written exchanges lasting a few months. AAA, the Glasgow based charity, has also had significant contact with Scottish politicians and petitioned the Scottish Parliament for a new autism research and treatment facility. The charity was also involved in the organisation of a march in 2002 through Glasgow city centre (BBC news 20/4/02). A march and demonstration to Parliament Square in London was also organised in 2000 and attended by several leaders of the English campaign groups, including JFAVDC and Vaccine Victims. JABS and AiA are quoted as having supported a petition for single jabs to be available on the NHS (Desumo, 2005).

Marches, lobbying and petitions are activities regularly linked to ‘pressure groups’ defined as organised associations that aim to influence the policies or actions of government (Heywood, 2000, p222). One important distinction in the literature is between ‘insider and outsider’ groups, as a way of classifying which groups are located closer to the centres of power, and aspire to be included, and which groups are permanently left out of the policy process<sup>16</sup>. At first glance, the campaign groups appear to be complete outsiders. As outsider pressure groups, the organisations are therefore left with no alternative but to ‘go public’ (Heywood, 2000) and make their case.

However, the empirical research complicates this picture somewhat and suggests that some of the groups do not always remain outsiders. For example, the leader of AiA was invited to sit on the recent Medical Research Council panel which investigated autism and was subsequently invited, but declined, to sit on another panel related to food safety. As already discussed in the section above on contemporary resistance, the APVDC played a significant role in the development of the Vaccine Damage Payment Act 1979 and was effectively ‘consulted’ on some of the detail. This role has been confirmed by published accounts of the period (Baker, 2003), as well as by the group themselves during the interview.

Second, some of the groups also fulfil a role described by the literature on ‘support groups’ or ‘patient groups’ (Wood, 2000). In the broad sense of the term, all the groups

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<sup>16</sup> There is a lively debate within this literature about the value of these terms for policy science, and various subcategories and clarifications have been offered. See, for example, Grant (1995). Kelleher (1994) credits the insider/outsider term to Katz and Bender (1976).

offer support to members and to others who share their concerns about vaccination. During the interviews, the groups confirmed that part of their original rationale was to bring together people with shared experiences. For example, the Informed Parent claims to have set up in order to;

...counter frustration and isolation experienced by parents in their efforts to seek information about immunisation...Link-up lists will be available for subscribers who wish to make contact with other like-minded people for discussion and support (Informed Parent website).

Some of the groups are more directly concerned with support. For example, Vaccine Victims aims to help parents apply for vaccine damage compensation. AiA and AAA are involved in offering support for families with autistic children. This includes diagnosis, coping with symptoms, finding treatments, and accessing state services. Support is thus both emotional and highly practical. In supporting those who share similar experiences, the groups therefore bear similarity with other patient groups or support groups. These support and lobby roles are unlikely to be recognised by the current over-concentration on the media and internet strategies of the groups.

### **Cognitive aspects**

The following three chapters consider the 'cognitive' aspects of the groups by looking in detail at the arguments and claims made in relation to childhood vaccination. However, two broad cognitive categories that have been developed by the author must first be explained.

In his detailed analysis of vaccine activism in the US, Johnston (2004) argues that the naming of individuals and groups as 'anti-vaccinationists' is itself a crucial part of the story. What is meant by this is that the labelling of resistance as 'anti-vaccination' is part of the way in which the views of activists have been grouped together and marginalised. Similar 'anti' terms have also been widely adopted in the UK (e.g. Gangarosa *et al*, 1998). Given the negative connotations of the term, and the insistence from several of the groups during the interview that they are not fundamentally against the use of vaccines *per se*, another more neutral term was sought.

The term 'Vaccine Critical groups' has been developed gradually throughout the research process after much critical reflection. As the latter part of the chapter has made clear, the groups differ in important organisational and strategic respects. What unites the groups, however, is their critical approach to vaccines or vaccination policy. Such a term can therefore include those such as Vaccine Victims, who identify with a generally positive attitude to vaccination but who still offer a critique of aspects of existing research or compensation procedures.

The term 'groups' may seem self-explanatory but was also deliberately adopted in preference to 'movement'. On a practical level the term 'movement' implies a coherence that the empirical research did not substantiate. The phrase 'vaccine critical movement' would also include individuals, such as certain scientists or journalists, who are vocal critics of vaccine policy but do not align themselves with any particular organisation. 'Groups' is therefore more accurate in reflecting the empirical focus of the research which is on organised resistance. On a more theoretical level, the term 'movement' also carries significant connotations associated with the literature on new social movements. Given the difficulty of labelling vaccine resistance as a social movement of the same order as student, feminist, environmental and peace movements (Byrne, 1997, p26), the term Vaccine Critical groups is preferred. An additional difficulty with the social movement literature, as argued by Byrne, is that it is often quite theoretical and difficult to apply to empirical cases. This difficulty was experienced by Brown in his attempts to classify toxic waste activism (1995) and the environmental breast cancer movement (Brown *et al*, 2004), resorting in the latter case to his own typology.

Similarly, a further typology has been constructed for this empirical work. As detailed in table 5, the groups have been divided into Radical and Reformist categories, in order to capture their significant cognitive differences. The Radical-Reformist distinction, more accurately seen as a continuum rather than a dichotomy, has been borrowed from social movement approaches (see Byrne, 1997).

Name of group	Vaccine focus	Cognitive approach	Cognitive dimensions
APVDC	DTP	Reformist	Personal experience of vaccine damage Broadly supportive of vaccination Focus on one vaccine Focus on compensation and treatment
JFAVDC	DTP	Reformist	
AAA	MMR	Reformist	
AiA	MMR	Reformist	
JABS	MMR	Reformist	
Vaccine Victims	All <sup>17</sup>	Reformist	
vaccination.co.uk	All	Radical	No personal experience of vaccine damage
VAN	All	Radical	Critical of vaccination in general
Vaccination Info.	All	Radical	Interest in all vaccines
Informed Parent	All	Radical	No focus on compensation and treatment

Table 5 : Key cognitive features of the Vaccine Critical groups

Each group will now be introduced in chronological order, within each cognitive category. Following this, a broad summary of the Radical and Reformist approaches will be provided. There are six Reformist Vaccine Critical groups: APVDC, JFAVDC, AAA, AiA, JABS and Vaccine Victims.

#### Association of Parents of Vaccine Damaged Children (APVDC)

APVDC is the oldest group under study and was started in 1974. The founder of the group has a daughter believed to have been damaged by an early version of the polio vaccine. The group was formed after an article the founder placed in a local newspaper prompted a large response, and when they discovered that Germany had a compensation scheme but the UK did not. As described earlier in the chapter, APVDC was involved in campaigning for the introduction of the Vaccine Damage Payment Act 1979. The group has not officially disbanded, but is much less active now. According to the leader, telephone callers do still get in touch via the Department of Health '0-5 years book' given to new parents, the National Autistic Society and through Citizen's Advice Bureau.

#### Justice for All Vaccine Damaged Children (JFAVDC)

JFAVDC was formed in 1981 and is based near Bristol. It was set up by the parents of a child believed to have been damaged by the pertussis vaccine (before the 1979 Act came into force) and was an attempt to highlight the problems associated with the Vaccine Damage Payment Scheme. JFAVDC produced leaflets and fact-sheets but now

<sup>17</sup> Vaccine Victims is concerned with pertussis, polio, hib, meningitis C, and single measles vaccines. They explained during the interview that they do not deal with MMR.

only occasionally takes telephone queries and directs callers onto other groups such as JABS.

### Allergy Induced Autism (AiA)

AiA was established in 1987 and is based in Peterborough. Like AAA, described below, the focus of the group is on autism but vaccination has become a particular concern. AiA concentrate on the food and chemical intolerances experienced by children suffering from autism spectrum disorders. The son of the leader of the group is believed to have suffered severe autism following MMR vaccination.

### Justice Awareness and Basic Support (JABS)

As already noted, JABS currently has the highest media profile of the groups with comments from the founder frequently appearing in national news items (e.g. BBC news 6/11/02; BBC news 7/7/02; BBC news 3/3/05). JABS was formed in 1994 and is based in Warrington. It describes itself as a 'self-help group' that provides information, as well as campaigning for a legal right to compensation. JABS is led by the parents of a son believed to be severely vaccine damaged by a variant of the MMR vaccine. It is unique amongst the groups in having around eight local 'representatives' located in different parts of the country whose contact details are available via the website.

### Vaccine Victims Support Group

In its current form, Vaccine Victims was started in 1997 and is run by a parent from Birmingham with a vaccine damaged child. The leader used to be involved in another of the Vaccine Critical groups but left to start her own organisation. The group does not have a website and does not have a high media profile, preferring instead to concentrate on giving advice to its members. The group represents claimants who have been awarded a Vaccine Damage Payment and supports others in applying. The group leader explained that parents are put in touch by staff at the Vaccine Damage Payment Unit.

### Action Against Autism (AAA)

AAA was founded in 2000 and is based in Glasgow. The leader of the group has a grandson believed to have developed autism following MMR vaccination. During interview the leader confirmed that although they would like to concentrate on establishing autism diagnosis and treatment protocols, the vaccination issue is still

highly relevant for the group. AAA have been particularly active in Scotland and have been involved in lobbying the Scottish Parliament.

In summary, the Reformist groups differ between themselves on several aspects but they have in common a broad view of vaccination as an effective and necessary technology. Interestingly, the data reveal that all the Reformist groups were established by individuals with children or close family members believed to have suffered serious vaccine damage. All share an interest in vaccine safety, compensation and in treatment for the conditions suffered. Whilst still taking a keen and active interest in debates about all childhood vaccines, with the exception of Vaccine Victims<sup>18</sup>, the Reformist groups concentrate on one vaccine.

There are four Radical groups: Vaccination Information, Informed Parent, vaccination.co.uk and VAN. These will now be introduced.

#### Vaccination Information

Vaccination Information is based in Hull and was established in 1988. During the interview the leader described it as a 'campaign group'. The issue of vaccination became important following the birth of the leader's children, but the original impetus for finding out more about vaccines was through concern about vivisection, and the identification of vaccines as products tested on animals. The role of the pharmaceutical industry is seen as a key area of concern that impacts beyond the topic of vaccination. Vaccination Information has been less active recently but still gets weekly phone-calls from parents requesting information and advice.

#### Informed Parent

Informed Parent was set up in 1992 in Harrow, but is now based from Worthing. It is run by a parent who looked into vaccinations when her children were born, and whose concerns were triggered by a particularly critical magazine article. The group leader gives and organises talks to parents in local areas. The Informed Parent also advertises presentations and events, many of which are linked to alternative health such as

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<sup>18</sup> Although expressing an interest in several childhood vaccines, Vaccine Victims does not offer a sustained critique of the use of all vaccines but aims to change aspects of vaccination compensation policy. The group is therefore considered Reformist rather than Radical.

homeopathy. As implied by the title of the group, the stated aim of the group is to provide information and to encourage parents to make an ‘informed choice’ on all vaccines.

#### vaccination.co.uk

Vaccination.co.uk, as the name implies, is primarily a web based site, although the leader has also given talks to local groups on vaccination. The founder is a qualified chiropractor and the group is clearly guided by discourses of alternative health: vaccination is seen as just one example of the ways in which the immune system is compromised. The leader explained that his interest in vaccination was initiated partly in response to symptoms of ill-health described by a patient following a measles vaccine, and partly in the light of a positive response he received after appearing on a national radio programme to talk about vaccination. The group was founded in 1995 and focuses on all vaccines, identifying the media debate about MMR as a ‘red herring’<sup>19</sup>. In common with Vaccination Information, the role and power of the pharmaceutical industry, and its relationship to the state, is seen as crucial.

#### Vaccine Awareness Network (VAN)

VAN was founded in 2002 but was recently ‘relaunched’ as Vaccine Information Service. (The acronym VAN is used throughout this thesis as this was the name in use at the start of the research). The organisation was based in Nottingham but is now run from Derby and has a particularly extensive website. The original impetus for getting involved with vaccination came from attempts by the founder to find out about and avoid vaccines containing animal products. The group’s website includes the strap-line ‘informed: educated: empowered’. This highlights the similarities between this group and the Informed Parent. VAN aims to challenge the rationale behind the use of all vaccines. Once again, the role of the pharmaceutical industry is regarded as central to understanding vaccine policy.

The Radical groups may use similar examples in their narratives to the Reformist groups. For example, they talk a lot about MMR and the perceived negative treatment of Dr Andrew Wakefield. In summary, however, what these groups share is frustration

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<sup>19</sup> This argument is returned to and explained in chapter seven.

at some of the arguments voiced by the Reformist groups. They see many of those arguments, and media debates, as ‘red herrings’ that distract from the more fundamental question of whether or not vaccination in general is the best approach to the management of disease. Consequently the Radical groups aim to challenge the underlying assumptions upon which strategies of mass vaccination rest. In contrast to the Reformist groups, the groups are led by individuals who did not describe personal experience with a vaccine damaged child. Rather, the Radical groups were started by individuals who had another broad interest – such as alternative health or antivivisectionism – that encouraged a critical interest in vaccination to be developed.

Before concluding the discussion in this chapter, a final table is provided to summarise the main organisational, strategic and cognitive features of the Vaccine Critical groups. The groups are listed according to their cognitive dimensions.

Name of group	1) Organisational dimensions		2) Strategic dimensions		3) Cognitive dimensions	
	Date	Members	Internet	Media profile	Vaccine focus	Approach
APVDC	1974	0	No	No	DTP	Reformist
JFAVDC	1981	0	No	No	DTP	Reformist
AAA	2000	Not given	Yes	Yes	MMR	Reformist
AiA	1987	2000	Yes	No	MMR	Reformist
JABS	1994	2000	Yes	Yes	MMR	Reformist
Vaccine Victims	1997	600	No	No	All	Reformist
Vaccine Info.	1988	60	Yes	No	All	Radical
Informed Parent	1992	1000	Yes	Yes	All	Radical
vaccination.co.uk	1995	0	Yes	No	All	Radical
VAN	2002	300	Yes	No	All	Radical

Table 6: Key features of the Radical and Reformist Vaccine Critical Groups

The use of tables in this chapter provides a concise way of expressing some of the differences and similarities between the groups. However, the more interesting nuances, ambivalences and contradictions will only be revealed through the detailed analysis in the following three chapters.

## CONCLUSION

This chapter serves as both a critical literature review of the topic of vaccination and vaccination resistance, and also utilises empirical data to introduce and categorise organised opposition in the UK. It was argued that in order to avoid a narrow understanding of vaccination resistance it is first necessary to understand the importance of mass vaccination strategies.

The shift away from compulsion at the end of the nineteenth century is the one of the significant changes in the social and political management of mass vaccination and public health in the UK. However, this does not mean that the state or power itself becomes irrelevant for an understanding of vaccination. Building on the work of Lupton (1995) on public health, the chapter argued that power has been transformed to form an imperative of vaccination. This imperative is sustained through reference to science, and the legitimacy and claims to rationality this provides; through experts and systems of expertise that construct a moral distinction between good and bad behaviour; and through risk discourses, that assume a particular model of the rational actor and individual rationality. Overall, the discussion demonstrates that vaccination is dependent on an integrated system involving science, the state, and the medical profession. Looking at only one part of this framework, such as science, would overlook the way in which the three dimensions work in combination to create the imperative.

There are two principal implications of this critical analysis: first, that the aims of vaccination, and other technologies of health, should not be regarded as self evident, beyond analysis, or simply justified by science. For example, the fundamental aim of disease eradication and reduction, embodied within mass vaccination, should be seen as part of a wider imperative of health. And second, that resistance to vaccination is likely to have to engage in, and counter, some aspects of this imperative. This is empirically investigated in the chapters that follow.

Where relevant, the chapter has adopted a social historical perspective. This longer-term view is useful in identifying vaccination as the product of a particular historical and cultural context characterised by the increasing involvement of the state and science in public health, an emerging concern with population level surveillance and preventive health, and new ideas about disease causation. There is evidence that discourses of public health continue to shift and we are now witnessing a 'new public health' (Peterson and Lupton, 1996) which includes a renaissance of ideas around the structural causes of ill-health, but, in addition, a greater focus on individual lifestyle, personal responsibility and local empowerment. This point is revisited in later chapters. In terms of historical opposition, review of the literature demonstrates various explanations for historical resistance, many focusing on compulsion and the libertarian discourse at the time. Whilst this is a crucial dimension, an alternative reading of the literature suggests that other explanations are also visible. As subsequent events have shown, removing compulsion does not remove all sources of controversy. A history of the public health movement confirms that the germ theory of disease was in competition with other approaches to health. The nature of historical resistance therefore also relates to the issues of risk, trust and science.

In addition to historical opposition, the chapter also discussed the literature and commentary that attempts to account for contemporary concerns about childhood vaccination. Comparisons have been drawn between the experience in the 1970s with the DTP vaccine and recent media debate over MMR. For example, in both cases decline in uptake has been dated to the publication of one clinically based paper, and key individuals have emerged as 'icons' or 'champions' of concerns (André, 2003). These similarities are interesting, but a more detailed and sustained comparison is required. From the point of view of vaccine policy-makers, what unites these episodes is the decline in national uptake and the increased political salience of vaccination. What is certain is that the so called 'MMR crisis' has led to more academic interest in vaccination behaviour and that more empirical work is expected to emerge. The small amount of existing literature on vaccination refusal discusses risk perception, trust, media coverage and individualism as explanatory factors. Some of these have also been used as explanations for nineteenth century concerns.

The main objective of reviewing the literature in this chapter is to demonstrate that organised opposition is a neglected area for social scientific research. Empirical findings were therefore discussed. These confirm the media and the internet as important strategic resources for vaccination resistance. The websites are particularly important as a way of interacting with the public and members, rather than simply a one-way mode of communication. However, the groups also fulfil other strategic roles more usually associated with lobby and support groups and not recognised in existing published accounts. Organisationally, the groups vary in geographical location and in size, although the latter variation is better understood as reflecting different aims and priorities, rather than a simple indication of relative influence. Most importantly, the data reveal that the groups were started at different times, and many of the groups pre-date the furore over autism and MMR. This is the clearest evidence that vaccination resistance in the UK cannot simply be assumed to be a response to Wakefield's claims. The existence of organised resistance to smallpox vaccination in the nineteenth century adds weight to this conclusion.

The final section of the chapter discussed the cognitive elements of the groups. The conclusion is that vaccination resistance is made up 'Vaccine Critical groups', a term justified in preference to others such 'anti-vaccine movement'. Vaccination resistance consists of Radical and Reformist groups; these labels were adapted from approaches in social movement studies. This classification in itself represents a significant advance in academic understanding of vaccination resistance. The main differences are that the Reformist groups are more likely to be interested in support, and to be led by those who have direct experience of vaccine damage. Their expertise usually relates to one vaccine, although interest is expressed in all aspects of vaccination. Their main critique is directed at aspects of vaccine policy, particularly vaccine damage payments. Although sharing claims and examples, the Radical groups go further in aiming to delegitimise the use of all vaccines. Rather than direct experience of vaccine damage, the leaders of the Radical groups had original interests in issues around alternative health, the use of animals in research and testing and the pharmaceutical industry. These critical discourses are then applied to the childhood vaccination issue.

This chapter begins to answer the first research question about the organisation of vaccination resistance. In the course of the discussion, supplementary arguments about

the nature of historical opposition and the nature of vaccination itself have also been made. The task of the next three chapters is to explore the relevance of concepts of risk, trust and science and the value of the Radical/Reformist distinction, for understanding how the imperative of vaccination is resisted.

## Chapter 5: Risk

In his article on the language of public health literature around AIDS, Tim Brown argues that 'risk, as a form of expert knowledge, acts on the level of the microphysical because it requires individuals to practice forms of self-regulation' (Brown, 2000, p1276). In other words, risk encourages and discourages certain forms of behaviour. As highlighted in the second chapter, risk is central to the language of health promotion. Risk is usually assessed through epidemiological research which is used to calculate risks of an adverse incident or to compare the relative risks of two proposed forms of action. Chapter four argues that risk creates the rationality that is at the heart of the imperative of vaccination: vaccination is constructed as the rational decision because the benefits of vaccination outweigh the risks and the risks of not vaccinating are greater. Those who oppose vaccination are assumed to have misunderstood this fundamental equation (Bedford and Elliman, 1998). Vaccination opposition has also been explained as resulting from an individualist approach to risk (Hodge and Gostin, 2003; Taylor, 2004; Rayner, 2002) and a failure to appreciate the community benefits of mass vaccination strategies, as promised by the concept of herd immunity.

This research does not take the centrality of risk as a given but instead addresses the second research question by interrogating the data to see whether and how notions of risk are used by the Vaccine Critical groups. As explained in chapter three, risk was deliberately not used as part of the interview agenda. The primary finding is that the groups engage in very little direct 'risk talk'. Risk is relevant to an understanding of vaccination resistance, but only in the sense that the groups are engaged in challenging and reframing assumptions about risk. This reframing is achieved in five different ways: by stressing unknowns; questioning the relationship between individual and community risk; constructing risk as manipulated; challenging the benefits of vaccination; and focusing on new vaccine related conditions not officially recognised as risks. The chapter presents the data that contribute to each of these arguments, at the same time highlighting any significant differences between the Radical and Reformist groups. The conclusion begins to suggest some of the ways in which these findings should be analysed.

## UNKNOWNNS

The data analysis revealed the importance of unknowns, a discourse that is significantly different to the realist idea of risk as an expression of probability, as discussed in chapter two. The Vaccine Critical groups provide several different examples, which function as alternative strands of this discourse.

### **Insufficient trials and reporting of vaccine reactions**

A majority of the groups make the argument that we do not know the effects of vaccination because of insufficient safety trials, both pre and post licence. The most common way this discourse is expressed is by reference to aspects of the standard model of 'good science'. The groups argue that there are no long-term safety trials for vaccination, and no double blind trials. For example, VAN expresses frustration that:

When they are doing the controls for the vaccine, they ought to have these double blind placebo controlled studies which is basically a vaccine tested against a placebo in X group of people. But it doesn't happen. You have a vaccine tested against another vaccine and if vaccine A has no side effect, more than what vaccine B would have, then they consider it safe. But how can you consider something as safe when you're not testing against a placebo? (VAN).

During the interviews, both JABS and VAN cite the same figure suggesting that the MMR vaccine was only tested for 3 weeks post-vaccination. VAN stresses that the short-term nature of the trial ensures that potential links between the vaccine and long term serious health problems will not be made:

Their tests last for 3 weeks post vaccination which doesn't, anything happens in the 4<sup>th</sup> week is considered out of the window, it's not in the trials. There has never ever been a follow up. Say you are 40 and have.... arthritis or whatever. They don't say 'what vaccines did you have as a child?'...They are not taking an approach to it that could possibility expose that as being a risk. There has never been a long-term study done on any vaccine safety, there has never been a study of whether vaccines have an impact on fertility, there's never been a study done into whether vaccines have a carcinogenic effect (VAN).

This idea that ‘they are not taking an approach to it that could possibility expose that as being a risk’ is an example of how existing risk statistics are seen as irrelevant for those groups making a Radical critique. Citing a *British Medical Journal* (BMJ) article, JABS also stresses that the size of the trial, as well as its duration, is problematic:

And it’s published in medical journals in the BMJ saying that pre-licensed trials are too small to show up the rare events, so you are relying on the monitoring system and when the monitoring system doesn’t work because doctors say it’s nothing to with the vaccine, it doesn’t get put forward for investigation (JABS).

This previous quote leads on to the second argument made by all of the Vaccine Critical groups: that we do not know the true risks associated with vaccination because vaccine reactions are not fully reported. For example, the Informed Parent asks:

Q. Are there any reliable figures to compare complications of a disease with complications from a vaccine? No. Most vaccine reactions go unreported and are usually dismissed as a coincidence (Informed Parent website).

This argument is also made by Vaccination Information:

I’ve never heard of one [doctor] that has entered the yellow card system to be honest. I have never heard of a single parent who said that I thought my child was **damaged** and the doctor has filled in a yellow card<sup>1</sup>. I’ve never heard it. (Vaccination Information).

This argument, about the failure to report and monitor vaccine reactions is not new and has not suddenly emerged with MMR. In their group leaflet, JFAVDC also discuss the ‘considerable under-reporting’ of vaccine reactions, despite the Committee on Safety in Medicines ruling that reactions must be reported, even if this is only suspected. In summary, the Vaccine Critical groups argue that insufficient trials and reporting of reactions mean that the true risks of vaccines remain unknown.

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<sup>1</sup> This refers to the ‘yellow card’ system which is a voluntary system for GPs to report suspected drug reactions.

## **Ignorance about the body, health and disease**

A wider discourse is also visible which relates to a more fundamental human ignorance about the body and the meaning and determinants of health and disease. The Informed Parent and [vaccination.co.uk](http://vaccination.co.uk) websites use very similar language posing straightforward and basic sounding questions, to which the answer is given that we simply don't know. The implication is that it is fruitless to try and rationally compare the benefits or risks of disease and vaccines:

1. How do vaccines affect the nervous system on a cellular level?  
No one knows
2. How do vaccines cause damage on a cellular level?  
No one knows. ([vaccination.co.uk](http://vaccination.co.uk) website)

During the interview, the Informed Parent expressed the idea that, fundamentally, we do not understand about the body:

And I think the more you read on it, the more you realise what little we know about the body and health. There's so much we still don't understand (Informed Parent).

This discourse is also used by Allergy induced Autism. This group talk a lot about MMR, and its possible link to autism. However, the argument goes further to stress a collective lack of knowledge about ill-health in general.

If you actually look at any disease you care to think of and say do we know what causes this disease I would say that [for] 99% of the disease states the answer would be resounding actually no we don't, not definitively... We are talking about viruses and we have a whole universe we don't know, and we have to admit that. We have to admit that to patients (AiA).

This kind of argument is part of a critical discourse which questions science and progress and is discussed further in chapter 7 on science. It is also linked to the idea that risk is not random and equal for each individual. This discourse will be revisited later in the chapter.

## **Alternative futures or histories unknown**

The discourse of unknowns, and how this undermines confidence in vaccination is not only levelled at the promoters of vaccination. The groups also argue that the impact of abandoning mass vaccination is also unknown. This is one reason why the Radical groups still feel wary of advising against vaccination. The impossibility of knowing what would have happened if society had taken a different path and not developed mass childhood vaccination, is recognised:

I cannot say it is better not to vaccinate the whole world because I don't know. Have we changed the immune system of a generation by feeding them all the antibiotics, by feeding them all the vaccinations? By what we've been doing to their immune systems, have we damaged them irreparably, so that if we did eliminate the vaccination programme tomorrow, would we have mass epidemics, would children be dying all over the place? I don't know...and the truth of the matter is no one really knows (vaccination.co.uk).

A similar point is made by APVDC:

On the other hand I think if they stopped vaccinating tomorrow, maybe we'd all get the diseases. I don't know. You have to look at third world countries where they don't vaccinate and all these kids get measles and polio and diseases like that so I presume there is some merit in it (APVDC).

The unknowns discourse was sometimes used in conjunction with more traditional risk/benefit language, the kind of which was not used as frequently as expected. The vaccination.co.uk website puts it succinctly:

Since no one knows the risk (i.e. how many children are hurt or killed) there is no way to assess whether the assumed benefits of vaccines are worth the risks (vaccination.co.uk website).

In summary, the interviews show that reference to unknowns forms an important part of the Vaccine Critical discourse. The strands of argument that support this discourse represent criticism of pre and post licence safety monitoring, including under or non-reporting of adverse reactions. More fundamentally, some of the groups also construct the body and disease as unknowns. This argument has implications beyond vaccination and is related to wider questions about science and progress. Groups also make the point that it is impossible to know what would have happened without vaccines, or what

would happen if vaccination was abandoned, and this is one reason why some of the groups feel unable to advise against vaccination. The next section discusses the complex issue of the relationship between individual and community risks and benefits.

## **INDIVIDUAL VERSUS COMMUNITY RISK**

Chapter four discussed the concept of herd immunity and indicated why it is central to an understanding of current mass vaccination policy and practice. For supporters of vaccination, herd immunity represents scientific shorthand for the collective nature of childhood vaccination. In this context, opponents have been accused of individualism or a failure to appreciate the community impact of individual vaccination decisions. Data analysis did not support this overall depiction, but revealed at least three different discourses that relate to this issue.

### **Mass vaccination ignores the individual**

The first strategy adopted by the groups is to point out that mass vaccination, by its very nature, requires that the individual submit to a procedure for the benefit to the community, rather than necessarily for the benefit of that individual. When talking about her son, the founder of JABS made this point:

From my point of view [my son] didn't need protecting from rubella, so why should he take the risk of arthritis, blood platelet problems or a paralysis syndrome? He wasn't in danger really of mumps at that age, so why should he be at risk of perhaps contracting juvenile diabetes, or deafness? Things like that (JABS).

This argument could indeed be claimed to represent a kind of individualism and an expression of unwillingness to accept risk for the benefit of the community. However, this type of argument was not made very often. Much more striking was the repetition of the broader argument that mass vaccination strategies tolerate individual vaccine damage. What is being criticised here is not necessarily the government statistics or stated risk of vaccine damage, but that any level of damage (in terms of number of children disabled) is tolerated. For example, JABS argues that proponents of the system

know there will be individual casualties but believe that 'the system can mop them up', for the benefit of the community.

The majority - they probably will be fine, but it's the blow to the minority and when you are vaccinating half a million children a year the Department of Health can afford one or two casualties. But parents can't (JABS).

Very similar language, which expresses moral outrage at the way mass vaccination and policy-makers conceptualise the individual, is used by VAN:

The individual doesn't really matter. They know damn well that out of x million people they vaccinate a certain percentage do get side effects (VAN).

Interviews with the two oldest groups confirms that this is not a new argument: in 1974 a letter was sent to the Department of Health by the Association of Parents of Vaccine Damaged Children raising this very issue:

We recognise that the decision to carry on vaccination is a matter for medical experts to decide, but we do question whether national immunity can be purchased at the expense of those few children who have been, or will be, sacrificed in the process (APVDC *Outline of the case for compensation for vaccine damaged children*).

This language of sacrifice is highly emotive and is used in a similar way by Justice for All Vaccine Damaged Children, in order to conceptualise the issue in terms of justice.

The injustice is that they are content to promote vaccination in this way and leave the risk to lie where it falls. The risk creates disaster for the child on whom it falls and for the child's family (JFAVDC *Be aware of the facts: the choice is yours*).

Justice, and the idea of sacrifice is also a key discourse for JABS – evidenced by the title of the group (Justice, Awareness and Basic Support), and made explicit in the following quote:

But at the end of the day you are getting a very small number of vaccine damage they should really be saying we will look after these because these kids are suffering for the rest of society. And I think parents will probably feel it is worth taking the risk (JABS).

The interesting point about this discourse is that it is not directly concerned with challenging the community benefits of vaccination but is concerned with questioning the utilitarian rationality that allows individual damage to take place. Furthermore, as demonstrated by the final quote from JABS, the community benefits argument, far from being denied or ignored, is actually utilised in this discourse by some of the groups as a way of demonstrating the morality of socially funded compensation. Another tactic adopted is to challenge a rigid distinction between the individual and the community by claiming that individual damage does in fact have a societal impact.

If that child is damaged, you are talking about emergency ambulance trips, hospital stays, medications, treatments, special needs schools, parents that can't work. So there is a major drain. And if we've got far more children coming forward believed to have damaged than did the bean counters originally estimated, then it's a bigger problem that we had anticipated as well (JABS).

A similar discourse of social risk is used by The Informed Parent, although their concern is even more explicitly orientated towards the population. The quote also demonstrates an awareness and rejection of the accusation of selfishness or individualism that has been levied at those who question vaccination:

A lot of time there are arguments 'oh you are just looking out for your own child and you are not thinking about society at large'. The thing is most parents I come across are actually concerned about society at large as well...Because they are concerned about the future, because what are we messing up? The next generation's health. Then how are they going to be able to deal with anything in life, you know? It's not just about their own child, because their child has got to interact with other children in life. I mean their child is their first priority. But beyond that. I am concerned about the future of mankind actually [laughs]... (Informed Parent).

This denial of individualism is important in reframing the dissenting parent as someone who is well aware of the needs of the community. The quote also touches on several issues, beyond the relationship between individual and community risk including the possibility of new risks to entire populations. This will be returned to in the final section of the chapter.

## **Risk should be individualised**

The second strand to this discourse is that risk (and healthcare) should be individualised. Vaccination, or conventional healthcare more generally, is criticised for treating everyone the same. Individualising risk is thus seen as a way of improving vaccination. For example, JABS criticises the practice of vaccinating premature babies, or those recovering from operations, at the standard recommended times:

We've got to actually make sure that what we're giving is right for the individual child. The Department of Health are not good at determining whether a child shouldn't have something. They treat them all as exactly the same (JABS).

This point is made in an article written for a VAN publication:

We are all different from each other...Standard vaccinations take no account of the genetic diversity of individuals... Apart from true twins we are all different. That is the first cause of risk' (Blanco in *SHOTS, VAN newsletter*).

The web homepage of [vaccination.co.uk](http://vaccination.co.uk) also makes this point:

What may be right for one child could invariably be wrong for another ([vaccination.co.uk](http://vaccination.co.uk), website).

During the interview, this issue was expanded on when comparing the individual approach of chiropractic, which requires multiple visits and monitoring of treatment outcomes, and most medical interventions:

But that is very different from most medical interventions which are based on a bell curve. If you fit in the middle of that they kind of say oh, this is great. It works on 75% of people, yes, we'll use it... But if you are outside and you are one who gets a real adverse effect that ain't a lot of consolation. In healthcare we need to treat people as individuals ([vaccination.co.uk](http://vaccination.co.uk)).

Certain policy implications are seen by the groups as flowing from this critique of vaccination as a one-size-fits-all strategy. Three of the Reformist Vaccine Critical groups suggest the possibility of developing a test to administer at birth or before the first vaccine is due, in order to identify those individuals with a 'vulnerability', who are 'predisposed' to vaccine damage (JABS), or those who are 'marginally

immunocompromised', have a 'genetic weakness' or 'immune fragility' to vaccines and vaccine damage (AiA). This proposed test represents a technical solution to the problem of individualised risk by breaking down the whole population into several populations with different treatment needs. This proposal, and what is implied about attitudes to science and technology, will be discussed further in chapter 7 on science.

Social, as well as technical solutions are also suggested. During the interviews one of the groups (JABS) was keen to praise the activities of a now retired local doctor who reportedly altered the vaccine schedule for each child, depending on their health and family history. In essence this is a request for more factors to be deemed vaccine contraindications but is also a call for the individualisation of risk. This represents a challenge to the dominant mode of mass vaccination. Overall, these critiques are not levied directly at vaccines but at the assumptions embedded in vaccination programmes.

### **Vaccination is privatising**

Third, there is a contrary and largely Radical argument that vaccination, far from symbolising the community good, is itself an individualising or privatising strategy. This argument is made most clearly by [vaccination.co.uk](http://vaccination.co.uk). They claim that although, on the surface, the concept of herd immunity can be seen as supporting the community or even conforming to 'socialist' ideals, in practice vaccination is a 'just an elastoplast over social problems' with the GP who is 'basically, you know putting his fingers in a sieve' ([vaccination.co.uk](http://vaccination.co.uk)). Problems of health and disease are conceptualised as social in nature requiring significant state involvement, in contrast to what was argued by a health professional on the radio:

So it's pretty much a social issue. So going back to the radio, the guy was talking about these kids in Ireland and everybody is getting scared, they are saying measles is a killer – see, proof. I would be arguing the proof is that governments don't want to invest in the inner cities and provide better housing. These families that might be on, whatever, unemployment, social security, they can't afford decent nutrition, not really educated so they prioritise the colour TV over vegetables. This is the society we have created.... ([vaccination.co.uk](http://vaccination.co.uk)).

Later on in the interview, how this negative image of society links to vaccination is clarified:

I just see vaccination programmes as a very cynical method, if you like, of social cohesion. Because if we didn't have vaccination programmes and children were dying I can tell you where people would be dying...It would be places like Brixton and there would be riots. They would be on the street...The children that would be dying would not be from Surrey. And that's the kind of reality of the society we live in so that's the kind of easy option (vaccination.co.uk).

What underlies this controversial argument is a particular view of health and disease. Whether an individual will get a disease or die from it is seen as being affected by social factors, other than vaccine status. The solution to the problem is therefore social in nature, or more social than vaccine technology. Other groups also adopt elements of this thinking, even if they do not use it to demand greater state intervention. For example, the Reformist AiA argues that:

Wild measles is more likely to be seriously detrimental to a child if that child is nutritionally compromised. How many children do we have in this country who are nutritionally compromised? (AiA).

The Informed Parent also argues that overall health status (including nutrition) will influence the likelihood of vaccine damage:

Well, my personal opinion is that whether we are damaged or not is that we are all damaged. But many of us, because we've got reasonable health, we can tolerate a certain number of vaccines, so some of us might have quite a number. And I don't think that, you might not see any obvious signs of damage, but who's to say how healthy we would have been if we hadn't? (Informed Parent).

These types of arguments relate to the social organisation of risk. The point being made is that risk or danger (of catching a disease, suffering complications from a disease, or suffering adverse reactions to vaccines) is not distributed equally or randomly but is partly determined by social inequality. In discussing alternatives to vaccination, The Informed Parent website makes the non-random nature of disease explicit:

Creating and maintaining a reasonably sound, stable and healthy lifestyle is the best way to avoid illness and complications. Diseases do not strike randomly. [T]here would have to be underlying factors and weaknesses (Informed Parent, website).

In summary, the Vaccine Critical groups discuss the relationship between the individual and community in several, sometimes contradictory ways. The groups do question whether low instances of individual vaccine damage should be tolerated in the interests of the majority and use this issue as part of a justice discourse. However, a second strand of the discourse argues that individuals are unique and that risk should be individualised. One way of ensuring this would be to adopt new technologies to screen out susceptible individuals. A third set of arguments, less commonly found, argue that despite appearances, mass vaccination as a policy is not social enough, and is instead a quick technological fix response to complex social problems. The next section discusses the idea that risk is deliberately concealed, manipulated or exaggerated.

## **THE MANIPULATION OF RISK INFORMATION**

As discussed in the first section of this chapter, unknowns is a central part of the Vaccine Critical groups' discourse. However, the groups also argue that risk is concealed, manipulated or exaggerated. In other words, in this instance the risk or danger is conceptualised as known or knowable, but is hidden or changed by various actors. This section has close links with chapter six on trust, where the critiques of government and the medical profession are discussed in more detail. For purposes of analysis, the discourse can be split into two sections relating firstly, to the perceived manipulation of vaccine risk, and secondly to the risk or dangers of childhood diseases.

### **The manipulation of vaccine risk**

Several of the groups argue that the actual risk of vaccine adverse events (events both currently recognised and not recognised as reactions) is being hidden from the public. The discourse is one of concealment and a lack of transparency, a discourse which feeds into their self identity as groups. For example, VAN see part of their role as communicators:

We feel that so much information is covered up and suppressed that we would like to bring it into the public forum and try to show that this information is out there and show that we are not being told the truth effectively about what is happening (VAN).

Vaccine Victims is more direct in naming which actors are guilty of concealing vaccine risks from parents. The group is particularly critical of doctors:

I think if parents are given the full facts...their confidence in the vaccine programme would improve if they were given the facts... So you've got doctors saying there is no such thing as vaccine damage, yet there is a Vaccine Damage Payment Act which belies the fact that they are not telling the truth (Vaccine Victims).

Another quote from the same group repeats this point but implies anger at the denial of the existence of vaccine damaged children, as well as denial of the risk. Vaccine Victims, along with other Reformist groups, calls for specialised sessions to be organised where parents can get information about vaccination:

There has got to be groups, not just a practice nurse, it's got to be specialised group that know vaccine inside out and I mean know vaccine inside out, contraindications, what can happen...to let parents know about vaccine damaged children. That this has happened in the past, this is the amount of Vaccine Damaged Payment Act has paid out. These are the amount of children...(Vaccine Victims).

Several of the groups cite vaccine manufacturer product sheets as evidence that some of the risks and dangers associated with vaccines are in fact known. These sheets are then contrasted with the 'glossy' leaflets given out to parents:

Because the drug companies' own product sheets give far more information than the glossy pamphlets about the products and it also states when not to give something (JABS).

In terms of not being told that there is a risk of vaccine damage or adverse events, this is clearly not a new issue. The APVDC complained of this in interview, when discussing their experiences in the 1970s:

Nobody ever told us there was a danger and I then I started checking out other people and other countries and things and discovered that lots of specialists said yes, there is such a thing as vaccine damage, whereas I was told 'you're mad'. And secondly that in Germany they had been running a compensation scheme for years for vaccine damage for years and I thought, oh well, in that case (APVDC).

As argued in the previous chapter, the form in which risk information is given to the public utilises techniques of risk comparison and relative risk. An article in a VAN publication goes through the production of relative risk statistics step by step and argues that they are easy to manipulate 'to what the researcher or funder wants to say' (Tucker in SHOTS, 24). This argument goes beyond the issue of vaccination and towards a critique of the methods used to present and calculate risk itself.

### **The manipulation of disease risk**

The second, and related discourse, surrounds arguments that claim that the risk of the disease, both in terms of the probability of contraction and of suffering complications, is manipulated for purposes of parental compliance. As JABS states:

We started off with drug manufacturers producing vaccines against the really serious illnesses like diphtheria, like tetanus, like polio, and then, because they can produce vaccines they are doing and you've got to change the public's perception of that illness to change the product (JABS).

One way that this is done, according to JABS, is through the leaflets given out to parents. This is compared with the situation in the United States where more information is given out about the possible side effects.

What we are presented with is a glossy pamphlet designed to promote the product which plays up the seriousness of the illness and makes them all out to be the bubonic plague (JABS).

A similar point is made by AAA, using humour to stress their argument:

They are into making money. I suggest to you that Merck or Aventis Pasteur or SmithKlineBeecham or whatever they call themselves today, if they could come up with a vaccine against in-growing toenails they would do it and they would have it in the marketplace pretty swiftly. And what I suspect is that the people who are in control of vaccine safety don't question that. Don't say hey, do we really need this? (AAA).

These arguments imply that manipulation of risk is done for purposes of compliance but that the motivating factor is profit. Industry is thus identified as the beneficiary of what is seen as misinformation. As the previous AAA extract exemplifies, the government

and those involved in vaccination are then criticised for failing to recognise the profit motive. This point relates to broader issues of trust and the image of science and technology, issues that are returned to in the following two chapters. Overall, what unites these arguments about manipulation is an underlying assumption of the difference between actual risk or danger, and risk perception. The next section describes the important role attributed to fear by the Vaccine Critical groups.

### **The role of fear in manipulation**

Fear emerged as an important concept for the groups, both Radical and Reformist. Generally, fear is seen as a key context for the whole vaccination issue, as exemplified by the following quote from JABS:

I think fear has actually driven a lot of policies...Fear of the Public Health Laboratory and the government that they are not seen to be doing the best by the parents and children, fear of the parents not to do the best by their children, and fear of death (AiA).

Fear is also discussed, very graphically, by Vaccination Information in an editorial in relation to bioterrorism and the development of an anthrax vaccine:

The current anthrax headlines have grubby, big business fingerprints all over them. It is the classic scenario. A relatively innocuous spore in most instances and of little use as a weapon of mass terrorism, is now being used as a very effective weapon – that of mass psychological terrorism (Vaccination Information, *Lifeforce magazine*, 2002).

More specifically, the use of fear and manipulated figures is discussed by JFAVDC as a kind of model with distinct phases. In this quote, the leader describes this process in relation to chickenpox:

I wonder why they are suddenly worrying about chickenpox, for instance. People have had chickenpox for hundreds of years...and there has never been any publicity from the Department [of Health] about this is a terrible disease and it kills hundreds of people every year. But if they put out the vaccine for it within a month they have produced the figures ‘thousands of children died last year’ [laughs]...Whether they think people are stupid or what I don’t know (JFAVDC).

The previous two quotes concern how fear is used in the promotion of new vaccines. Fear is also discussed as a key logic for the promotion of vaccines that are already part of the current recommended vaccine schedule. For example, in relation to MMR, [vaccination.co.uk](http://vaccination.co.uk) argues:

Measles? That was a week off school, you know? I can remember when I had measles and no body was like 'oh my God he's in mortal danger'. This is a complete misconception. The terror they are putting in peoples' mind about measles today ([vaccination.co.uk](http://vaccination.co.uk)).

Fear is not just seen as a strategy used by those promoting vaccination, but the public are seen as important actors too. For some of the Radical groups, the public are conceptualised as complicit in a cycle of fear. The point is made most clearly by VAN:

The whole debate from the government's point of view is controlled by fear. Fear is the only motivating factor... If your child is not vaccinated it's going to die of measles, your child is going to die of diphtheria... This whole thing has been built up in the last 100 years, particularly last 50 years since the war, 60 years, of indoctrination and telling people that diseases are scary. And if they all of a sudden turned round and said these diseases aren't quite so bad or the vaccines are dangerous to your health there'd be a massive public outcry... there'd be mass hysteria (VAN).

During the interview the Informed Parent also stressed that their aim is not to replace fear of disease with fear of the vaccine. Rather, the best case scenario is of a parent who feels confident enough to question the need for vaccination. In other words, for the Informed Parent, and other Radical groups, the reason or psychological motivation for non-vaccination is important, rather than simply the outcome:

But there's always going to be a certain number that are scared of the vaccine side effects and they'll just not do it [vaccinate] because of that, and they'll just think 'oh, I'll take my chances' and that is not a good frame of mind to be in because you are always going to be panicking whatever. [Interviewer: like the fear thing?] Yes, the fear thing is not a good place to be. You've got to really know why and what you're doing otherwise you will just get scared all the time and panic (Informed Parent).

This section has discussed the data which construct risk as known, as evidenced partly by manufacturer product sheets, but concealed and manipulated by those promoting vaccination. The risk or seriousness of diseases and vaccines is seen to be deliberately manipulated in order to ensure parental compliance. Fear was frequently mentioned as a

crucial part of this strategy. For two of the Radical groups, the public were specifically highlighted as complicit in this strategy, and warn against fear as a 'good place to be'. The next section discusses ways in which vaccines are challenged, not by focusing on the risks or dangers associated with vaccination, but by questioning the benefits usually ascribed to vaccination.

## **CHALLENGING THE NARRATIVE OF SUCCESS**

This section refers to the data which focus on the benefits or need for vaccination, rather than on the risks or dangers associated with it. There are three main ways in which this discourse is constructed: by challenging claims to historical success, by arguing against claims to efficacy, and, more radically, by questioning the underlying aim of disease eradication.

### **Not responsible for historical success**

The argument that vaccines are not responsible for the decline in death and disease that proponents claim is more associated with the Radical groups. For example, [vaccination.co.uk](http://vaccination.co.uk) argues that:

The fact is if you look at the life expectancy increases over the last 150 years, the person who has contributed the most is Basil Jet who designed the sewage systems. There's no question about that ([vaccination.co.uk](http://vaccination.co.uk)).

This point is also made by Vaccination Information in a letter written by the group to explain their case against vaccination:

Proponents of vaccination hark back to the days when infectious disease was a major killer in the western world and try to claim that these diseases were defeated by vaccination. This blatant rewriting of history...(Vaccination Information, *open letter*).

During the interview the same group makes clear the implication of this argument, and how it can be used to criticise the medical profession. This argument is linked to ideas of trust in the medical profession, which will be discussed in chapter six:

The medical professional cannot, does not shout about cancer and heart disease – look what a wonderful job we are doing. What they do say is if it wasn't for us you'd all be dying of...[infectious diseases]. Take away that as well and say 'that had zip to do with you'...they've got nothing...They are living on a reputation that isn't theirs. That's why I think that the medical profession is hanging on to the fact that vaccination works and they can take the credit for it. There's no evidence for it (Vaccination Information).

Even more controversially, VAN argues that vaccination has actually been responsible for prolonging disease historically, in contrast to other public health measures such as sanitation:

And it wasn't until the latter part of the 1800s that there was widespread sanitation and widespread education and widespread health measures put in place and knowledge about diet and other things so you eliminate these diseases. You can find by looking at the disease charts they decline like this [gestures a steep decline] as soon as health improves... Things like the smallpox vaccine did prolong the life of smallpox in the country. And it wasn't until they stopped mandatory smallpox vaccination that smallpox decreased as a disease (VAN).

It should be stressed that not all of the Vaccine Critical groups would fully subscribe to a discourse which questions the relationship between vaccination and historical disease rates. For example, Vaccine Victims were keen to distance themselves from true 'anti-vaccine groups' who do not admit that vaccination is necessary. During the interview this group stressed their view that the risks of vaccines are real, under-recognised and should be compensated, whilst still insisting that credit should be given to vaccines for their historical role in preventing death and disease:

I've got a child's death certificate who died from smallpox vaccine. Children will die from it, it's a nasty vaccine, But the benefits again outweigh the risks. Those people that are anti-vaccine. If there's a smallpox epidemic in their area, what will they do? Will they take their child to be vaccinated against the disease or, will they because they are anti-vaccine, not? I think you will find they will be in the queue waiting for their child to be vaccinated (Vaccine Victims).

The next section considers related arguments that question the contemporary efficacy of mass vaccination strategies.

## Does not prevent disease

Chapter four expressed the public health claim that mass childhood vaccination is a highly effective technology which succeeds in protecting children from disease. This is undermined by those groups who question the efficacy of vaccination. AAA, when discussing MMR sees the changes in the recommended schedule, and the introduction of the booster, as evidence against efficacy:

I mean the MMR doesn't work basically, it doesn't seem to work for a lot of the kids and the combining of 3 vaccines doesn't seem to have been a successful move because when they brought it in, in 1988, they didn't know they were going to need a booster. They needed a booster in 1996 because it wasn't working, but nobody apologised for that. In other words it wasn't tested properly (AAA).

Vaccination Information uses this argument, about vaccines more generally, at the same time as attempting to buttress themselves against criticism:

Why do I oppose vaccination? It is because, as suggested on several news programmes, I have no sense of proportion about the infinitesimally small risk that accompanies vaccination? Am I selfishly benefiting from the protection that vaccines offer without taking any risk with my child's health? The reason I oppose vaccination is because it does not protect against disease but in fact causes it (Vaccination Information, *open letter*).

One key way in which vaccine efficacy is challenged is by using alternative health discourses which provide a competing understanding of the relationship between health and disease. For example, during the interview the Informed Parent identified stress as a predictor (or cause) of disease:

I think one thing we underestimate is mental balance as well because people always think diet, which is really important, yes, and a certain amount of exercise but emotionally you can become very susceptible to things if you are very stressed for other reasons, mental stress. So I think you know it's like trying to find a happy medium, moderation with everything' (Informed Parent).

This type of discourse challenges the germ theory of disease. In short, if ill health is not caused by a germ then good health will not be created by a vaccine. The next section

moves on to address a related argument, very much tied to an alternative health discourse, which questions the underlying rationale of disease prevention.

### **We should not aim to prevent disease**

The third set of arguments are strongly associated with the Radical groups for whom concepts from alternative health forms an important part of their discursive repertoire. For example, the Informed Parent states:

You may decide that contracting measles will play a beneficial role, resulting in priming and maturing your child's immune system (Informed Parent, website).

In a similar vein, [vaccination.co.uk](http://vaccination.co.uk) imply that the contraction of natural measles may in fact be beneficial. The following quote demonstrates this, but also suggests an awareness that the group recognise the controversial nature of such views. The leader harks back to a historical practice of the deliberate exposure of children to disease, and speculates about whether this practice could be done on an organised level, but complains that it is difficult to discuss this in an 'open intellectual way'.

Because if you look at it they say kids used to go to these measles parties to catch, to create natural immunity. And that is 100%. Vaccines aren't 100%. So, getting the disease in a mild form when you are strong kind of makes sense. Couldn't we kind of expose, if we were doing that on an organised level? But these things cost money, and then the kid is going to be sick...I think it's such a shame that we can't have discussions like this in a open intellectual way looking at the health of society and the possible benefits ([vaccination.co.uk](http://vaccination.co.uk)).

The following quote from the same group implies a desire to move away from risk as probability – 'the likelihood of measles', in favour of a more holistic view of health which sees health as something broader than simply determined by the absence or of measles:

So if you want to vaccinate my children I want to know, I couldn't care less about the likelihood of measles, because I know my children have a strong immune system. I want to know can you tell me? Are they going to be healthier because they have been vaccinated? And to me that is the simple question. That is only question the government should be asking ([vaccination.co.uk](http://vaccination.co.uk)).

The way in which health is defined by this group is clarified further, later in interview. The extract is also notable for its inclusion of the sociological concept of medicalisation, a concept that was voiced by other groups but not labelled as such:

Health is a concept which children need to understand, it's something you're born with, so when you start off by vaccinating people the assumption is almost that there are unhealthy so we've kind of medicalised lots of conditions. Pregnancy is a natural phenomenon, now it's almost an illness. You know, we scan, we do things. And the baby as soon as it's born, [we imply] it could die if it gets any of these horrible diseases. Not like health. So we vaccinate (vaccination.co.uk).

In summary, this section has covered those arguments that question the historical or contemporary benefits of vaccination and question both need and efficacy. Some elements of the discourse, recognised by the groups themselves as more radical, question the rationale of disease eradication. Underlying these critical positions that question the benefits of vaccines, are ideas from alternative health discourses about the nature of health and disease. One of the reasons why disease contraction rather than disease prevention may be seen as beneficial relates to the role of chronic conditions. This leads on to the next section that looks at 'new vaccine related conditions'.

## **FURTHER VACCINE RELATED RISKS**

The chapter so far has presented data in relation to the idea of risk as unknowns, the relationship between the individual and the community, the manipulation of risk and those arguments which undermine the claims to historical and contemporary benefit. The remainder of the chapter considers the importance of arguments that do not question the benefits of vaccination *per se*, but focus on the wide ranging medical and other conditions that are claimed to be linked to mass vaccination. The section ends with a brief discussion of an additional source of risk that is argued to be relevant for those children who have already suffered from vaccine damage.

### **Autism and chronic conditions**

Given the media dominance at the time of the research, as expected the topic of autism emerged as an important topic through the interview and documentary analysis. When

asked whether AAA has a policy towards vaccination, and whether this is a fair question, the leader responded:

Unfortunately it is a fair question because that in a sense is what brought us together in the first place, a common belief that vaccination was deeply implicated in what had happened to these children. I don't think we could ever deny that (AAA).

The reason that autism is not recognised as being linked to vaccines by those in charge is explained as a result of ineffectual testing and monitoring. In this respect, this argument goes back to the discussion of risk as unknowns at the start of the chapter. According to AAA:

They test the vaccine. It's not like a drug. They test it for 3 weeks but the autism we describe as following MMR takes place over 6 months, 7 months, even a year period, long-term adverse effect. They wouldn't find that with the research that they do just now or the testing they do just now, or the yellow card system which they have. The yellow card system doesn't recognise autism as an adverse event following vaccination so it's never reported as such. And then they bring up the yellow card system and say 'look, it doesn't cause autism because it's never been recorded in the yellow card system'. And again we are into one of these circular arguments we have great difficulty breaking down (AAA).

Autism is not only conceived of as a risk for the individual child and their family, however. Several groups create an almost nightmare scenario, linked to the increasing numbers of autistic children. After explaining the impact of a disabled child on their own family, the leaders of JABS argue:

So you repeat that with thousands of families who have currently got autistic children, as well as brain damaged children, children with epilepsy *et cetera et cetera* and these numbers are increasing at a dramatic rate...A lot of these childhood problems, they have actually doubled in the last 10 years, you know diabetes, chronic arthritis, epilepsy, as well as autism...And for all that the Department of Health want to protect the vaccine programme, and I understand why, but they cannot afford to carry on ignoring the situation and they've got to start research and listening to people like Wakefield and the families affected, or else this thing is going to get really bad and out of control and they will end up with a generation that will not work (JABS).

In taking about the future, The Informed Parent also worries:

But long term, what does that hold out for the future? For the new generations of children who are so vaccinated and so suppressed and their immune systems are so compromised. What hope do they have of having a full life ahead of them? Stuff like, what's going to become of, because if you think of autism alone you're talking big figures now aren't they. And what does that mean for society at large? If there's going to be all these kids with slightly distorted views on life, how can they ever run the country? (Informed Parent).

What these quotes demonstrate is the blurring of the boundary between the individual and the community, a topic discussed in detail earlier in the chapter. The idea of vaccine damage as causing population level problems will be returned to shortly.

Although the relationship between MMR and autism is an important topic for the groups, detailed analysis of the interview transcripts reveals that this subject is placed in a wider pre-existing discourse, once again with links to alternative health, about the apparent rise in chronic conditions. The groups explain this rise as a response to the suppression of the immune system caused by vaccination. JABS puts it very succinctly:

Fair enough we want to try and eradicate these diseases but at what cost?...We can't exchange acute conditions for chronic conditions. Just try and stop the child catching measles but give them epilepsy instead, but at what cost? (JABS).

Another of the groups makes a similar point:

There is no doubt that a child with a weakened immune system is at greater risk from infectious diseases, than a healthy child, but there is no evidence that vaccinations make people healthier, on the contrary it is most likely that we have traded what were normal childhood illnesses 40 years ago, for normal childhood diseases today such as asthma, eczema, and allergies (vaccination.co.uk, website).

However, elsewhere on the website, vaccination.co.uk is clear that what has happened is not a straightforward swap between infectious and chronic disease or a choice between vaccination or disease. The group argues that vaccine use, amongst other things, has 'compromised' the immune system, thus possibly creating the risk of complications from infectious diseases:

During a measles epidemic in 1959 (51000 cases), the British Medical Journal reported that measles was the commonest disease in the world and normally a mild infection. Now we are warned that children are in danger from the disease.

Either this claim is true or in recent years, as hypothesized by Vithoulkas in 1991, children's immune systems have been compromised by chemicals such as Calpol, excessive use of antibiotics, inhalers, and the increasing number of vaccinations being given (vaccination.co.uk, website).

This point is also made by JFAVDC, a group far more Reformist than vaccination.co.uk, whose activities focused mainly on campaigning for a safer pertussis vaccine. In the following quote they construct an idea of overload of the immune system, an idea more commonly associated with an alternative health rather than biomedical discourse:

The problem I find today is, and I've said this in one of our leaflets. Vaccinations are an assault on the immune system. They destroy the immune system. And you think back, we are having more and more problems, health-wise, with youngsters and I tend to think, even though I'm not a medical person, that because so many vaccines are pumped into young babies, who've got the immunity from the mothers at any rate, this is destroying the immune system and they can't fight these diseases anymore (JFAVDC).

This 'increasing number' of vaccines (vaccination.co.uk website) and the idea that risk is cumulative is a theme throughout and links strongly with the idea of 'risk as manipulated' and the role of fear as discussed previously in this chapter. The next section presents those arguments which directly claim a relationship between vaccination and population or social problems.

### **Population and social problems**

The Radical groups discuss various examples of risk understood on a population, rather than an individual basis. As the following interview extracts demonstrate, it is sometimes difficult to delineate whether the leaders of the groups are themselves committed to such views, or whether they wish to merely report them as part of a wider Vaccine Critical discourse. VAN is one group who discusses a 'conspiracy theory' which links vaccination, particularly in the developing world, with fertility problems:

There's a conspiracy theory that it's about population control because the studies that have been done show there is a big impact on fertility, people that have been repeatedly vaccinated. It hasn't been done by the vaccine manufacturers but it's by people who've had fertility problems that have looked into their vaccination history. Independent researchers that don't get a lot of coverage. It does affect

your fertility. And there's increasing literature that it can affect your genetic make up as well. It can change the way the genes structure themselves slightly, which is maybe why we are seeing more of these in inverted commas 'genetic disabilities' or conditions that are starting or repeating through families and stuff (VAN).

The use of the phrase 'conspiracy theory' is interesting, given its generally negative associations of paranoia. During the interview, the opportunity was taken to probe: 'do you buy into that theory or do other groups?'. The leader responded:

Certainly XXX (leader of vaccination.co.k) will do. He's probably the best person to talk to about conspiracy theory related themes. I didn't used to subscribe to it too much. It's something that's coming out more and more in the mainstream, not in the mainstream but in the alternative mainstream if you know what I mean. It's being discussed more (VAN).

Later in the interview the issue of genetics is used again by VAN in constructing a kind of nightmare vision of the future:

On vaccination, well I don't know because they're talking about genetically modified vaccines and all kinds of things using gene technology, that raises GM food as well. You are eating GM food and you are already a GM person yourself if you like. The implications are absolutely humungous and once you start it you can't stop it...And especially from the genetically modified vaccine side of it. And how they are using that, especially stuff like cancer vaccines and stuff. It's quite worrying, very worrying. But I don't claim to know enough about that to really comment to be honest (VAN).

This extract reveals how the group have adapted concerns about genetic modification in agriculture and applied these arguments to express concern about the genetic modification of vaccines. This scepticism about genetics contrasts markedly with a positive portrayal of genetic science by the Reformist groups which is discussed further in chapter seven. As predicted by the leader of VAN, vaccination.co.uk did mention a 'conspiracy theory' about the relationship between polio vaccines and the development of AIDS.

It's like HIV and AIDS...I don't know if you're familiar with that book, The River...Now, his hypothesis is that polio vaccines created HIV, well not created, the HIV was there, but either it was because they had taken, they had used chimpanzee kidneys to culture the vaccine...With the original Salk vaccine there were problems when they first used it. So they stopped. So what they did was

they went out to Africa to do massive clinical trials around the Uganda area and this is why the book is called the River because you are tracing the source of HIV. I mean it's well documented and referenced and. It's been dismissed but I think, I think he has made a really strong argument (vaccination.co.uk).

The Informed Parent also discusses population or societal level problems during their interview. This group goes further to implicate vaccines in causing behavioural problems beyond the field of health. The group later cite a book by Harry Coulter called 'Vaccination, social violence and criminality' (1990), where these arguments about personality and behavioural problems are said to originate.

Even neurologically if it's affecting people, subtle damage, people can't even think straight. I'm not one for saying that everything out there that's a problem is to do with vaccination. But vaccination could be, could be linked to all these different aspects. Everyone these days, lots of older generations say all the time 'what's happening to young people these days'? Their attitudes, beyond a joke now. An aggressiveness out there now that wasn't there before. People are aggressive for not even a reason anymore. Even way back in history, Vikings or whatever, they raped and pillaged but they were after money and this and that. Now they just do nasty things just to be nasty. It's shifting. I think even all these little things, where's it all coming from? (Informed Parent).

Overall, the way that these issues of population or social problems are referred to by the groups is more careful in tone than some of their other arguments. For example, the final quote from the Informed Parent stresses that vaccination 'could be, could be' linked to small changes in behaviour, and the argument ends with a rhetorical question, perhaps indicating a level of uncertainty. In addition, reference by both the Informed Parent and by vaccination.co.uk to published books as sources for these ideas could be analysed as ways of distancing the groups slightly from these ideas that originate from other sources.

### **Drugs to treat vaccine damage**

The third and final way in which vaccines are linked to new risks is related to the pharmaceutical drugs used to treat the symptoms of vaccine damage. Although this topic was only touched on by two of the groups – JABS and Vaccine Victims – it was unanticipated prior to interview and is therefore particularly interesting to analyse. When asked to describe the main activities of their group, Vaccine Victims related the following episode:

We found one drug had been given to one child. Well, child, he was a man. [He] landed up in a psychiatric unit of a hospital and then somebody else had rung up and said my son or daughter, I can't remember, also landed up in hospital on the same drug. So then we had letters sent round to every member of the group if anybody had had an adverse reaction to this particular anticonvulsant drug and the reports that came back was pretty... We then were able to say that the children that were damaged by vaccines should not be given this drug... If it [the child's condition] is digestive, no, you don't put your child on that drug because these are the reactions that vaccine damaged victims are having, so that's an effect. A person that's on their own cannot do anything, but as a group you are stronger (Vaccine Victims).

This fascinating extract could be analysed as exhibiting a communal solution to the problem of uncertainty and risk – where resources, knowledges and experience are shared. It could also be analysed as a form of data collection or popular epidemiology (Brown, 1995), a topic that will be discussed further in chapter seven. The previous quote, and the following extract from JABS are included here in order to demonstrate that risk of vaccination does not just mean vaccine damage but can also involve longer term risks associated with further medical interventions. This suggests, and is confirmed by JABS, that the role of the pharmaceutical industry does not stop with the development of the vaccine:

All the treatments for the children are from the same drug companies so the drug companies are not catching ... XXX's [her son's] anticonvulsants are made by the company who produced the vaccine and the anti-inflammatory treatments are made by the same drug companies. So I know the drug companies are not trying to damage, but as I say they are not catching any harm (JABS).

This final section has discussed the problems that the groups associate with childhood vaccines. The risk of autism following MMR is an important one, particularly for some of the Reformist groups, although this should be seen as located within a wider discourse that associates vaccination and biomedicine with increases in chronic health conditions. A minority of the groups also cite vaccine critical books and arguments that suggest a relationship between vaccines and fertility, genetic problems and AIDS, and construct a kind of nightmare image of the present and the future.

## CONCLUSION

This chapter has demonstrated the ways in which the Vaccine Critical groups undermine, challenge and reframe risk in order to resist the imperative of vaccination. After the Reformist and Radical discourses are summarised, wider conclusions are drawn about the nature of risk and its role in explaining vaccination resistance.

Half of the Reformist groups call for the introduction of a test at birth in order to 'screen out' vulnerable individuals before vaccination. This was analysed as an example of the individualisation of risk. Information about the dangers of vaccination is seen as known by vaccine authorities, but manipulated in order to promote fear and maintain vaccine uptake. Fear also emerged as an important concept for the Radical groups, some of whom stress that fear of vaccine risks is not a good reason for vaccine decision-making, and that the public is complicit in the dominance of fear. Rather than implying that risk should be individualised, the Radical groups construct vaccination as privatising, functioning as 'an elastoplast over social problems' (vaccination.co.uk). The Radical Groups utilise elements of an alternative health discourse to question the logic of disease eradication, and thus question the overall benefits of vaccination. The claim to historical benefit is also undermined, but the impossibility of knowing what a history or future would look like without vaccination, is cited as a reason for wariness in advising against it. Autism, if discussed by the groups, is firmly located as part of pre-existing concerns about the rise of chronic conditions. Wider health, behavioural and social problems are cautiously suggested as possibly linked to vaccination, but seen as unlikely to be revealed by current methods of research. Both Radical and Reformist groups draw heavily on a discourse of unknowns.

Broader conclusions and implications can be drawn out of the data. Overall, what is most striking is the lack of direct discussion of risk, or 'risk talk'. The groups do not make their case by directly arguing that the risks of vaccination outweigh the benefits. In other words, risk may be a crucial part of vaccination promotional campaigns but is not the primary language of vaccination resistance. This finding is valuable in itself. What is even more interesting, however, is to analyse *how* risk assumptions are undermined.

First, is the way in which the groups challenge the realist idea that risk statistics represent some kind of objective representation of reality. This is achieved by using a discourse of unknowns. One crucial way in which this is done is through the identification of conditions, such as autism, that are not even recognised as related to vaccination, and are therefore not part of official risk statistics. This broad finding confirms the value of Wynne's (1992) distinction between risk and unknowns. In its radical form, this discourse of unknowns challenges the orthodox relationship between science, nature and human progress, a topic that is returned to in chapter seven.

The groups also make ambivalent claims which imply that the true statistics (on the risk of disease or vaccine damage) *are* in fact known but are systematically manipulated by those who want to promote high uptake. This finding relates back to the argument made in chapter four, about the close relationship between those institutions involved in promoting vaccination. The analysis suggests that, for the Vaccine Critical groups, it is impossible to separate science or epidemiology from political decision-making and that risk statistics should be seen as a product of this nexus, rather than an objective or reliable representation of reality.

Second, in terms of the relationship between individual and community risks and the charge that the groups are individualistic, the data do reveal a critique of the government's tolerance of individual casualties. However, this should be understood as a legitimate critique of utilitarianism, rather than a misunderstanding of the community rationale behind mass vaccination. Furthermore, the chapter also revealed two ways in which the basic idea that population statistics are relevant for the individual is undercut: calls for genetic tests to screen out vulnerable individuals represents a demand for the individualisation of risk and a critique of the one-size-fits all nature of mass vaccination. Conversely, claims that the individual chance of contracting disease is related to social factors, such as housing and lifestyle, rather than vaccine status, conceptualise vaccination as privatising. This latter critique bears similarity with the political economy perspective in the sociology of health and illness (Lupton, 1994, p8). Although initially very different, what these discourses have in common is the idea that risk is not equal for all individuals. These discourses share much with the idea of the new public health, as discussed by Lupton (1995), which focuses on environmental

factors and life-style choices. The implication, to be revisited in chapter eight, is that it is vaccination, rather than vaccination resistance, that should be regarded as the historical anomaly in need of justification and explanation.

And finally, the data reveal the way that the discourse of vaccination success, identified in chapter four as symbolically important for medicine and public health, is undermined. The benefits, necessity and efficacy of mass vaccination are challenged by the Vaccine Critical groups. This could be analysed as simply about the other side of the cost-benefit calculation. However, an uncritical focus on risk would miss the importance and strength of these arguments. By questioning the rationale behind disease eradication, questions of risk, if not entirely irrelevant, are at least relegated to secondary importance. Taken together with the previous strands of analysis, the main conclusion of this chapter is that vaccination resistance involves a reframing of risk. Overall, therefore, it should not be understood as about risk, if risk is narrowly defined as risk perception.

Further theoretical and policy implications of these findings are returned to in the final chapter. The discussion now moves on to investigate the extent to which trust is more relevant for an understanding of vaccination resistance.

## Chapter 6: Trust and expertise

According to Lupton's Foucauldian understanding of medicine and public health, experts and expertise play an important role in mediating between authorities and individuals (Lupton, 1995, p10). From a more structuralist perspective, experts are also seen as important in the power they have to influence individual action. In chapter two, this was discussed through the concept of trust. Detailed analysis of the empirical data suggests that risk is not the appropriate framework for understanding resistance, if risk is used to imply a misperception of risk. To return to the second research question, is a discourse of trust more relevant for an understanding of vaccination resistance?

This chapter takes seriously Möllering's call for empirical work which examines the 'fine details of interpretation' and analyses 'the nature of trust rather than take it for granted' (Brownlie and Howson, 2005, p223). The objective is to investigate whether and how trust or professional expertise is undermined and challenged by the Vaccine Critical groups, and what this means for a broader understanding of the nature of trust. The main argument to be taken forward from this chapter is that vaccination resistance represents a challenge to faith in professional expertise.

The chapter is structured around four discourses that emerged from the data. First, conflict of interest is diagnosed by the groups as a problem and is constructed as a systemic, rather than an isolated issue. Second, a discourse of openness and transparency is used to criticise the spin and secrecy that surrounds vaccination policy. Third, previous policy mistakes are marshalled in order to place current concerns in a wider context. Other policy mistakes, such as BSE, are referred to, but are better understood as part of a discursive frame, rather than events which precipitated a crisis of trust. And finally, trust as faith is conceptualised by the groups in highly negative terms. Those discourses which encourage the parent to become an expert themselves are argued to create another kind of moral imperative.

## CONFLICT OF INTEREST

Interview and documentary material reveals the importance of arguments that relate to the idea of conflict of interests, where the interests of those in positions of authority are seen as compromised. This argument is made by referring to three main examples: GP target payments, the close ties between policy-makers and industry, and a generalised economic imperative for efficiency.

### **Paying doctors to vaccinate**

As explained in chapter four, GP surgeries currently receive bonuses if a high percentage of vaccine uptake is achieved. Several of the groups referred to this issue as evidence that one cannot trust the doctor to promote the child's best interest. The profit motive is thus seen as dirtying the relationship between doctor and patient. The following quote is typical of how this issue was raised. For the Radical groups, in particular, GP payments are not seen as an isolated policy but as part of a wider system of vested interests involving large pharmaceutical companies:

Then there's the money. Doctors who achieve a 90% vaccination take up rate qualify for a financial bonus. A 70% take-up rate results in a reduced bonus. Below that and they get nothing. Of course, big drug companies have an even bigger interest in vaccination. They make millions of pounds annually from it. Vaccination, in short, is big business. At the Informed Parent we think you are entitled to the independent information that will help you make up your own mind. And that vaccination should be no one's business but your own (Informed Parent, *leaflet*, original emphasis).

One group leader was particularly keen to talk about the issue of GP payments as he had personal experience of being pressurised to vaccinate, pressure he diagnoses as a response to the payment system. This individual group leader was clearly angry about the way his family had been treated, and his personal experience provides both a strong narrative and justification for concentrating on this as a campaign issue.

We had gone to our original GP and said we wanted to delay the decision and they said right we are going to strike you off our list basically....And then we had to see an emergency doctor for a few weeks while we found another GP and we asked him about it and he said it was due to financial reasons that we'd lose

our targets. We are on the border of 90% but he said he can't say that officially. It would blow us apart (VAN).

As already noted, the issue of payments to doctors was not discussed in isolation. It was frequently framed in opposition to adverse events reporting, for which no equivalent payment system operates. In summary, the groups felt that the wrong incentives (i.e. financial interests) are created by having a system where doctors are paid to vaccinate but are not required to report adverse reactions. This was neatly summarised during the interview with Vaccination Information:

Well, (a) they are paid to vaccinate and (b), [laughs] what possible incentive would you have to do that? If you get paid for what you are doing on a daily basis then... (Vaccination Information).

As well as focusing on economic disincentives to report reactions, some non-economic explanations are also offered. In the following extract several claims are made: that there may be negative legal implications (or a fear of legal implications) if reporting was mandated, and that the doctor may suffer psychological stress (i.e. feelings of guilt):

They did acknowledge that there was a bit of a problem with doctors....If they vaccinated a child and discovered it was damaged they might feel a certain amount of guilt or they might feel somebody would want to sue them.... But if they introduced a system of reporting that was tight and confidential and it wouldn't do that and it wouldn't allow the doctor to be blamed that would allow them to know what was going on, then I would have thought that was the best way of stopping parents getting upset and shouting when something went wrong. But they won't do it, why they don't do it, you can ask them. What the hell are they doing? (APVDC).

This quote functions as justification for the introduction of a compulsory reporting system and suggests ways – for example confidentiality – as a way of reducing potential problems that stem from the individualisation of responsibility. It also demonstrates the difficulty of separating criticism of national policy and criticism of doctors. 'What the hell are they doing' refers to the policy-makers, but the implied outcome is a lack of trust in doctors.

## **The pharmaceutical industry and vaccination**

The role of the pharmaceutical industry is seen as crucial by the Vaccine Critical groups. The critique is not usually directed at industry itself, however, but at the close ties between industry and those who make policy decisions. Just as doctors' motivations are seen as compromised by the introduction of financial incentives to vaccinate, so links with 'big pharma' are seen as inevitably compromising the authority of regulators. This discourse was used by most of the groups, whether Radical or Reformist. The following quotes from two groups demonstrate the desire to buttress possible accusations of naivety or extremism when discussing the role of big business:

I am not that naïve that I don't understand the government wanting to promote the British pharmaceutical industry and any other industry abroad, you know. That's what it's all about, that's how the economy works, it keeps people employed *et cetera et cetera* (JABS).

Now I am not saying that drug companies are only interested in money, because that would be silly ...(APVDC).

Rather than criticising industry directly, part of the groups' critique is levelled at the perceived lack of independence of individuals involved in vaccination decisions. Specific institutions are criticised, as exemplified by the following quote from the Informed Parent:

If you think of the Committee on Safety in Medicine and all these other Joint Committee on Immunisation, again just a couple of years ago they had to declare their interests. The majority had ties to the industry in some way and so that doesn't reassure parents either. They want to see independent bodies that are overseeing all these things so that that body is always looking at the interest of the child, the health of the child (Informed Parent).

How conflicts of interests compromise the independence of individuals is a key issue for the Vaccine Critical groups. However, a systemic failure is also conceptualised. Firstly, the current system of research funding is criticised. This implies that even if the individuals in charge were changed, the underlying system would still create the wrong incentives. For example, AAA voice their frustration that financial links of members of the main UK regulators are not seen as controversial, and an awareness that research on immunisation takes place in a wider medical context:

That is not healthy. No other industry, no other profession would allow that to happen, but it happens in medicine and there seems to be a sort of climate in Whitehall that if everybody is doing it it's ok and that's not right. The doctors I mention to this say, Bill, that's the system. That's how we get funding for research it's through the pharmaceutical industry, that's the system. Well, I'm sorry, the system stinks. The monitoring of vaccine safety should be carried out by totally independent people who have absolutely no connections to the vaccine industry and their only belief is that children should be safe and vaccination should be safe (AAA).

This same group also voice frustration at what they perceive as a naivety on the part of doctors for not appreciating that they are part of this wider context and are therefore themselves 'contaminated' by the profit motive. The individual doctor, in spite of GP payments, may have an entirely honourable set of priorities but the problem lies in their failure to understand that it is the system that is 'contaminating':

I think there is a blind belief system... I'm not suggesting that they are naïve but I am suggesting they are naïve [sic]. They don't seem to realise that the profit motive has an agenda which is entirely different from theirs. It's not to drive away, to eliminate childhood diseases. It's to make profit. And I really wish doctors would stand back and realise that they have become, I'll use the word, contaminated by the whole system (AAA).

Secondly, industry is seen as distorting interests because of their funding of medical education:

A lot of education is financed from the pharmaceutical industry so, you know, in terms of the way that GPs are probably... There is a vested interest in many different levels in the pharmaceutical industry and in big industry, working very closely with government. It's where do you distinguish? Where does one start and finish? You know, they overlap that much (JABS).

One of the key impacts of this systemic conflict of interest is argued to be on the relationship between doctor and patient. The following quote is an example of a romanticisation of the historical doctor-patient relationship, that was evident in the discourses of several of the groups. In talking about the situation a few decades ago, vaccination.c.uk summarises that:

Basically we were at a time in society where the pharmaceutical industry didn't have such a huge influence on healthcare politics a doctor was like with a sick

child. Maybe even spend the evening there, hold their hand, and that was the kind of society we lived in (vaccination.co.uk).

In this example, the influence of industry is being indirectly blamed for damaging the close, caring and personal relationship between the doctor and patient.

### **The economic imperative**

Chapter four highlighted how vaccination is lauded by supporters as a highly cost effective healthcare intervention. Mass vaccination could thus be framed as sensible resource allocation. However, the Vaccine Critical groups portray this 'economic imperative' far more negatively, implying that cost overrides safety and other issues. This claim is made by both Radical and Reformist groups. For example, the Reformist JABS uses this discourse to explain the trend for more combined vaccines:

Their main objective is to try and eradicate diseases but in the fastest most economic way possible. For them, to have more and more vaccines going into one needle is cost effective and if one or two are damaged along the way the system can mop them up. What we are saying is that is not as it should be (JABS).

VAN, a Radical group, also uses the economic imperative argument and relates it to national economic efficiency. What is being argued is that vaccination is used, not because it is the best thing for children or health, but because it is better for the economy than the impact of childhood disease. Interestingly, this implicitly assumes the efficacy of vaccination, an assumption that is rejected or denied in other parts of the interview:

I think a lot of it now is down to financial motivation. Because it costs employers and governments money when parents have time off work to nurse a sick child and it's cheaper to spend 5 quid on a vial of measles vaccine for the child than it is to have 100,000 working hours off per year or whatever number it would be for parents to look after children and nurse them properly, which is what the children need if they are poorly (VAN).

Such arguments about the economic imperative are a particular important part of the discourses of vaccination.co.uk. The following quote from their website is used to highlight how the economic imperative distorts healthcare. For vaccination.co.uk and

the other Radical groups, vaccination represents a quick fix and cost driven solution which fails to deal adequately with the underlying causes of risks to health.

Governments all over the world are ignoring the facts and manipulating statistics to support mandatory vaccinations because it's cheaper to vaccinate and pay out on some serious side effects, rather than deal with the relevant social and environmental issues that put children at risk in the first place (vaccination.co.uk website).

This section has indicated how both the Radical and Reformist Vaccine Critical groups use the broad idea of conflict of interest to criticise contemporary medical and political institutions. Many of the groups construct a negative image of a system corrupted by the profit motive or the drive for economic efficiency. The remedy for this situation is often left implicit, particularly for the Radical groups. The next section moves on to consider how spin and secrecy are conceptualised as threatening public confidence in vaccination.

## **POLICY-MAKER SECRECY AND SPIN**

The previous chapter discussed how risk statistics are seen as deliberately withheld or distorted in order to promote compliance. How this argument relates to trust is the subject of this section.

### **Secrecy**

The data reveal that the Vaccine Critical groups are unhappy with what they perceive as secrecy on the part of vaccination regulators, policy-makers and health professionals. There are different ways in which these claims are made. VAN, like other groups, actually use the idea of concealment as a rationale for their existence as a group. Parts of this extract were also used to illustrate a point in the previous chapter:

What we'd like to do it to try and really bring a, in quotes, a 'greater public debate' on the subject because we feel that so much information is covered up and suppressed that we would like to bring it into the public forum and try to show that this information is out there and show that we are not being told the truth effectively about what is happening. It's a great scam (VAN).

APVDC argue that the information is there for health professionals, in the form of the so called 'green book' (Department of Health, 1996), but that this information should be routinely available to parents. This group seemed genuinely happy with the information that is provided within this publication. The problem was merely one of access:

This is a criticism of the Department [of Health] because they don't make an awful lot of information available. I mean this book, Immunisation Against Infectious Disease. First of all you have to buy it... they send it to clinics and doctors and one or two parents have rung me up and said well, I went to the clinic and I asked them and they said 'oh you can't have that'. Almost as if it's a confidential bible, so they don't make enough information available (APVDC).

Vaccine Victims makes a similar point in relation to doctors and the concealment of information:

You've got doctors saying there is no such thing as vaccine damage, yet there is a Vaccine Damage Payment Act which belies the fact that they are not telling the truth. So this is where parents would have more confidence if the powers that be said yes, there are some children that will be damaged by vaccines because of so and so and so and so. Give us all the facts and let parents decide, because the confidence isn't there (Vaccine Victims).

However, the following quote from a Radical group demonstrates an awareness that exactly what to tell the public is a difficult political issue. In other words, 'the full facts' as summarised by Vaccine Victims in the previous quote, is problematised, as is the practical implementation of the principle of informed consent.

I have it there, the British Pharma. There's a book, it's thick with side effects of drugs and you wouldn't give this to patients. So basically you don't bother so then it becomes an issue of, in the courts, of informed consent. Is it an ethical or a legal concept? And of course in the courts it becomes a legal concept, and you just, you give the piece of paper within the thing and you didn't read it, you know. Were you negligent? No, because the expert witness on your behalf is going to be a reasonable, and say look, we don't have the time to go into everything. It's up to the person, he did what any reasonable doctor. So that would be the guideline for it, and it's quite vague and problematic (vaccination.co.uk).

The groups also recognise the difficult position that healthcare professionals are in, having to balance the idea of informed consent but also promoting compliance:

How do you not talk about it publicly yet admitting that it happens, it's a very, very difficult one I think (APVDC).

This point also made by JFAVDC :

Officials know that a detailed discussion of all possible risks in every vaccination case would defeat the object of getting every parent to cooperate...(JFAVDC *Be aware of the facts: the choice is yours*).

Whilst recognising this difficult balancing act, the groups overall are still highly critical of the lack of information made available to parents. The next section discusses the related concept of spin. In this discourse, some information may at least be made available, but the way it is presented is criticised.

## **Spin**

The term 'spin' is only used by one of the Vaccine Critical groups. However, the broad notion that facts are being deliberately manipulated or twisted for a certain end is voiced more widely. This relates closely to the section in the previous chapter on the manipulation of risk information.

In comparing UK and Japanese MMR vaccine policy, JABS characterises the government (in this case the three key figures in the Department of Health, Health Protection Agency and Great Ormond Street Hospital) not as lying but as 'playing chess with words'. This phrase is also repeated later in the interview:

It's as I said to you, they play chess with words...you can see the truth is there but when you actually break it down there is more to it than what they are actually presenting (JABS).

The leaflets that parents routinely receive from their GPs are particularly criticised:

We did a critique of one of the leaflets, that's on the website as well, where we've gone through it blow by blow, what they say, and how to make sense of what they said, because it's accurate, but they are just not giving you the full truth...and so you are only given half the story (JABS).

During the interview, AAA uses the word spin to describe how parents are persuaded. Interestingly spin is contrasted with 'common sense'. This phrase is used here as a kind of proxy for rationality: to say something is common sense puts pressure on the audience to align themselves with a particular view and removes the need to consider any alternatives. All this rhetorical work is achieved without having to describe what policy would actually flow from common sense. Interestingly, the aim of disease prevention is described as 'common sense' by the WHO (see chapter 1):

Such emotive language. If children don't go for the MMR and go for single vaccines they will have to have 6 painful injections. Now, ok, take out the word painful, but they don't need 6, you don't need boosters for single vaccines, that's spin. And then they say children will be exposed to these 3 dreadful diseases during the period between vaccinations, then you point out that MMR doesn't immunise 10% of the kids who get it, so they are exposed for 3 years. So it's ok to be exposed for 3 years but not for 6 weeks [laughs]. And once you start to point this out to people this *emotive spin* being against *common sense*... (AAA, emphasis added).

This same group also criticise spin for failing to achieve the objective of increased public confidence and compliance. For example, money spent on MMR promotion campaigns is constructed as wasted money that could have been diverted elsewhere (i.e. to find out the causes of autism). This is a kind of resource allocation argument. In reply to a question about the aims of mass childhood immunisation policy, AAA focus on the issue of confidence:

Nobody wants to harm children, let's get that out of the way. They are not sitting in Whitehall and saying lets go out there and harm children with the MMR. They believe as firmly as I believe that the MMR vaccine is unsafe they believe it is safe. They are adamant that they've got to make sure that the public don't lose confidence in the vaccination programme and that's what their main aim is. The public must not lose confidence in this vaccination programme. What they should have done, if you don't mind me going back a way, what they should have done, instead of spending three and a half million on propaganda... You do not resolve a scientific dispute by spending three point five million pounds on advertising. You solve it by spending 3.5 million pounds on scientific research, that's how you do it (AAA).

This final quote indicates the interconnectedness of trust and spin. An awareness is demonstrated that the government have to focus on uptake and are therefore keenly interested in 'confidence'. However, their policy approach is ridiculed by being

emotively labelled as 'propaganda' and 'advertising' and contrasted with 'scientific research'. How the groups construct science is discussed in the following chapter.

In summary this section has demonstrated how the serious accusations of spin and secrecy are used to criticise those involved in vaccination policy and delivery. What is implicit is a call for openness and transparency. The next section goes on to show how the groups use examples of perceived policy failures, both to justify and to contextualise their current concerns with vaccination policy and practice.

## **PREVIOUS POLICY MISTAKES**

This section presents data which refer to past incidents and shows how they are utilised in order to challenge the authority of those responsible for vaccination policy. The section is sub-divided to consider vaccine policy 'mistakes', before moving on to demonstrate reference to other political and medical controversies.

### **Previous vaccine policy mistakes**

As explained in chapter three, the interview schedule includes questions that are open in nature and does not include questions about specific vaccines. However, the groups were keen to offer detailed examples of perceived policy failures in order to justify their scepticism. The data reveal a widespread reliance on similar stories or narratives.

MMR vaccine policy was frequently discussed in this context of policy failure, especially by those Reformist groups for whom MMR is the primary concern. Several of the groups made the same point about the withdrawal of previous versions of the combined vaccine. For example, the following is taken from the JABS website. The final rhetorical question, left hanging, makes clear their intention to use what has happened historically to cast doubt on confidence in present and future vaccine policy:

In September 1992 two brands of MMR vaccines were withdrawn from supplies because of a risk of mild transient mumps meningitis. In the latest measles campaign the same manufacturers of these brands produced the measles/ rubella

vaccine using the same Schwartz and Wistar strains, but of course leaving out the Urabe mumps strain. Concerned parents of school-age children are reporting similar problems following MR vaccinations: same time periods, similar initial symptoms: such as high temperatures, rashes, convulsions. Will we see the same long term problems? (JABS website).

Changes in the recommended vaccine schedule, or small changes in vaccine policy are welcomed by the groups in some circumstances. However, such changes in policy are also used to support a discourse which criticises policy-makers for implementing change without admitting problems. A fascinating metaphor of washing powder development is used by JABS:

It's like new improved Persil, but we aren't admitting what was wrong with the old one. They are producing nasal spray vaccines without saying there is a problem with live injected ones. And it's trying to ignore a group of children because it doesn't suit them. Same with the whooping cough jabs...So they have now created an acellular one which is strands of the illness and it's a safer vaccine, but they don't say it's because the other one was causing damage. They just say we have brought this one in, so they are making changes without owning up to the damage (JABS).

What is being criticised here is not the policy changes in themselves, but the perceived lack of admission of the reasons why changes are being made. This is felt as particularly galling when the policy changes are claimed to be a result of agitation by the Vaccine Critical groups. This leads to a kind of resentment at being written out of history. For example, AAA expresses frustration that the medical profession are given credit for the introduction of national vaccine compensation and for changes in the pertussis vaccine:

I listen to, Jack McConnell I think it was, the first minister in Scotland, in a recent debate about this issue saying we can't go back to the pertussis scare when children died of whooping cough because parents wouldn't vaccinate them...Parents have always driven for safer vaccination and this issue with MMR is eventually going to end up with safer vaccination too. But it's parent driven, it's not medically driven. The medical profession did not set up a Vaccine Damage Payment Unit (AAA).

In many examples, the profit motive is seen as the driving force behind negative episodes in the history of vaccination policy, a discourse closely linked with the power of the pharmaceutical industry as discussed in the previous section. For example, three of the groups expressed outrage at the alleged practice of selling off faulty vaccines to Brazil and other developing countries. JFAVDC explains:

To destroy defective vaccines would not only imply an error on the part of the manufactures but also a loss of money (JFAVDC *Be aware of the facts: the choice is yours*).

This final quote exemplifies how the discourses of conflict of interest and admitting previous mistakes become interlinked and are used to reinforce each other.

### **Previous health policy mistakes**

All groups were asked during the interviews whether the debate about vaccines reminded them of any other issues. The aim of this strategy was to excavate the underlying discourses of critique that are applied to vaccination but may in fact originate elsewhere. The examples that were mentioned by the groups were mainly 'popular' in nature – i.e. have received widespread media and public attention. For example, JABS discussed thalidomide:

Thalidomide, well it took them years, 20 years to get it recognised and properly acknowledged and yet they are the children that are being born with physical malformalities, malformed bodies or limbs missing, so it's quite obvious they've got a particular problem but it took them 20 odd years to get that identified (JABS).

The surrounding discussion makes clear that thalidomide is mentioned in order to demonstrate that even when there is obvious physical evidence of damage, the link with the recommended drug was still not made by 'them' (meaning medical authorities) for twenty years. According to this line of argument, no wonder, then, that autism, a condition difficult to diagnose and more neurological than physical is yet to be linked to the MMR vaccine.

The impact of previous 'mistakes' or other contemporary controversies is not just on the groups' attitudes but is also conceptualised as influencing the public. During the interview, AAA links the issue of parental knowledge with recognition of past mistakes, and the drive to seek alternative sources of information:

Let's take a reasonably intelligent mum. Parents are so, so aware of the shortcomings of the medical profession and their history with BSE, Alder Hay,

Bristol babies hearts, Beverley Allott, Shipman, shall I go on? They are so aware that they are so suspicious of not just the medical hierarchy but government assurances that they go to the internet now to seek out information (AAA).

Trust is thus seen as a direct casualty of professional 'shortcomings'. The VAN website discusses this issue very succinctly:

Why should you just accept what the doctor and government tells you? Remember the BSE fiasco? We were assured it would not hurt people and it did. Likewise with Thalidomide and numerous other drugs (VAN website).

The length of this extract belies the fact that a lot of persuasive work is being done here. The term 'just' in 'just accept' indicates negative associations with this type of blind faith. The question 'why should you just accept...' functions as a rhetorical device to challenge the audience and to shake any remaining complacency. BSE and thalidomide are mentioned as other instances when the public were 'assured' that no harm would be caused, based on assumptions that were subsequently found to be incorrect. During the interview a very similar point was made by this group. When probed about whether or not a more questioning and demanding public is a good thing, VAN responded in the affirmative:

From our point of view it's a good thing because they're having to think about it more. They're not going along with just what the government say....and that's just not about vaccines, that's a general thing. People are more distrusting about what government says...They see that the government lied about BSE, they see that they lied about thalidomide, and now all of a sudden we are told this is safe even though the evidence contradicts that and parents are sceptical about it and they want the safer alternative in their opinion (VAN).

This questioning attitude, seen by VAN as evident beyond MMR and vaccination, is the subject of the final section, which considers those arguments that construct blind faith in opposition to an enlightened, educated parent.

## **THE PARENT AS EXPERT**

The discussion so far has presented examples and explanations that challenge the authority of individuals and institutions responsible for vaccination policy, and imply that they should not be trusted. In summary, this is to do with a perceived conflict of

interest, the tendency for spin and secrecy, and the existence and non-admission of previous policy mistakes. However, the data also suggest the significance of another discourse which relates directly to how the public is seen in relation to traditional sources of expertise.

### **Passive compliance versus 'free thinking'**

The Vaccine Critical groups, both Reformist and Radical, construct an image of the parent who has to make a decision about vaccination for their child. The following extract from Vaccination Information is used to exemplify one dominant image:

I mean the majority of the population thinks vaccination is a good idea. To look into it, to question it. Who would? If you are a busy parent. It's so much easier. The doctors are telling you it's the right thing to do, TV adverts, friends and family. Just go with the flow. You don't have to think about it again. People are inherently lazy. We are all inherently. If you don't have to research something then why do it? I feel privileged by the fact that I already had doubts because I'm just as lazy as anybody else (Vaccination Information).

The admission that 'I'm just as lazy as anybody else' and reference to the 'busy parent' makes clear that the aim of this discourse is not to criticise parents but to construct vaccination compliance as the easiest option, rather than the result of a weighing up of risks and benefits. The difficulty of questioning vaccination is highlighted more clearly by VAN during their interview. The idea of 'cultural conditioning', suggests a deep rooted impulse that is difficult for the individual to resist:

If you stop and think about vaccination then it's challenging your cultural conditioning that you've grown up with all your life and once you look into vaccination you can't help but question other things you are doing in your life...and it looks massive when you look at it to start with and it's probably quite intimidating...(VAN).

This image of the parent is also adopted by the Informed Parent. The following quote explicitly argues that vaccination compliance is a result of 'not thinking', rather than as a result of an active choice in favour of vaccination:

I hear so many times health professionals saying 'most parents want their children vaccinated'. I said, it's not. Those parents who have got their children

vaccinated haven't thought about it. They just get their card and go. They don't think to question it, why would they?...A lot of people just go ahead with it. I think people don't challenge enough, people don't think, well hang on, there's nothing wrong with what I'm asking, why can't that happen? (Informed Parent).

This image of passive acceptance is made more stark by comparing it to an image of those parents who do question vaccination. The following quote from APVDC was in response to an interview question about what type of person does not vaccinate their children.

They don't follow the herd and just because you do it doesn't mean they are going to do it. They have an individual approaches to various things. I don't really know to be honest...I know that there are now probably a percentage of people who won't do it because they are afraid of what might happen, but I think the real original people who wouldn't vaccinate their children are not in that group. I think they are just individuals who have different ways of thinking of things and I couldn't explain that either (APVDC).

This interviewee is finding the description of non-vaccinators a difficult exercise as indicated by 'I don't really know' and 'I couldn't explain that either'. Other groups find this issue less difficult to summarise. VAN, for example, contrasts sheep with free thinkers:

From our point of view it's a good thing because it means that people are actually having to think about the thing rather than just being sheep and going along because they are told to do it (VAN).

And later:

It's more the free thinking people or people who have a deeper scepticism of what the government are saying. Or just unease about it generally (VAN).

In a VAN publication which included a form for parents to sign and join the group, the header reads 'protect your child for less than 2p per day'. This could be simply analysed as an attempt to stress the low cost of group membership and persuade as many parents as possible to join and increase the financial stability of VAN. However, the use of the verb 'protect' is significant in this context. For supporters of vaccination, the process of vaccination is what protects the child from risk. However, for VAN and the Radical groups in particular, protection is promised to flow from the acquisition of information and the process of education.

Vaccination.co.uk also makes explicit the importance of education for parenthood. For this group, what signifies a good parent and what signifies a bad one is not vaccine status:

Good parents are not necessarily by definition those who vaccinate their children and bad parents those who don't or vice versa. What may be right for one child could invariably be wrong for another. Whatever decision you make you will be the best parent any child could wish for if you take the time to make an informed choice. Making informed vaccine/vaccination decisions and taking responsibility for them is not an easy thing to do. It may seem a lot easier to simply go along with whatever the prevailing wind tells us to do. But remaining ignorant and trusting blindly can be the biggest risk of all. Only you really know what is the best decision for your child and hence the importance of learning enough to give you the ability to make that decision (vaccination.co.uk website).

The reference to 'trusting blindly' is particularly significant and will be returned to later. For now, the important point is that the 'free thinking' alternative is not constructed as easy. However, as the next section reveals, the Radical groups conceptualise the potential for responsibility and empowerment as extremely attractive.

### **Responsibility and empowerment**

Whilst drawing contrasts between those who behave more like sheep and those who are more 'free thinking', the group interviews, websites and documents also detail the process of education that the parent is encouraged to undertake. The image that is constructed is a process of personal enlightenment, where the parent moves from 'darkness' into 'light'. In many ways this mirrors the process that the various leaders describe in their gradual realisation that vaccination may not be the best strategy, or that vaccines may be responsible for their child's disabilities. This is evidenced by the following quotes from JABS:

When XXX [her son] was due for the jabs I asked the health visitor to come down and discuss it and I asked all the right questions of the health visitor about how safe it was, how many side effects have been reported, how long has it been used for, and what she gave me and in my naivety I didn't know to ask anything else... (JABS).

This group then goes on to discuss how and why parents get in touch with them. She makes the comparison between their difficulties and her own:

As I said with myself, I thought I had asked all the right questions, but, with hindsight we find out we hadn't (JABS).

The leader of the Informed Parent also graphically describes the process that she went through, that starts with a kind of naivety:

So they [her children] initially had the early ones [vaccines]. I think I was just typical. Most parents you don't. Especially before you have children you don't even think about these things...(Informed Parent).

For the Informed Parent this stage of 'not thinking' was then replaced by a period of intensive reading and contacting other people, as a result of a chance encounter with a critical article in the *Evening Standard*. The reference to 'open your eyes' is used metaphorically but is literally describing a gradual 'awakening':

So I sent off for their suggested reading list and then got a whole list of books and of course I thought oh, where do I start? So I just literally started with one and phoned up book suppliers and just chatted to a few people and asked well which ones do you recommend and then in the end I ended up with them all because as I started to read I thought, goodness me, I didn't know all this about this. It just led you to open your eyes more and more (Informed Parent).

The Radical Vaccine Critical groups are more likely to use a discourse of 'taking responsibility' for health, and claim that this is empowering for the individual. Indeed, the strap-line for the VAN group that appears on all websites and publications is 'informed: educated: empowered'. During the interview the role of empowerment was confirmed as important by [vaccination.co.uk](http://vaccination.co.uk):

In health promotion and in the health of society, there's far more issues than just stopping them getting measles, there's issues of empowerment in healthcare. I would argue the whole vaccination thing is very dis-empowering because the concept is hey, do this, and you don't get these diseases and they won't kill you. So you'll be alright then ([vaccination.co.uk](http://vaccination.co.uk)).

The alternative for these groups to the disempowerment of vaccination and contemporary 'quick fix' healthcare is personal responsibility that results from taking a

broader attitude to health. The Informed Parent indicates an awareness of why, at one level, the germ theory of disease is attractive to people but also why if you 'look at it from a different angle' alternative approaches are empowering:

The germ theory is much easier to latch onto and be popular because it means you don't have to take on responsibility because you are blaming the germ always. You see any disease you've had, it's like oh I am very unlucky because this person coughed on me and they had some virus and now look at me... So, and I think what's nice about not being frightened of the germs and all that stuff, when you actually start to look at it from a different angle it's actually empowering. [Interviewer: How do you mean?] Empowering in the sense that you can do something about it, it's your choice how you live your life (Informed Parent).

This 'different angle' refers to ideas that are central to a discourse of alternative health, a discourse that is particularly important to the Radical groups. The following quote from [vaccination.co.uk](http://vaccination.co.uk) makes explicit the link between health and responsibility. What is being constructed here is a different understanding of health and disease, where the doctor/patient relationship is less central. In these narratives, the process of education and empowerment does not, it seems, involve traditional experts:

Health isn't a commodity, it's something you cherish, something you look after so, something you build on. People think they can go to their doctor and acquire health so they can abuse their bodies and do what, it's kind of ridiculous. And I'm not talking about a blame culture. I'm talking about an understanding of how our bodies function and work which should be part of our education ([vaccination.co.uk](http://vaccination.co.uk)).

This section has indicated how a very positive image of the dissenting parent is constructed, who is highly educated and who takes individual responsibility for promoting their own health. One group argues powerfully that this image is both encouraged and resisted by the NHS:

You've got the National Health Service. We are looking after you cradle to grave and this is our responsibility because we are the National Health Service, thing, and this is part of our responsibility to protect you against disease... The National Health Service gives out mixed messages. Part of the stuff is, that's put out is that we have to take responsibility for our own health... whenever the general public try to take responsibility for its own health, we are knocked down (AiA).

What this apparent contradiction means for healthcare policy, and for our understanding of trust, will be returned to in the final chapter. Before concluding, this chapter will briefly present data which demonstrate that as well as calling for personal responsibility and empowerment through education, the groups also diagnose an existing crisis of public trust.

### **Decline in public trust?**

As well as talking at the micro-level about the individual parent and their experience of and attitude to health decision-making, the groups also provide a more macro-level analysis of shifts in contemporary society. During the interviews the groups were not asked to comment on trust or a decline of trust directly, but were simply encouraged to expand if trust was mentioned. Interestingly the Reformist groups were more likely to diagnose an existing decline in public trust than the Radical groups. The following quote from JABS offers a summary of a decline in deference to medical authority:

I think what we've got in this country and probably my father's generation, our mother and father were terrified of doctors, they were so highly regarded, you didn't argue, you didn't discuss, you didn't challenge anything at all. And I think I was brought up that way, where you had total trust whereas over the last 10 years that basically has absolutely fallen apart now (JABS).

For AAA the internet is a key trigger for these changes and is argued to have 'changed society completely':

A mum in Scotland whose child was developing normally and received the MMR and the child drifted away over a period of time can talk to a mum in Hawaii who has the same experience and they can share that experience and they can debate it and debate it with others and they eventually form groups, they form groups which are pro-active groups, then they hold marches....And the medical profession churn out the same duff information and they think if they repeat it often enough we are all going to start believing it (AAA).

This 'sharing of experience' with other mothers contrasts sharply with the image of the medical profession 'churning out the same duff information' in a repetitive way. The internet, according to this claim, is leading to new forms of expertise, or at least new types of relationship. Education is also theorised as an engine for change, most clearly by Vaccine Victims:

You can't put them into pens, you know, parents, human beings into pens without them asking questions, I think years ago they didn't, you were boom boom boom, on a conveyer belt, you know, it was the done thing...you didn't question it. Now people are more educated they know there is a problem (Vaccine Victims).

This final section has presented data which relate to how the parent, and their relationship with experts, is discussed by the Vaccine Critical groups. Particular images of the parent are constructed. Vaccination acceptance is constructed as kind of passive, done in response to following others or expert advice uncritically. In contrast, the Radical groups in particular see resistance to vaccination as a far more active process, resulting from the parent empowering themselves to take personal responsibility for health and after finding out about vaccination. As well as making certain demands of parents, some of the groups diagnose existing shifts in relationships with experts, brought about by social changes.

## **CONCLUSION**

The second research question is addressed in this chapter through an investigation of whether and how the Vaccine Critical groups problematise relations of trust in order to resist the imperative of vaccination. The analysis reveals only limited differences between the Reformist and Radical groups.

The Reformist Groups criticise the system of financial bonuses to GPs as damaging the doctor patient relationship by distorting or 'contaminating' doctor's interests. This is one of the things that creates, or increases, the pressure on the parent to vaccinate. A discourse of openness is also used to criticise the perceived spin and secrecy associated with vaccine policy and is closely related to the previous chapter's identification of risk as manipulation. The Reformist groups cite vaccination policy episodes and other well known examples of policy failures, in order to suggest that public trust has been misplaced in the past. Finally, those who question vaccination are characterised as 'free thinkers' who are willing to take personal responsibility for health, as opposed to those who just follow others or have blind faith in what they are told. The data also suggest

that some of the groups diagnose an existing crisis of public trust in authority spurred on by mass education and the widespread availability of the internet.

The Radical Groups make very similar arguments but place additional emphasis on criticising the power of the pharmaceutical industry in society in general, and in highlighting the close ties between industry and vaccine policy-makers. For some of the groups the entire rationale for disease eradication is explicable, not just by the dominance of certain underlying scientific theories, but because of cost effectiveness. Overall the Radical Groups are more explicit in their reframing of the good parent, not as one who does or does not vaccinate, but as someone who achieves the empowerment associated with 'free thinking'. Rather than being already evident, the data suggest a demand for a decline in deference: the individual parent, rather than trusting or not trusting expert advice on vaccination, has the capacity to become the vaccine expert themselves.

In summary, the data confirm the importance of trust for the discourses of all the Vaccine Critical groups. How the data should be analysed further, and which arguments will be taken forward to subsequent chapters, is now clarified.

Chapter two identified competing definitions of trust that are implicit and explicit in the literature. The regularity with which conflicts of interest were discussed in the data confirms the importance of trust as 'interest promotion', where trust is partly about confidence that another person will both understand and promote my interests. More striking, perhaps, is the way that even for the Reformist groups, conflict of interest is conceptualised as *systemic*. This means that a policy of professional financial incentives is seen as just one example of a wider corrupted system, which allows close ties between the government, the medical profession and the pharmaceutical industry. It also suggests that openness or transparency in terms of declaring interests will not address this critique.

Reference to previous policy mistakes functions as a way of providing historical context and longer-term legitimacy to current concerns. This discourse can be analysed as a challenge to trust as 'role performance' and the groups' discussion of past policy mistakes exemplifies a disruption in this type of trust. Not surprisingly, perhaps, vaccine

policy mistakes are lamented alongside other policy examples seen as justifying a lack of trust. The implication is that some examples, such as BSE, gain importance as part of a discursive frame. In other words, BSE did not necessarily 'cause' or even precipitate a loss of trust in this case, but rather functions as a convenient short-hand for the problems associated with policy making and delivery on health.

The most interesting finding from the data is the way in which groups construct a type of trust – more accurately labelled as faith or deference - as highly negative. Both the Radical and Reformist groups demand that the individual parent becomes the expert on vaccination. This process of becoming expert is described positively as taking responsibility and achieving individual empowerment, in stark contrast to the sheep-like mentality associated with unthinking vaccination compliance. Although the groups do use popular frames like openness, independence and transparency, implementing policies designed to promote these would only represent a partial response to the overall critique.

This vision of the parent demands further analysis. It bears some resemblance with the concept of the 'expert-patient' that is described and encouraged by the Department of Health, and which will be critically discussed in the final chapter. This vision is also usefully understood through a Foucauldian perspective. In resisting the imperative of vaccination, the groups are actually involved in constructing another moral imperative. In the resistance model, the good parent is not defined in relation to whether or not vaccination is complied with, but is judged according to whether or not they have engaged in the process of self education. This role of 'self' is anticipated by the notion of the governance of the self or 'care of the self', where the individual is constantly obliged to improve on and cultivate themselves (Foucault cited in Shawver, 1999). Data from the groups suggest the recognition that this process of re-education or 'challenging the cultural conditioning' is difficult, but is ultimately worth it for the prize of greater personal responsibility. The concluding chapter will argue that, ironically, this discourse contains elements of the deficit model of the public understanding of science, together with a certain view of contemporary citizenship and a particular model of subjectivity.

The main conclusion to be taken forward from this chapter is that trust is empirically demonstrated to be important to an understanding of vaccination resistance. More

accurately, the data suggest a challenge to faith or deference towards professional expertise. Before drawing out the wider implications, the next chapter shifts focus to look directly at the way in which science, a key part of the imperative of vaccination and source of cultural authority, is constructed by the Vaccine Critical groups.

## Chapter 7: Science and medicine

If vaccination is claimed to be one of the greatest scientific and public health success stories (Poland and Jacobson 2001) and science is indeed an ‘icon of modern society’ (Wynne, 1991), then what does this mean for an understanding of vaccination resistance? Modern medicine, it has been argued, gains its social legitimacy from science. As a key technology of medicine, vaccination borrows and benefits from this legitimacy. Epidemiology is the scientific process by which research is carried out and risk statistics produced. The medical and political support for vaccination is justified by reference to scientific evidence. In short, vaccination provides a case study which reveals the close relationship between risk, trust and science.

This research was not designed to measure ‘scientific understanding’ or literacy. As demonstrated in chapter two, research in the social sciences, particularly qualitative empirical work, has problematised the methods and assumptions behind such research. Instead, the data from the Vaccine Critical groups are investigated in order to clarify whether science itself is the focus of critique and, if so, how science is conceptualised. This chapter therefore contributes to answering the second research question, by explaining the relevance of science for an understanding of vaccination resistance. The main finding is a significant contrast between the groups: the Radical groups provide a deep critique of the relationship between science, knowledge and progress; science itself is constructed as part of the problem. In contrast, suggestions from the Reformist groups for changes in policy and research practice should be analysed as representing faith and optimism in modern science. The main argument to be taken forward to the final chapter is that, considered as a whole, the Vaccine Critical groups have a highly ambivalent relationship with science.

In common with the previous two chapters, this discussion is organised around the discourses found within the data. First, the relationship between science and progress is considered by looking at how the Radical groups warn against ‘glorifying science’, and how science is constructed in opposition to nature. Next, ideas from alternative health are used to challenge the scientific theories that underpin mass childhood vaccination. The third section details the largely Reformist critique that the ‘wrong type’ of science

dominates vaccination: more clinical and genetic research is demanded. The fourth section is entitled 'The dogmatism of medicine' and discusses the way that some of the groups use science to criticise the closed nature of the medical profession. This is analysed as conforming to, rather than resisting, a traditional Mertonian image of science. And finally, a different analytic approach is adopted in order to discuss the data indicating that a minority of the groups are themselves involved in a process of 'scientific' data collection. This is classified as an example of popular epidemiology (Brown, 1995).

## **THE DANGERS OF 'GLORIFYING' SCIENCE**

This section discusses those arguments, usually made by the Radical groups, that represent a challenge to the dominant association between science and progress. This is either done directly, by using a negative narrative about scientific development or indirectly, by constructing science in opposition to nature.

### **The relationship between science and progress**

Those organisations in the Radical category are more likely to express what could be defined as a 'deep' critique of science: that is they develop arguments which challenge the modern association between science, technology and progress. For these groups, tinkering with vaccines or vaccine policy would not be enough. The [vaccination.co.uk](http://vaccination.co.uk) website provides a striking example of a macro critique of science:

We live in an age of science and throughout this century in particular man has made extraordinary progress both in his understanding of the universe and the use of scientific knowledge to improve quality of life. One must also consider negative aspects, we are chopping down forests, pouring noxious substances into our environment, destroying ecosystems, possibly bringing about long-term and perhaps irreversible changes to the world's climate and people's health. It is incumbent on everyone to question current government policies if we have any concern at all for future generations ([vaccination.co.uk](http://vaccination.co.uk) website).

This quote begins with a positive statement about the use of scientific knowledge to improve quality of life, before going on to provide a long list of problems that humans

have created for themselves. This challenges the automatic association between science and human progress, a view that is criticised as ‘adulation’:

In 21st century culture, science along with its high tech applications predominates. The *glorification* and *adulation* of science gives the word scientific a connotation of quality, it has become a synonym for being excellent, trustworthy and reliable (vaccination.co.uk website, emphasis added).

The Reformist groups also make arguments that could be considered as utilising elements of this critical discourse. AiA, for example, may overall be positive about science and about what future advances will be able to do for autistic children, but is also keen to stress the idea of unknowns. This idea, and the following extract was discussed previously in chapter five on risk. During the interview the leader argues:

If you actually look at any disease you care to think of and say do we know what causes this disease, I would say that 99% of the disease states the answer would be resounding actually no we don't, not definitively. We have got an idea how to treat the symptoms, we have got an idea how to stem the disease, I mean, unless it's genetic. Pure genetic, quite simple, the biochemist, it's a biochemical problem, like PKU<sup>1</sup>, we know it's definite, they are the only ones. We are talking about viruses, and we have a whole universe we don't know, and we have to admit that. And we have to admit that to patients (AiA).

By stressing what we do not understand, the groups are aiming to unhinge the relationship between science and knowledge. Underlying this is a normative commitment to ‘truth telling’: we cannot be sure of what is claimed as knowledge but we can be certain about our ignorance. The next section looks at the importance of the concept of nature and the natural for this type of discourse.

### **The relationship between science and nature**

The idea of the body and health as mysterious is part of a wider discourse, popular within complementary and alternative medicine, which argues for the wisdom of nature. This wisdom is frequently contrasted with science or scientific knowledge which is assumed to be more incomplete, fallible, and short-term. For example, in a recent VAN

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<sup>1</sup> PKU refers to phenylketonuria blood test, done to measure the levels of phenylalanine, an amino acid necessary for normal growth and development. The screening takes place at around a week after birth (UK Newborn Screening Programme Centre, 2005)

publication, an emotive account of a child's death following vaccination is provided before the editor concludes:

The true war is not against disease: we have somehow become our worst enemy by putting our faith in science instead of nature (VAN, *SHOT*, 24).

This short quote is interesting for its adoption of metaphors of war ('the true war', 'our worst enemy') and religion ('putting our faith in') for describing humanity's relationship with nature and with science. JFAVDC is unique amongst the groups in taking this further to use the image of God in direct contrast to humans. In the following quote, God's work is perfect whilst man's is dangerous. God is thus constructed in opposition and superior to science:

Despite progress in other fields of medicine, the safety and efficacy of Pertussis (Whooping cough) vaccine is still in question...God gave us all perfect children, but man knowing the dangers of Pertussis vaccine damaged God's perfect work (JFAVDC *Be aware of the facts: the choice is yours*).

Vaccination.co.uk also consciously adopts a metaphor of war to try and make the case that evolution and nature are infinitely more wise than 'us' and will, in the end, be successful. This argument is made by reference to superbugs, a topic that had been frequently in the news at the time the interview took place:

Because if you look at health in evolutionary terms, our bodies have always adapted and eventually...So a hundred years ago the measles was deadly to certain genetically pre-disposed individuals and it probably killed them. So as evolution goes, the gene gets stronger. That's why we've got these bacteria, the super bugs. And it's no different with humans, but the bugs regenerate much quicker than the humans. Each generation for us is 50 years, while the bacteria, this is why the problem with the super bug, they're just way ahead of us in, to look of it in terms of an arms race (vaccination.co.uk).

This quote represents a Darwinian view of development and evolution, where species are in competition with each other. For vaccination.co.uk, then, the development of superbugs is a predictable response to their natural speed of adaptation. What is radical about this is the implication that, despite progress in science and technology, humans have not yet achieved mastery over nature and may, in some senses, be progressing more slowly.

VAN's attitude to technology is clarified during the interview when asked whether other topics bear similarity with mass vaccination. VAN then discussed genetic modification of agriculture and genetic engineering (a discourse previously analysed in chapter five on risk). The mode of critique is similar in implying unnaturalness:

But nature has been selecting children. It normally selects the strongest structures and if you are doing it in a test tube then it is going to bypass all that. Weakened gene sequences and weakened structures. .... On vaccination, well I don't know because they're talking about genetically modified vaccines and all kinds of things using gene technology, that raises GM food as well. You are eating GM food and you are already a GM person yourself if you like. The implications are absolutely humongous and once you start it you can't stop it (VAN).

Other groups discuss the issue of naturalness, most frequently in relation to vaccines and the immune response. The Informed Parent, for example, objects to vaccines partly because of their unnatural mode of delivery:

So I think the vaccines will place the biggest burden...If they sneak in through an injection into the blood system and then start travelling around and accessing different parts of the system that it wouldn't naturally access initially coming in...so it stimulates the immune system in an unnatural fashion and therefore you don't get any proper immunity from that experience (Informed Parent).

This same argument is made by [vaccination.co.uk](http://vaccination.co.uk):

So the first thing you do when you do a vaccination, you penetrate the skin, so that's quite unnatural from the start. So it might be more natural to take them orally and see, if they give more time for the physiology to do. But introducing foreign bodies straight into the blood stream I think is questionable ([vaccination.co.uk](http://vaccination.co.uk)).

This section has discussed those claims that contribute to a 'deep' critique of science in challenging the linear idea of science-driven progress and warning of the dangers of an uncritical view of science. This is achieved through the use of metaphors such as war and religion and by contrasting the technology that humans and science have produced, with the 'naturalness' of evolution.

## THE LIMITATIONS OF SCIENTIFIC THEORIES

The previous section outlined the ways in which science is criticised and contrasted with 'nature'. The Vaccine Critical groups also critique science by arguing against some of the broad scientific theories that were previously argued (see chapter four) to underpin current vaccine policy. In brief, the basic aim of disease eradication is justified by the germ theory. Claims to the efficacy of vaccination are justified by the theory of antibody response. These theories, and how the Vaccine Critical groups discuss them, will now be discussed.

### Challenging the germ theory of disease

Chapter four explained the importance of the germ theory of disease to the development of vaccine technology. Some of the Vaccine Critical groups, particularly the Radical ones, criticise this theory, thereby challenge the entire rationale for vaccination. One way of doing this, as demonstrated by VAN, is simply to stress that this is a theory, thereby implying that it is not set in stone and is open to challenge:

I think there are incontrovertible flaws in the science...The fact it's based on a theory that's been disproved countless times, the germ theory. And the vaccination theory is not proven, they don't know how vaccines work. It is a theory. Like all theories it is subject to scrutiny and to problems (VAN).

This same group later elaborate why they have a problem with the theory and why Beauchamp's approach is preferable to Pasteur's. According to VAN, Beauchamp, a contemporary of Pasteur's believed that:

A germ can cause multiple illnesses depending on the host it's living on.... If that was the case it would blow the whole vaccination thing out of the water. Because you are protecting against the effects of the measles virus when the measles virus can cause x, y, and z, not just x...(VAN).

The implication of this alternative theory is that health policies should concentrate on the health of the host, rather than the eradication of disease. The Informed Parent also makes a similar point to criticise Pasteur. Reference to his theory having 'flourished'

reveals an awareness of how dominant this approach has become within medicine. This then makes their assertion that Pasteur himself finally changed his mind all the more powerful:

Fear of the germ has been propagated since Louis Pasteur came up with the 'Germ Theory of Disease' and this belief system has flourished since. It is interesting to note that Pasteur, himself, declared on his death-bed that 'the seed (germ) is nothing, the soil (body) is everything' (Informed Parent, website).

The Informed Parent also condemn the government for their 'eradication mentality' that follows from an uncritical belief in the germ theory. This relates to the discussion in chapter five on risk, and the Radical argument that questions the logic of disease reduction. The previous quote and its reference to 'fear' also relates back to the earlier discussion in chapter five, of the relationship between fear and the manipulation of risk, and is in stark contrast to the positive sense of empowerment claimed to be the prize of individual responsibility for health.

As with the earlier discussion about those discourses that questions the logic of disease eradication, it should be stressed that not all of the Vaccine Critical groups directly question the germ theory of disease. However, other groups still argue that vaccination is the wrong mechanism for fighting these 'germs'. One way that this is done is to construct a complex vision of immunity.

### **Challenging the theory of immunity and antibody response**

In addition to the germ theory of disease, mass vaccination relies on a particular view of immunity. As chapter four discussed, vaccination aims to stimulate the body in order to be better prepared if disease causing organisms are encountered. More specifically, the scientific notion of 'antibody response' claims that vaccines work by encouraging the production of antibodies to diseases. An analysis of the data demonstrates some challenge to this standard approach to immunity.

First, the claim that vaccination creates or promotes immunity is undermined by those Radical groups who construct a more complex version of immunity that cannot be measured by antibody response. For example, the Informed Parent objects that:

I'm no immunologist but every system of the body works with each other. You can't knock one and expect everything else to be fine. Or you can't just inject into the blood, which naturally you wouldn't have, all these things going into our systems in such a manner (Informed Parent).

This quote indicates, once again, the importance of 'nature' or 'naturalness' as a mode of argument for some of the groups. As the previous section demonstrated, to call something unnatural is a powerful rhetorical device. The idea that 'every system of the body works with each other' is part of an alternative health discourse which elevates holism. According to this philosophy, aiming at only one section of the immune system represents a naïve reductionism. Later in interview, the Informed Parent claim that their argument is supported by bodies such as the World Health Organisation:

The whole vaccine procedure isn't even an exact science. It's very wishy-washy. It's like we were saying about the germ theory and also the antibody theory is, you know, the idea of antibodies producing some kind of immunity and when the World Health Organisation admit that is not the case (Informed Parent).

Reference to the WHO is clearly an attempt to lend credibility and legitimacy to the construction of a complex vision of immunity. The WHO, according to the Informed Parent, 'admit' that immunity is more complex than the antibody theory implies. Vaccination Information hold a similar view, arguing that 'the entire theory of vaccination doesn't hold water'. This group, amongst others, voice a kind of frustration with the media and the public for failure to discuss the problems of vaccination at this level. For example:

The BBC are pathetic. If they discuss the issue it's always on some little aspect of the issue. It's like. The whole theory of it is never questioned. It's a given that vaccines got rid of these diseases and we live longer. That is never challenged in the media. I've never once heard that being challenged. If people aren't tackling that main issue. I'm not interested in [debates] about having one vaccine or three vaccines, or anything (Vaccination Information).

Second is the argument that vaccination does indeed act on the immune system but in unintended and negative ways. This is therefore part of a broader risk discourse which was discussed in chapter 5. The most common way that this claim is made is to invoke the example of auto-immune diseases.

I think there is concrete evidence and there is no doubt in my mind that the incidence of auto-immune disorders, mainly asthma, and eczema, is directly related to vaccinations (vaccination.co.uk).

Sometimes vaccination is argued to directly cause or increase the likelihood of these chronic illnesses: sometimes the lack of exposure to what are regarded as normal childhood illnesses is seen as worrying and a causal factor for auto-immune problems:

So we don't challenge the immune system from an early age like the previous generation... (vaccination.co.uk).

This idea of 'previous generations' is vital and is reference to a previous age where disease such as measles and mumps were considered a 'normal' part of childhood. The leader of JFAVDC uses a romantic tone to describe his own childhood where measles parties were common:

Vaccinations are an assault on the immune system. They destroy the immune system. And you think back, we are having more and more problems health wise with youngsters... My mother always used to say Jenny Wren has got measles, you go and play with her. We had to go and play with her to catch the measles to get the immune system to come in (JFAVDC).

In this example, immunity is still constructed as the goal and the immune system the target, but the methods used to achieve this goal are very different – individual exposure to disease, rather than mass vaccination.

The chapter so far has discussed those claims which relate to the fundamental role of science in modernity, and those which challenge the scientific theories upon which vaccine technology rests. These claims are made predominately, although not wholly, by those groups in Radical group. The next section considers arguments made more frequently by Reformist groups who argue that the wrong type of scientific vaccine research is being done.

## THE WRONG TYPE OF SCIENCE

The Reformist groups who have a particular interest in MMR and vaccine damage argue that that the wrong type of science is currently being done to investigate possible problems with the vaccine. This section illustrates how clinical and genetic science are positively contrasted with epidemiology.

### Clinical versus epidemiological research

Epidemiology is like a bikini. What it reveals is interesting, but what it conceals is crucial [laughs] (AAA).

The leader of AAA clearly believes in the power of this joke, attributed to a medical humourist, to represent a real problem with epidemiology. In short, the perceived reliance on epidemiology is criticised for failing to spot vaccine risks. In contrast, clinical research, such as that carried out by Wakefield, is seen as crucial, but lacking. This key distinction between epidemiological and clinical or laboratory research is the most common way that the argument about the wrong type of science is expressed. For example, AiA repeatedly made the same point:

I have yet to see evidence that any of these people have actually looked down the microscope and seen the damage. I mean the science behind the damage and this type of vaccine damage we are talking about is second to none. We are well into the 95% plus with scientific certainty that we are right in what we are saying (AiA).

This group also argued that vaccine damage is more likely for a genetically predisposed sub-section. Looking at the wider population using population based data may thus miss the effect on this one small group. When criticising the behaviour of the Public Health Laboratory Service (now the Health Protection Agency), AiA complain:

So they say 'oh epidemiology'. Well, Joe Public doesn't even know what epidemiology means, let alone be able to say it. And so you go along and you may pick up a leaflet and it says studies have shown that it's perfectly safe, so we look at the studies and it's crap. I am not a statistician... but I can understand the basic tenet that if you have a very small effect you have to look at a very, very large population to identify that effect otherwise you are going to miss it (AiA).

This direct critique of epidemiology is also made by JABS:

A lot of the reports that the Department of Health are quoting as evidence that the vaccine, MMR, doesn't cause damage are based on epidemiological studies and they were not designed to pick up the type of problems we are dealing with. We are looking here at chronic conditions in many cases. They weren't designed for that. What we should have is a proper reporting mechanism for adverse events, we've got a yellow card system that doesn't work (JABS).

This quote covers an array of topics and shows an awareness that just as there are different types of conditions (chronic and acute) there are also different types of scientific evidence, aims and research design. What is being criticised is not the sub-discipline of epidemiology but its appropriateness for the investigation of vaccine damage. What is also demonstrated is an awareness of the relationship between epidemiological reports and GP practice. For these groups, the voluntary reporting system for adverse reactions is ineffective. Any reports based on epidemiological data are automatically constructed as illegitimate and flawed.

The work of Andrew Wakefield and colleagues is a crucial element in this clinical versus epidemiological narrative. Wakefield's methods represent exactly the kind of methods that the Reformist groups are demanding. AAA expresses anger and frustration that his research has not been replicated:

They should have said to Wakefield, minute 1, we do not believe you, we think you are totally wrong. Here's the money, prove us wrong. And they didn't...I say somebody in this room guess how many children have they examined to disprove Wakefield's hypothesis that the MMR vaccine is involved in this, 50, a hundred, a thousand? Would you like to guess Pru?...Zero, yes, none...and people are astonished (AAA).

The key phrase here is 'how many children have been examined' as it reveals the type of research that would be considered the only route by which Wakefield's hypothesis could be disproved. Further research based on epidemiological statistics or GP reports of reactions would simply not be acceptable to AAA and most of the other Reformist groups. Later during the interview the group describe correspondence with a Royal College, in the course of which the College argued that they had looked at the clinical evidence which confirmed the safety of MMR. AAA replied by saying:

Kindly provide us with the clinical evidence. We would like to study that too. No reply. There's no clinical evidence. The only clinical evidence is Andrew Wakefield's clinical evidence (AAA).

The next section looks at the data that refers to the use of new genetic technologies, and how they should be applied to mass childhood vaccination.

### **The promise of new genetic technologies**

This chapter began by presenting those arguments which question the relationship between science and progress. One example brought up by VAN was the genetic modification of food and the possible risks that this technology engenders. This may be assumed to be part of a broader critique of new developments in science and technology. However, genetic technologies are also framed positively as a possible solution to the problem of vaccine damage, and as one part of the picture in understanding autism. During the interviews three of the Reformist Vaccine Critical groups (JABS, Vaccine Victims and AiA) demanded the introduction of genetic testing for young babies in order to 'screen out' those individuals who would be more predisposed to vaccine damage. For example, JABS predicts:

I would think that there could come a point, in the same way as they can do like litmus paper type tests. Very simple, very straightforward, I believe if there was enough involvement by the Department of Health, a pharmaceutical company would take this on and develop such a simple test (JABS).

This short extract shows an awareness that such a technology does not exist at present and would need government involvement in order to encourage the necessary research and investment. AiA also recognise the financial implications of such a regime:

You see my ultimate feeling, and it has been amongst many of us for a long time, is that we can probably screen the children at birth and probably get a big wodge of them out by the children who are marginally immunocompromised, or who are reacting badly to gluten and casein early on. [Interviewer: And you can tell that with a blood test eventually or?] No, it's a urine test, so it wouldn't be that dear. You can't do it first, it's not as early as the PKU is (AiA).

Overall, this section has discussed different kinds of arguments related to science and technology. What unites them is the claim that the wrong type or method of science is currently being used in relation to mass childhood vaccination. The implication of the use of this discourse, for how the groups should be analysed *vis-à-vis* science, is returned to in the conclusion. The next section discusses an argument frequently made by the groups, but which is difficult to summarise, about the relationship between science and medicine, and the perceived dogmatic nature of medicine.

## **THE DOGMATISM OF MEDICINE**

The previous section discussed those arguments which propose that the scientific research currently being done is of the ‘wrong’ type. This implies that the critique of the Vaccine Critical groups will not be addressed by the current type of research, whatever the conclusions. This section deals with a very different set of arguments that criticise medicine as a profession for being ‘closed’. The negative treatment of Andrew Wakefield is used as important evidence in support of this view.

### **The closed and unscientific nature of medicine**

During the course of the interviews, doctors, other health professionals and the ‘medical profession’ were referred to frequently. Overall, the portrayal of such individuals and institutions was fairly negative. This portrayal was commonly achieved by arguing that the medical profession is closed, dogmatic and unable to change. As the following quote from the Informed Parent website makes clear, this is the background in which individual health professionals are seen to operate:

You probably think that the one person you feel you can trust in this debate is your family doctor. While no one is suggesting that he or she would deliberately mislead you over vaccinations, doctors are under a lot of pressure to toe the official line (Informed Parent website).

This pressure to toe the official line is analysed by AAA as evidence of the ‘freemasonry’ nature of medicine:

Now a thread...of unity is put up, you know everybody in health supports the MMR policy. Nothing could be further from the truth. All hell is breaking loose back-stage, we are just not being told about it because that's the nature of their profession. I use the expression a freemasonry. There's a freemasonry in this profession which is very difficult for us to break into (AAA).

The groups cite telephone calls they have received from concerned health professionals as evidence of this pressure, and recount episodes where individuals are afraid to 'speak out'. For example, in response to prompting about what kinds of people are members of their group, JABS summarises:

We've actually got parents who work within the medical profession and they are reporting that their children have been damaged as well but they've been, when we say are you prepared to speak out they say oh no we don't, our jobs could be on the line. One staff nurse said when she raised it with her consultant about her own boy he said you'd better be careful where you go with this, there could be repercussions with your job. We've got one consultant who said to me but my pension might be at stake if I speak out, so you've got this threat, blackmail... if you speak out you are in trouble (JABS).

The data show a high degree of consensus between the groups that medicine and doctors are closed to new ideas and approaches. Where the groups differ, however, is in the proposed solution to this problem. The Radical groups use this discourse in order to argue against a reliance on biomedicine and the medical profession. A few of the Reformist groups, however, suggest that more science is the answer. For example, AAA argues that:

An awful lot of the people involved in vaccination are medical doctors, they aren't scientists. You really need scientists in there. Scientists tend to have a much more questioning attitude to things, these medical doctors accept everything that's delivered to them (AAA).

AiA in particular are very vocal on this subject and relate it, not surprisingly given their organisational focus, to the autism issue. They argue that the problem is when medics, and other professions (such as psychologists), think they are scientists:

And I think a lot of it goes back to the biochemistry, because the vast majority of medics do not understand biochemistry, and even as a non-scientist, you know, you look at the biochemical pathways and you look at them and you look at them and you look at them. And you think, oh, I recognise that bit. It's a bit like the tube map... Psychologists think they are scientists and they are not (AiA).

This extract reveals the assumption that individual parents have the capacity to learn about the intricacies of 'biochemical pathways' but that 'medics' do not. Using the lay analogy of the tube map, the speaker argues that although the understanding may be a slow process – 'you look at them and you look at them and you look at them' – it is possible – 'Oh, I recognise that bit'. This links back to the previous chapter on trust, which showed how the groups construct the parent as an expert-in-the-making. Data were also found which makes the same point in relation to science:

What you actually have to do is do it by the age old method of pen and paper and observation, which seems to be quite alien to the majority of the greater parts of the medical profession these days which is most unfortunate, but no, the parents will do it and they'll sit down and start keeping diaries (AAA).

This quote does not use the term science, although this is implied by the terms 'method' and 'observation'. What is being hinted at, therefore, is that parents are actually more scientific than the majority of the medical profession. Science is also defined by this same group in contrast to gossip.

The medical profession is the most bitchy profession I have ever come across. All it takes is two guys to walk down a corridor and one to cock his head at the door and say [whispers] he's a bad scientist. I mean for people who are supposed to be scientists, do they go and look at the science and do they actually start to take a paper to pieces and say this is good, bad or indifferent? No they don't. They are the worst for unprecedented, uninformed gossip that I have ever come across (AiA).

In summary, the data suggest that the groups construct the medical profession as unscientific. Several of the groups argue that medicine is closed, and imply that more strict scientific methods – such as observation – would help. The Reformist groups argue that science and the scientific method is the solution to this problem. However, this positive image of science is potentially complicated by the example of Wakefield, an example that is now discussed.

## The 'ridiculing' of Wakefield

In terms of understanding how the Vaccine Critical groups view the medical profession, the role of Andrew Wakefield is crucial. His perceived poor treatment by the government and health professions is discussed more frequently, during the interviews, than the actual content of his scientific articles. Wakefield, or more accurately the treatment of Wakefield, emerges as highly symbolic evidence for the closed nature of medicine. For example, [vaccination.co.uk](http://vaccination.co.uk) describe how he has been ridiculed by his own profession. As is made clear by other extracts, his 'profession' in this context refers to medicine, rather than science:

When you get onto things like MMR and autism, I feel that that's a red herring, I think it's a huge red herring the whole thing. I think it's really unfortunate and it's been almost a god send to the proponents of vaccination because Andrew Wakefield raised this question based on not many children. Now it was, but Andrew Wakefield did kind of say it was worth investigating. This guy has been ridiculed by his own profession ([vaccination.co.uk](http://vaccination.co.uk)).

This ridicule is described in more detail by the group through recounting an episode about a medical internet chat-room where Wakefield was criticised. This is analysed by [vaccination.co.uk](http://vaccination.co.uk) as evidence for the closed, 'arrogant' nature of the profession:

It was just so arrogant, it was just unbelievable to kind of think that we are so closed minded that we weren't able to look. The guy does raise some interesting questions but I think a lot more research should be done before any conclusions, which is after all what Wakefield was saying. He never said there it was definite proof that there was a link and this is why it's been easy to dismiss ([vaccination.co.uk](http://vaccination.co.uk)).

For other groups, the treatment of Andrew Wakefield is identified as the reason why health professionals feel unable speak out against MMR:

There is a culture of fear amongst a lot of medics. I get a lot of medics phone and say [whispers] we know you are right and we are on your side but we are too frightened to speak out...too frightened for their own jobs. They see what has happened to Doctor Wakefield who dared to stand up and say there is a problem (AiA).

What happened to Wakefield is summarised by JABS as 'forced out of his job'. Serious professional and personal financial implications are thus seen as the reward for

criticising vaccination policy. The following quote from AiA makes explicit the link between openness and science, and about how science is seen not to be done in this case:

This is why I was saying it's something wrong fundamentally with the whole medical profession and there are a few medics who are like Andy [Wakefield]. He helped and he said maybe you are right and he looked into it. And that's what it's supposed to be. It's supposed to be a science. It's not supposed to be we have a little rule book here, it can't be broken otherwise the universe will implode kind of thing. It's supposed to think well oh, there's a different observation (AiA).

In summary, medicine is criticised by some of the groups for being 'unscientific'. The solutions offered to deal with this problem include involving more scientists but also the application of scientific principles – such as openness and careful and sustained observation. The Wakefield case is also used to illustrate the dangers of what happens when these principles are not seen to be applied to medicine.

## **THE GROUPS' ACTIVITIES IN RELATION TO SCIENCE**

This final section changes tack slightly to discuss the data which relate to the activities of groups in terms of science, rather than the content of their discourses. The data reveal different ways in which the groups use and refer to scientific information. JABS is one group who was keen to explain their role in terms of helping parents 'make sense' of the Department of Health information leaflets:

We did a critique of one of the leaflets, that's on the website as well, where we've gone through it blow by blow, what they say, and how to make sense of what they said. Because it's accurate, but they are just not giving you the full truth. They say the child might have a mild temperature 6-12 days afterwards, they might have a fever fit. What they don't tell you is that fever fit can lead to epilepsy or the mild temperature and the fit could be symptoms of inflammation of the brain. It's the same symptom but with a different outcome (JABS).

The Informed Parent also claims to perform a similar function with journal articles, extracts of which are reproduced on their website with (critical) editorial comments:

You can highlight the way that things are worded or some of the conclusions and you think that actually it doesn't really fit with the rest of the article. So I

might reproduce it and then make editorial comments and say oh well, it's interesting that they said that when this happened at the end or whatever...And so I try and spot a few things and then hope that other people start reading it in that way because then you can start to think well actually, none of it makes sense, you know (Informed Parent).

VAN's website stresses that medical sources (i.e. scientific journals) are used in their written publications:

Part of our remit is to encourage debate about vaccinations, so if you agree or disagree with what we are saying we'd love to hear from you, but remember what you read is not generally our own opinion, it is fully referenced and usually to medical sources. Our aim is to help you become more informed (VAN website).

The examples so far refer to the ways the groups report their interaction with medical and scientific data. However, the interview and website analysis also revealed something else: that some of the groups are involved in collecting data themselves. The websites of VAN, Vaccination Information and JABS all request that parents contact them in order to report vaccine reactions or report the health experiences of those who have not been vaccinated. What happens next varies by group. Vaccination Information promise to send out forms:

PLEASE TAKE 5 MINUTES TO FILL IN OUR VACCINATION SURVEY. We are particularly interested in the experiences of non-vaccinated individuals. To receive a form send us an email...(Vaccination Information website).

VAN's website includes a weblink to 'REPORT REACTION NOW'. The user is then directed to an online discussion forum and encouraged to enter basic details such as age and location, plus details of which vaccine, the batch number and manufacturer, and the 'REACTION RECIPIENT IS EXPERIENCING'. The purpose of this exercise is, according to the website:

So we can try to identify trends and patterns of which vaccines are causing what side effects with the aim being able to draw valid statistics from the data gained and preventing vaccine injury in the future (VAN website).

This language adopted is interesting in being quasi-scientific – the information gained is *data*, the aim is the identification of *trends* and patterns to draw *valid statistics*. JABS

also adopts a similar discourse during the interview, with reference to the timing of vaccine reactions:

What we did as soon as we started up, we set up a computer database and started to put the parents' details in, responses of the kids, and sent out a questionnaire. And they were quite detailed. You know, we asked for the parents to put it into their own words, the problems, the initial reaction time, the symptoms, what happened, what are the long term-problems etc. It's only through building up that database that we started to identify bowel disorders, epilepsy, autism, speech and learning difficulties, and all these things that parents were reporting. The children were perfectly normal prior to the vaccine, and then you started looking at timescales for the vaccines, when they reacted, what the initial reaction was, what the long-term problems came to be (JABS).

This process of gathering data to try and establish trends and patterns was not only done in isolation. During their interview, JABS describes their contact with another support group as useful in this process. The 'hang on' feeling described below bears similarity with a kind of eureka moment sometimes experienced by scientists:

When I contacted the Encephalitis Support group. The types of children you've got, [I asked them] have you ever worked out why this particular group is vulnerable? And they say well a lot of these families have got a history of allergies, immune system problems. So you think, hang on. We've got a group of individuals that may be more susceptible to viruses because they've got certain traits. But when you are given a vaccine you are not given an option (JABS).

As previously discussed in chapter five under the heading 'drugs to treat vaccine damage', the leader of Vaccine Victims also describes how the contact between members of the group enabled the identification of some of the risks involved in the use of a drug designed to reduce convulsions. This episode is important as an example of a success narrative. The group themselves do not identify this as data collection or science, but see this as flowing from the networking that organisation allows - 'as a group you are stronger':

So then we had letters sent round to every member of the group [asking] if anybody had had an adverse reaction to this particular anti-convulsant drug and the reports that came back was pretty [conclusive]. We then were able to say that the children that were damaged by vaccines should not be given this drug. So because parents knew each other, and had got the circle, something that was serious could be addressed, so sort of warning that the others shouldn't...A

person that's on their own cannot do anything, but as a group you are stronger (Vaccine Victims).

In summary, this section has collated those arguments that relate to how the groups deal with scientific data. It has also demonstrated that some of the groups see themselves as instrumental in the process of data gathering, as well as information dissemination. Unfortunately, it is unclear from the interview transcripts what then happens to the data. In some cases it appears that data are passed on to more traditional 'experts', such as university researchers working on autism studies.

## CONCLUSION

The main conclusion from this chapter is that science is indeed an important discourse for vaccination resistance, but that the Vaccine Critical groups have an ambivalent relationship with science, technology and medicine. To argue that the imperative of vaccination is resisted by resisting or rejecting science would therefore be an oversimplification. To a greater degree than the previous two chapters, the research demonstrates a significant distinction between Reformist and Radical groups. This distinction will now be summarised, before wider implications, about the role and position of science, are drawn.

One of the key criticisms of the Reformist groups is that the 'wrong type' of science is being done in relation to vaccination. In this context, 'epidemiology' is almost a dirty word, with resulting studies dismissed as fundamentally flawed. In contrast, clinical examination of the type carried out by Wakefield is privileged, as is the potential of genetic science for 'screening out' risk. In this discourse, the problem is not science itself, but the perceived dominance of one particular method. The medical profession are strongly criticised for being closed and unscientific in their unwillingness to consider new hypotheses or ideas. The 'ridiculing' of Andrew Wakefield is cited as one example. In this discourse, science, or the scientific method, become the tools used to criticise the medical profession. Overall, the Reformist groups are therefore positive about the scientific method and its potential to add to knowledge and solve problems of health and disease. The critique is basically about the direction of science in the vaccination domain.

The Radical groups use some of these discourses but also provide a deeper critique of science by questioning our knowledge of health and disease, and by using examples which question the relationship between technology and human progress. This critique constructs a sharp division between science and nature, the latter sometimes seen as mysterious and sometimes wise. To argue that something is natural or unnatural is a common rhetorical device used in arguments intended to persuade: in this context, unnatural implies foolhardy, dangerous, or 'wrong' - all attributes that the groups wish to apply to childhood vaccination. As argued by Coward, nature has taken on a highly symbolic meaning in late capitalist society, related to virtue, morality, cleanliness and purity (Coward, 1989). The use of metaphors of war also help set up a good versus evil narrative. The Radical groups are more likely to provide a fundamental critique of vaccination, by challenging those theories on which it rests: the germ theory and antibody response theory are argued to result in an uncritical eradication mentality and a simplistic view of immunity. This discourse borrows from alternative health ideas to offer different understandings of the nature of health and the causes of disease. From within this discourse, issues of relative risk or the details of vaccine policy are relegated to marginal concerns. Overall, the Radical unhinging of the relationship between science and progress constructs science and medicine as part of the problem.

There are several ways in which these findings relate back to the discussion of the literature in chapter two, and the previous chapters on risk and trust. The Radical arguments about the dangers of glorifying science, and the unnaturalness of vaccine technology are partly anticipated and understood by the literature on the rise of the new social movements since the 1960s. This literature identifies a common theme amongst the movements of questioning the relationship between nature and culture, and a rejection of modernity (Touraine, 1995). Taken together with the argument that vaccination has produced new chronic health problems (see chapter five), this critique also bears similarity with Illich's (1976) identification of the limits to medicine and iatrogenic disease. In short, science as a system of knowledge is criticised for failing to result in positive progress and for actually causing harm. This is in stark contrast to the positive representation of vaccination and science that are central features of the imperative for vaccination.

The data presented in this chapter confirm the centrality of unknowns, a discourse identified previously as undermining the claims of risk statistics to satisfactorily represent reality. One of the things that science is also criticised for is an uncritical attitude to current theories (the germ theory and the antibody theory of immunity). These arguments represent empirical evidence for Wynne's claim (1993) that sceptical and critical attitudes are partly a result of the failure of science to admit uncertainty, despite its rhetorical claims to openness and reflexivity. However, this interpretation is complicated by data from the Reformist groups who criticise medicine and the medical profession for being unscientific. This critique aims at unhinging the historical relationship between medicine and science but actually succeeds in *confirming* the Mertonian image of science as epitomising openness and scepticism. Surprisingly, even the perceived negative treatment of Andrew Wakefield is not interpreted by the Reformist groups as upsetting this image but rather as evidence of the dogmatism of medicine. More generally, the importance of Wakefield as maverick bears similarity with Epstein's discussion of 'heretics' in the AIDS case (1996), and Michael's (2001) identification of the importance of (counter) scientific experts in controversies.

The finding that overall the groups cannot be summarised as 'anti-science' is further supported by the data that refers to the 'wrong type of science'. The stark distinction made by the Reformist groups between clinical and epidemiological research shows an awareness of scientific method and faith in the former. In chapter five, the demand for the introduction of genetic screening prior to vaccination was analysed as the individualisation of risk. It can now be argued that this is also striking evidence of faith and optimism in the ability of science and technology to solve human problems. As will be discussed in the next chapter, it is also an example of a kind of 'lay geneticization'.

And finally, the chapter presented data which demonstrates that a minority of the groups (from both the Reformist and Radical categories) are involved in the collection of new data. This is an interesting finding and was not identified as a strategy by the limited amount of existing research on vaccination resistance. This finding can be compared to Epstein's analysis which found that AIDS activists are engaged in carrying out research of their own, albeit with professional cooperation (Epstein, 1996, p32). The implication is that the Vaccine Critical groups should not be analysed as merely translators or

consumers of science, but are also actors who are directly involved in the production of new knowledge.

By sharing information on experiences and side effects, the groups are drawing on local knowledge, in a similar way to Wynne's (1992) sheep farmers. They are also engaged in a form of lay epidemiology (Davidson *et al* cited in Williams, 2004, p137), where knowledges from a variety of sources are combined. However, the groups are doing more than this. They are not simply drawing on personal and social networks or their experience as parents, but are also actively engaged in designing survey techniques aimed at producing new data. This activity is therefore better explained by Brown's (1995) concept of popular epidemiology, which implies the construction of new knowledge or hypotheses and an original linking of issues or problems. Given that epidemiology is traditionally the preserve of scientific institutions, and is associated with large-scale surveillance measures, the identification of a popular epidemiology provides further insight into how the imperative of vaccination is resisted in practice. The implications of these conclusions, for academic consideration of resistance to technology, are drawn out in the next and final chapter.

## **Chapter 8: Conclusion: understanding vaccination resistance**

This research was motivated by a puzzle: given the scientific claims to extraordinary success, why is it that opposition to vaccination exists and how should this opposition be understood? My original interest in vaccination was narrowed to consider mass childhood vaccination in the UK and opposition was redefined as organised vaccination resistance. Using insights from social science, including social movement studies, medical sociology and science and technology studies, this puzzle was channelled into two specific research questions:

- *How is resistance to childhood vaccination organised in the UK?*
- *How do discourses of risk, trust and science contribute to an understanding of vaccination resistance in the UK?*

In answering these questions, this chapter also draws out the wider theoretical and policy implications from the research. The discussion has five main sections. The first revisits some of the findings of chapter four and argues that the use and promotion of vaccination should not be regarded as neutral, or even a direct result of scientific advice but constitutes a powerful imperative of vaccination. Section two looks directly at the nature of vaccination resistance and offers conclusions in relation to how the groups themselves, as well as how the significance of risk, trust and science, should be understood. This complex argument is summarised in tabular form at the end of the section. Part three considers the theoretical implications of the research for issues beyond vaccination. Policy implications are then considered. The chapter concludes with my observations and recommendations for fruitful avenues for further research.

### **UNDERSTANDING THE IMPERATIVE OF VACCINATION**

The aim of this research - to understand vaccination resistance – required some background investigation of the nature of vaccine technology. The symmetrical research model used (see Sismondo, 2004) does not assume that resistance is the only phenomenon in need of explanation and does not take technology for granted. Whilst

chapter three explains why a fully symmetrical approach was not adopted as far as the analysis stage, chapter four does discuss vaccination policy and practice and adopts an explicitly critical perspective. Due to the more inductive approach adopted, the value and applicability of this critical perspective became clear towards the end of the research process and is itself informed by the literature and reflections on the research findings. In other words, I did not decide on the nature of vaccination, and the relevance of a governmentality perspective, *a priori*, but this emerged through the detailed analysis of the phenomenon of vaccination resistance.

Analysis of the scientific and medical literature showed that vaccination is associated with a powerful narrative of scientific success. Hopes for the future eradication or control of disease are built on vaccine technology. In claiming to be responsible for disease reduction and eradication, it was also argued that vaccination symbolises the promise of modernity. The historical account of the birth of vaccination is particularly important for the main narrative, with figures like Edward Jenner discussed as founding fathers of the technology. A historical approach is useful in placing vaccination in a wider public health context. Lupton's (1995) discussion of historical trends in regimes of public health presents a complex picture, but this may partly reflect the existence of several continuities and discontinuities across periods of public health. In short, mass vaccination is associated with a modern form of public health which focuses on surveillance and intervention at the population level, is a preventative approach to medicine and is closely associated with the germ theory of disease. Over 200 years after Jenner's experiments, claims to the efficiency and safety of vaccination still depend on reference to science and scientific evidence.

These claims to safety suggest the importance of risk for understanding the use and promotion of vaccination. An analysis of health promotional material shows a scientific recognition of some dangers or risks from vaccination but a belief that these are far outweighed by the benefits for the individual and, through herd immunity, the whole community (Hobson-West, 2003 – see appendix 7). Not only does this use of risk assume a rational actor, and exhibit utilitarian assumptions, but risk also creates a specific form of rationality that is hard for the individual to resist. The role of risk in the promotion of vaccination can be understood by adapting Peterson and Lupton's analysis. They argue that risk is more and more relevant to public health, particularly

since the 1970s, and that the language of risk and risk assessment allows 'government at a distance' (1996, p19), so that health promoters are not seen as coercing or punishing. This leads on to the role of experts.

Trust was argued to be important for vaccination, particularly given that achieving high vaccine uptake in the UK now relies on persuasion, rather than strategies of compulsion. Vaccination is promoted and administered by professional experts who embody expertise and gain the status of expert because of medical or scientific training. The relationship between the individual and the expert relies particularly on the notion of 'trust as faith', identified in chapter two as one important dimension of trust. Taken together with risk and science, this analysis demonstrates that vaccination is part of a wider system of governmentality, where the individual is encouraged in multiple ways to adopt certain behaviour for the sake of their interests. Building on Lupton's Foucauldian analysis, the notion of the imperative of vaccination therefore serves as a way of linking the conceptual domains of risk, trust and science.

The implication of this critical analysis is that vaccination, like any technology, is not self evident or beyond analysis. Vaccination should not therefore be regarded as a 'taboo corner of public health' (Stone, 1995, p113) that cannot be subjected to critical social scientific analysis. Rather, vaccination should be analysed as built on particular notions of science, trust and risk that work in combination to give vaccination its legitimacy and status as an imperative. This analysis then opens the way for an informed investigation of how the imperative of vaccination is resisted.

## **UNDERSTANDING THE NATURE OF CHILDHOOD VACCINATION RESISTANCE**

Vaccination resistance was defined in chapter one as organised resistance by groups established to campaign about vaccines, or groups who spend a significant amount of time critically dealing with the childhood vaccination issue. Very little research exists on these groups so a wide range of literature on vaccination refusal and resistance to technology was reviewed. This uncovered assumptions about the importance of risk and risk perception, trust and the domain of science. The empirical data were analysed using

these three themes as a conceptual framework. This section will discuss the empirical findings and what they mean for existing accounts of vaccination resistance, but will start by considering how Vaccine Critical groups themselves should be understood.

### **Vaccine Critical groups and their multiple roles**

Chapter four justified the construction of the 'Vaccine Critical groups' category and explained why this term is preferable to others such as 'anti-vaccination' and 'movement'. The identified groups had been subject to very little previous empirical research, although this is likely to change following sustained media interest in the MMR vaccine. Existing literature and comment tends to focus on how campaign groups use the internet and the media to get their message across. The tone used is almost fearful or apocalyptic, for example in describing the internet as a 'pandora's box' (Nasir 2000) and their use of the media as 'skilful' in promoting 'scientific terrorism' (Poland and Jacobson, 2001). This can be seen as part of a wider concern with the internet as an unregulated source of healthcare information.

The importance of the media and internet as strategic resources was confirmed by the empirical research. The finding that seven out of ten of the groups have a website and six of these provide links to other groups in the UK and internationally helps demonstrate the importance of the internet and why commentators worry about the potential for communication technology to create an 'emergent anti-vaccine diaspora' (André, 2003, p594). However, the empirical research also stresses the importance of the websites, not just as a way of providing information, but as a mechanism to allow two-way interaction with the public. The most interesting example of this is the facility to report vaccine reactions, an example that is analysed later in terms of science. As highlighted by existing research (Cookson, 2001; Howard, 2003; Streefland, 2001; Poland and Jacobson 2001), the media is indeed an important source of information and also as a tool for getting the message across to a wide audience. However, ambivalent attitudes about the media and some elements of frustration were also revealed through analysis of the interviews.

My findings show that the groups are also involved in other activities such as lobbying, petitioning and marches that are more usually associated with pressure groups. This

empirical evidence suggests that the groups should not be assumed to be of the 'outsider' variety and are sometimes encouraged to act close to the centres of power. This insider status was achieved by some of the AIDS activists studied by Epstein (Epstein, 1996, p32). The groups function as support groups for their members. These pressure group and support group functions were not included in the existing literature on vaccination resistance.

Organisationally, the groups are driven by a small core of committed parents. They differ substantially in terms of membership and geographical location, but overall should be categorised as small and relatively informally organised. Their size is anticipated using Wood's (2000) empirical analysis of patient groups in the UK. Because of their different aims and strategies, the figures on membership cannot be taken as evidence of relative importance or impact. Chapter four also demonstrates that the groups were started at different times and that most pre-date the publication of Andrew Wakefield's controversial research. This establishes the inadequacy of explanations that rely on the introduction of Wakefield's hypothesis and recent media coverage as simple triggers for organised vaccination resistance. Indeed, a historical perspective indicates the existence of organised resistance as far back as the early nineteenth century. These findings demonstrate that there is a problem in automatically dating public concerns to the media 'feeding frenzy' over MMR (Spier, 2002) and in those accounts, discussed in chapter two, for whom the contemporary media is the dominant explanatory factor (Leask, 2002; Critcher, 2004; Harrabin *et al*, 2003).

The most significant contribution of the empirical research to an understanding of the nature of the groups concerns the explication of their 'cognitive' dimensions (Eyerman and Jamieson, 1991). As explained in chapter three, a lack of existing research on organised resistance meant that constructing and defining the Vaccine Critical group category required a large amount of interview data to be collected, and is the outcome of a process of critical reflection. As Johnston (2004) argues, the naming of the groups is important and has previously been used as a way of discrediting and marginalising those who question vaccination. The term Vaccine Critical group avoids the negative connotations of terms like 'anti-vaccine'. Cognitively what unites Vaccine Critical groups is their critical approach to vaccines or vaccination policy. In order to

differentiate between the groups the Radical/ Reformist distinction was adapted from social movement studies and applied to the ten Vaccine Critical groups.

The Reformist groups (JFAVDC, APVCD, Vaccine Victims, JABS, AAA and AiA) differ between themselves in important respects but broadly share the belief that vaccines are often an effective and necessary technology. They want to see reform in areas of vaccine policy and practice, such as the implementation or scope of the Vaccine Damage Payment Act. The groups were started by individuals with children or family members believed to have suffered vaccine damage and all have an interest in vaccine safety, compensation and in treatment for the conditions suffered. The Reformist groups are likely to make use of ideas from alternative health discourses but these do not form a dominant part of their guiding philosophy. Whilst taking an interest in all vaccines, the expertise of the Reformist groups is more likely to be related to one vaccine. In summary, their arguments are about harm, the reliability and appropriateness of vaccines, and victim support.

The finding that Reformist group leaders have had difficult personal experiences is particularly interesting and relates to the point made in chapter two about the 'performance of suffering' (Brown and Michael, 2002), and how, in some cases, this performance may be more relevant than knowledge in gaining trust. This finding could also be analysed according to Irwin and Michael's related argument about the 'ethos of testimony' and how suffering is sometimes seen to authenticate reasoning (2003, p125-126). In making reference to such concepts here it should be stressed that the aim is not to devalue the 'intellectual' nature of the groups' arguments. The data as they stand cannot confidently be used to make assumptions about personal motivations. Further academic research, perhaps based on identity, would be required to discuss this issue more adequately.

The Radical groups (VAN, Vaccination Information, [vaccination.co.uk](http://vaccination.co.uk) and the Informed Parent) use similar examples as the Reformist groups to support their claims. For example, the data show the importance of issues like the MMR vaccine and the perceived negative treatment of Dr Andrew Wakefield. However, a more in-depth analysis suggests a level of frustration at the arguments and positions taken by the Reformist groups. They see many of those arguments and media debates as 'red

herrings' (vaccinion.co.uk), which fail to get the heart of the matter. The groups in the Radical category are more likely to voice ideas from alternative health discourses, if not have direct involvement with these healthcare arenas. They also challenge the standard history of vaccination as responsible for the dramatic decline of death and disease from infectious disease (although the Reformist groups sometimes borrow from this too). Crucially for policy-makers, Radical groups are more likely to be supportive of complete non-vaccination of all recommended vaccines. However, their literature may not always make this explicit, and the groups are cautious during the interview in predicting what would happen if non-vaccination occurred on a wide scale. Rather than direct personal experience of vaccine damage, the leaders of the Radical groups have foundational interests in issues around alternative health, the use of animals in research and testing and concerns about the power of the pharmaceutical industry. This is an example of 'social movement spillover', where concerns or approaches are adapted to produce critiques in a new domain (Mayer and Whittier cited in Epstein, 1996, p13).

The Radical/Reformist distinction represents a significant finding and contribution to the literature as it reveals the different strands and tensions within vaccination resistance. These categories do bear some resemblance to Johnston's (2004) recent distinction between the fringe and the mainstream of the movement in the USA. The Reformist groups could be considered 'mainstream' in their focus on issues like compensation and MMR, that are more often discussed in the mass media. In contrast the Radical groups could be seen as occupying the 'fringe' in their questioning of the entire rationale of mass childhood vaccination. The Radical and Reformist distinction essentially provides the framework for understanding and analysing the nature of vaccination resistance and represents a response to the first research question about the organisation of resistance to vaccination in the UK. The second research question is about the relevance of discourses of risk, trust and science. The answer to this question, and the relative applicability of the Radical/Reformist distinction, will now be clarified.

### **Resisting vaccination by reframing risk**

As argued in chapter four, risk is a crucial part of the imperative of vaccination as it is the language by which vaccination is justified and promoted. One of the most interesting findings is the lack of direct 'risk talk' amongst the Vaccine Critical groups.

In other words they do not make their case by arguing that the risks of vaccination outweigh the benefits. It would be misleading, therefore, to assume that because vaccination (or another technology) is defended using language of risk-benefit, that this is also the main language of resistance. Rather, detailed empirical research reveals that the Vaccine Critical groups engage with risk primarily by challenging the realist notion that risk statistics and risk comparison are an accurate and reliable summary of the probability of harm.

This challenge is visible in various forms. Risk is constructed as unknowns by both the Radical and Reformist groups, either because the kind of research demanded is not being done and is not likely to be done, or because of the impossibility of knowing the result of going down a different historical or future path. In its various forms, this is a powerful critique which challenges the fundamental status of epidemiological research as the determinant of vaccination policy. This critique supports work in the social constructionist tradition discussed in chapter two, where it was argued that non-compliance with risk advice may not be due to a misunderstanding of risk, but rather a recognition of inherent uncertainty or unknowns that cannot be captured by risk statistics.

However, unknowns is not the only discourse aimed at undermining risk. The critique of vaccination policy is also made by arguing that the dangers of vaccines are in fact well known, but that statistics are concealed or twisted by policy-makers and health promoters. Politics and risk are therefore entangled. This sees risk as strategy, rather than as a simple expression of epidemiological or scientific fact. Chapter two discussed the distinction between actual and perceived risk as realist and as assuming that the former is fixed and quantifiable whereas the latter is social and malleable. This model is usually used to express frustration at vaccination concerns. However, the data show that the groups themselves actually adopt this realist distinction in order to critique vaccination policy-makers. Furthermore, the groups identify fear as a strategy used deliberately to manipulate public understanding of risk. This bears some resemblance to the idea of fright factors originating from work with social psychology which is used to explain public misperception.

Even though the groups exhibit very little 'risk talk', the data show that the groups are indirectly involved in challenging the risk/benefit calculation by aiming to challenge received wisdom about the benefits of vaccination. This is significant for risk assessment in that by questioning the rationale for disease eradication and by challenging the received version of history, questions of risk are relegated to secondary importance. This is not evidence for Bedford and Elliman's (1998) view that those who criticise vaccination have forgotten the benefits of vaccination and therefore overestimate risks. Given that the aim is precisely to challenge the standard version of history, and vaccination's success narrative, and question whether disease eradication is the best policy, such statements are greeted with anger and frustration by the Vaccine Critical groups, who reject outright this analysis. This discourse which questions the benefits is used more by the Radical Groups and utilises ideas from alternative health about the meaning of health and the causes of disease. A narrow focus on risk would miss the importance of those arguments that question the benefits or need for mass childhood vaccination. This issue is returned to later when considering wider theoretical implications of the study.

Chapter five demonstrated that autism is an important ancillary topic, particularly for the Reformist groups. However, this is firmly placed in context of pre-existing concerns (that predate Wakefield's 1998 paper) about the rise of chronic diseases and is therefore part of a wider discourse that should not be seen in isolation. In addition, the groups point to a variety of other conditions or social problems that are postulated as linked to the widespread use of vaccines. It would be possible to conclude that this represents a focus on risk. However, the main point is that these conditions are not even currently recognised as risks by mainstream science, the medical profession or the government. The aim of the groups is therefore not to contradict the current cost/benefit equation that justifies vaccine policy. Under this discourse the published tables of risk become an irrelevance or as further evidence of the failure of the Department of Health to grasp the problem.

Chapter four identified individualism as a label that has been applied to those who question or refuse mass vaccination. This is perhaps understandable, given the importance of herd immunity and the popularity of the argument that scientists define risk in terms of the population whereas the lay audience is concerned with the effects on

individuals (Bennett, 1999). The data do not confirm a simple individualistic discourse amongst the Vaccine Critical groups. Instead, the groups demonstrate an awareness of the concept of herd immunity and a keen interest in the relationship between individual and community risk. It is indeed the case that discourses around compensation criticise the rationale of tolerating individual costs for community benefit, so that the groups sometimes appear as defenders of the interest of the individual. However, this should be seen as a legitimate critique of utilitarianism, rather than a failure to appreciate the consequences of individual action.

What is more striking, however, is the way vaccination is resisted by challenging the 'one size fits all' nature of mass vaccination. This is achieved differently by the groups. Some of the Reformist groups call for the introduction of screening in order to identify vulnerable individuals who should not be vaccinated. This was analysed as a call for the individualisation of risk. The Radical groups argue that the chance of catching disease or suffering complications is affected by lifestyle and environmental factors. In this discourse, vaccination functions inappropriately as a privatising strategy. What both of these perspectives share is the reframing of risk as different for each individual and essentially non-random. This reframing is not evidence of selfishness or 'rampant individualism' (Taylor, 2004), a charge levied at those individuals who refuse or question vaccination.

To take this argument further, the groups construct risk as non-random by arguing that individual risk is determined either by genetic or environmental factors, including lifestyle. This focus on the individual, each with their own mix of risk factors, bears similarity with some of the discourses of the 'new public health', emerging since the 1970s, as characterised by Lupton (Lupton, 1995). This discussion supports Rogers and Pilgrim's (1995) original but under-developed assertion that it is vaccine technology, rather than vaccine opposition, that should now be regarded as an anomaly in the current climate.

In summary, risk discourses are only indirectly applicable to vaccination resistance. The Vaccine Critical groups challenge vaccination, not by directly using the language of risk/benefits but by reframing risk. Risk is reframed as non-random, determined by wider factors than vaccination status, unable to capture unknowns and non-objective.

This is one key way in which the imperative of vaccination is both challenged and resisted.

### **Challenging faith in professional expertise and the ‘Critically Informed Parent’**

The imperative of vaccination is supported by systems of professional expertise that are embodied in individuals and institutions. One way that the relationship between the individual and these professionals is captured is using the concept of trust. Trust was also found to be important to existing explanations of resistance to technology, as reviewed in chapter two, and to vaccination opposition, as discussed in chapter four. The data analysis therefore involved an investigation of whether and how trust is undermined as a way of resisting the imperative of vaccination.

The data confirm that trust is an important concept for understanding the meaning of vaccination resistance in several respects. Both the Radical and Reformist groups use similar arguments and examples aimed at undermining the legitimacy of those who make and deliver mass childhood vaccination policy. The groups argue that doctors, vaccine policy-makers and vaccine regulators exhibit a conflict of interest and that this conflict is systemic. The problem is systemic because it results from the way in which the pharmaceutical industry funds medical research and education, and the perceived close ties between vaccine production and regulation. It is in this systemic context that pressure to vaccinate is expressed and within which a policy of paying doctors to vaccinate is understood. In terms of the original definitions of trust discussed in chapter two, this exemplifies how ‘trust as interest promotion’ is damaged. Rather than promoting the health interests of the child or the public, this means that vaccination policy and practice is driven by an economic imperative. For some of the Radical groups the entire rationale for disease eradication is explicable, not just by the dominance of certain underlying scientific theories or approaches to risk, but because of cost effectiveness. In chapter four, this claim to cost effectiveness was discussed as part of the vaccination’s narrative of success. However, instead of evidence for success or sensible resource allocation, the Vaccine Critical groups use this as a way of challenging trust in those promoting vaccination.

The effects of this systemic conflict of interest on levels of trust are further exacerbated by government and medical spin and secrecy, and compounded by past health and other policy mistakes. The importance of past mistakes is supported by the findings of the PABE report on attitudes to GM (Marris *et al*, 2001), an issue that is revisited more critically later in the chapter. These discourses question trust as role performance. Openness, transparency and independence are explicitly or implicitly seen as 'solutions' to these problems of trust. Overall this could be analysed as part of a popular 'accountability' discourse that is visible in other political fields and contemporary debates.

As discussed in chapter two, measures to improve transparency are criticised in the literature for potentially creating further crises and for failing to recognise that these are simply proxies for trust (Brown and Michael, 2002). The data empirically support wariness about such measures but from a different angle: according to the analysis, such solutions could be only ever partial, as certain types of trust (trust as faith or deference) are constructed as highly negative in themselves. In this context what is fascinating is the way in which the Vaccine Critical groups construct a vision of the 'good parent' or the ideal citizen. According to Peterson and Lupton, 'ideal "healthy" citizens have their children immunised according to state directives', as well as comply with other procedures such as cervical screening (1996, p69). In contrast, the Vaccine Critical groups, and the Radical groups in particular, do not define the good parent by whether they do or do not choose vaccination. Rather, the groups argue for individual parental responsibility for health. This personal responsibility is apparently achievable through a process of self-education, where the parent gradually becomes a vaccination expert. Clear dichotomies are constructed between blind faith and active resistance, uncritical following and critical thinking, and vaccination as habit versus vaccination as a serious moment of decision-making. Non-vaccinators are not described in terms of class, gender, location or politics, but are 'free thinkers' who have escaped from the disempowerment offered by vaccination. Interestingly, the Reformist groups are more likely to diagnose an existing shift in society towards personal responsibility whereas the Radical groups are more likely to demand it.

To return to the question of trust, the groups do not present themselves in some kind of market for trust, in competition with established authorities on vaccines, but instead

claim to help the parents to educate themselves. If trust is understood as faith or deference to expertise then this discourse serves to bracket out or undermine trust. How precisely the parent is expected to become an expert is not clear from the data. However, what is striking is the way in which this discourse creates another imperative, perhaps just as powerful as the imperative of vaccination. To adapt one of the names of the groups, what results is the construction of what could be called the 'Critically Informed Parent'. The process of becoming a critical expert through self-education is recognised as difficult. As one group puts it, this will require a challenge to 'cultural conditioning' (VAN). However, the prize is constructed as greater responsibility and empowerment. The use of this discourse was not anticipated at the design stage of the project or following the literature review. Other theoretical work was therefore accessed to try and make sense of this interesting finding.

The imperative for self education and personal responsibility depends on the construction of a certain type of subjectivity, where the individual and the individual body become a project to be worked on. This is anticipated by Foucault's notion of the governance of the self or 'care of the self', where the individual is encouraged to improve on and cultivate themselves (cited in Shawver, 1999). This process of self management and self improvement is in stark contrast to the more passive subject envisaged by the functional view of trust as faith or deference that was discussed in chapter two, where the individual defers to another's authority in order to help cope with the complexity of life. The use of the empowerment discourse is also interesting as it conforms to, rather than resists, moves towards a new public health, for which some kind of empowerment, personal responsibility and participation are expressed in highly positive terms (Lupton, 1995; Peterson and Lupton, 1996).

An alternative way of analysing the data is through the concept of citizenship. In his Foucauldian analysis of the representations of measles and measles vaccines, Dew argues that the state relies on a 'duties of citizenship discourse to foster this conformity' (Dew, 1999, p379). In contrast, the Vaccine Critical groups offer a reconstruction of citizenship, similar to an informed scientific citizenship (Irwin and Michael, 2003, p17) which requires interest in and understanding of science. This assumes that the parent is capable of understanding complex information, and so avoids some of the negative assumptions attributed to the deficit model. However, the groups' view of citizenship

actually conforms to some elements of the deficit model, in assuming that knowledge 'is a good thing' as it promotes full community participation (Michael, 2001). For the Vaccine Critical groups, parents become full and active citizens only when they take on personal responsibility for health and vaccine decision-making.

The image of Critically Informed Parent also bears some similarity with the vision of the 'expert patient' actively supported according to recent government reports (e.g. Department of Health, 2001). The image is also encouraged by other policies designed to encourage moves towards consumerism in healthcare (see Gabe, 2004). For example, public demand for single MMR vaccines (BBC 08/02/02) and for these to be made available on the NHS is an example of the public embrace of principles of consumer choice. What the data demonstrate is the fundamental difficulties with such concepts, when patient choice or expertise leads to decision making (such as avoiding vaccination) that is not in line with the advice of health promoters. This results in a contradiction, explicitly identified by one of the Reformist groups (AiA), where the individual patient receives 'mixed messages'; on the one hand to value choice and feel encouraged to take responsibility for health and healthcare decisions, but on the other hand 'knocked down' when this is attempted in practice. The implication is that more examples of resistance or questioning of health services or technologies should be expected, and cannot be brushed aside as misunderstandings of risk or addressed by greater levels of openness or transparency. They may, ironically, be encouraged by wider changes that those in authority are themselves promoting.

In summary, discourses around trust are indeed an important part of vaccination resistance in the UK. Both the Radical and Reformist Vaccine Critical groups resist the imperative of vaccination by challenging trust in those individuals and institutions who promote and deliver childhood vaccination. The conceptual separation between trust as interest promotion, role performance and trust as faith proved a useful way of revealing the multiple ways in which trust is undermined. Most striking is those data which construct faith in professional expertise as passive and disempowering. Ironically, the vision of the Critically Informed Parent constructed by the groups is in keeping with other discourses including the new public health and the expert patient that are encouraged in other domains by health promoters. This adds weight to the argument

that it is not those who question vaccination but vaccination, or the way the technology is promoted, that should be regarded as anomalous.

### **The critique and embrace of science and technology**

Science, it was demonstrated in chapter four, is crucial for the construction and articulation of the imperative of vaccination. Chapter two identified public knowledge of and attitudes towards science as key variables that are assumed to explain resistance to technology. The analysis therefore involved a detailed investigation of how the Vaccine Critical groups discuss science. The data reveals the importance of discourses of science for understanding vaccination resistance, but also a greater degree of difference between Radical and Reformist groups than is the case with either risk or trust. Two competing discourses can be identified.

If the Radical groups were analysed alone then it may be tempting to conclude that vaccination resistance should be understood as a fundamental challenge to the role of science in society. Website, interview and document analysis suggests a deep critique of the way that science is organised and funded, and a warning against 'glorifying' science. This is not the same as 'anti-science' but could at least be labelled as an attempt to unhinge the relationship between science and human progress, or as a fundamental critique of modernity.

This discourse represents a rejection of the imperative of vaccination, given the way in which vaccination is imbued with historical and future success narratives. The Radical groups, and some of the Reformist groups, also challenge the scientific theories underpinning mass vaccination. For example, the germ theory is argued to encourage an uncritical eradication mentality, and vaccination is argued to fail to appreciate the complexity of immunity. This is a powerful strategy: by questioning the scientific rationale for vaccination, other considerations, such as the risks of vaccine damage, become mere distractions.

The Radical discourse also relies on ideas from alternative health in order to challenge the aims of vaccination, and hence question the assumption that vaccination has led to enormous benefits. One important strand of this critique involves appeal to nature as

something positive, in opposition to vaccine technology. This finding confirms Leask and Chapman's (1998) identification of nature as an important theme for vaccination debate in Australia. This interest in nature is anticipated and understood by the literature on the rise of the new social movements, discussed in chapter two, and is analysed as a rejection of modernity (Touraine, 1995). This finding is consistent with existing research that identifies nature as a continuing battleground in contemporary debates over technology (Sismondo, 2004; Marris *et al*, 2001; Macnaughten, 2004; ESRC, 2004).

However, the analysis also identified a Reformist discourse in relation to science and technology. The Reformist groups make much of the distinction between epidemiological and clinical research, arguing that the former is not suited to investigating the effects of vaccination, and demanding more investment in the latter. This should not be interpreted as 'anti-science' but as demonstrating an awareness of competing scientific methodologies. Several of the groups also call for the introduction of some kind of genetic test, in order to screen babies who should not be vaccinated. This was argued above to represent a technical solution to the problem of individual risk and a critique of the 'one size fits all' nature of mass vaccination strategies. However, in terms of science, it is also evidence for a faith in science and an example of a popular geneticisation (rather than one that is elite or professional led) where 'genetic explanations gain ascendancy' (Hedgecoe, 2003, p51). It also conforms to a positive image of genomics, where genetic testing is predicted to be as routine as blood testing (Rabinow and Rose, 2003, p33). Here, new technology is being embraced, rather than opposed. This is in stark contrast to the usual framing of vaccine opponents as 'roadblocks' to progress and new science as enabling 'future promises' in vaccine development (André 2003).

Both the Radical and Reformist groups direct their critique more frequently at medicine, rather than science. An extreme dogmatism and unwillingness to listen to critical voices is identified with the medical profession. It is in this discursive context that the Andrew Wakefield episode should be understood, rather than as an isolated incident. Indeed, the perceived negative treatment of Wakefield and his forced resignation is analysed by the groups as evidence for the closed nature of medicine, rather than science. Interestingly, some of the groups make this argument by actually invoking science: medicine is

labelled as an 'anti-scientific' profession which needs more scientists and more basic scientific methods, such as careful observation and a sceptical attitude. In other words, science itself becomes the stick used to beat the medical profession. The use of this critique is not confined to the groups and was recently evident in a newspaper article entitled 'why can't doctors be more scientific?' (Pennington, 2004). In other words, medicine is critiqued for not exhibiting 'organised scepticism'. This image privileges the scientific method and therefore serves as confirmation of, rather than a challenge to, the traditional Mertonian vision of science.

Chapter seven also presented evidence that a minority of the groups are involved in the production, as well as the consumption and translation of science. This was not anticipated by existing literature on vaccination resistance and was surprising, given the small size of the groups and their lack of research funding. However, other social scientific literature can be used to make sense of this finding. In essence, the groups are engaged in a form of epidemiology in trying to draw causal links between vaccination and aspects of health status, through the dissemination of questionnaires. This could be analysed as a form of lay epidemiology (Davidson *et al* cited in Williams, 2004, p137), where people draw information from a wide variety of sources and observations in order to make sense of their environment. However, the term 'popular epidemiology', as used by Brown (1995) is even more appropriate. Popular epidemiology implies that non-experts actually gather together new information and then make their own links between variables.

Epstein's (1996) work on AIDS activism in the US also provides a useful critical comparison. Although on a different topic and scale, Epstein found evidence that early AIDS activists were involved in organising research on their own, admittedly with professional cooperation, as well as trying to influence the direction of science (p32). More broadly, Epstein also identified tensions or 'cleavages' within the AIDS activist movement, about how closely to move towards science (p342). In reflecting overall on what kind of critique of science is offered, Epstein concludes that activists increasingly became 'believers in science' (p343). In summarising Epstein's contribution, Elston notes that the AIDS activists' call for more scientific engagement contrasts with other movements in healthcare, such as the disability movement, who campaign for less

scientific involvement and medicalisation, and identify these as sources of oppression (Elston, 2004, p226).

Epstein's work is valuable in anticipating the competing Radical and Reformist discourses within vaccination resistance in terms of science. Despite their criticisms of vaccination policy and practice, the data suggest that the Reformist groups are also 'believers in science'. The Reformist groups call for more scientific research and demonstrate particular faith in clinical and genetic developments. As with the AIDS activists, more scientific engagement is ultimately hoped to solve some of the current problems. The Reformists do not therefore offer a fundamental challenge to science, but rather make claims in order to justify shifts in the direction and application of science. In contrast, the Radical groups make a deeper critique and exhibit a broader questioning of the relationship between science and human progress. This fundamental difference between the Radical and Reformist positions makes them difficult to summarise. What can be said is that despite their significant differences, all the Vaccine Critical groups appeal to and criticise science as a way of resisting the imperative of vaccination. In terms of science, overall their attitude reflects tension and ambivalence.

To review the chapter so far, although vaccination is currently voluntary in the UK a powerful imperative of vaccination exists which encourages compliance with the recommended vaccine schedule. In order to resist vaccination, the Vaccine Critical groups must resist this imperative. The data analysis suggests that this resistance is achieved through reframing of risk, challenging faith in professional expertise, and by demonstrating an ambivalent attitude towards science. These complex arguments are summarised in the following table.

<b>Discourse</b>	<b>The imperative of vaccination</b>	<b>Resisting the imperative of vaccination</b>
<b>Risk</b>	Known and quantifiable Population risk gives individual risk Benefits outweigh the risks Objective	Unknown or un-quantifiable Risk different for individuals Impact not considered beneficial Not objective but used as strategy
<b>Trust</b>	Community interests are promoted Successful policy-making history Policy supported by experts Medicine is scientific	Systemic conflict of interest Past policy mistakes Parental expertise/empowerment Medicine dogmatic/unscientific
<b>Science</b>	Past and future success narrative Supported by scientific theories Vaccines proven safe and effective Epidemiology produces knowledge	Question the link to progress Theories challenged as partial Wrong type of science dominates Groups as producers of science

Table 7: The role of risk, trust and science in the imperative of vaccination and resistance to the imperative of vaccination.

To return to the second research question, which referred to risk, trust, and science, this research has shown that, in specific ways, these discourses are indeed relevant for an understanding of vaccination resistance in the UK. Overall, what has been argued is that the Vaccine Critical groups make their case, not only by criticising elements of vaccination policy, but by offering an alternative reconstruction of notions of risk, relationships of trust, and images of science. The next section moves on to consider some of the more theoretical implications of these findings.

## **THEORETICAL IMPLICATIONS**

As made clear in chapter three, this research aims to contribute to an understanding of an observed social phenomenon – the Vaccine Critical groups. In this sense it was empirically driven. However, the findings have theoretical implications that go beyond the topic of vaccination. This section will discuss the implications for academic consideration of risk, trust and science in relation to resistance to technology.

### **Limits of the realist view of risk and risk society**

Chapter two compared the realist and constructionist approaches to the topic of risk. The empirical research provides an example of how the realist view of risk is challenged and undermined. The traditional realist approach assumes that risk statistics are

statements of probability that reflect reality, and function as a logical way of comparing different courses of action. This model implies that understandings of behaviour that run counter to these calculations need to be explained by research, and increasingly sophisticated methods are found in order to explain risk misunderstandings or misperceptions. Risk, if understood loosely as about danger or harm, is undoubtedly relevant to understanding vaccination resistance and in understanding attitudes to science and technology. However, if risk as probability is seen as an accurate reflection of reality, then this research casts doubt on the usefulness of the concept for explaining and capturing competing positions in contemporary controversies.

The Vaccine Critical groups do not use the frame of risk, and do not use the language of cost-benefits. They do not, therefore, try to offer reasons why vaccination is riskier than disease, or that the benefits of vaccination are outweighed by the risks. Rather, the data show the different ways that risk statistics are constructed as invalid. One key way is to concentrate on unknowns. This finding supports the value of Wynne's (1992) typology discussed in chapter two. For such nuanced distinctions or typologies to be more widely adopted, however, there is a need for greater clarity when talking about risk. Because of the well established nature of risk comparison in the medical and healthcare fields and the dominance of risk perception in fields related to social psychology, there is a danger for social scientific researchers in uncritically adopting the language of risk.

The data also demonstrate the way in which the benefits of vaccination are challenged. Although in cost benefit analysis, risk and benefits are essentially two sides of the same calculation, too much focus on risk can result in insufficient attention being given to whether or not, and for whom, benefits have been demonstrated. This research showed the importance of Radical arguments that challenge the historical and contemporary success narrative of vaccination and question the underlying rationale for disease eradication. This finds resonance in research on GM (Marris *et al*, 2001) which concluded that a failure to demonstrate benefits may be an important reason for public resistance, rather than fear over the risk of contamination or health effects. The implication is that future research on risk should be carefully designed to ensure that there is enough scope for discussion of benefits and whether or not claims to benefits are trusted. This applies to research in a realist, as well as a more constructionist tradition.

More broadly, it may be the case that risk or theories of risk are not always the most useful starting point for understanding resistance to technology, even if risk is the dominant media or policy framing. Just as attempts at capturing emotion as affect in social psychology were criticised, so sociologists' attempts to offer increasingly detailed models of risk should perhaps be treated with caution. This empirical research implies that more sophisticated methods of measuring risk perception, and the inclusion of more and more variables or factors, are little more than an attempt to 'squeeze in' other dimensions, including socially situated ones, into an essentially realist model. Given the renewed enthusiasm for the concept of risk across the social sciences it may prove tempting for those carrying out empirical work to look for risk, (and find it), when it is not necessarily there (Hobson-West, 2003). In some cases it is undoubtedly better to start with another concept (such as trust, science or responsibility), rather than try and continually expand the concept of risk. This point has methodological as well as theoretical implications, and these will be reconsidered in the final section on avenues for further research.

One reason for the continued dominance of risk in contemporary social science is due to the high profile of the risk society thesis articulated by Beck and Giddens. The aim of my research was not to function as an empirical test of Beck's thesis, although others have done this using case studies, such as MMR (Moore, 2003). However, some concluding observations are appropriate here.

On first sight, vaccination resistance seems to be good example of the heightened awareness of risk that Beck discusses. However, this is to assume that resistance to vaccination is primarily about risk and that opponents question vaccination because of the unintended consequences of mass vaccination. The empirical research found that the picture is far more complex and that part of the critique, particularly from the Radical groups, is about questioning the benefits of mass vaccination. As has been shown, this challenging of the relationship between science and progress is successfully theorised by others (such as Touraine, 1995 or Illich, 1976), without needing to elevate risk to the extent that Beck does.

In addition, Beck famously argued that 'smog is democratic' (Beck 1992, p36) to highlight how contemporary risks are characterised by their potential to affect everyone, regardless of social status, place or nationality. In contrast, and as argued in chapter five, the Vaccine Critical groups resist the mass nature of childhood vaccination, either by pointing to the individualising nature of risk or by arguing that vaccination is a privatising strategy. The result of these contradictory discourses is the same: both stress that the chance of contracting a disease, suffering complications from that disease, or suffering problems following a vaccine are non-random and are not the same for each child. The implication is that ill-health and risks associated with vaccines are, unlike smog, wholly *undemocratic*. This argument is better understood, not via the risk society thesis, but as a challenge to the privileged position of epidemiology in vaccination policy, where epidemiology is used to calculate risk. In this context, calls for more clinical observation represent resistance to a particular form of governmentality which relies on the calculations of probability through population level surveillance (Lupton, 1999, p92). In short, the empirical evidence contradicts Beck's thesis of risk as equalising.

Finally, chapter four adopted a historical perspective in order to demonstrate that a critique of vaccination has long historical roots and did not start with Andrew Wakefield and concerns over MMR and autism. It was argued that a close reading of the literature suggests that 19th century resistance was not only about compulsion but should also be understood as a comment on risk and science. Part of the force of Beck's argument comes from arguing that we are now living in qualitatively different times. The data therefore support the critique of Beck and Giddens which accuses them of a lack of historical awareness and for assuming that a reflexive critique of science only began to be articulated in late modernity (Lupton, 1999, p82).

### **The multifaceted nature of trust and a 'crisis of deference'**

Chapter two discussed the main social science debates about trust that are relevant for an understanding of resistance to technology. This section will reconsider these in the light of the empirical evidence.

The literature review revealed that trust has been defined in competing ways. Analysis of the empirical data confirms how trust operates in practice, and how different types of trust are undermined. Trust is partly about the promotion of interests, but is thereby vulnerable to a perceived conflict of interest. Trust as role performance is threatened by past policy mistakes. Trust as faith or a 'leap of faith', where the advice of another is deferred to because of some other characteristic such as expertise or professional training, is challenged through the identification of different sources of expertise. The contribution of the data therefore comes in showing how each type of trust is undermined. Overall, the analysis implies that trust is multifaceted, complex and provisional.

Giddens (1990) argues that trust in expert systems is required by the complexity of modernity and other functional accounts stress the need for trust (Misztal, 1996). In contrast, the empirical findings demonstrate how trust as faith is constructed in highly negative terms. Rather than trust in other experts systems, the alternative scenario constructed is of a parent who becomes the expert themselves, through a difficult process of personal education and empowerment. Future qualitative research may demonstrate that a similar discourse is used amongst 'the public' in general. If so, then this suggests that talk of a crisis of trust would be more accurately described as a crisis of faith or a 'crisis of deference'.

This finding also has important methodological implications. The literature review highlighted the centrality of methodological issues to debates about whether or not a crisis of trust exists. Academic and market researchers have attempted to assess this by asking 'who the public trust' and by asking people to rank professions such as 'journalists' or 'scientists' (MORI, 2002). However, this misunderstands both the nature of trust itself and the nature of contemporary challenges to the status quo. This type of survey research constructs trust almost as a commodity or finite resource which is bestowed on institutions and can be switched back and forth between different organisations. However, if the research on vaccination resistance is generalisable to the wider public, then a crisis of deference (or declining levels of deference) would fail to be revealed through such research methodologies, as they do not give the respondent the option of expressing this. This supports the case against the use of the rational actor model in relation to trust, and for less research which aims to measure trust in favour of

more research which looks in detail at examples, such as vaccination, where expert advice is and is not followed, in order to better understand the multifaceted nature of trust and how the legitimacy of institutions or agencies is called into serious question.

Having argued that evidence exists for a crisis of deference, it also needs to be recognised that the language of 'crisis' is often uncritically used and always carries very negative connotations. As highlighted in chapter six, for the Vaccine Critical groups, a decline in deference in contemporary society is positively encouraged, as well as diagnosed. In other words, interesting questions are raised, both theoretically and empirically, about those organisations such as social movements for whom the situation is felt as a moment of opportunity, rather than crisis.

There is another problem with phrases like crisis of trust or crisis of deference. Such generalised talk ignores those individuals for whom a lack of deference may not be an option. According to the data, part of the impetus for a decline in deference is the availability of information (for example on the internet). If this is indeed the case then issues of access and education become paramount. The data suggest that the Vaccine Critical groups recognise that a shift away from deference and towards greater responsibility can be difficult, but do not offer solutions as to how to make sure all parents have the time, money and skills needed to fulfil their vision of personal empowerment. This broadly supports the argument that socio-economic background impacts on the potential for resistance (see Lupton, 1995, p115). An inability to use new sources of health information may also become problematic for some individuals in identity terms. As Sue Ziebland concludes after completing a study of access to cancer information on the internet: 'The ability to access health information on the internet may provide patients with an opportunity to display a particularly modern marker of competence and social fitness' (Ziebland, 2004, p1792). This then causes real problems for those who cannot demonstrate this 'social fitness'. This adds weight to the previous argument that the Vaccine Critical groups may resist vaccination but their arguments actually create other kinds of imperative, with their own problematic characteristics.

The distinction between different types of trust and the finding that deference is important also has theoretical implications in terms of identifying what, if anything, has precipitated a crisis of trust or deference. Wynne (1996) criticises Giddens' (1991)

assumption that one of the features of risk society is that experts disagree and that this is what has precipitated a loss of trust in their authority. Such an assumption is also visible in those accounts that assume that public vaccine concerns can be dated to the publication of Wakefield's paper, as if this represents a sudden moment of disagreement within the scientific community. However, the data show that concerns predate Wakefield and are about far more than the risk of autism. The groups' critique of deference is also about claiming responsibility and individual empowerment and is not a simple response to expert disagreement. Wynne's critique of Giddens' assumptions is therefore supported by this empirical research.

Regardless of what triggered a so-called crisis or whether a crisis is seen as positive or negative, once a crisis has been diagnosed then policy and academic debate then turns to how to respond. However, before rushing into debates about transparency, accountability, or public involvement in policy making it is worth pausing to consider the broader implications of focusing on trust as a key issue. After carrying out research on attitudes to GM, Marris and colleagues found that trust did emerge as an important dimension. However, they still conclude: 'We are convinced that public (lack of) acceptance, or (lack of) trust, should not be defined as the central problem, since this implies that the problems all lie with the public (and agencies which influence it like the media and NGOs)' (Marris *et al*, 2001 p95). For Marris and colleagues, the crucial issue was not public attitudes but rather the image of the public, and the persistence of 'myths', as articulated by policy-makers. (Policy implications of my study are discussed below.) Others have also recently criticised some analyses of trust for adopting just another deficit model – 'if the public is not accused of a deficit of understanding, there is a public deficit of trust' (Zeiss, 2004). What these arguments suggest is the value of approaches, like the one adopted, which use an analytical framework which includes multiple concepts. By looking at risk and science, as well as trust, other issues, such as strategies of expert risk communication (see below) are revealed as important and open to critique.

### **Ambivalence and the distinction between science and progress**

Chapter two critically discussed the hypotheses that resistance to technology is explicable either as a lack of public scientific literacy or the result of anti-scientific

attitudes. Although the empirical research was not designed to measure literacy or knowledge, and cannot be easily generalised to the wider population, this section considers what implications can be drawn from the research for wider issues beyond vaccination.

The data suggest that resistance to technology or to advice that relies on science should not be assumed to be easily explicable by a lack of faith in science or a wholesale rejection of science and technology. This does not mean that the issue of science is irrelevant to resistance. For example, the data from the Radical groups offers some support for Touraine's argument that although we still believe in science we no longer believe in progress (1995). As already argued, the way the Radical groups construct nature in opposition to science is anticipated by Touraine. The research also validates Illich's (1979) theoretical claims about the limits to medicine and the rising importance of iatrogenic diseases (the Vaccine Critical groups would put autism and chronic conditions in this category).

The Radical critique, and in particular the idea of conflict of interest, is anticipated by Lyotard's argument that the disillusionment with science comes from the realisation that science has become the servant of industry (cited in Irwin and Michael, 2003). This shatters the Mertonian norm of disinterestedness. The research could also be interpreted as empirical evidence for Beck's (1992) contention that our faith in experts is shaken by the realisation that contemporary risks are often 'man-made'. Taken together, this promotes the conclusion that in contemporary society (whether we label it risk society or postmodern society), science and technology are not straightforwardly synonymous with stability or progress, at least for certain actors.

However, as was concluded in chapter seven and articulated above, the Vaccine Critical groups, particularly the Reformist ones, also exhibit confidence in science to solve contemporary problems. This confirms the overall dominance of science in society, even amongst those groups who have a particular reason to be critical of a certain technology. More specifically, this research supports the need to look closely at how different types of science are discussed during issues of controversy. This suggestion is validated by work on other topics; Bickerstaff and colleagues (Bickerstaff *et al* 2004) argue that during the foot and mouth crisis in the UK, arguments evolved between vets

and epidemiologists about how best to respond to the crisis. This supports the argument that science is not a monolith and arguments are evident, both within scientific professions and without, over the vision of good science or, more accurately, what kind of science is most appropriate to a particular health or policy arena, as well as specific issues within a given arena.

As discussed above, the empirical research also found attempts at science production, as well as consumption, by the Vaccine Critical groups. On its own, this finding does not support any particular theoretical stance on science. However, in combination with other empirical research, such as that carried out by Epstein (1996), it points to the conclusion that science is not simply the domain of the scientific profession. Instead, science is many things including a variety of methods, a profession, a philosophical position that truth can be known, and a form of rhetoric and discourse. At the very least what the data on vaccination resistance confirm is that in practice science is a powerful ideological resource (Sismondo. 2004). For future academic research on attitudes to science and technology, care is needed to consider which of these aspects of science are being resisted, or borrowed, if any. Furthermore, if science is not a monolith then it is not logically possible to be 'pro' or 'anti-science'. The implication is that research also needs to be sufficiently open to allow *ambivalent* attitudes to science to be expressed. When the Radical and Reformist discourses are taken together, this research demonstrates a profound ambivalence about science in relation to vaccination. This confirms the value of Irwin and Michael's (2003) focus on ambivalence in discussing the relationship between science and society in general.

To continue the point about the multiple dimensions of science, science is also a system of expertise that is represented and epitomised by individuals. It is not surprising, then, to find that the role of Andrew Wakefield is crucial in terms of the vaccination issue. However, the analysis shows that the negative treatment of Wakefield is not discussed in isolation but is seen as entirely to be expected, given the close relationship between the state, science and medicine in the area of vaccination, and the lack of tolerance of dissent in medicine. This leads back to the point made in the previous section, that the Wakefield affair did not trigger vaccination resistance. This finding is similar to the conclusion of the PABE report (Marris *et al.*, 2001), discussed in chapter two, that although BSE is frequently mentioned by respondents as an example of problems in risk

governance, BSE *did not*, as is widely claimed (e.g. Harriss, 2000) trigger a collapse of trust. The implication of this argument is that high profile examples such as BSE and Wakefield are important but should be treated as cultural tropes that are useful in arguments, and through which multiple dimensions of science are made visible and understood, rather than as catastrophic and isolated events which demand special explanation.

## **POLICY IMPLICATIONS**

Throughout the period of this research the author has noted an increase in the number of studies published in medical or health journals aiming to examine vaccination behaviour. This includes qualitative and quantitative work, and such research should be welcomed and is appreciated by policy-makers who are keen for research evidence. As Lachman argued in 2002, there is a definite role for social science here: 'Those of us in medicine would greatly value advice from social scientists, on how this problem could be best addressed' (Lachman, 2002, p98). Whilst not taking a realist approach in aiming to 'address' vaccination resistance in the sense of combating it, the research does have important implications for vaccination policy and practice. This discussion is divided to consider the framing of resistance, possibilities for engagement and strategies of risk communication.

### **Re-framing the problem of vaccination refusal and resistance**

How vaccination refusal and resistance is understood matters beyond social science. In particular, how the government respond to future vaccine 'crises' or falls in uptake depends very much on the lessons that are derived from the experience of MMR case. It is therefore important to consider how best to understand this episode.

The focus on Andrew Wakefield, or rather the media coverage of Wakefield's ideas, is an understandable focus for policy-makers. The hypothesised link between MMR and autism offers a useful way of summarising the debate and one that fits well into pre-existing models of risk such as the social amplification model and the identification of media triggers and fright factors. The fact that uptake has dropped markedly since

media coverage of this issue is also taken as proof that Wakefield is the catalyst for the current crisis. As argued in chapter four, the focus on one man also chimes with the history of the pertussis controversy in the 1970s where 'one zealous champion' is blamed for igniting the story (André, 2003). Assumptions about the importance of the media were also argued to be visible in social scientific (e.g. Critcher, 2004), as well as policy-maker accounts.

However, by taking a discourse approach, this research implies that public anxiety about autism fits into pre-existing concerns about the rise of chronic diseases and concerns about the ability of science to understand fully contemporary problems. This is important as it suggests that even though Wakefield may indeed have triggered the media focus on the MMR vaccine, existing cultural tropes were available to be drawn upon and found resonance in certain sections of society. An awareness of the social history of vaccination also indicates that concerns over vaccination predate Wakefield (and pertussis), and are visible as far back as the nineteenth century. This supports the argument that vaccination concerns are not wholly episodic but a persistent feature of society. The implication is that the MMR issue should not be framed as a one-off crisis to be understood only in its own terms, with individuals acting as heroes and villains, but rather as the latest manifestation of long standing concern over vaccination.

The tactic of emphasising the maverick status of Wakefield, within the scientific community, is understandable from the point of view of those trying to promote the recommended schedule. However, the data from the Vaccine Critical groups suggest that the treatment of Wakefield and his 'ridiculing' and marginalisation simply served to confirm the closed nature of the medical profession and its corruption by state policy-making. The Wakefield affair is seen by the Vaccine Critical groups as the rule, rather than the exception. For those attempting to manage future vaccine controversies, a better tactic would be to explore ways in which a controversial hypothesis can be seen to be taken seriously. This relates to the question of methods, identified in chapter seven as being of crucial importance. For example, the latest research cited in support of MMR on the main NHS website relates to a study in Japan based on tracking the data of thousands of children. The study found that withdrawal of the MMR vaccine had no impact on rates of autism (Honda *et al*, 2005). However, for vaccination resistance, epidemiology has become almost a dirty word and a symbol of the 'wrong' type of

science, used to dismiss those with genuine concerns. The 'right sort' of science, in this case, more clinically based studies, is what is required, rather than yet more epidemiological 'proof'. This would reduce the ability of critics to dismiss easily the latest large scale epidemiological study or research based on GP records, by testing some of the claims and hypotheses of the Vaccine Critical groups.

As well as reflecting on the role of Wakefield and the MMR-hypothesis, policy-makers also need to consider further reasons for non-uptake of vaccination, whether for MMR or any other vaccine. Although this research focused on vaccination resistance rather than refusal and so cannot offer firm conclusions about individual decision-making, the Vaccine Critical groups were studied as locations for discourses, discourses that are expected to be shared beyond the groups themselves. If this is the case, then the research implies that non-vaccination should not be framed as a failure of risk perception or a lack of awareness about the historical benefits of vaccination. Rather, attitudes to vaccination must also be understood as influenced by and related to matters of science and trust. The latter in particular causes problems for policy-makers. If a decline of deference is indeed widespread then this is a fundamental issue for society, and one that cannot be solved or simply 'addressed' by the Department of Health. Indeed it may be that the recent rhetoric from the Department about patient choice and the expert patient may encourage, or at least add legitimacy, to these trends. This point will be returned to below.

The discussion in chapter four about the concept of herd immunity helps explain why policy-makers are concerned with uptake levels and why so much effort is directed at trying to maintain high uptake levels for childhood vaccination. This strategy may be justified by the science but is insufficient, politically and sociologically. The PABE report on public attitudes to biotechnology argues that 'the relationship between the predominance of public concerns and the intensity of public controversy is not a simple one' (Marris *et al.*, 2001, p15). In terms of vaccination research, this warns against an assumed linear correlation between levels of public concern, controversy (beliefs) and vaccine uptake (action). Long-term resentment or opposition could be being fostered even when uptake levels appear high. This mirrors Brian Wynne's argument that the public can feel alienated from an institution (in his case, science), even when this is not shown in open resistance (Wynne, 1993, p334). In a similar way, Wynne has also

argued that a lack of controversy does not necessarily equal trust (Wynne, 1996). The implication is that policy-makers need to promote research that looks at attitudes to vaccines or vaccination, even when there does not appear to be an identifiable controversy. An over-concentration on MMR as the vaccine with current uptake problems is therefore ill-advised in the longer term.

This point about uptake figures is related to a broader point about the dominance of the rational actor model in health promotion strategies. The model assumes that decisions are made after carefully weighing up the costs and benefits, and that decisions are 'active'. Whilst vaccine decision-making for many parents is no doubt a highly active process, as critics of Beck have pointed out (see Lupton, 1999, p120) the rational actor model may miss the importance of habit governed behaviour, which does not involve the weighing up of costs and benefits. One legacy of MMR for the current generation of parents may therefore not be seen in uptake figures, of MMR or any other vaccine, but in the movement of vaccination out of the sphere of 'habit' and into the sphere of 'difficult decision-making'. This conclusion is partially confirmed by recent ethnographic research which found that 'MMR talk' (regardless of which decision is made), has become a 'social phenomenon in itself' (Poltorak, 2005, p709). To reiterate, even if national or local uptake figures are high, then, this should not be framed as public confidence or satisfaction with vaccines and vaccination policy. Equally, lower uptake figures may not reflect a sudden collapse of trust but may instead reflect a greater degree of individual responsibility for vaccine decision-making.

### **Engagement with the Vaccine Critical groups?**

After reviewing issues of science, social theory and public knowledge, Irwin and Michael conclude that, in order to move forward, what is required is that government 'listen and respond to messages which are not expressed according to the discourse – or agenda – of government' (2003, p150). Undoubtedly the Vaccine Critical groups, whether Radical or Reformist, use discourses that are not part of the government's agenda. Having identified what discourse of critique are visible, should vaccine policy-makers should try to 'engage' with the Vaccine Critical groups or their arguments, and, if so, would this engagement look like?

On one level, engagement is already taking place. Chapter four demonstrated that some of the groups are 'insiders' whilst others have contact with senior policy-makers through letter writing and exchanges via the media. Contact was also visible in the 1970s through the involvement of groups in the setting up of the Vaccine Damage Payment Scheme. Doing this more publicly, however, may be opposed by government for fear of adding legitimacy to the claims of the groups or giving too much weight or attention to the arguments and interests of a small minority. Far better, it may be argued, to concentrate efforts and limited resources on maintaining herd immunity by producing information to persuade those wavering parents who may simply have been temporarily put off by negative media reports about autism.

However, to ignore the existence or discourses of the groups would be unwise. This research reveals the paucity of descriptive terms like 'anti-vaccine' and shows the wide spectrum of views exhibited by the groups. From the point of view of those promoting mass childhood vaccination, reference to the groups in less monolithic terms with a more nuanced understanding of the different types of arguments – Radical and Reformist – would be a useful first step and reduce the immediate potential for antagonism.

Secondly, policy-makers need to recognise the important role played by the groups, particularly the Reformist ones, in their role as support groups in helping those families who have children who are suffering with often severe disabilities, and in the role played by the groups in assisting those attempting to go down the compensation route. Taking this research finding on board and admitting the importance of this role more publicly would be helpful. There may also be a case for state funding for some of the groups to enable them to fulfil some of these functions more effectively. Of course, this would not necessarily be welcomed by the groups, who value their independence. On a related point it may prove useful for policy-makers to consider and accept the ways in which Vaccine Critical groups have directly or indirectly had a positive impact on vaccination, for example in the development of a safer pertussis vaccine. Instead of seeing resistance as evidence of irrationality, anti-science or as symbolic of a crisis, this would require an alternative (more functionalist) understanding of resistance, as advocated by Bauer (1995b), that sees resistance not as a nuisance but as necessary for technological development.

This research also provides a resource for those interested in identifying possible reformist changes to vaccination policy and practice. For example, there is definite scope for a re-examination of the way that payments are made to GP practices as this functions as a potent symbol of conflict of interest. Undoubtedly health professionals do fulfil an important function in their delivery of vaccination policy and considerable time and effort is spent on the vaccine issue. As discussed in chapter four, recent discussion at BMA conferences suggests that health professionals themselves find the current system of payments problematic. Further thought is warranted into alternative ways of funding this function. Likewise, further consideration is needed into the way that vaccine damage payments are currently financed. There may be scope to look at the US scheme which is partly resourced through a levy on the vaccine manufacturers (see Pywell, 2002). Whilst the government would no doubt argue that they cannot compensate for conditions like autism (at present not seen to be linked to vaccines with sufficient scientific evidence), scope is definitely there to make the process of compensation claims less stressful for those who do qualify as claimants. Since this project started, changes have been made in the way that possible vaccine reactions are reported. There is also a good case for making the reporting of suspected vaccine reactions mandatory, rather than voluntary.

Such changes in vaccine policy and practice are suggested with the recognition that they are mainly directed at the concerns expressed by the Reformist side of vaccination resistance and would be regarded as ‘tinkering at the edges’ by the Radical Vaccine Critical groups. Indeed this itself is one policy implication that flows from the research – that small changes in policy direction will not silence those who express a more fundamental critique of vaccination. For example, changes in how doctors are paid to vaccinate may reduce one potent symbol of conflict of interest, and satisfy some critical voices in the medical profession. However, because conflict of interest is believed to be systemic, through the economic imperative and the relationship between industry, medicine and regulation, small changes in policy would not address this critique.

The question of engagement with the Vaccine Critical groups relates to broader theoretical debates that could only be discussed briefly in the literature review about the governance of science and technology and whether and how ‘non-expert’ actors should

be brought into decision-making. Hagendijk and Kallerud's European report (2003) identifies six different types of governance but talks of a general shift towards the language of public participation, precaution and reflexivity in the recognition of uncertainty. This shift has also been discussed by Irwin and Michael (2003) amongst others. Interesting debates are then opened up about how actors can be brought into decision making process. To return once again to the PABE report on attitudes to GM, the authors warn that public participation should not be seen as an add on, once the real scientific issue is settled, but rather that 'the objective of public participation should be to open up expert knowledge to reflexive questions about its own framing' (Marris *et al*, 2001, p93).

However, vaccination policy currently provides a valuable counter-example to much of the current academic discussion of governance and participation in relation to new technologies. Overall, government has not become more reflexive about vaccination, has not embraced the concept of uncertainty and continues to adopt a 'discretionary' model of governance (Hagendijk and Kallerud, 2003). The brief discussion of policy-making in chapter two made reference to the one lay member on the JCVI but did not discuss strategies for public consultation, as these do not exist. This adds weight to the argument made previously that vaccination functions as an anomaly in important respects. The theoretical implication is that academic discussion of governance models need to be policy specific, and it should not be assumed that the shift from deficit to dialogue and from government to governance (Irwin and Michael, 2003, p57) has occurred in all domains. For policy, if the same discretionary model of governance continues to be applied to vaccination then this leaves little room for any serious engagement with the Vaccine Critical groups or their critical discourses.

### **Reassessing strategies of risk communication**

A key dimension lying outside the purview of my research concerns the way individual parents make decisions about vaccination. Consequently, firm, empirically based conclusions cannot be made about the impact of strategies of risk communication on the population or individual parents. However, the research does indicate the kind of discourses that are likely to be drawn upon by parents in challenging or questioning the advice given to them about childhood vaccination. Three main points will be made.

First, the empirical research suggests that using tables of risk comparison such as those provided by the Department of Health may help to graphically represent choices as conceived by risk assessment based on the 'best available science' but cannot address concerns about the processes by which those risk statistics were calculated or about unknown or uncertain risks. This contradicts the traditional model of risk analysis which sees risk communication as the final end point of the process, once all the calculations are complete. The research implies that the politics of risk communication are seen as affecting the risk calculations much further 'upstream' in the process. Therefore, if expert risk advice does not appear to be being followed, changing the style of risk communication may represent wasted resources. In short, the policy of trying to change risk 'misperceptions' through the provision of information is not empirically supported.

Second, the findings on trust also represent a potential problem for health professionals who are involved in risk communication strategies. Chapter three made reference to a joint statement entitled 'Endorsing the continued use of the MMR Triple Vaccine' that is signed by four Royal Colleges (Faculty of Public Health Medicine *et al*, 2001). This was clearly intended to demonstrate medical and professional support for the vaccine and for the government's commitment to continued use of the vaccine. Such a strategy may be well intentioned. However, the research reveals a discourse which identifies a systemic conflict of interest and problematises trust in doctors, policy-makers and regulators. One of the points of concern is the close relationship between these institutions. For the government to enlist institutions as supporters in this way only succeeds in confirming the impression of a lack of independence, given that it is the 'system' itself, and not just isolated policies, that is being criticised.

There is some evidence that vaccine policy-makers are aware of the difficulties of responding to the issue of trust. For example, during the period of study a dedicated MMR website was set up ([mmrthefacts.nhs.uk](http://mmrthefacts.nhs.uk)) which includes copies of all leaflets in several languages. This could be simply seen as an effort to make existing information more accessible with no real attempt to go beyond the deficit model of public understanding of science. However, the website also now includes hyperlinks to original scientific articles (including Wakefield's). The way these links are presented makes clear that the overall intention is to show that the weight of scientific evidence does not

support the MMR-autism hypothesis. Nevertheless, the inclusion of links to the original science still suggests a recognition of (or, at least, the potential for) public scientific literacy and scrutiny, and an awareness that simple statements from the Department of Health that refer to the science is not enough. This is therefore an attempt to circumvent the perceived problems of trust in government. However, this would not, of course, address either the Reformist or Radical critiques of science that this research identified.

Third, and related to the last point, the research demonstrates the importance of unknowns for vaccination resistance. Given the realist assumptions in standard risk communication techniques it is unlikely that this can be taken into account. Another method must be found to stress that even with a technology as old as vaccination there are still impacts that are unknown and, to some extent, unknowable. This should be openly admitted. This policy recommendation is supported by Marris and colleagues in the context of GM who argue that the public are not fearful of the concept of unknowns and would rather that science admitted this. Ironically, it is the denial of uncertainty or unknowns that causes problems of trust (Marris *et al*, 2001, p87-92). Ogden *et al* (2002) argue that in the context of medical practice, recent work encourages doctors to share uncertainty with patients. However, their questionnaire research warns that context is important in influencing how individual patients receive and cope with expressions of uncertainty. Serious thought and research must likewise be devoted to the issue of unknowns and uncertainty in vaccination by those involved in planning and carrying out risk communication strategies. The ultimate challenge is to find a way to engage with different conceptions of risk, unknowns and uncertainty without forcing all concerns into a narrow technocratic framework (Irwin and Michael, 2003, p151).

## **AVENUES FOR FURTHER RESEARCH**

At various stages I have expressed the need for further research which would address the remaining gaps in the literature and take forward some of the ideas developed in this thesis. These suggestions, and some methodological implications, will now be made more explicit.

This research has revealed some fascinating results in relation to science. A significant difference was found between the Radical and Reformist discourses, the former using ideas from alternative health and nature to unhinge the relationship between science and progress and the latter embracing new technologies and using science to criticise the medical profession. Overall, this finding is useful in contradicting the simple assumption that vaccination resistance represents a rejection of science or modernity. However, several additional questions are raised about precisely how the groups engage with science and scientific literature *in practice*. Further research is warranted that looks beyond the discursive construction of science to consider how the groups interact with scientific publications and whether there exists some kind of ‘alternative’ or ‘counter science’ (Moore, 2003) and how this differs from mainstream science. In discussing autism campaign groups in the US, Silverman refers to their research as ‘research taking place at the margins of legitimized science’ (Silverman, 2003, p3). Further research on the UK groups would contribute to debates within science and technology studies and other research where science is the primary territory over which the debate is fought.

More historical and cross-cultural research on vaccination refusal and resistance is also needed. The value of historical research was shown in chapter four through reference to nineteenth century debates. Existing attempts at comparing and contrasting current and historical concerns were referenced, but these are often commentary pieces. Further social scientific analysis that builds on the questions raised in chapter four about the extent to which historical resistance was about factors other than compulsion, would be extremely useful. Cross-cultural comparisons would also be valuable and, in addition to further analysis of interview data from policy-makers, the author has plans to look more closely at primary and secondary data on vaccination resistance in the US and Australia. Such historical or cultural comparisons provide a graphic way of unsettling the tendency to assume the uniqueness of current events. The fact that resistance to vaccination is evident in other countries and in other historical periods tells us much about the topic of vaccination but also much about resistance. Another interesting research trajectory to follow would be to look at vaccine resistance in developing countries. ‘Spillover’ of vaccine concerns from the West to developing countries was mentioned by some policy-makers during the interviews and does sound plausible, given the availability of internet technologies. However, without detailed research evidence on this, such assertions risk sounding like knee-jerk attempts to use the groups

as scapegoats for health policy failures and the serious infectious disease situation in developing countries.

Another research path turns the research questions on their head to ask more about compliance with vaccination policy. By not adopting a completely symmetrical approach and focusing on resistance, this research could be criticised for fuelling the image of technology acceptance as natural and resistance as the phenomenon that demands special explanation (Jasanoff, 2002). This criticism has some substance, although is addressed by the critical way in which vaccination was discussed through the imperative of vaccination. The demand for more research on compliance could be narrowly interpreted as promoting research that looks at the social or psychological differences between those individuals who refuse and those who comply. This type of research would be no doubt of interest to vaccine policy-makers. However, Jasanoff's argument also has broader implications for social science in encouraging more analysis in general of those instances or technologies where public controversy or resistance is not easily visible. This is a different version of an argument made earlier about the importance of examining claims to benefits, as well as issues of risk and danger.

And finally, my research has wider methodological implications. Overall, the research suggests the need for caution in assuming that resistance to vaccination, and resistance to any technology, is necessarily about risk or a failure of risk perception. In other words, the framing of the vaccine debate, and other contemporary controversies as all about risk may be unjustified (Hobson-West, 2003 and see Gofton and Haimes, 1999). This conclusion was only made possible through the use of an open research methodology that allowed the multiple dimensions of resistance to be revealed. The methodological approach adopted, which did not question informants directly about risk or trust, proved useful and has much to recommend it for future research. Asking questions about risk is a risky endeavour, if part of the aim is to assess the meaning of risk and how the concept is operationalised in practice. As Lupton and Tulloch found out in their analysis of risk talk amongst people in Australia, different ways of asking produced different discourses on risk (Lupton and Tulloch, 2002).

More open research methodologies also encourage a more nuanced understanding of resistance. To return to the argument made in the second chapter, 'What is being

resisted is normally complex and requires empirical analysis' (Bauer, 1995a, p19). As argued, just because risk is crucial for governmentality and is the primary language used to justify a technology does not necessarily mean that this is the best way of understanding resistance. This research has also shown that risk is closely related to issues of trust and science. The task of social science should therefore be to examine resistance to technology in detail, without adopting prior assumptions about the nature of resistance. The advantage of this approach is that it also allows a more critical understanding of the technology itself: examining the discourses of vaccination resistance has ultimately helped reveal the power of the imperative of vaccination.

### **And finally...**

And finally, reference to a widely cited article by Poland and Jacobson seems a good place to end. The title of the article, published in the journal *Vaccine* in 2001 is 'Understanding those who do not understand: a brief review of the anti-vaccine movement'. Although the text is disappointing in not justifying why a lack of understanding is diagnosed, due credit must be given to the authors for at least discussing vaccine resistance in a scientific journal, targeted, according to the website, at 'research workers, product developers, clinicians and practitioners'. However, the patronising language used in the title still stands as a useful symbol of the dominant discourse used to describe those who challenge one of the great icons of success for science, biomedicine and the role of the state in protecting its citizens. Until very recently, social science was absent in accounts of vaccination refusal and resistance. This thesis is one contribution to belated attempts to move beyond models of paternalism or ignorance and towards a greater understanding.

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## Appendix 1: Organisations targeted for research

Category	Name of organisation	Type of organisation	Position of individual contacted	Interview conducted	Interview location	Focus for data analysis
1	AAA	Vaccine Critical group	Founder	yes	Glasgow (telephone)	yes
1	AiA	Vaccine Critical group	Founder	yes	Peterborough	yes
1	APVDC	Vaccine Critical group	Founder	yes	Warwickshire	yes
1	Vaccine Victims	Vaccine Critical group	Founder	yes	Birmingham	yes
1	JABS	Vaccine Critical group	Founder	yes	Warrington	yes
1	JFAVDC	Vaccine Critical group	Founder	yes	Bristol (telephone)	yes
1	vaccination.co.uk	Vaccine Critical group	Founder	yes	London	yes
1	VAN	Vaccine Critical group	Founder	yes	Derby	yes
1	Vaccine Info.	Vaccine Critical group	Founder	yes	Hull	yes
1	Informed Parent	Vaccine Critical group	Founder	yes	Worthing	yes

1	British Naturopathic Association	Alternative Health: Prof. Association	Head of research	yes	London	no
1	Faculty of Homoeopaths	Alternative Health: Prof. Association	Vice President	yes	London	no
1	Jehovah's Witnesses	Religious group	Public Affairs Officer	yes	London	no
1	Christian Science Church	Religious group	Committee on Publications	yes	Nottingham	no
1	Alexander Harris Solicitors	Legal	Senior Partner	yes	Norwich	no
2	Joint Committee on Vaccination and Immunisation	Expert Advisory Committee	Chair	yes	Birmingham	no
			Lay member	yes	Nottingham	no
2	Department of Health	Government	Head of Immunisation Programme (and Principle Medical Officer)	yes	London	no
			Head of Immunisation Information	yes	London	no
2	Health Protection Agency	Independent advisory body	Head of Immunisation Department	yes	London	no
2	Great Ormond Street Hospital Institute for Child Health	Child Health Hospital	District Immunisation Coordinator Lecturer	yes	London	no
2	Royal College of General Practitioners	Professional Association	Immunisation spokesperson	yes	Berkshire (telephone)	no
2	UK Vaccine Industry Group	Vaccine Industry	Chair	yes	London (telephone)	no

1	What Doctors Don't Tell You	Alternative health: Magazine	Editorial director	no	N/A	N/A
2	UK Government	UK Government	Public Health Minister	no	N/A	N/A
1	Guild of Catholic Doctors	Religious group	Master	no	N/A	N/A
1	Anthroposophical Medical Movement	Alternative Health: Trust	Spokesperson	no	N/A	N/A
1	Desumo Information and Healthcare Ltd	Healthcare clinic	Co-founder	no	N/A	N/A
2	Community Practitioners and Health Visitors Association	Professional Association	Director	no	N/A	N/A
2	Faculty of Public Health	Professional Association	President	no	N/A	N/A

Reformist groups
  Radical groups
  Organisations interviewed but not analysed
  Organisations contacted but not interviewed

Category 1 = Groups identified originally as part of the 'anti-vaccination movement'

Category 2 = Groups identified as involved in vaccine policy making and 'pro-vaccination'.

**Appendix 2: Example of interview request letter for  
Category 1 groups (see overleaf)**

**Appendix 3: Example of interview request letter for  
Category 2 groups (see overleaf)**

**Institute for the Study of Genetics,  
Biorisks and Society**

Law & Social Sciences Building  
University Park  
Nottingham  
NG7 2RD

Tel: +44(0) 115 8466 135  
Fax: +44(0) 115 846 6349

[www.nottingham.ac.uk/igbis](http://www.nottingham.ac.uk/igbis)

XXX

Action Against Autism  
Eastwood Business Centre  
Greenhill Avenue  
Glasgow  
G46 6QZ

16th October, 2003

Dear XXX

I am carrying out doctoral research into UK groups that are important in contributing to the childhood vaccination debate. The research is based at the University of Nottingham.

Although the research looks at childhood vaccination in general, the question of the relationship between the MMR vaccine and autism has become particularly controversial. Your website and associated links have proved very useful but I would like to follow this up with a more detailed discussion. The interview should last approximately 50 minutes.

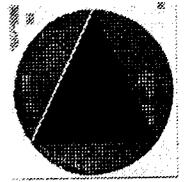
I have already spoken to several key groups in the UK and have also spent time carrying out interviews in the US. I realise that you are probably very busy but hope that we can arrange a convenient time to talk. If you have any queries then please feel free to get in touch by phone or email.

I look forward to hearing from you.

Yours sincerely

Pru Hobson-West  
Leverhulme Research Training Fellow

Direct line – (0044) 115 8466861  
Email – [ldxph@nottingham.ac.uk](mailto:ldxph@nottingham.ac.uk)



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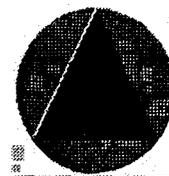
The University of  
**Nottingham**

**Institute for the Study of Genetics,  
Biorisks and Society**

Law & Social Sciences Building  
University Park  
Nottingham  
NG7 2RD

Tel: +44(0) 115 8466 135  
Fax: +44(0) 115 846 6349

[www.nottingham.ac.uk/igbis](http://www.nottingham.ac.uk/igbis)



GENETICS · BIORISKS · SOCIETY

XXX

Department of Health  
Skipton House  
80 London Rd  
London  
SE1 6LH

30<sup>th</sup> January, 2004

Dear XXX

**Vaccination groups and childhood vaccination resistance in the UK**

I am writing to ask for your help with a research project which investigates UK groups that are important in contributing to debates around childhood vaccination. The research is based at the University of Nottingham and is funded from 2001-2005.

The research has so far involved in-depth interviews with the leaders of parent organisations who are critical of certain vaccines or vaccination policy, as well as an analysis of websites and printed materials that are made available to the public. I have also spoken to similar groups in the US, as well as key policy-makers at the CDC and DHSS in Washington.

The aim of the project is to increase understanding of how vaccine policy is made in the UK and about the best strategies for communicating information about vaccines, science and epidemiology. I should stress that the research covers all childhood vaccines, and not just MMR. I also plan to contact representatives of HPA, MHRA, JCVI, and the relevant Royal Colleges.

HPA and NHS related websites and links have proved extremely useful, but I would like to follow this up with a more detailed discussion. The interview should last approximately 50 minutes. I realise that you are extremely busy but hope that we can arrange a convenient time to meet. I will telephone your office next week to see if a meeting may be possible.

Yours sincerely

Pru Hobson-West  
Leverhulme Research Training Fellow  
Direct line – 0115 8466861  
Email – [ldxph@nottingham.ac.uk](mailto:ldxph@nottingham.ac.uk)



The University of  
**Nottingham**

## **Appendix 4: Interview schedule**

### **Background**

- 1) What is your job title or area of responsibility?
- 2) How long have you worked for your organisation?
- 3) How many people work for your organisation?
- 4) Could you summarise the main aims of your organisation?
- 5) When was the organisation set up / when did it join the vaccine debate?
- 6) What is your organisation's policy towards childhood vaccination? (why?)

### **Theme 1: Individual and societal risks / benefits**

- 1) What do you think are the main objectives of the current policy of mass childhood vaccination?
- 2) Do you think the policy is designed to benefit certain individuals, groups of people, or the whole community?
- 3) Do the interests of individuals and the community conflict? How can they be balanced?

### **Theme 2: Images of science and biomedicine**

- 1) How important is scientific evidence to vaccine policy and to the wider debate on vaccination?
- 2) To what extent are groups critical of vaccination critical of science and biomedicine in general?
- 3) Do you think other vaccinations (such as flu) involve similar or different issues to mass childhood immunisations?
- 4) Are there any other medicines or technologies which you think throw up similar issues as mass childhood vaccination?

### **Theme 3: Institutional relationships and governance**

- 1) Who do you see as the main organisations involved in promoting childhood vaccination in the UK? To what extent are they successful?
- 2) Are you aware of any (other) organisations involved in criticising childhood vaccination in the UK? What are they critical of? To what extent are they successful?
- 3) Do you think the companies who manufacture vaccines play an important part in vaccine policy and the wider debate?
- 4) Do you think the legal framework around vaccination is effective? (Vaccine Damage Payment Scheme?)
- 5) Do you think that the media has an important influence on the vaccination debate?

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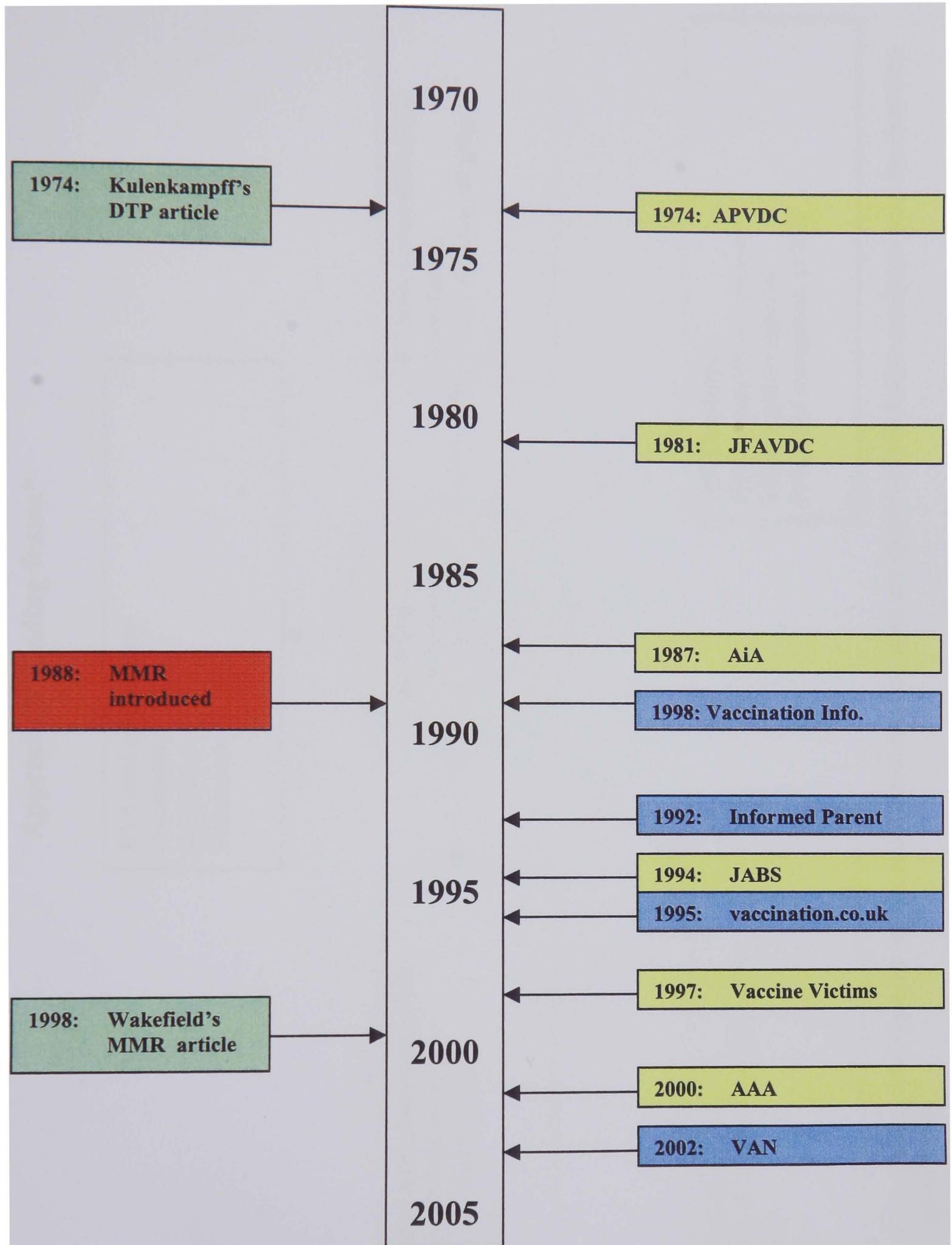
#### **Theme 4: Responsibility, duty and participation**

- 1) Who has responsibility for making decisions about whether to vaccinate an individual child? (child, parent, doctor, politician)
- 2) In some countries childhood vaccination is more compulsory. What do you think of this policy?
- 3) Are there any groups, such as parents or non-scientists, who you think should have more of an influence on the direction of vaccine policy?

#### **Theme 5: Perception of 'the public'**

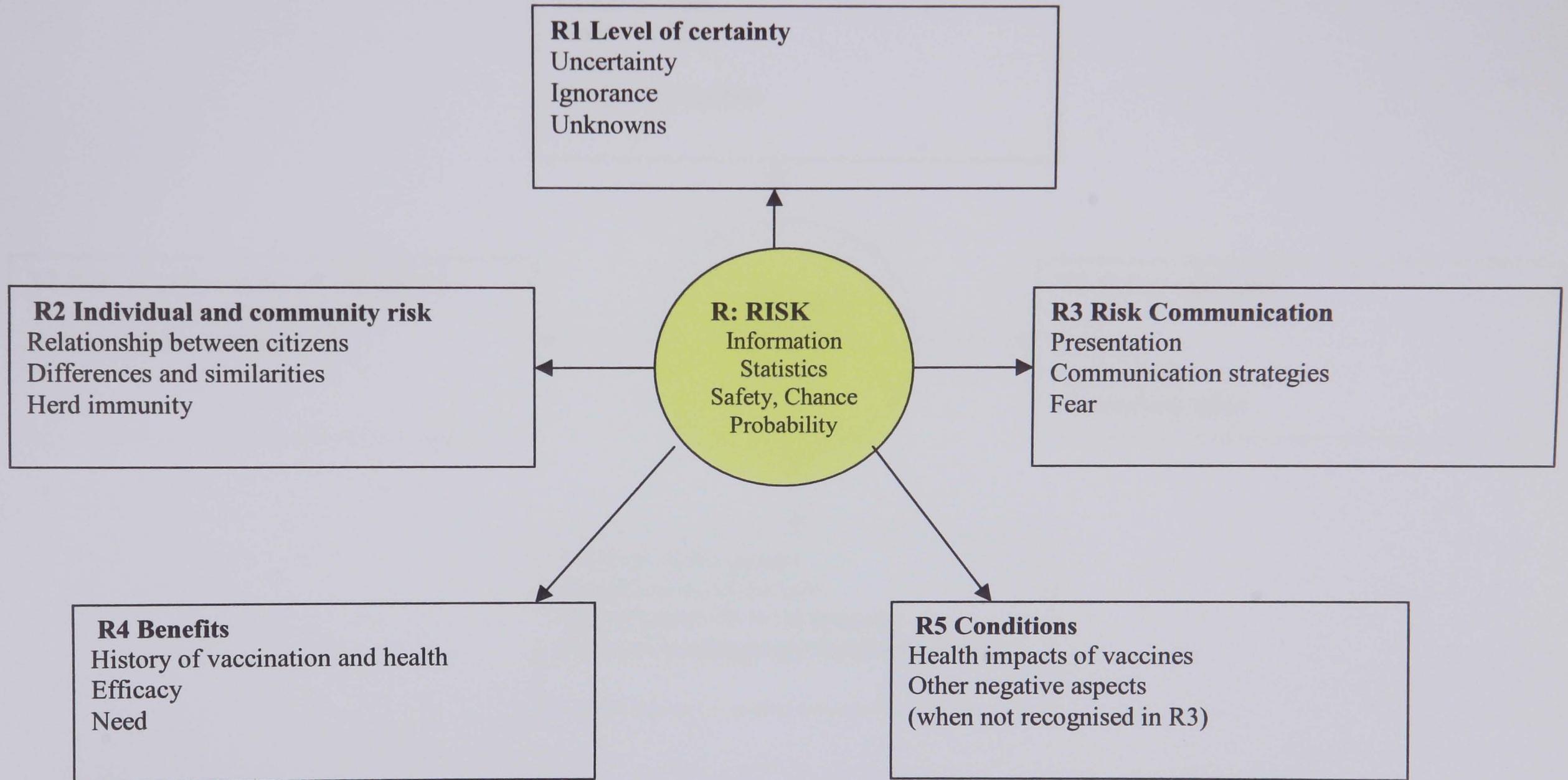
- 1) Are the public well informed about the issues involved in vaccination policy?
- 2) What factors do you think influence a parent's decision about whether to vaccinate their child? (are the factors the same for all vaccines?)
- 3) What sort of people do not get their children vaccinated?
- 4) How could the uptake of childhood vaccination be improved?
- 5) Do you know of any other groups or organisations that are part of the vaccine debate that we haven't mentioned?

## Appendix 5: Timeline illustrating key vaccination events and the formation of the Vaccine Critical groups.

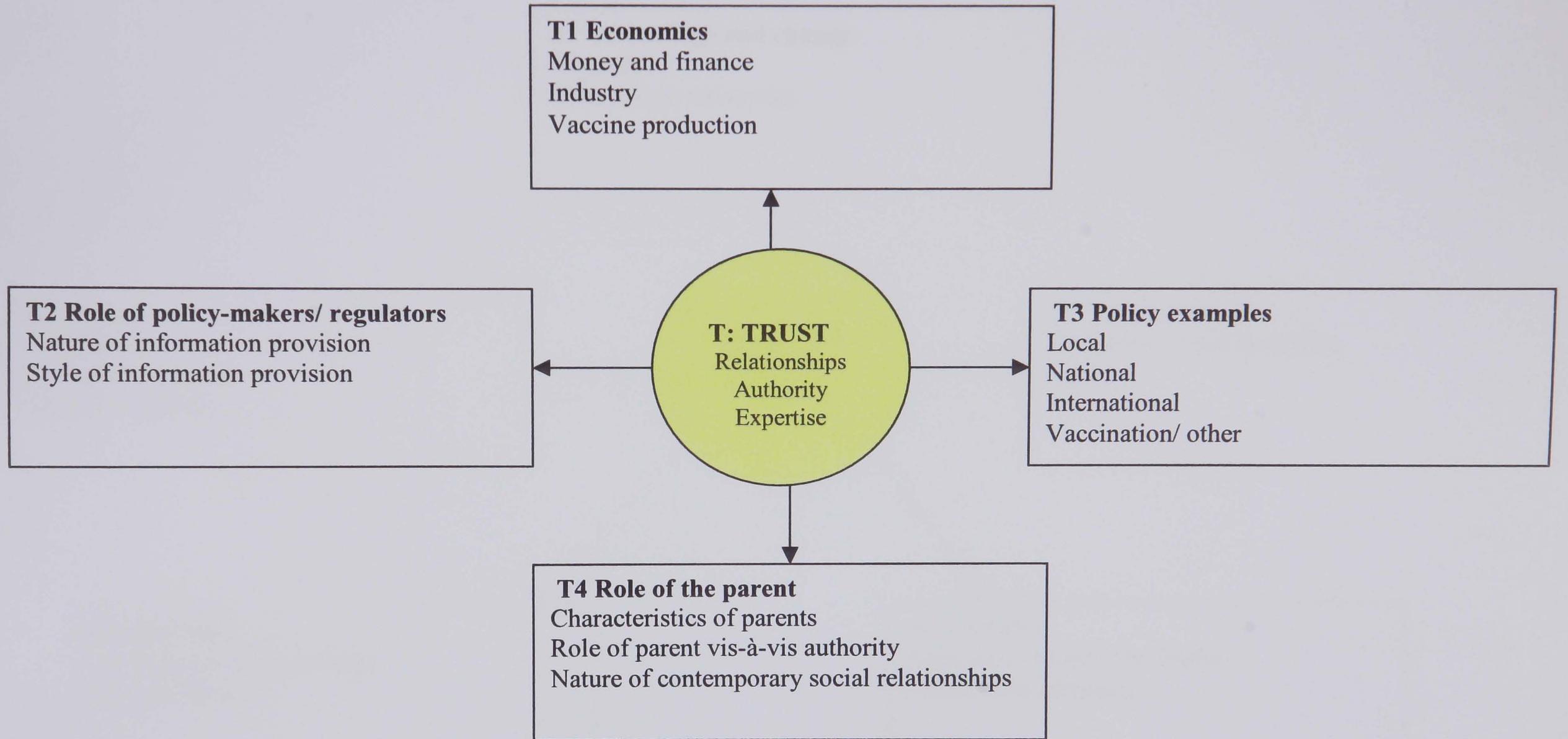


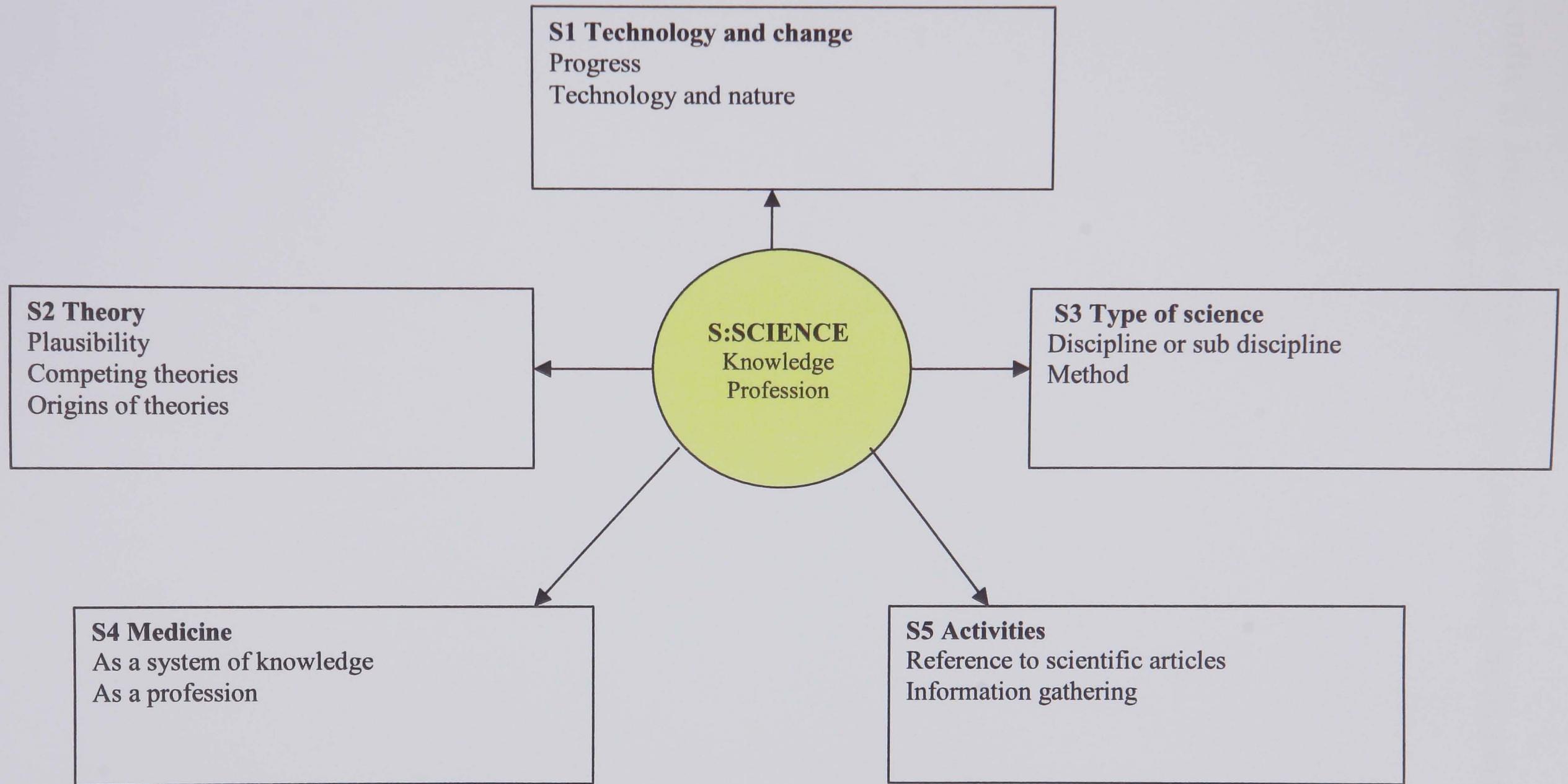
Key article  
  Vaccine introduction  
  Radical groups  
  Reformist groups

## Appendix 6: Coding frame\*



\*Codes were assigned to interview, document and website text and were not specifically linked to questions from the interview agenda (see appendix 4)





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**Appendix 7: Journal article published during thesis period  
(see overleaf)**

# Understanding vaccination resistance: moving beyond risk

PRU HOBSON-WEST

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**Abstract** *Mass childhood immunisation (MCI) is of primary importance to all modern public health systems and relies on high levels of uptake. Recent controversy in the UK about the safety of the MMR (measles, mumps, and rubella) vaccine has prompted widespread concerns and a government response that concentrates on providing more information to the public. This information has mainly adopted the language of risk, as exemplified in recent health promotion materials designed to persuade parents to choose the MMR vaccine. The paper analyses the key material and reveals three contestable assumptions; first, that individuals make decisions through a comparison of individual risk; second, that public concern about vaccination is due to a miscalculation of risk; third, that a policy of providing more risk statistics is the best response to the controversy. Through criticising these assumptions it is argued that some resistance to MCI is about alternative understandings of basic categories of health and disease. Further research is needed to investigate the role of uncertainty and trust in understanding anti-vaccination.*

**Key words:** risk, vaccination, immunisation, resistance, trust, policy

## Introduction

Immunisation is often regarded as one of the most successful medical interventions and is credited with a dramatic reduction in morbidity and mortality from infectious disease. For this reason, resistance to vaccination has been seen as puzzling by many inside and outside biomedicine. Individual refusal to vaccinate is regarded as very serious, as the science of mass immunisation relies on high uptake levels. Concern expressed about a particular vaccine, such as MMR, is also seen as potentially damaging to the entire vaccination programme.

A literature search reveals remarkably little social scientific research into vaccination and anti-vaccination (for exceptions see New and Senior 1991; Rogers and Pilgrim 1995). Following the increased media debate over MMR from 2001, it is predicted that more social scientific attention will be devoted to the issue of vaccination in general, as well as specific analyses of how the government and health professionals have responded to concerns raised. This article is intended as a contribution to this emerging literature. Its starting point is the

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IGBiS, University of Nottingham, UK

Address correspondence to: Pru Hobson-West, Institute for the Study of Genetics, Biorisks and Society (IGBiS), University of Nottingham, Law and Social Sciences Building, University Park, Nottingham, NG7 2RD, UK. Tel: 0115 846 7173; Fax: 0115 8466349; E-mail: ldxph@nottingham.ac.uk

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empirical observation that the concept of risk is currently very dominant in attempts to explain and counter vaccination resistance. The main theoretical conclusion is that risk should not be assumed to be the main conceptual tool for understanding resistance to vaccination.

The argument is inspired by a short leaflet produced by Health Promotion England entitled 'MMR The facts' (2001) which is made widely available in GP surgeries, health centres, chemists and on the web. A close textual analysis of the MMR Leaflet was carried out which revealed fundamental assumptions about the way individuals make decisions about vaccination, the reasons for a supposed public miscalculation of risk, and about the rationale for more risk research.

Vaccination, in terms of science and public policy, is undoubtedly an international issue (Hobson-West forthcoming). The following discussion focuses on the UK case, but the arguments are of relevance to other countries. Disease itself does not respect national borders, particularly in the context of increasing freedom of movement (Schmitt *et al.* 2003: p. 103). All states therefore have an intrinsic interest in international disease levels, vaccine policies, and political responses to vaccine controversies. The development of global communications also allows concerns about vaccination to be rapidly spread to an 'emergent anti-vaccine diaspora' (André 2003: p. 594; Clements and Ratzan 2003). Before getting into the debate about risk, background is provided through an introduction to vaccination science, policy, and resistance.

### **Childhood vaccination and vaccination resistance**

Immunisation, and child immunisation in particular, is central to any modern public health system. The history of vaccination is a fascinating one, and accounts usually start from the experiments by Edward Jenner on a boy called James Phillips in 1796. James was successfully inoculated against smallpox with the vaccinia virus (derived from cowpox). The science of vaccination is thus very well established, although new vaccines, vaccine combinations, and vaccine delivery systems (Poland *et al.* 2002), are being continually developed. A brief look at the timeline for vaccine development indicates that the number of vaccines has increased rapidly since World War 2 (André 2003). Although the ultimate aim of vaccination is the eradication of the disease and therefore the need for the vaccine (as witnessed and widely celebrated in the case of smallpox), the near future looks like involving more vaccines, not less. The government has recently expressed its expectation that more vaccines and more combined vaccines will be developed (Department of Health 2002).

Childhood vaccination in the UK has been classified as a centralised system (Schmitt *et al.* 2003: p. 104) and is controlled by the state and administered free through the NHS. Vaccinations are usually carried out by doctors or nurses employed to assist them. The current recommended schedule includes vaccines against diphtheria, tetanus, pertussis (whooping cough), haemophilus influenzae type B, measles, mumps, rubella, polio and tuberculosis. This list is similar to that recommended in the rest of Europe and the US, although the timings of vaccination do differ.

For the purposes of this paper, one of the central points to make about childhood vaccination is that it is 'voluntary' in the UK, a situation which contrasts markedly with the US and France, where fulfilment of the schedule is linked to state school entry or the payment of child benefit. However, parents in the UK are actively encouraged and expected to present their child for immunisation, and are contacted by letter to confirm appointment times. Although there are no official sanctions for dissenters, there have been recent reports of parents being struck off GPs lists, in order that practices maintain their uptake percentages and receive financial bonuses (Rogers and Pilgrim 1995; Scanlon 2002). The UK government also spends significant public health resources on promotional material, such as the recent £3

million MMR TV campaign (BBC news 2001). Such strategies of persuasion are arguably more important in a voluntary system, such as the UK.

The policy of Mass Childhood Immunisation (MCI) is built upon the scientific notion of 'herd immunity'. This idea stresses the need to achieve high vaccination uptake (usually said to be around 95%, although the percentage varies by disease). This ensures that those that cannot be vaccinated for medical reasons or those who do not fully respond to immunisation are still protected, as the overall incidence of disease is reduced in the 'herd'. For this reason, non-uptake is potentially very serious and may threaten herd immunity. Even more worrying, perhaps, is the claim that MCI with poor levels of uptake can actually have a detrimental effect, as this may increase the age at which those who catch the disease do so, thereby increasing the chance of medical complications (Health Education Authority 1998: p. 12).

An analysis of Health Education Authority reports on childhood immunisation research suggests a clear desire to establish what proportion of non-uptake is due to physical or structural barriers, such as access to clinics, and what proportion is due to a deliberate, active decisions by parents (see Bedford and Kendall 1998: p. 28). The answer to this quantitative question will not be provided here. Rather, the term 'resistance' is deliberately used to refer to those parents who make a conscious decision to refuse the recommended vaccination, or to refer to the discourses and arguments critical of vaccination policy. Further in-depth empirical research is needed to investigate the social and political background of individual dissenters. *Resistance*, as opposed to individual *refusal*, is used here to imply collective action (Streefland 1999). A basic web search using a standard search engine such as Google or Yahoo reveals a significant number of organisations that are sceptical of vaccination or certain vaccines, for differing reasons. For example, 'JABS', 'The Informed Parent', 'Vaccine Awareness Network', and 'What Doctors Don't Tell You' currently campaign in the UK. In addition, non-secular groups, such as Christian Scientists and Seventh Day Adventists oppose childhood vaccination. Surprisingly, perhaps, the role of social movements in anti-vaccination has not yet been subject to much social scientific analysis (although see Nasir 2002).

### **Individual decision making and risk**

'No parent of a young child can have missed the worrying headlines about MMR over the past few years. I have no doubt that MMR is the safest way for parents to protect their children. I understand how difficult it can be for parents to get the facts they need to make a positive decision' (Health Promotion England 2001. *MMR. The facts*).

This quote is from Professor Liam Donaldson, Chief Medical Officer for England and is included in a leaflet (henceforth 'The MMR Leaflet'). In brief, this quote neatly encapsulates the government position. The 'worrying headlines about MMR' suggest a recognition that there is some sort of problem; 'MMR is the *safest* way for parents to protect their children' implies that the decision involves a risk comparison; and the reference to 'the facts' promises that the leaflet will contain the true statistics that parents need to make a decision (in favour of MMR).

The MMR leaflet is an important part of the government response to concerns expressed in the media about the safety of the combined MMR vaccine, concerns often blamed on the activities of Dr Andrew Wakefield, formerly of the Royal Free Hospital in London. Wakefield's research suggested the possibility of a link between the triple MMR vaccine, bowel disease and a type of late-onset autism (Wakefield *et al.* 1998). Leask argues that negative media coverage of this issue has led to a 'small but significant decline in UK MMR immunisation rates' (Leask 2002: p. 124). It has also led to more publicity and greater public demand for single measles, mumps and rubella vaccines.

The leaflet is entitled 'MMR. The facts'. But what exactly are the facts that parents apparently want and need? A table is prominently displayed in the centre of the Leaflet that compares the 'serious effects' of the diseases and vaccine 'reactions' (see Table 1).

For example, the number of children suffering convulsions after the natural disease is estimated to be 1 in 200, whereas the risk drops to 1 in 1000 after the first dose of MMR. The table is clearly intended to 'make risk visible' (Prior *et al.* 2002) to persuade parents of the rationality of making a 'positive decision' to have the MMR vaccine. Such a table is a classic method for displaying risk comparisons (e.g. Clements and Ratzan 2003: p. 24) and such risk comparisons are also found in other pro-vaccination literature (Health Education Authority 1997) and Government reports (Scottish Executive 2002).

The inclusion of risk calculations in such promotional material only makes sense if health promoters believe that individuals, in this case parents, make decisions in this way. It is then only a short step to the assumption that any public resistance can be explained as a miscalculation of risk, and a further short step to arguing for a policy that aims to explain the known risks more clearly, or commissions further research to generate more risk statistics. Alternatively, this logic can be used to justify a policy of compulsion or state sanction to try to 'correct' the public's misconception. The following discussion aims to problematise this line of argument by discussing risk at these different 'levels'.

Firstly, then, is the assumption that individuals make decisions about vaccination through a comparison of *risk*. Surprisingly, perhaps, relatively little qualitative research has been carried out into childhood vaccination to confirm or question this assumption. In terms of decision making, vaccination is not the one-off decision it is sometimes portrayed as (e.g. National Consumer Council 2002: p. 2), but is part of a *process*, with parents being asked to present their child at various points from 2 months onwards. As research into non-compliance and medicine has found (Stevenson *et al.* 2002), context is important and consent is more of a process than an isolated action. The decision about whether or not to receive the MMR vaccine may therefore be affected by factors other than a strict risk comparison, such as past experience of other vaccines or health services. In addition, it is worth stressing that vaccination is just one decision of many that parents are faced with. Other day-to-day concerns about child health and nutrition may take priority at certain times, or influence willingness to vaccinate. These social and historical factors would influence the vaccination decision but may not necessarily influence an individual's calculation of risk. It is therefore not enough to say that risk is affected by context.

To take a different perspective, perhaps risk itself is a useful concept, but its *object* is misunderstood. The MMR leaflet assumes that the vaccination decision is made by the individual parent in the best interest of their child. It is not the intention here to suggest that

**Table 1.** Source: MMR. The facts (2001) Health Promotion England

Condition	Children affected after the natural disease	Children affected after the first dose of MMR
Convulsions	1 in 200	1 in 1000
Meningitis/Encephalitis	1 in 200 to 1 in 5000	Less than 1 in a million
Conditions affecting blood clotting	1 in 3000 (rubella) 1 in 6000 (measles)	1 in 22,300
SSPE (a delayed complication of measles that causes brain damage and death)	1 in 8000 (children under 2)	0
Deaths	1 in 2500 to 1 in 5000 (depending on age)	0

most parents do not worry about their child's health and well-being. However, what is crucial to realise is that the policy of mass vaccination relies on the scientific notion of herd immunity which has a clear community or social focus. MCI is usually argued to be beneficial to individuals, but the benefit to the community is the main concern and may be greater than the sum of individual health benefits, and more important than any individual costs. Such arguments about community benefits have been considered powerful enough to justify quite radical state sanction. This sanction includes the fining or imprisoning of resisters in the UK in the 19th century (Wolfe and Sharp 2002); the withholding of child benefit payments in contemporary France; and the US requirement of proof of vaccination for state school entry. One of the driving ethical rationales behind these historical and contemporary policies is the prioritisation of community benefits over individual costs, whether these 'costs' are understood as health risks or a restriction of individual liberty.

So, the question then follows: Why isn't the social benefits argument prioritised as part of promotional campaigns in the UK? As one attendee at a recent event entitled 'MMR: Learning lessons' pointed out, the MMR controversy was a prime opportunity for the media to discuss vaccination *as a public duty* (Science Media Centre 2002: p. 5). Why did this not happen?

One answer could be related to the reported dominance of the language of choice, empowerment and individual responsibility in current public health discourse (Petersen and Lupton 1996). According to Garratt, for example, the USA at the end of the 20th century was 'reeling under the weight of its new found libertarianism: the collective be damned, all public health burdens and responsibility fell to the individual' (Garratt 2000: p. 267). This stress on the individual could in turn be part of broader social trends towards a post-traditional society (Giddens 1994), where the social bonds of community are seen as less strong. In this context, concentrating on community benefits would be deemed unfashionable or unproductive.

Comparisons of risk are intended to demonstrate the irrationality of refusal to vaccinate. However, in a de-traditionalised society vaccination refusal, far from being puzzling, could actually be regarded as wholly rational. If society is indeed made up of individuals behaving as risk-minimising-autonomous-rational-consumers, then it makes sense to 'free ride'. In other words, if we believe that others will continue to vaccinate it is rational for the individual to refuse the jab and avoid the personal risk, whilst still enjoy the collective benefits of herd immunity (European Commission 2001). This is an extension of Rogers and Pilgrim's (1995) suggestion that in a society which currently promotes health by focusing on lifestyle and individual action, it is vaccination policy, and not the dissenting parents, that should be seen as the anomaly.

This section has demonstrated that state attempts to persuade of the benefits of vaccination rely on a certain understanding of the individual which conforms to the rational actor model. Paradoxically, this construction may contradict the key medical rationale for mass vaccination which relies on some notion of community good. Risk is then brought into this confusion as the explanatory factor for how individuals make decisions. As will be discussed in the next section, one result of this narrow understanding is the seemingly natural conclusion that refusal to vaccinate is evidence of public inability to understand risk.

### **Public miscalculation of risk**

'The decision to immunise your child is never simple. Information can often be confusing, made worse by stories in the press and on TV' (Health Promotion England 2001, *MMR. The facts*).

The above quote, referring to 'stories in the press and on TV', hints at outside influences which confuse the individual when he or she comes to make a decision about whether to vaccinate their child. This is based on a vast amount of risk communication research, which

has identified the importance of factors such as media triggers and emotion which combine to influence public risk perception (Bennett and Calman 1999; Spier 2001). Applied to vaccination, this approach helps to predict why vaccination is perceived as particularly risky; it is about children and the vulnerable, parents have a lack of control over the outcome, the benefits are difficult to see or quantify, and damage is potentially long-term or fatal. A linked argument is that the public under-estimate the risks from the diseases as they cannot remember a time when childhood diseases and complications were widespread (Bedford and Elliman 1998: p. 2). In a horrific irony, proponents argue, the success of vaccination undermines itself. These arguments are used to explain public concern about vaccination.

This position can be challenged on a number of levels. The whole notion of risk *perception* assumes that there are at least three separable domains—the actual and objectively calculated risk, the distorting factors, and the perceived risk as outcome. This separation can be criticised for denying that the risk statistics themselves are only one representation of reality and are, to some extent at least, socially constructed. Denying this means that alternative socio-cultural meanings are simply reduced to ‘bias’ (Lupton and Tulloch 2002). Similarly, after conducting focus groups across Europe into public attitudes to Genetically Modified (GM) food, Marris *et al.* (2001: p. 85) argue that when public responses cannot be put down to risk, they are often automatically labelled as ‘other’, implying they are non-intellectual or less worthy of analysis.

In terms of public attitude to vaccination, it is precisely this ‘other’ or this ‘bias’ which needs unpacking. For example, a small-scale study in Bath, UK, found that homeopathy and religion were the two most common reasons for vaccination refusal (Simpson *et al.* 1995). A review of anti-vaccine websites also found that alternative health, and homeopathy in particular, is an important line of opposition (Nasir 2000), although the Faculty of Homeopathy has refused this characterisation (Fisher 1990). However, the main point is that such studies do not explain how homeopathy or religion operate as ‘reasons’; this is usually not discussed. A deeper analysis is needed to appreciate the significance of these ideas.

Biomedicine in general, and MCI in particular, has traditionally conformed to a ‘static’ model of health and disease (Lauritzen and Sachs 2001: p. 499). The germ theory of disease defines health primarily as the absence of disease, and disease as the result of an attack from outside that the immune system attempts to ward off. Homeopathy, by contrast, sees health as something holistic that can continually be improved by strengthening an individual’s ‘vital force’ (Frank 2002: p. 812). In this world-view, ‘dis-ease’ takes on a highly personalised meaning and is ‘evidence of the body’s natural and automatic efforts to heal itself’ (The Society of Homeopaths 2000). As Martin has argued, resistance to vaccination may be less about refusing a vaccine and more about choosing ‘positive health’ (Martin 2000: p. 135). Some resistance to vaccination may therefore signify a fundamental opposition to the dominant biomedical understanding of health and disease. This critique will not be uncovered by only using the traditional language of risk and risk perception.

Religion has also been closely associated with resistance to vaccination. Historically, opposition came from those who saw vaccination as interfering with the will of God or Providence (Porter and Porter 1998; Spier 2001), as disease and health were understood as moral categories related to sin. Currently, the relationship between religion and vaccination is particularly contentious in the USA, as in some states exemption from vaccination is allowed if a parent can prove that their religion does not allow it. On the whole, this discourse is not about risk, (individual or community), but is about alternative meanings of health, disease and illness—more specifically about alternative notions of responsibility. To simply say that religion affects one’s risk perception does not seem to get us very far.

Although the influence of religious and homeopathic discourses would be difficult to quantify, such ideas are given voice through the proliferation of social movements, self-help groups and the electronic media. This implies that even if an individual parent would not

classify themselves as religious or a follower of alternative health, concepts from these alternative discourses do have some wider social and cultural impact. The focus on risk as the dominant mode of explanation for vaccination behaviour, the bemoaning of 'misinformation' on the internet (Leask 2002: p. 126; Spier 2001: S82), and the conclusion that public loss of confidence is all about safety (Salisbury *et al.* 2002), may miss the potential significance of these challenges.

An alternative way of thinking about vaccination resistance is through the concept of uncertainty. Research into public attitudes to a technology may talk about perception of *risk*, simply because it has been assumed that this is the meaning of the debate to the public. In other words, research often looks for risk, and finds it, when it isn't necessarily there (Hobson-West forthcoming). It may be more accurate to talk about public perception of uncertainty and understand the debate as uncertainty vs. need, rather than risk vs. benefits (Marris *et al.* 2001). On a basic level, of course, risk is fundamentally about uncertainty. In the debate over vaccination, however, we need reminding that risk is just one possible response to uncertainty, and is our attempt to place order on an uncertain world by making the 'incalculable calculable' (Beck 1994: p. 181). As Nettleton argues, the concept of risk functions psychologically as a mechanism for gaining control of disease and is thus used to confirm our faith in medical science (Nettleton 1997). Although uncertainty is recognised in risk communication literature, it is framed as a temporary phase that will be overcome by the accumulation of evidence which will refute or deny a supposition (Calman 2002). The normal assumption is that all risks are discoverable and measurable (Gabe 1995: p. 2), and that 'more research' will eventually solve a controversy (Levidow *et al.* 2000: p. 190).

The concept of uncertainty could instead be used to admit 'unknowable unknowns'. For example, some groups opposed to MCI have expressed concerns about long-term evolutionary consequences for human health of using vaccines derived from animal tissue (People Advocating Vaccine Education 2000). Such unknowns would clearly be difficult to factor in, no matter how much risk assessment is carried out. Comparisons of risk, such as those presented in the MMR leaflet, will fail to persuade, if there is doubt in the processes by which the figures are arrived at, and in the ability of the concept of risk to accurately portray the meaning of the vaccination decision to the public.

### **The policy of more risk**

'Extensive research into this possibility shows that there is no link between MMR and autism. These research studies have been carried out in this country, the USA, Sweden and Finland, and involve thousands of children. Experts from around the world, including the World Health Organisation, have agreed that there is no link between MMR and autism' (Health Promotion England 2001, *MMR. The facts*).

This quote is used here to demonstrate that more research and information about risk factors has been the main policy response to public concerns in the UK over the MMR vaccine. The preceding discussion has explored the bases for this policy, and why the assumptions upon which it rests may be flawed, or at least open to debate. International research is referred to in the MMR Leaflet—'experts from around the world'—in an attempt to stress the weight of the evidence available which supports current UK government policy of continuing to recommend the MMR vaccine and refusing to offer single measles, mumps and rubella jabs on the NHS.

The idea that more scientific research and further risk communication from experts will positively influence public attitudes and behaviour is part of the deficit model of the public understanding of science. Education is the main policy tool in this case and ignorance or misunderstanding identified as the main enemy. Paradoxically, this potentially contradicts the

rational actor model and helps to reveal a confused understanding of the public. As Marris *et al.* have argued, negative public reactions to a technology are usually blamed on an irrational misunderstanding. By contrast, in calculating benefits, the public are supposed to be hyper-rational actors who carefully weigh up the personal risks and benefits (Marris *et al.* 2001: p. 80).

Even if the problem were a lack of understanding about vaccination risk, the policy of providing more information to the public assumes that the information will be trusted. As work in Science and Technology Studies (STS) has long demonstrated, messages are judged first by source and not by content (Bennett and Calman 1999). Wynne has also argued that it is wholly rational for the public to link risk and trust. Surprises will occur and so the issue is whether the public have confidence that somebody will be able to deal with them (Wynne 2001). However, if the concept of risk can take trust into account it is only by including it as an influence on risk perception of a particular technology. Trust is thus relegated to just another distorting factor.

The socio-cultural concept of trust may prove crucial to a deeper understanding of the vaccine debate and help guide policy responses (Taylor-Gooby 2002: p. 111). If some of us no longer trust our individual doctor or the government committees that investigate vaccination safety, then more risk statistics (or any advice for that matter) will not be automatically accepted. Schmitt *et al.* have argued that in a centralised vaccination system, such as the UK, a general lack of trust in government means that vaccine recommendations may be viewed with suspicion (Schmitt *et al.* 2003: p. 105). More empirical research needs to be done which focuses on trust rather than risk. However, caution is needed in romanticising a historical 'golden age' of trust. This is clearly far too simplistic. In addition, trust is notoriously difficult to measure and delineate. Indeed, Barbara Misztal has argued that trust is 'one of the most difficult concepts to handle in empirical research' (Misztal 1996: p. 95). In terms of vaccination, who or what don't we trust? Is it the individual doctor, the medical profession, science in general, or all expert systems?

Trust has also proved difficult to theorise and has traditionally been subsumed under larger concepts of civil society (Misztal 1996). Giddens has argued that 'risk and trust, as well as their various opposites, need to be analysed together in conditions of late modernity' (Giddens 1994: p. 186). This type of social theory may aid our understanding of some aspects of concern over vaccination. Whether one uses the term high modernity, post-modernity or risk society, these analyses stress that we live in a new type of social order, where systems of expertise and science have lost their monopoly on truth (Beck 1994: p. 28). In a de-traditionalised society (Giddens 1994) we are all to some extent experts. All decisions must be justified and nothing goes without saying any longer (Beck 1994: p. 21). This may now include the decision to vaccinate our children.

## Conclusion

The policy of mass childhood immunisation relies on the scientific concept of herd immunity. Central to this is the notion of community good or community benefit. An analysis of promotional leaflets reveals that this dimension does not seem to have been prioritised. The focus on individual risk and benefit is perhaps understandable in a climate of de-traditionalisation and the current importance placed on individual choice and responsibility in healthcare. However, if individuals do indeed behave as autonomous rational agents, as the rational actor model implies, it may make sense to 'free ride' and refuse vaccination. In theory, this logic would undermine the whole vaccination programme.

The article suggested that a focus on individual risk does not take into account the fact that childhood vaccination is more of a process than an isolated action. As such, the individual decision to vaccinate may be influenced by factors other than risk, such as the timing of other

important parental decisions. From the assumption that risk is key it is only a short step to the conclusion that refusal to vaccinate or concern about vaccination is due to a misperception of the relative balance of risk. This discussion has challenged this assumption and the implication that more information about risk will be enough to change attitudes and behaviour. This view is part of the much discredited deficit model of the public understanding of science. It also assumes that the public will trust the sources of information about risk, an assumption that may no longer hold. The policy of providing more information in the form of risk comparisons will also not have the desired effect if the process by which the statistics are calculated are seen by some to be problematic. Risk information will not overcome the controversy if people believe that risk cannot take into account long-term effects or more radical understandings of uncertainty.

In summary, falling uptake levels and public concerns about vaccination pose a serious problem for public health policy makers. Their current response to this problem is embedded in health promotion literature, such as 'MMR. The facts' (Health Promotion England 2001). This response relies on risk communication and the mantra of 'more research is needed'. However, this strategy fails to appreciate the meaning of anti-vaccination. At least some resistance functions as a critique which problematises the basic assumptions upon which vaccination rests, assumptions about the relationship between the individual and community, citizen and state, and health and disease. These are undeniably political issues that deserve to be treated as such, and investigated using social and political analysis. Risk, by contrast, tends to de-politicise the debate. Instead of trying to include social meanings by stretching the concept, further academic research is needed which moves beyond risk and does not automatically assume its relevance to the public or to health-care controversies.

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