“I said no for a reason”

Understanding factors influencing vaccination acceptance during pregnancy in Hackney, London

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I Rose Wilson, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Background: In England, influenza and pertussis vaccinations were recommended to all pregnant women from 2010 and 2012 respectively. However, in some areas, vaccination uptake rates have been low. The aim of this study was to gain a contextualised understanding of factors influencing vaccination acceptance during pregnancy in Hackney, a borough in north-east London, UK.

Methods: Hackney was chosen as the study site because it has one of the lowest vaccination coverage rates in pregnancy in the UK. A maximum variation sampling method was used to recruit 47 pregnant and recently pregnant women from a wide range of backgrounds, as well as ten healthcare professionals from three general practices; two community antenatal clinics; nine parent-toddler groups; and four community centres. In-depth interviews and a focus group discussion with pregnant and recently pregnant women, as well as a video-recording of a pregnant patient's consultation, explored experiences of care within the National Health Service during pregnancy, and women's views about maternal vaccination. In-depth interviews with healthcare professionals explored their views towards, and how they discuss and provide maternal vaccination. Study data were analysed both deductively, through drawing on insights from anthropological works that address diverse conceptualisations and practices around vaccination as well as on notions of governmentality, biopolitics and relational autonomy; and inductively, with a thematic analysis approach.

Findings: Reasons for hesitancy surrounding maternal vaccination are complex. The findings of this study indicated three broad themes influencing acceptance of, and access to maternal vaccination. These include; the various constellations of governance involved in vaccination; the socio-economic positions of both pregnant women and healthcare professionals; and patient-healthcare professional relationships. A major finding was that while many participants had received no recommendation to vaccinate during their pregnancy (and often instead were just provided with an information leaflet), they said that if a conversation with their healthcare professional had taken place, where their concerns could be discussed, they would have been likely to accept the vaccines.

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My heartfelt gratitude also goes to all my participants, without whom, this research would not have been possible.

My office-mates have kept me sane throughout the process, with the office get-togethers and tea (or wine) and cake. I also appreciate the on-going emotional support and advice from my boyfriend, Owen, who also proofread a number of chapter, as well as my family.

Finally, I would like to acknowledge the National Institute for Health Research (NIHR) for funding my research.

During the first year of my PhD, my nephew was born. Dylan is an affectionate, bright and bubbly two-year old. However, after his birth, he was kept in hospital for a week with a possible meningitis infection. Dylan had to have a lumbar puncture, was put on an intravenous drip, and received antibiotics. A vaccine against meningitis is not currently available for use during pregnancy but if it was, and if it was accessible and accepted, babies like Dylan would not have to suffer this way in the first week of birth. It was during this week of worrying about Dylan that the importance of maternal vaccination was brought closer to home, and gave me a renewed energy for researching ways in which all pregnant women can have access to such life-saving technologies.

Abbreviations

BCG - Bacillus calmette-guérin

CDC - Centre of Disease Control and Prevention (USA)

cCMV - Congenital cytomegalovirus

CMV - Cytomegalovirus

dTaP/IPV - Diphtheria, tetanus, acellular pertussis and inactivated polio (vaccine)

FGD - Focus group discussion

GBS - Group B streptococcus

GP - General practitioner

HPV - Human papillomavirus

JCVI - Joint Committee on Vaccination and Immunisation

MMR - Measles mumps and rubella

SAGE - Strategic Advisory Group of Experts (on Immunisation)

NHS - National Health Service (UK)

UK - United Kingdom

USA - United States of America

RSV - Respiratory syncitial virus

TB - Tuberculosis

UN - United Nations

VAERS-Vaccine Adverse Events Reporting System

WHO - World Health Organisation

Section 1: Introduction and background to the study

Maternal vaccination in the UK

In England, influenza vaccination was first recommended to all pregnant women, irrespective of gestational age in November 2010 after the 2009 influenza A(H1N1) virus outbreak (PHE 2015). Influenza is the most frequent single cause of death in pregnancy and pregnant women are at increased risk from complications, such as premature birth and smaller infant birth size and weight if they contract influenza. After the introduction of the vaccine, it was found that women who received it were 51% less likely to experience stillbirth than those who were not vaccinated (Regan A, Moore H et al. 2016). The vaccine is also 71% effective in preventing infant influenza virus infection and 64% effective in preventing infant influenza hospitalisation in the first few months of life (Dabrera G, Zhao H et al. 2014). The maternal[1] influenza vaccine provided in England-Agrippal®-is manufactured by Seqirus Vaccines Limited (eMC 2016).

Additionally, in response to a pertussis outbreak in 2012, which resulted in 14 infant deaths, the UK Department of Health followed the recommendation of the Joint Committee on Vaccination and Immunisation (JCVI) in October 2014, to temporarily introduce the (low dose) diphtheria, tetanus, acellular pertussis and inactivated polio vaccine (dTaP/IPV) (commonly known as the 'pertussis' vaccine), for all pregnant women from the 28th week of pregnancy (Flory 2012). Pertussis is a highly contagious disease of the respiratory tract. The disease is most dangerous in infants and consists of a paroxysmal cough followed by whooping-sounding cough (which is why it is often referred to a 'whooping cough'). In the youngest infants, the cough may be followed by periods of apnoea. Pneumonia is a relatively common complication, and seizures, encephalopathy and death can occur (WHO 2015). Due to the introduction of the vaccine, there was a 79% fall in infant deaths from pertussis in England between 2012 and 2013 (Amirthalingam G, Andrews N et al. 2014); back to levels observed before the 2012 peak. From 1st April 2016, Public Health England (PHE) guidance on the schedule of dTaP/IPV vaccination during pregnancy was updated to reflect JCVI advice

[1] I use the term 'maternal vaccination' throughout the thesis to refer to either the dTaP/IPV vaccine provided during pregnancy, the influenza vaccine provided during pregnancy, or both.

that vaccines could be administered from week 16 of pregnancy (Royal College of Obstetricians & Gynaecologists 2016). This was because it was shown that maternal dTaP/IPV vaccination in the second trimester significantly increased neonatal pertussis antibodies. It was also hoped that the change in schedule would provide more opportunity for pregnant women to be offered the dTaP/IPV vaccine during pregnancy (PHE 2016). However, for operational reasons, PHE advise that vaccination should be offered from around 20 weeks, on or after the foetal anomaly ultrasound scan (PHE 2016). The maternal dTaP/IPV vaccine provided in England-Boostrix-IPV®-is manufactured by Glaxo-Smith-Klein (GSK).

When this study commenced (in 2014), in England, the influenza vaccine uptake rate in pregnancy was 39% (PHE 2014) and is currently 45% (PHE 2017). The dTaP/IPV vaccine uptake rate was 54% in 2014 (PHE 2017) and is currently 71% (PHE 2017)[2].

Vaccine hesitancy

The term *vaccine hesitancy* is used in this thesis to explain one's decision not to vaccinate, to partially vaccinate, or to delay vaccination. For the majority, vaccinations are part of established healthcare routines. However, despite assurances of the efficacy and safety of the dTaP/IPV and influenza vaccines in the scientific literature (WHO 2013), and from PHE (PHE and Department of Health 2014), there are many challenges to obtaining optimum vaccination rates during pregnancy. The Strategic Advisory Group of Experts on Immunisation (SAGE) Working Group, define vaccine hesitancy as,

> A delay in acceptance or refusal of vaccines despite availability of vaccination services. Vaccine hesitancy is complex and context specific varying across time, place and vaccines. It includes factors such as complacency, convenience and confidence (WHO 2012).

Whilst a useful term to describe various views and approaches to vaccination, the phrase vaccine hesitancy should be used with caution, as there are a number of conceptual ambiguities related to it, which may create problems in addressing vaccine concerns or access issues. One of the main problems with the term vaccine hesitancy is that it is conceptualised as on a continuum, with individuals sitting somewhere between

[2] It must be noted that there are issues with coding for pregnancy in patient's records, with some women still recorded as pregnant after they have given birth, so denominators may not be accurate.

complete refusal and complete acceptance of vaccination. This linear model does not take into account the complexities and contradictions that often come with making vaccination decisions, and accessing vaccination. For example, people may happily accept some vaccines, and be suspicious of, or strongly reject others. The continuum also assumes an active decision-making process, an often anxiety-provoking process which depends on people's level of commitment to neoliberal notions of self-care[3], and their level of confidence in health authorities (Peretti-Watel P, Larson HJ et al. 2015). Additionally, vaccine hesitancy should not always be viewed as negative. One could argue that it is natural that the public query and would like more information about health interventions. Questioning science is not a sign of ignorance but is endorsed by highly educated individuals (Beck U 1992), who perceive the biggest risk to be trusting blindly (Hobson-West P 2007). Thus, throughout this thesis, I aim to move away from sentiments that blame women who do not vaccinate, towards an in-depth understanding of the variety of concerns relating to vaccination.

Some, like Ulrich Beck, also see vaccine hesitancy as a manifestation of a broader 'age of anxiety' afflicting contemporary western society, and believe that we lack trust in various institutions more often today than in the past (Beck U 1992). This view imagines vaccine hesitancy as new and ignores the fact that anxiety around vaccination in Britain has existed since the early 1800s, with the introduction of the smallpox vaccine (Baker JP 2003). Vaccination at this time attracted considerable dissent, libertarian arguments and vaccine anxieties (Leach M and Fairhead J 2007).

Are we to be leeched, bled, blistered, burned, douched, frozen, pilled, potioned, lotioned, salivated, by Act of Parliament? (Gibbs J 1856).

James Gillray's 1802 caricature of Jenner vaccinating patients who feared it would cause the sprouting of cattle-like appendages. Image source: Wellcome Library / Wellcome Images.

[3] For a definition of neoliberalism, please see page 17.

The generalised rhetoric of a recent loss or breakdown of trust also does not answer many questions, such as what exactly trust is, and how it should be conceptualised. This causes problems with the ways that notions of trust, risk and resistance are leveraged in dominant policy arguments. Emphasising the negative, such as deficits of public trust, obscures people's thoughts and actions surrounding vaccination; how people's socio-economic positions influence vaccine acceptance and how they are treated in healthcare settings; and how vaccination makes sense within people's everyday lives, experiences and values. As Shiloh (age 19), a participant in this study stated when discussing her maternal vaccination decision, "I said no for a reason".

Additionally, discourses about loss of trust impose a normative vision of the state and the pharmaceutical industry as technocratic, trustworthy and a-political (Leach M and Fairhead J 2007), so that when the public are suspicious of certain technologies, they are perceived as irrational or ignorant. On the other hand, when they accept vaccination, some population groups are portrayed as passively complying, when they may not actually be comfortable with their decision, for example due to feeling pressured into vaccinating, or not having a discussion about it with their healthcare professional in which their concerns were addressed.

Along a similar vein, research focusing on parents' engagement with vaccines has been dominated by analysis of the direct influences on their choices, in particular scientific and media information, which have led health policy to focus on information and education campaigns, which normally focus on the benefits of vaccination, and the risks of diseases (Poltorak M, Leach M et al. 2005). Discourses about risk are beneficial to institutions promoting vaccination because they imply predictability, control and manageability, which is important given the large-scale universal aspirations of mass immunisation. However, due to being women, and in a liminal space (an intermediate state of "in between", in which individuals are removed from their usual identity while undergoing personal or social transformation (Turner V 1969)), pregnant women are conceptualised, according to the risk discourse, as doubly at risk as they are responsible for two bodies. In this way, they are perceived to be risky and dangerous to sociocultural order, held to extremely high standards of risk management, and requiring surveillance and self-regulation (Lupton D 1999).

In this way, reproductive risk is individualised, and focuses on pregnant women's 'chosen' behaviour as the primary site where reproductive risk ought to be rationally self-managed to ensure the optimum health of her foetus, without appreciating the social nature of decision-making or-with regards to vaccination-notions of herd immunity[4] (Kukla R 2010). Such discourses make healthcare decision-making during pregnancy, including around maternal vaccination, particularly difficult. It also means that when people dissent from, question or fail to respond as expected to public health messages, or healthcare interventions such as vaccination, a common tendency is to interpret this as a failure to understand, or a breakdown of public trust. Such perceptions focus on what the public do not think or understand, rather than what they do think and understand, and ignores the forms of knowledge, experiences, emotions, and social commitment that people bring to how they perceive vaccination, and which shape their concerns about it. Ultimately, risk discourses miss the disconnect between people's own framings and expectations of vaccines, and those of the institutions involved in providing them. In reality, decisions regarding vaccination are not always based upon conscious deliberations of available information and calculable probabilities (MacDonald NE, Smith J et al. 2012), but are made based on personal and family health histories and engagements with health services, birth experiences (in the case of maternal vaccination), emotions, social relations, and individual characteristics.

Debates around vaccination also reflect questions of morality, critical engagements (or disengagement) with local and national political histories, and the legacy of particular interactions between populations and institutions of the state, science, and the media (Leach M and Fairhead J 2007). Perceived risks (such as vaccine side effects) often require expert identification and calculation and so people must rely on expert advice about what risks are prevalent. However, the public are aware that experts disagree with each other, that science and technology often generate risks, and that there are conflicting business, political and financial motives in the development and delivery of healthcare technologies. As a result, people are challenged by continued uncertainties about what information and advice to trust (Giddens A 1990).

[4] The shared protective effect conferred on unimmunised individuals when a sufficiently large proportion of the population is immunised. Committee on the Assessment of Studies of Health Outcomes Related to the Recommended Childhood Immunization Schedule (2013). The Childhood Immunization Schedule and Safety: Stakeholder Concerns, Scientific Evidence, and Future Studies Washington, DC, National Academies Press.

For anthropologists, social context must be taken into account, and an understanding of the relations between the body and the socio-political economy gained, to turn mere speculation about a population, into meaning (Douglas M 1994). For example, the worry about receiving too many vaccines could relate in some contexts to an individual focus on 'overloading the immune system' (Hilton S, Petticrew M et al. 2006). However, in a more socio-political sense, it can also be argued to echo everyday experiences and concerns with unpredictable and complex government, corporate, and technical systems (Biss E 2015), especially today in the UK, where funding cuts to the National Health Service (NHS) are greatly affecting the quality of, and access to healthcare (Robertson R, Wenzel L et al. 2017), and are a source of considerable public concern.

As a medical anthropologist, throughout this thesis, I hope to demonstrate that vaccine questioning or refusal is not simply a resistance to science and medical technology, but is also social, political, extremely varied, complex, and context-specific. In order to understand these complexities, I focus on how maternal vaccination fits into the various, and always changing spheres of social and political life.

Study aim

To gain a contextualised understanding of access to, and attitudes towards maternal vaccination among pregnant and recently pregnant women and healthcare professionals in Hackney, London.

Objectives

1. To identify factors influencing maternal vaccination acceptance.
2. To identify attitudes and practice among healthcare professionals around maternal vaccination and the maternal vaccination programme.
3. To compare perceptions of vaccination, and determinants of vaccination acceptance during pregnancy, between healthcare professionals and pregnant/recently pregnant women.
4. To make policy recommendations based on the research findings, so that maternal vaccination can be tailored to be more acceptable and accessible to diverse populations.

Research questions

The key research questions addressed in this study are:

1. What ideas, norms, beliefs and experiences concerning maternal vaccination prevail among pregnant/recently pregnant women from various backgrounds and identities?
2. What ideas, norms, beliefs and experiences concerning maternal vaccination prevail among healthcare professionals?
3. How do ideas, norms and beliefs about maternal vaccination differ between healthcare professionals and pregnant/recently pregnant women?
4. How could factors influencing vaccination acceptance articulated through this research inform strategies to improve maternal vaccination acceptance?

A note on the use of the term 'ethnicity'

Socio-economic status, gender and ethnicity are key factors of interest in this thesis in terms of how these identities influence access and attitudes towards maternal vaccination. I believe it is important to explain how I use the term 'ethnicity' throughout the thesis due to the problems that have in the past, been associated with the use of the term.

Ethnicity is imprecise and fluid, and can be described as a multifaceted quality that refers to a group to which people belong or are perceived to belong due to certain shared characteristics, including geographic and ancestral origins, usually with an emphasis on language and traditions (Bhopal RS 2007).

In this study, I aimed to capture the views of women from a wide range of ethnicities, as well as recent migrants. I also took into account how other intersecting identities, including class and gender may affect vaccination acceptance. This is because in focusing on only one aspect of a person's identity or social situation, such as ethnicity or class, researchers can implicitly deny the validity of others (Crenshaw K 1991). In doing so, they miss the ways in which power is exercised over the *various* social categories one belongs to. For example, Black women, at the intersection of belonging to both a sex and an ethnicity that experiences prejudice, may experience higher levels

of discrimination and oppression than White women, who, while experiencing discrimination for their sex, do not normally suffer socially due to their ethnicity.

An analysis of differing levels in access of, and acceptance of healthcare technologies requires data and classification by socio-economic status and ethnic group. The categorisations of various ethnicities are socially constructed, and the process of categorisation is in itself an exercise of power. However, to acknowledge this is not to say that such categories have no significance in our world (Crenshaw K 1991). It is possible to retain the idea of race/ethnicity, provided that it is used only as a politicised concept and in order to ascertain between which groups health disparities exist (Fischer M 2007). With this in mind, for the demographic questions included in my topic guide, I asked participants how they would describe their nationality/ethnicity and in which country they were born. Self-assignment does pose some problems because people can change their assignment over time. For example, in a study following the 1991 British census, 12% of 'Blacks' altered their ethnic group, as well as 22% of the 'Other' category (Bhopal RS 2007). However, by taking this approach, I was able to avoid making assumptions about ethnicity, or classifying people into tightly defined categories within which they may not feel represented. For example, the term 'Asian' is popular as a means of categorisation in surveys, however, it is an extremely broad term which masks variation by country, religion etc.

Ethnicity in this study was thus understood as a factor that could influence vaccination acceptance, but, even in Chapter 5-where I explore the specific concerns related to maternal vaccination among Black British Caribbean participants-was by no means pre-determined as the only factor related to vaccination acceptance. Through this approach, I aimed to avoid the realm of moral assumptions regarding who vaccinates and who does not, and to move into the socio-political domain of vaccination.

Outline of thesis

Thus far, I have provided an introduction and background to the study, including the reasons for, and the state of maternal vaccination in the UK, and an analysis of the history of vaccine hesitancy, and highlighted current vaccination concerns. I have also outlined the study aim, objectives and research questions. In Chapter 1, I include a detailed review of the literature on maternal vaccination acceptance globally, in order to

outline what is currently known about the topic in academia and in healthcare settings. In Chapter 2, I explain why the study was conducted, highlighting the gaps in knowledge around factors influencing maternal vaccination acceptance, and the importance of anthropological, in-depth research into vaccine hesitancy. In Chapter 3, I describe how the study was designed, including an outline of the theories informing the study design, fieldwork, and analysis. These theories draw on anthropological works that address diverse conceptualisations and practices around vaccination and healthcare, for example (Leach M and Fairhead J 2007) and (Mol A 2008). Additionally, ideas for a relational approach to care are explored using the theory of relational autonomy (Mackenzie C and Stoljar N 2000). These theories are supported by Foucault's notions of biopolitics' and 'governmentality'. Governmentality seeks to,

> …incite, reinforce, control, monitor, optimize, and organize the forces under it: a power bent on generating forces, making them grow, and ordering them, rather than one dedicated to impeding them, making them submit, or destroying them (Foucault M 1976).

According to Foucault, this regulation of society is achieved through 'biopolitics', which, guided by the state, involves the "explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (Foucault M 1976). Within this thesis, I use these framings to explore the contradictions that exist between the push for high levels of vaccination acceptance, and popular notions of patient choice.

The final sections of Chapter 3 explain the reasons for choosing the study site (Hackney) and information about the borough; methods used for recruiting sites within Hackney (such as general practitioner (GP) practices) through which participants were recruited; methods used for participant recruitment; and data collection methods (such as in-depth interviews). Finally, I explain how the data was analysed with a thematic analysis approach.

The beginning of Section 2 provides details of the included sites through which participants were contacted; the number of participants recruited for each data collection method, as well as their key demographics; and includes an overview of the themes identified from the fieldwork. The subsequent chapters 4-6 in Section 2 of the thesis contain the fieldwork findings. The key focus of each of these chapters is based on one

or more of the key themes identified from the fieldwork, underpinned by the theories that have informed the study mentioned above.

Drawing on notions of governmentality and biopolitics (Foucault M 1976), in Chapter 4, I analyse pregnancy in the particular context of neoliberal forms of governance. The neoliberal turn in the early 1980s engendered an ideology of "liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong property rights, free markets and free trade" (Harvey D 2005). Neoliberalism also included the desire to expand the domain of markets in areas such as healthcare, education and water provision which, until the 1980s, were largely outside the market economy in the UK and other Western nations (Ives A 2015). In analysing what it is to be pregnant in this context, I demonstrate how wider socio-economic and political concerns (such as the neoliberal focus in healthcare, which expects pregnant women to be autonomous, self-caring individuals (Lupton D 1995)), influence how pregnancy is 'performed', and thus, perceptions of, and access to maternal vaccination. I analyse how factors pertaining to the structural features of the health care system, features of individuals, process factors, and the cultural acceptability of vaccination, influence vaccine acceptance; cautioning that efforts to increase acceptance of, and access to vaccination among specific population groups should not blame certain population groups for under-vaccination. In turn, I also analyse why vaccines provided during pregnancy become the focus of wider socio-political reflection.

While in Chapter 4 I analyse the broader ways in which 'the system' can influence access to, and acceptance of healthcare interventions such as vaccination, in Chapter 5, I focus more specifically on how the healthcare system and the state can exclude specific population groups from healthcare and produce inequities in access to healthcare between populations of various intersecting identities. I take into account social influences and current and historically located dimensions of governance, focusing especially on family influences on perceptions and decisions concerning vaccination, and consider how these factors affect vaccination acceptance, particularly among the self-described Black British Caribbean women in my study. This is because participants from this population had striking concerns about vaccination, which were linked to perceptions of the UK government, and were greatly influenced by familial views towards vaccination. I demonstrate how a more holistic and context-specific approach to encouraging vaccination acceptance, which tailors immunisation services to specific

communities, and where family members are involved in discussions about vaccination decisions, would enable healthcare professionals to be better equipped to talk about vaccination concerns with pregnant women.

In Chapter 6, I critique the illusion of autonomy and choice that is popular in healthcare settings today, while policy-makers and healthcare professionals simultaneously *expect* the public to comply to vaccination advice. I demonstrate how the relational conception of autonomy-which I use in this chapter to analyse how relationships with, and recommendations from healthcare professionals affect pregnant women's vaccination decisions-can be used to more effectively engage with pregnant women and their vaccine decision-making. This is because such an approach considers the impact of social relationships on healthcare decisions, and (as focused on in this chapter), in the form of support from healthcare professionals, is not an affront to individual autonomy, but can actually support it (Kukla R 2005). I discuss how the features of a relational approach to care could increase levels of trust in vaccination and thus create higher rates of vaccination acceptance, whilst acknowledging the difficulties of implementing this approach within the currently difficult financial state of the NHS.

In chapter 7, I discuss how the focal theories which run through the thesis contributed to the analysis and synthesise the findings according to the study's research questions. I also outline the main limitations to the study. Finally, in Chapter 8, I make recommendations as to how the findings of this study can contribute to ensuring maternal vaccination is accessible and acceptable to more women during pregnancy.

Chapter 1: Literature Review

In this chapter, I present a review of the literature, conducted in April 2015 as part of my PhD, on factors influencing maternal vaccination acceptance globally. The review was published in Vaccine in October 2015 (Wilson RJ, Paterson P et al. 2015). At the end of this chapter, I summarise the literature on factors influencing maternal vaccination acceptance identified since the literature search for this review was conducted.

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SECTION A – Student Details

Student	Rose Wilson
Principal Supervisor	Heidi Larson
Thesis Title	"I said no for a reason" Understanding factors influencing vaccination acceptance during pregnancy in Hackney, London

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?	Vaccine		
When was the work published?	November 2015		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	RW designed and conducted the literature review, and wrote up the manuscript with the support of the co-authors.

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Understanding factors influencing vaccination acceptance during pregnancy globally: A literature review

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ABSTRACT

Maternal vaccination has been evaluated and found to be extremely effective at preventing illness in pregnant women and new-borns; however, uptake of such programmes has been low in some areas.

To analyse factors contributing to uptake of vaccines globally, a systematic review on vaccine hesitancy was carried out by The Vaccine Confidence Project in 2012. In order to further analyse factors contributing to uptake of maternal immunisation, a further search within the broader systematic review was conducted using the terms 'Pregnan*' or 'Matern*'. Forty-two articles were identified. Pregnancy-related articles were further screened to identify those focused on concerns, trust and access issues regarding maternal vaccination reported by pregnant women and healthcare workers. Thirty-five relevant articles were included which were then searched using the snowballing technique to identify additional relevant references cited in these articles. A search alert was also conducted from February to April 2015 in PubMed to ensure that no new relevant articles were missed. A total of 155 relevant articles were included.

Most of the literature which was identified on hesitancy surrounding vaccination during pregnancy reports on determinants of influenza vaccine uptake in North America. Research conducted in low-income countries focused primarily on tetanus vaccine acceptance. The main barriers cited were related to vaccine safety, belief that vaccine not needed or effective, not recommended by healthcare worker, low knowledge about vaacines, access issues, cost, conflicting advice. From the point of view of healthcare workers, barriers included inadequate training, inadequate reimbursement and increased workload. Twenty-seven out of 46 (59%) articles mentioning ethnicity reported lower rates of coverage among ethnic minorities.

Barriers to vaccination in pregnancy are complex and vary depending on context and population. There are wide gaps in knowledge regarding the attitudes of healthcare workers and how ethnicity and gender dynamics influence a pregnant woman's decision to vaccinate.

1. Introduction

Over the past two decades, tremendous progress has been made in halving worldwide maternal and child deaths, supported by the drive to meet Millennium Development Goals (MDGs) by 2015. One of the targets of UN The Sustainable Development Goals (SDGs) aims to continue this momentum by reducing the global maternal mortality ratio to less than 70 per 100,000 live births [1].

Maternal vaccination programmes have been evaluated and found to be extremely effective at preventing illness in pregnant women and new-borns [2]. The pertussis vaccine is given as part of a combined product: diphtheria/tetanus/acellular pertussis/inactivated polio vaccine (dTaP/IPV) [3]. Influenza and pertussis vaccinations during pregnancy are now offered in many countries, including Australia, Belgium, Canada, China, France, Germany, India, Mexico, the Netherlands, Poland, Spain, Slovenia, Switzerland, Turkey, the UK and the USA. The monovalent maternal tetanus vaccination is implemented as part of the routine immunisation programme in most developing countries. Group B Streptococcus (GBS), Respiratory Syncytial virus (RSV) and Cytomegalovirus (CMV) vaccines are also currently being developed for use in pregnancy.

Pertussis and influenza are preventable diseases with potentially severe consequences for new-born infants and in the case of

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influenza, for pregnant women. Infants under the age of 6 months are vulnerable to transmission of pertussis and influenza infection from others, especially their mothers. The most common clinical syndromes due to pertussis, requiring intensive care admission in infants, are apnoea, pneumonia and seizures. Most deaths are associated with the presence of pneumonia [4].

Over six million children under the age of five died in 2013 and more than half of these deaths were due to conditions that could be prevented or treated with access to simple, affordable interventions such as vaccination [5]. Mortality reduction in new-born infants under 1 year of age has been gradual, especially in the highest burden countries in Africa [6], declining on average three percent per year since 1990 [7]. The relative proportion of new-born deaths now accounts for about 44% of the total under-five mortality and new-borns are projected to make up 55% of all under-five mortality by 2035 [8]. If the present rate of decline continues, it will be over a century before an African new-born baby has the same survival probability as one born in Europe or North America in 2013 – three times longer than this decline took in industrialised countries before neonatal intensive care began [6].

Childhood deaths associated with influenza are most frequent in infants under the age of 6 months; influenza can also cause bacterial pneumonia and otitis media. Maternal influenza infection has been associated with an increased risk of hospitalisation relative to non-pregnant women of the same age: in an analysis of acute respiratory illness visits within a managed-care organisation, non-pregnant women had ten excess visits per 1000 compared with 23.7 excess visits per 1000 among pregnant women [9].

Influenza and pertussis vaccine uptake in pregnancy are around 40% [10] and 62.3% [11] respectively in England. However, lower uptake rates have been reported in some areas of the UK and in other countries, due to challenges such as lack of knowledge on the part of health care workers (HCW) and pregnant women related to the safety and efficacy of vaccines provided during pregnancy [12], complex delivery arrangements involving different HCW, challenges in data collection and reporting [13] and because the vaccines were newly introduced. Pregnant women and HCW also report feeling confused by mixed messages regarding vaccination and medication in pregnancy.

Maternal and neonatal tetanus (MNT) are among the most common lethal consequences of unclean deliveries and umbilical cord care practices in many countries [14]. However, on the basis of cause-of-death trends (2000–2012), tetanus had the largest relative decrease, of more than two-thirds from 1.3 deaths (per 1000 live births) to 0.4. This decrease is associated with substantial increases in tetanus toxoid vaccination [15] and may also relate to improved cleanliness, cord care practices and education [16]. High vaccination uptake however, must be sustained as there is no herd immunity effect against tetanus. Neonatal tetanus is an acute disease presenting initially with loss of ability to suck, followed by generalised rigidity and painful muscle spasms as the disease progresses. Most (90%) cases of neonatal tetanus develop symptoms during the first 3–14 days of life with the majority presenting at 6–8 days. Mortality is very high: in the absence of medical treatment, case fatality approaches 100% [17].

In terms of new vaccines in the pipeline, preclinical and human phase I studies of GBS vaccine have been completed demonstrating the safety and immunogenicity of the vaccine. Phase III vaccine trials are still needed to determine the clinical efficacy of maternal GBS vaccination [18] but acceptability of this vaccine would be extremely important as women colonised with GBS during pregnancy are at increased risk of premature delivery and perinatal transmission of the organism. Amniotic infection can result in maternal sepsis and very rarely, meningitis [19]. Though there are very little data on neonatal GBS disease worldwide, studies in African countries have indicated incidence as high as 1.21 per 1000 live births [20].

Multiple vaccine candidates and at least one second-generation monoclonal antibody are currently in clinical testing for RSV. Globally, RSV is responsible for over 30 million new acute lower respiratory infection episodes in children under five, resulting in more than 3.4 million hospital admissions each year. Over 90% of all RSV-associated deaths are estimated to occur in low and middle-income countries (LMIC) [21].

With regards to CMV, two different vaccines showed promising results in phase II clinical trials that studied healthy adults and immunocompromised solid-organ and bone-marrow transplant recipients, respectively [22].

Some challenges to obtaining high vaccination uptake during pregnancy are due to "vaccine hesitancy". Vaccine-hesitant individuals may refuse some vaccines, but agree to others or delay vaccines and are influenced by a number of factors including issues of confidence, complacency and convenience/access [23].

The Strategic Advisory Group of Experts (SAGE) on Immunisation established a Working Group dealing with vaccine hesitancy in March 2012 [24]. The working group drafted a "Model of determinants of vaccine hesitancy" (Fig. 1) organised around three key domains: (1) contextual influences – including historic, sociocultural, environmental, health system/institutional, economic or political factors; (2) individual and group influences – including influences arising from personal perceptions of the vaccine or influences of the social/peer environment; and, (3) vaccine and vaccination-specific issues which are directly related to the characteristics of the vaccine or the vaccination process (Fig. 1). This model includes a broad selection of factors that have been identified as potential influencers of vaccine hesitancy drawn from the collective experience and insights of the SAGE WG members [23]. The model has been used in this literature review to categorise concerns surrounding vaccination during pregnancy.

To address some of these issues, communication strategies around the safety and effectiveness of the inactivated influenza and acellular pertussis vaccines in pregnancy have targeted pregnant women and HCW in some settings [25,26]. However, a vaccine hesitancy literature review conducted by The Vaccine Confidence Project in 2012 found only 42 out of 1164 articles focusing on vaccination during pregnancy and there have only been four systematic literature reviews conducted on factors associated with vaccination uptake during pregnancy. All of these reviews focused solely on the influenza vaccine. Two were published in 2010 [27,28], one in 2011 [29] and one in 2014 (with a search that was performed up to November 2013) [30]. The Bulifon et al. [27] article identified influences on decision-making for influenza A/H1N1v vaccination among pregnant women. The lack of information on influenza vaccination for pregnant women and confusing information relating to the risk of adverse foetal events following vaccination were reported. In France, these concerns led to the vaccine being discredited by the mass media and in the population before it became available. The Guthmann et al. [28] article focused on reasons for the low uptake of the influenza vaccine in all groups in France, including pregnant women. Bish et al. [31] carried out a systematic literature review to examine the psychological and demographic factors associated with uptake of vaccination globally during the 2009 pandemic and Yuen et al. [30] carried out a literature review of factors influencing uptake of influenza vaccination during pregnancy in North America.

With reference to the barriers to vaccination during pregnancy mentioned above and in the SAGE working Group Model of Determinants of Vaccine Hesitancy, the aim of this literature review is to analyse factors influencing uptake of vaccines in pregnancy, focusing on maternal and HCW concerns, trust and access issues.

Fig. 1. SAGE Working Group (WG) "Model of determinants of Vaccine Hesitancy".

Source: Larson et al. [23].

2. Methods

2.1. Search strategy

To analyse factors leading to uptake of all vaccines globally, a systematic review on vaccine hesitancy was carried out by The Vaccine Confidence Project in 2012 [23]:

2.1.1. Systematic review on vaccine hesitancy search strategy

A search strategy was developed in Medline and then adapted as required by differential indexing across several multidisciplinary mainstream and regional databases including: Medline, Embase Classic & Embase, PsychInfo, Cochrane, CINAHL Plus, Web of Science, IBSS, LILACS, AfricaWideInfo and IMEMR. The strategy included an extensive list of keywords (Table 1) and related MeSH/subject headings in an effort to capture the many dimensions and expressions of vaccine confidence, trust and hesitancy.

Table 1
Keywords used in search strategy for literature review on vaccine hesitancy.

Vaccin* OR immunis* OR immuniz*
AND
Anxiety OR doubt* OR trust OR intent* OR dilemma* OR attitude* OR distrust OR mistrust OR controvers* OR objector* OR awareness OR dropout* OR Perception* OR misconception* OR uptake OR behavi*r OR exemption* OR refus* OR misinformation OR barrier* OR belief* OR fear* OR rejection OR opposition OR choice* OR criticis* OR hesitanc* OR rumo*r OR delay OR mandatory OR accept* OR concern* OR compulsory OR knowledge OR confidence OR decision making OR anti-vaccin* OR parent* con*
Additional limits
• Publication dates (2004–2012)
• Languages (EU only)
Databases
• Mainstream & regional (SR on VH determinants)
• Mainstream and regional (SR on VH strategies)

Table 2
Inclusion and exclusion criteria.

Inclusion criteria
- Articles that include research on the following:
  - Vaccine hesitancy, trust/distrust, perceptions, concerns, confidence, attitudes, beliefs about vaccines and vaccination programmes (relating to vaccination in pregnancy) by individuals (pregnant women, HCW) or communities

  Keywords for search by title: (*vaccin** OR *immuni**) AND (*pregnan** OR *maternal*) AND (*attitude* OR *awareness* OR *access* OR *predictors* OR *factors* OR *determinants* OR *refusal* OR *hesitancy* OR *acceptance*)
- Location: any
- Publication years: any
- Vaccine: vaccines provided during pregnancy (influenza, dTaP/IPV/monovalent tetanus vaccine)
- Concerns: all concerns
- Populations: pregnant women, women who have recently given birth, HCW
- Languages: any
- Vaccines not currently available, such as group B Streptococcus vaccine

Exclusion criteria
- Not about vaccines provided during pregnancy
- Non-peer reviewed articles such as editorials, letters, comment/opinion, pilot studies
- Research and development
  - Safety research
  - Serologic investigations
  - Immunogenicity studies
  - Efficacy trials
  - Pre-clinical trial research
  - Cost-benefit analysis or cost effectiveness trials

In order to analyse factors influencing uptake of vaccines in pregnancy, a further search was conducted, within the broader systematic review, using the terms 'Pregnan*' or 'Matern*'. Forty-two articles were identified. The pregnancy-related articles were then screened to identify those which focused on maternal and HCW concerns, trust and access issues regarding vaccination. Thirty-five relevant articles were included which were then searched using the snowballing technique [32] to identify relevant references cited in these articles. The snowballing technique was also used on articles recommended by peers as well as articles identified in a PubMed search as the original search conducted by the Vaccine Confidence Project commenced in 2012 and more relevant articles may have been published since then.

The PubMed search commenced on 19/02/2015 and ran until 22/04/2015 with the following terms: (*vaccin** OR *immuni**) AND (*pregnan** OR *maternal*) AND (*attitude* OR *awareness* OR *access* OR *predictors* OR *factors* OR *determinants* OR *refusal* OR *hesitancy* OR *acceptance*) (all dates were included).

2.2. Study selection

Once retrieved, peer-reviewed articles were screened by title and abstract according to a set of inclusion and exclusion criteria (Table 2).

2.3. Data analysis

Data was extracted from included articles and analysed in Excel.

3. Results

Thirty-eight out of 42 articles were included from the 2012 systematic literature review [23]. An additional 239 articles were found after using the snowballing technique with these articles (Fig. 2). Fourteen articles were added from peer recommendations and 111 from the additional PubMed search alert. A total of 364 articles were screened by title and abstract. One hundred and eighty-three articles were excluded by title and abstract, two were not available by full text and one was not able to be translated (from Hungarian) due to copyright issues relating to the article. One hundred and seventy-eight articles were screened by full text and 61 were excluded by full text, resulting in 117 articles. There were a total of 155 articles including the relevant articles from the earlier vaccine hesitancy search (2012) [23]. These articles included 113 focusing on the influenza vaccine (A(H1N1), seasonal influenza or both), 16 on tetanus, seven on dTaP/IPV, two on GBS and 17 on any vaccine given in pregnancy.

3.1. Main findings

Almost all of the studies (113/155, 73%) focused on the influenza vaccine and of these, 73/113 (65%) were conducted in North America. Studies focusing on the tetanus vaccine were focused mainly in Asia and Africa (8/16, 50% and 4/16, 25% respectively) (Fig. 3).

There has been an increase in articles focusing on the determinants of influenza vaccination uptake in pregnancy since 2008, peaking at 26 articles in 2011. This has since declined to just seven in 2014 and three as of 21st April 2015. Most articles focusing on the tetanus vaccine (14/16, 88%) were published between 1990 and 2005 [33–46]. There were very few articles focusing on dTaP/IPV with the most (4/7, 57%) published in 2014 and 2015 [47–50] (Fig. 4).

Sample sizes of pregnant women surveyed/interviewed in the included articles were between 10 and 55,570. Nine articles reported on the number of women intending to vaccinate.

The main concerns cited in the included articles were regarding the safety of vaccines in pregnancy (64/155, 41%). Other frequently cited barriers were: concerns about the efficacy or the belief that the vaccine is not necessary (28/155, 18%); low knowledge about the vaccines and/or the diseases they prevent (among both pregnant women and HCW) (22/155, 14%); no recommendations from HCW (17/155, 10%); and access/availability issues (6/155, 4%). From the point of view of the HCW, barriers included inadequate reimbursement [51–53] and training [54] and increased workload [55] (6/155, 4%). Other barriers were conflicting advice [56–58], cost [47,59] and religion [60] (Fig. 5).

When these varied concerns were mapped against the SAGE Working Group model of determinants of vaccine hesitancy (Fig. 1), for all vaccines, more than half were grouped under 'risks/benefits (perceived/heuristic)' which includes safety concerns (83/155, 54%). The role of healthcare professionals was the second biggest category of issues (26/155, 17%) and included concerns such as no recommendation from the HCW. Inadequate knowledge of why, where, what and when vaccines are needed was also a barrier to vaccination (25/155, 16%). The main concerns regarding the influenza, dTaP/IPV and GBS vaccines fell into the 'risk/benefit (perceived/heuristic)' category (mostly regarding the safety of the vaccine). The main concerns regarding the tetanus vaccine fell into the 'knowledge of why/where/what/when vaccines are needed' category (Fig. 6).

One hundred and eleven out of 155 (72%) articles focused on attitudes towards vaccination in pregnancy among pregnant women/women who had recently given birth, 29/155 (19%) on attitudes of HCW and 15/155 (10%) on the attitudes of both. The main vaccine of focus was influenza both groups (i.e. pregnant women/mothers and HCWs). Articles focusing on attitudes of HCW were more likely to cite barriers regarding 'knowledge of why/where/what/when vaccines are needed' (7/29, 24%) than those focusing on pregnant women (15/111, 14%) (note that these figures do not include the articles that focused on both pregnant women/new mothers and HCW).

These concerns were grouped into larger overarching categories according to the SAGE Working Group model of determinants

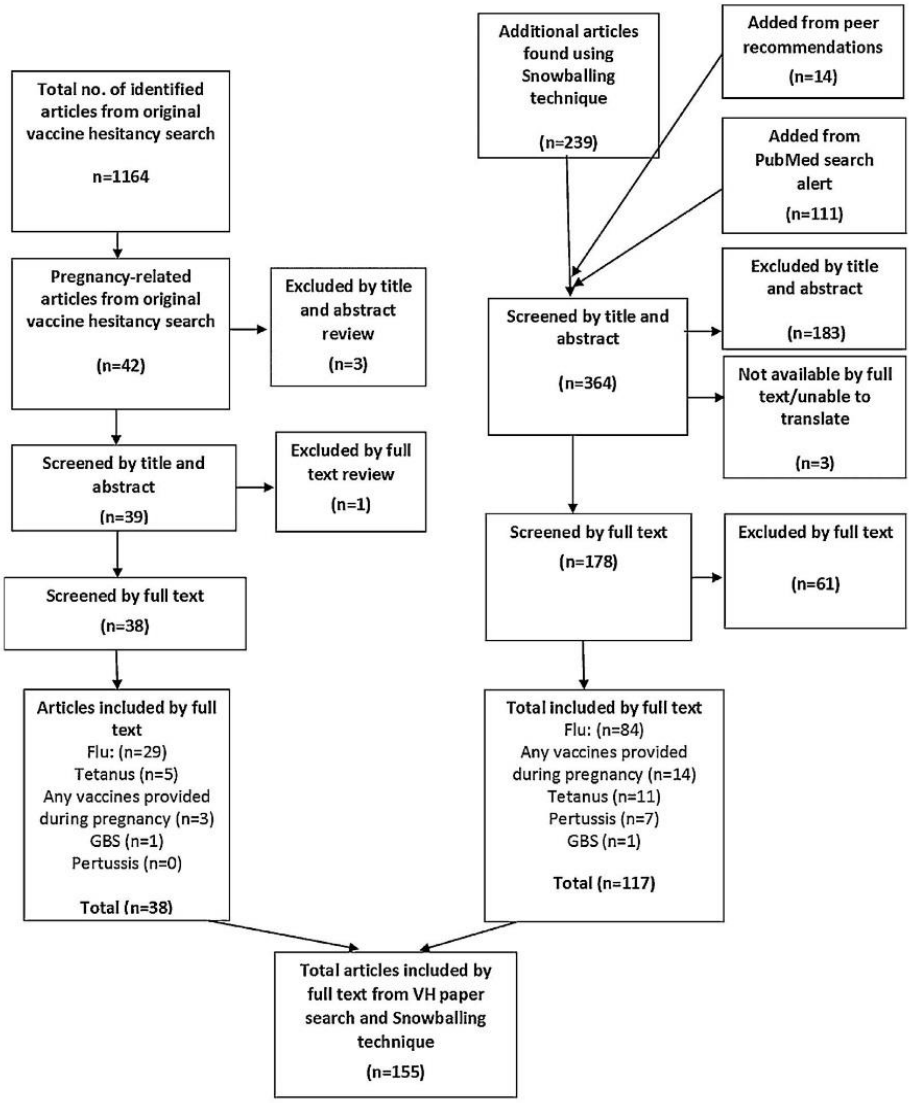

Fig. 2. Search process flow chart.

(Fig. 1). Most concerns fell into the 'Individual/social group influences' category (106/155, 68%), followed by 'Vaccine & vaccine-specific issues' (37/155, 24%) and 'Contextual issues' (11/155, 7%).

Only 46/155 (30%) articles mentioned ethnicity as a factor influencing vaccine uptake. Of these, the majority (38/155, 25%) focused on the influenza vaccine. Twenty-seven out of 46 (59%) articles reported lower rates of vaccination coverage among ethnic minorities [42,56,60–83]. Only 8/46 (17%) reported higher uptake rates among ethnic minorities and 11/46 (24%) reported no difference. One hundred and nine articles (70%) did not mention ethnicity as a factor related to vaccination uptake.

Five articles found that agreement/advice from the pregnant woman's husband/partner significantly affected her likelihood to vaccinate [44,45,84–86]. In Canada, advice from a spouse was frequently considered important in the immunised group [87]. In the Ivory Coast, the agreement of the husband is considered necessary because he is the head of the family, the decision maker, and controls the money [44]. In Pakistan, unmarried females are not encouraged to get themselves vaccinated [45]. In Turkey, 37.9% of the study group stated that they made their decisions on their own, 10.5% said their vaccination decisions were made by their spouses and 51.5% said they decided with their spouses [86] and in the USA, women cited their partner's dissuasive role; often due to the latter's lack of knowledge or own lower vaccine uptake [84].

The recommendation from a HCW to receive vaccination during pregnancy was reported in most articles to increase vaccination uptake. In a study by Walker et al. [88], it was found that women who were offered influenza vaccination by a HCW were more likely to be vaccinated (71%) than women who were not offered the vaccine (14%) and they were more likely to have positive attitudes about vaccine effectiveness and safety.

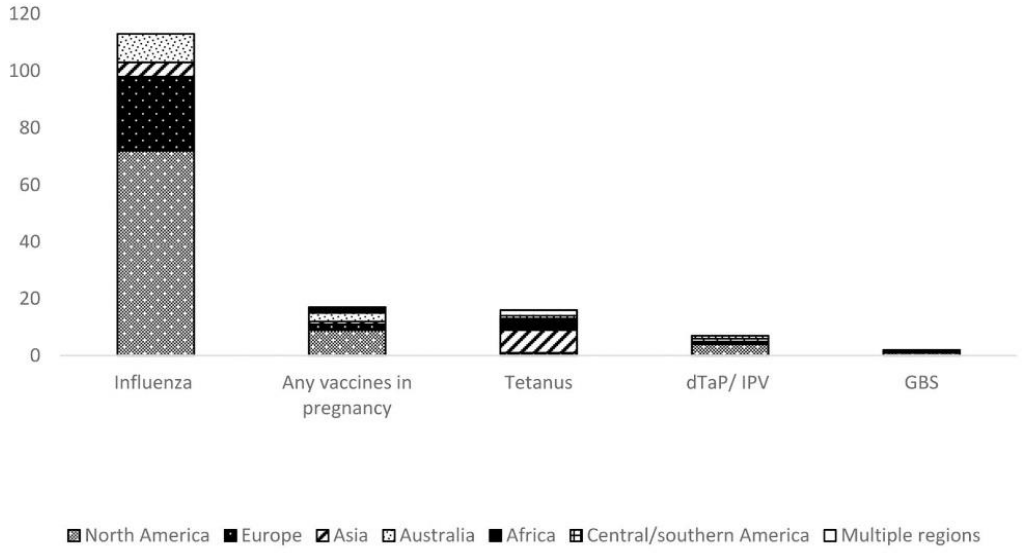

Fig. 3. Vaccines mentioned in the literature by country.

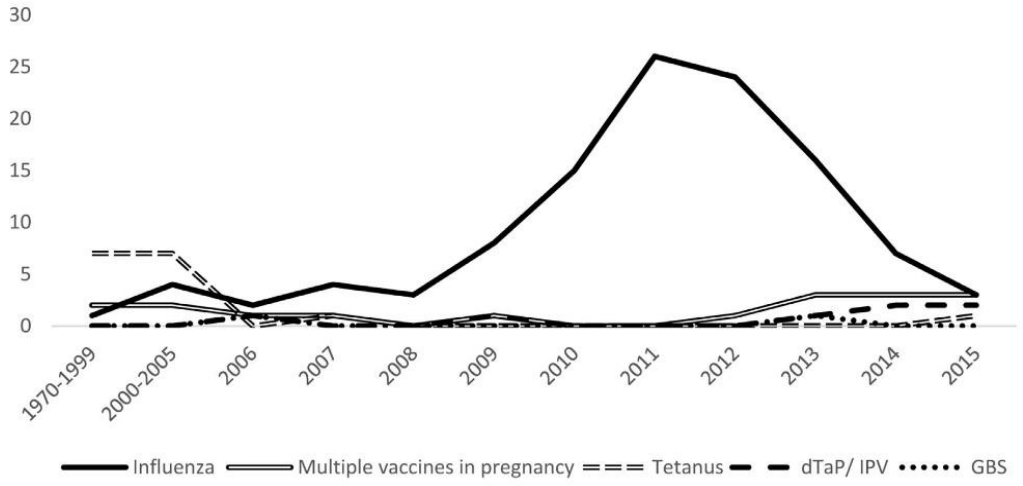

Fig. 4. Articles by publication date and vaccine.

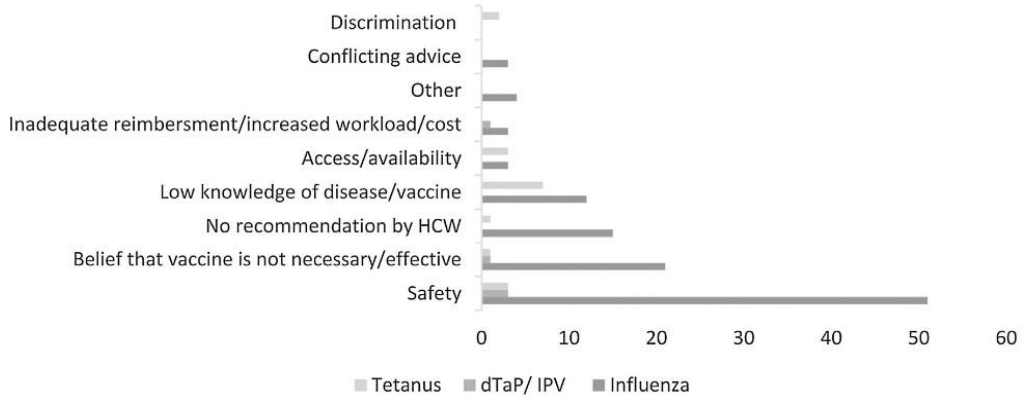

Fig. 5. Concerns by vaccine. Note: numbers do not add up to total number of articles as only articles specifying a particular, currently available vaccine were included in this chart.

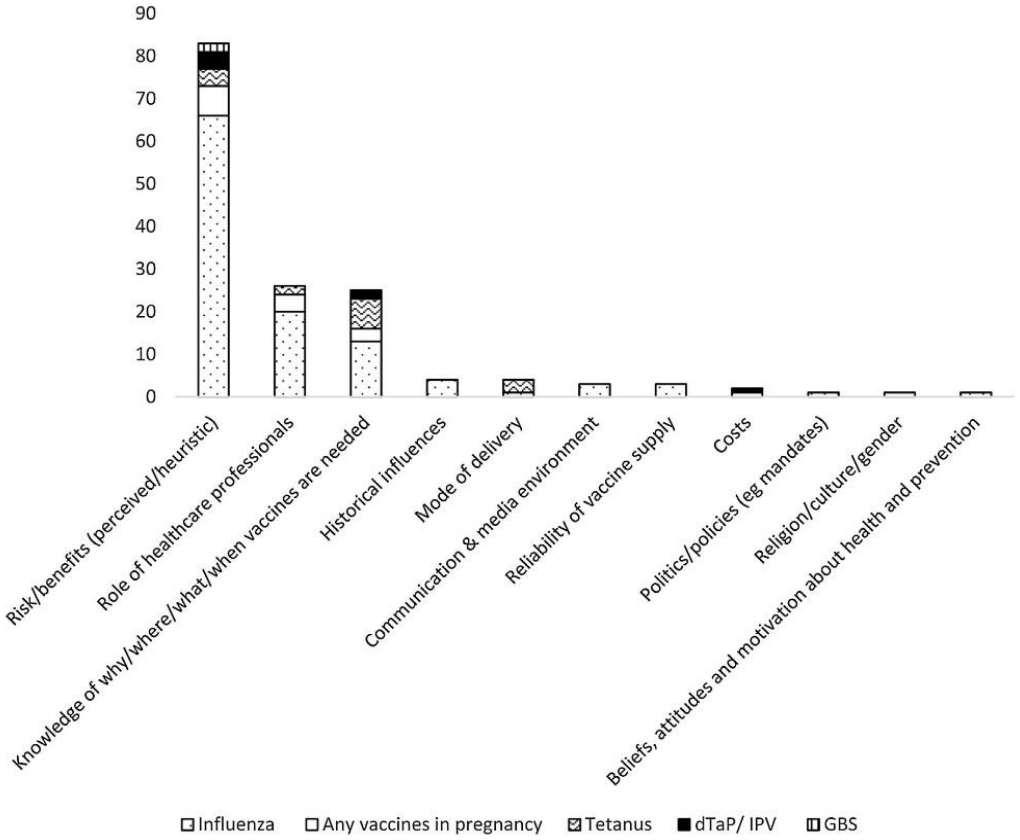

Fig. 6. Concerns by vaccine according to SAGE Working Group Model of Determinants.

4. Discussion

The aim of this literature review was to analyse factors contributing to uptake of vaccines in pregnancy, focusing on the perspectives of pregnant women and HCW to identify the spectrum of concerns, trust and access issues.

The largest number of articles focused on the influenza vaccine and the primary focus on the influenza vaccine was in North America and most were published in 2011 due to the 2009 A(H1N1) pandemic. The number of articles focusing on the influenza vaccine has since declined and could be because it has now been 6 years since the last influenza pandemic.

Articles focusing on the tetanus vaccine were primarily in research on low-income countries and were mostly published between 1990 and 2005 [89], reflecting the growing momentum around tetanus immunisation after WHO called for neonatal tetanus elimination in 1989 with an initial target of 1995, which was then extended to 2000. In 1999, the Maternal and Neonatal Tetanus Elimination Initiative was launched by UNICEF, WHO and UNFPA with yet another new target date of 2005 [14], which has since been extended to 2015 While there has been considerable progress, the extended targets reflect some of the challenges that were faced.

There were very few articles focusing on dTaP/IPV which could be due to the relatively recent introduction of the vaccine during pregnancy in some countries.

The main concerns cited in the included articles were related to the safety of vaccines in pregnancy. However, most studies did not offer the opportunity for participants to detail what these safety concerns were. While low knowledge about the vaccines, their efficacy, their availability and the diseases they prevent, were among the reasons for low vaccine uptake, as some studies reported, the role of the media regarding pregnant women's knowledge about and decisions to vaccinate cannot be ignored [85–87,90–92]. Almost all articles mentioned that recommendations from a HCW to receive the vaccine had a large impact on vaccination uptake [88].

When concerns were grouped into larger overarching categories of the SAGE model of determinants, most concerns fell into the 'Individual/social group influences' category (106/155, 68%). This demonstrates the extent that a pregnant woman's social context and members of the local community, family and friends influence her decision to vaccinate. Five articles explicitly stated the husband/partner's role in the decision to vaccinate but did not analyse this aspect of vaccination uptake in detail.

Twenty-seven out of 46 (59%) articles reported lower vaccination uptake among ethnic minorities. One article [80] on Ghana suggested that women from ethnic minorities are discriminated against due to their poor socio-economic position, language barriers that prevent them from understanding and communicating with HCW, access issues related to their geographical location and less health education.

Very few (four) literature reviews were found which focused on identifying factors associated with vaccination uptake in pregnancy. All four reviews focused on the influenza vaccine and the views of pregnant women. Two of the reviews [27,28] focused on uptake in France.

Most of the literature focused on the views of pregnant women. Only 29/155 (19%) solely focused on views of the HCW. There is the need for more in-depth analysis on the barriers HCW cited to vaccination, including inadequate training, inadequate reimbursement and increased workload.

Although West Africa has the highest global burden of whooping cough thus far in 2015, with 500 cases reported in Liberia [93], the dTaP/IPV vaccine is not yet provided in pregnancy. However, it must be noted that the reason for the recent outbreak of pertussis in Liberia could be due to the childhood immunisation programme being affected by the recent Ebola outbreak. As the burden of pertussis disease was highest in young children [94], maternal vaccination may not be the most appropriate strategy.

As of March 2015, maternal and neonatal tetanus is still a public health problem in 23 countries, mostly in Africa as well as Afghanistan, Cambodia, Equatorial Guinea, Haiti, India, Indonesia, Iraq, Pakistan, Papua New Guinea, Philippines and Yemen [14]. However, literature on vaccine uptake and reasons for under-vaccination is under-reported in low-income countries: research on the tetanus vaccine was only found in four African countries, as well as Bangladesh, India, Indonesia, Pakistan, Peru and Turkey.

A limitation of this literature review was that there was no quality criteria applied to the selection of papers for inclusion of the review, therefore there is no comment on the quality of the studies reported and this could affect the validity of some of the conclusions. The studies selected were primarily qualitative, and our aim was to identify the spectrum of concerns and issues identified in the literature we found which were expressed by pregnant women and health care workers.

5. Conclusion

This literature review has shown that both pregnant women and HCW cite safety concerns as a main barrier to obtaining/providing influenza and pertussis vaccines during pregnancy. However responses differed depending on geographical area: in low-income countries for example, pregnant women were more likely to cite access issues as a barrier to vaccination. There are also wide gaps in knowledge regarding the attitudes of HCW to vaccination in pregnancy, which is significant considering the impact they have on a woman's decision to vaccinate.

From the supply side, regulatory agencies still do not have a licensing pathway for many vaccines for pregnant women, manufacturers remain concerned about liability and providers perceive that pregnant women are unwilling to accept vaccines [95].

As the MDG era comes to an end, the development agenda beyond 2015 is widening to include other important health issues such as non-communicable diseases (NCDs). However, neither stillbirths nor neonatal deaths are mentioned in post-2015 documents [96] risking that the current momentum for new-born health may be lost.

Barriers to vaccination in pregnancy are complex and can differ from barriers and concerns affecting uptake of routine childhood vaccinations. Maternal vaccination is administered at a time when the patient is cautious about various behaviours, including taking medications and vaccinations, and feels responsible for not just her own life but of that foetus. Depending on the cultural context, different norms are also established around the time of pregnancy. Barriers also vary depending on context and target population.

Taking these points into account, 'quick-fix' interventions which aim to increase vaccination uptake, such as health communication messages and training physicians in communication strategies [97], without understanding addressing the root cause of vaccine hesitancy in specific contexts, are likely to have little effect on patients' decisions to vaccinate or on the provider's own confidence in communicating with parents about vaccines.

It is important to understand how cultural and gender dynamics in different settings can influence a woman's decision to vaccinate. This can be done through in-depth local ethnographies, taking the views of all community members and influencers into account, complemented by in-depth individual interviews and focus groups. Research could also examine some of the complex socio-political reasons for under-vaccination in certain communities must to inform vaccination policies and delivery strategies. With more understanding of the perspectives of pregnant women, their providers and communities, maternal vaccine strategies will be more likely to reach and protect pregnant women and their newborns from preventable disease.

Authors' contribution

The manuscript has been read and approved by all named authors, who have worked collaboratively on the study design, search strategy, analysis and write-up. RW and CJ performed the literature search; and RW and PP screened the articles.

Conflict of interest

HL has done consulting on vaccine confidence with GSK and is a member of Merck Vaccine Strategic Advisory Board.

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Summary of literature on factors influencing maternal vaccination acceptance published since April 2015

Since conducting the literature review, 20 relevant articles have been published (between April 2015 and June 2017), which analyse factors influencing maternal vaccination acceptance. Two of these articles were literature reviews and one of these included a literature review alongside a survey. Of the 20 articles, 45% (9), focused on the influenza vaccine, which are fewer than in the review published in 2015 (in which 73% focused on the influenza vaccine). This is likely due to the 2009 A(H1N1) influenza pandemic occurring more recent to 2015. Five articles focused on both maternal influenza and dTaP/IPV vaccines, three on the dTaP/IPV vaccine, two on the tetanus vaccines and one on the newly developed GBS vaccine.

Concurrent with the findings of the 2015 study, most (15) focused only on high income countries. However, studies conducted since 2015 have taken place in a wider variety of countries, than was found in the 2015 review. Four studies were conducted in England (one across England (Campbell C, Jan Van Hoek A et al. 2015), one across London (Donaldson B, Jain P et al. 2015), one in Hackney (Winslade CG, Heffernan CM et al. 2017) and one in Oxford (McQuaid F, Pask S et al. 2016)); four in the USA (Healy CM, Ng N et al. 2015a, Healy CM, Rench MA et al. 2015b, Frew PM, Kriss JL et al. 2016, Barnard JG, Dempsey AF et al. 2017); two in Australia (O'Grady KA, Dunbar M et al. 2015), with one of these including part of their study in Scotland (Davis M, Stephenson N et al. 2015); one in Belgium (Maertens K, Braeckman T et al. 2016); one in Brazil (Mendoza-Sassi RA, Cesar JA et al. 2015); one in Canada (Kowal SP, Jardine CG et al. 2015); one in Germany (Bödeker B, Walter D et al. 2014); one in Hong Kong (Wong, Thomas et al. 2015); one in Malawi (Pathirana J, Nkambule J et al. 2015); one in Pakistan (Khan AA, Varan AK et al. 2015); and one in Spain (Vila-Candel R, Navarro-Illana P et al. 2016). The article reporting on a study in Malawi also included a literature review of studies conducted in developing African and Asian countries (Pathirana J, Nkambule J et al. 2015). Out of the two other literature reviews, one was globally focused (Schmid P, Rauber D et al. 2017), and one focused on low-income communities in the Americas (Till SR, Everetts D et al. 2015).

In line with the 2015 review findings, most articles (14) focused on the views of pregnant/recently pregnant women, with only four focusing on both groups, and two on

healthcare professionals. Concurrent with the 2015 literature review, the most common reason cited for under-vaccination among pregnant/recently pregnant women were concerns about the potential for the vaccines to harm to their foetus. Other issues reported were that there was no recommendation from a healthcare professional; the perception that vaccination was not necessary; a lack of awareness about the vaccines or diseases that they aim to prevent; a lack of information provided about vaccination; believing misconceptions about vaccination; and the inconvenience of obtaining vaccination. The study conducted by Maerten et al., in Belgium, found that some women felt the dTaP/IPV vaccination was unnecessary as they had received it during their last pregnancy (Maertens K, Braeckman T et al. 2016). Two studies conducted in the USA found that because vaccination is a relatively new focus for obstetrician gynaecologists, they can experience significant barriers to providing vaccination services compared with primary care providers, including a lack of familiarity and infrastructure to stock and administer vaccines, and usual work flows not incorporating vaccination practices (Barnard JG, Dempsey AF et al. 2017), (Healy CM, Ng N et al. 2015a). The study conducted by Pathirana et al., in Malawi also reported inadequate storage space and long waiting times for patients to receive vaccinations (Pathirana J, Nkambule J et al. 2015). Two studies found a shortage of the vaccines (Pathirana J, Nkambule J et al. 2015), (Maertens K, Braeckman T et al. 2016). In another study, healthcare professionals felt they had little time to educate women about the vaccines (Healy CM, Ng N et al. 2015a). McQuaid et al., found that healthcare professionals commented on the challenge of practice changing recently, from advising against medication and vaccination during pregnancy, to promoting antenatal vaccination. Some also worried about the cost effectiveness of vaccination, and echoed pregnant women's vaccination concerns, especially around the introduction of a new vaccine against GBS (McQuaid F, Pask S et al. 2016). Two studies even found that some healthcare professionals discouraged vaccination (Maertens K, Braeckman T et al. 2016), (Wong, Thomas et al. 2015). Vila-Candel et al., found that among pregnant participants, those who were healthcare professionals were much more likely to decline vaccination than other pregnant participants (Vila-Candel R, Navarro-Illana P et al. 2016).

Khan et al., found that 96% of respondents rated healthcare professionals as highly reliable sources of vaccination information (Khan AA, Varan AK et al. 2015). Vila-Candel et al., found that midwives were a source of vaccine information for 89% of

women (Vila-Candel R, Navarro-Illana P et al. 2016), and McQuaid et al., found that participants considered midwives to be the authoritative source of information on GBS vaccination (McQuaid F, Pask S et al. 2016). However, in another study, women stated that doctors were not a reliable source of vaccination information (Mendoza-Sassi RA, Cesar JA et al. 2015) and the literature review conducted by Schmid et al., found reports of distrust in the NHS in general (Schmid P, Rauber D et al. 2017). Wong et al., found that only 6% of pregnant women reported that a healthcare professional had discussed influenza vaccination with them (Wong, Thomas et al. 2015). This is an important observation considering that all studies highlighted the important role of healthcare professionals in recommending vaccination. For example, Healy et al., found that 83% of pregnant women were willing to be vaccinated if recommended by their physician (Healy CM, Rench MA et al. 2015b). However, in the study conducted by Khan et al., in Pakistan, despite a physician recommendation being critical for influenza vaccine acceptance, parents-in-law and husbands were often considered the primary decision-makers for pregnant women seeking healthcare, including vaccination (Khan AA, Varan AK et al. 2015). Donaldson et al., found that pregnant women in London prefer medical providers to discuss vaccine information with them, rather than receive an electronic prompt to get vaccinated (Donaldson B, Jain P et al. 2015). Similarly, the literature review by Till et al., found that effective communication by providers, who demonstrate empathy and understanding, is more likely to improve patient knowledge, health literacy and shared decision making, thus encouraging return visits (Till SR, Everetts D et al. 2015).

Only nine studies reported on ethnicity in relation to vaccination acceptance. Of these studies, seven reported that ethnic minorities had lower vaccination rates than the ethnic majority, and two reported no difference between ethnicities. For example in Pakistan, Khan et al., found that Bengali and Pashtun migrants have the lowest diphtheria, tetanus, pertussis (DTP3) vaccination rates among all ethnic groups of Pakistan (48% and 67%, respectively). Bengalis were also significantly less likely to accept the influenza vaccine when it was introduced, compared with the reference group of Urdu-speaking individuals (Khan AA, Varan AK et al. 2015). Healy found that Black women in the USA were less likely to receive the antenatal dTaP/IPV vaccine than women of other ethnicities. However, according to the authors, the reasons behind this were difficult to discern. Healy states that under-vaccination among this group is unlikely to be related to insurance status since this observation has been reported in both insured

and non-insured populations (Healy CM, Ng N et al. 2015a). Donaldson found that in London, maternal vaccination rates differed by up to 15% between ethnicities, with the highest uptake amongst White women (30%), and the lowest among Black Caribbean women (7%) (Donaldson B, Jain P et al. 2015).

Overall, similar to the 2015 literature review, out of the 20 papers included in this update, most focused on the influenza vaccine in developed countries, and on the views of pregnant or recently pregnant women. There has been a slight shift however, to more studies being conducted in various low-income countries. Concurrent with the 2015 literature review, the most common reasons cited for under-vaccination were concerns about vaccine side effects; that there was no recommendation from a healthcare professional; and the perception that vaccination was not necessary. Also similar to the 2015 review, was that relatively few studies reported on ethnicity in relation to vaccination acceptance (most simply reported that ethnic minorities had lower vaccination rates than the ethnic majority), and almost all studies highlighted the importance of the role of healthcare professionals in recommending vaccination. These observations demonstrate that the findings of the studies conducted on factors influencing maternal vaccination acceptance identified since April 2015, do not change the main conclusions of the 2015 review.

Chapter 2: Rational for research

The majority of research on vaccine hesitancy to date has focused on the role of vaccine hesitancy on parental decision making related to childhood vaccination, with few studies related to hesitancy surrounding vaccines recommended during pregnancy. This means that there are wide gaps in knowledge regarding attitudes and access to maternal vaccination. As evident from the literature review, even studies that have analysed maternal vaccination acceptance, most only asked participants about their vaccination concerns-with most citing safety concerns-but did not elicit details about what exactly these safety concerns were, or how they varied by participant background. In this way, the majority of studies did not address the deeper social and structural factors influencing vaccine hesitancy.

In this chapter, I highlight the importance of in-depth qualitative research for understanding hesitancy and access issues relating to maternal vaccination, as well as the importance of addressing disparities in vaccination acceptance between people of various backgrounds. The importance of including the views of healthcare professionals in research into vaccine hesitancy is also analysed. Finally, I argue that it is important to understand public perceptions and behaviour to currently available maternal vaccines, so that appropriate policies can inform future maternal vaccine introduction.

The importance of qualitative research

> *The primary determinants of disease are mainly economic and social, and therefore its remedies must also be economic and social* (Rose G 1990).

Evidence in the form of detailed accounts given by local people should be drawn on in creating policies because the promise of, and actual effects of medical technologies, are embedded in the socio-political contexts (the overlapping political, historical and social arenas) in which they are applied (Lock M 2010). Qualitative research brings to light these contextualised meanings of social life (Saussure, 1974), providing in-depth accounts of the subjective experience. This means that the very notion of objectivity (i.e. the absence of interpretation) is not viable in qualitative research, rendering analysis largely outside and positivistic endeavours for objectivity (Denzin, 1994).

Instead, the value of qualitative research lies in its exploratory and explanatory power (Attride-Stirling 2001). It highlights culturally constructed value systems and citizen-government and corporate institution engagement. Studying local narratives and metaphors allows for a reflection on the ways in which competing claims and practices emerge as a result of the ceaseless appearance of new knowledge (Lock M and Kaufert PA 1998). Such an approach challenges the power dynamics between scientific disciplines, which has caused research into social factors relating to human behaviour to be treated as residual and only examined after the 'serious' biomedicine[5] has been done (Kelly MP, Kelly RS et al. 2014). Qualitative research also often challenges the distinctions between scientific experts and non-experts, and the perception that knowledge is legitimate only if it complies with Western notions of scientific rationality. This perception, coupled with a focus on narrow, risk-based framings in public health research, ignores the ways in which people's knowledge is embedded within socio-political processes, concepts and moralities. In this way, qualitative methods allow for the inclusion of public expertise and force one to ask how the medical perspectives that drive and justify healthcare interventions such as vaccination programmes arose, how they have become authoritative, and what broader social or political agendas might underlie and be supported by them.

While qualitative research on vaccine hesitancy has increased recently (for example (Poltorak M, Leach M et al. 2005, Leach M and Fairhead J 2007, Poltorak M 2007, Larson H, Jarrett C et al. 2014, Larson H, Wilson R et al. 2014, Larson HJ, Jarrett C et al. 2014, Wilson RJ, Paterson P et al. 2014, Peretti-Watel P, Larson HJ et al. 2015, Wilson RJ, Paterson P et al. 2015, Wilson RJ, Paterson P et al. 2015, Paterson P, Meurice F et al. 2016, Dubé E and Macdonald N 2017), there are still large knowledge gaps regarding how specific socio-political contexts, and experiences of interactions between the public and healthcare professionals and government institutions, influence vaccination acceptance (Streefland et al., 1999). Through interviews, a focus group discussion (FGD) and a video recording of a consultation, I aim to provide an opportunity for both those providing and receiving, or declining/missing out on maternal vaccination, to voice their opinions about vaccines and talk about their experiences. I analyse how an individual's wider social context (i.e. gender, socio-

[5] Biomedicine focus on how cells, organs and systems function in the human body University of Oxford. (2017). "Biomedical Sciences." Retrieved 3rd August, 2017, from https://www.ox.ac.uk/admissions/undergraduate/courses-listing/biomedical-sciences?wssl=1.

economic status, ethnicity, education and political environment) affects their access to, as well as their perceptions of vaccination, in order to provide a more in-depth understanding of the multiple, complex factors influencing maternal vaccination acceptance.

How experiences of marginalisation affect access to healthcare, and vaccination decisions

> *[Healthcare] services will be accessible, appropriate and sensitive to the needs of all patients. No eligible patient shall be excluded or experience particular difficulty in accessing and effectively using this service due to their race, gender, disability, sexual orientation, religion and/or age* (David Flory, Deputy NHS Chief Executive 2012).

Inequitable access to healthcare between populations in the UK, especially between various ethnic groups, is under researched. In the literature review (Chapter 1), only 8/155 (5%) of articles focused on maternal vaccination acceptance in the UK and of these, only two mentioned ethnicity as a factor influencing vaccination acceptance.

For most of its history, the NHS has cared for recently settled British residents, some of whom were unfamiliar with how to access services or did not speak English. Despite this history, and the opening quote by Flory, who said that that services will be accessible to all patients; availability of healthcare promotion materials in minority languages, as well as ethnic minority advocacy services, are still not standard practice within the NHS (Bhopal RS 2007). This is concerning considering a study by Raleigh et al., found that pregnant women from ethnic minorities were more likely than White British women to access services late, and experience complications during pregnancy and birth. Some women from ethnic minority groups were also less likely to say that they had her midwife's contact details (White Other, Black), and that they attended NHS antenatal classes (Asian), than White British women (Raleigh VS, Hussey D et al. 2010).

As ethnic minority groups are often disproportionately represented within lower socioeconomic groups, discrimination attributed to ethnic differences could be confounded by socioeconomic differences (Lindquist A, Knight M et al. 2013). In

England, women of lower socio-economic status, as well as single women, are less likely to receive any antenatal care or to have been seen for the first consultation before 12 weeks of gestation, than women of higher socio-economic status, or who have a partner (Lindquist A, Kurinczuk JJ et al. 2014). Additionally, Raleigh et al., found that women with higher levels of education were more likely to access services early and attend antenatal classes than those completing education at sixteen years or younger, and were less likely to experience complications at birth (Raleigh VS, Hussey D et al. 2010).

Bhopal states that, "Health needs assessment of ethnic minority health is too often limited to… consultations, sometimes only with members of the ethnic majority community or with health professionals" (Bhopal RS 2007). This means that specific, complex concerns of certain population groups are often overlooked. Through research methods which elicit current accounts of real-life, everyday experiences of, and attitudes towards the healthcare service from pregnant and recently pregnant women, this study identifies different perceptions of vaccination and experiences accessing vaccination among those from various ethnic and socio-economic groups. In this way, I hope to enrich the area of research into socio-economic influences on maternal vaccination acceptance and access, so that strategies can be put in place for such services to be more equitably accessible to all.

Healthcare professional participation

Any efforts to increase vaccination acceptance relies on the participation of healthcare professionals. Nonetheless, relatively few studies identified in the literature review focused on the views of healthcare professionals towards maternal vaccination (19%). Research that does take into account patient-healthcare professional views and interactions tends to focus on the influence of healthcare professional characteristics, such as levels of job satisfaction and frustration, technical or communicative skill competence, or healthcare interactions, with little examination of healthcare professionals' and women's perspectives on vaccination (Campbell C, Scott K et al. 2015). This could in part be due to a difficulty in recruiting healthcare professionals for qualitative research. A recent study by Campbell et al., on healthcare professional's attitudes to vaccination in the UK, only had a 10% response rate, and most respondents were white (93%) and female (99%) (Campbell H and Yates J 2016).

However, it is important to understand healthcare professional's views towards maternal vaccination, and any difficulties they face in providing it, as they have a key role in recommending vaccination. Research that has included healthcare professionals has identified issues that could greatly influence maternal vaccination acceptance. For example, the study by Campbell et al., found that healthcare professionals sometimes lack confidence in recommending vaccines and do not know where to look for information. Only 34% of nurses and 14% of health visitors surveyed had any training in providing vaccination for pregnant women. Around 60% said that they routinely recommend the vaccines but only 9% vaccinated pregnant women, whereas 67% said they would be happy to if they had training. Additionally, 80% of midwives wanted more information and training (Campbell H and Yates J 2016). These findings reflect those of an earlier study among midwives in London, which found that only 25% felt prepared to inform women about the maternal influenza vaccine (Ishola, Permalloo et al. 2013). A literature review on vaccine hesitancy among healthcare professionals also found that healthcare professionals are more likely to recommend vaccination if they themselves are vaccinated (Paterson P, Meurice F et al. 2016). Through interviewing healthcare professionals, my study fills some of the knowledge gaps surrounding healthcare professional's views towards maternal vaccination, and provides an understanding of the extent to which healthcare professionals' views towards vaccination, as well as difficulties providing them, affects acceptance of the vaccines among pregnant women.

New vaccines under development

It is important to understand attitudes towards recently introduced vaccines (such as the dTaP/IPV and influenza vaccines provided during pregnancy), not only so that appropriate policies can be put in place to increase acceptance of these vaccines, but also to inform strategies for future vaccine introduction, such as for the various new vaccines for pregnant women currently under development. These include those designed to prevent respiratory syncitial virus (RSV), group B streptococcal disease (GBS) and cytomegalovirus (CMV). Below I provide an overview of the state of development of these vaccines, and details about the diseases they aim to prevent, illustrating the importance of the acceptability of these vaccines.

A large phase three clinical trial of an RSV vaccine is currently being conducted (ClinicalTrials.gov 2017). Like the dTaP/IPV vaccine, the administration of an RSV vaccine for pregnant women is the best way to protect infants during the first few months of life, when the risk of infant mortality is highest because infants are too young to be vaccinated (they are not yet able to produce an effective immunological response to the vaccine). Globally, RSV is responsible for over 30 million new acute lower respiratory infection episodes in children under five, resulting in more than 3.4 million hospital admissions each year. Over 90% of all RSV-associated deaths are estimated to occur in low and middle-income countries (WHO 2015).

Several hundred women have been vaccinated in phase two clinical trials with experimental GBS vaccines, with promising results (Abramson JS and Maso E 2016). Acceptability of this vaccine would be extremely important, as women colonised with GBS during pregnancy are at increased risk of premature delivery and perinatal transmission of the organism. Amniotic infection can result in maternal sepsis and very rarely, meningitis (Schuchat 1999). Although there are very little data on neonatal GBS disease worldwide, studies in various African countries have indicated incidence as high as 1.21 per 1000 live births (Johri, Paoletti et al. 2006).

Two different CMV vaccines have shown promising results in phase one clinical trials (Rieder and Steininger 2014). Most CMV-related disease occurs following transmission during pregnancy, manifesting as congenital CMV (cCMV) disease in children. Estimates of the prevalence of cCMV infection among live-born infants range from 0.5 to 0.7% in the USA, Canada and Western Europe, to 1-2% in South America, Africa and Asia. Approximately 13% of new-borns with cCMV infection are symptomatic, presenting with prematurity, slow intrauterine growth, jaundice, microcephaly, seizures, or focal neurologic deficits (Krause PR, Bialek SR et al. 2013).

Vaccines against other microbes causing serious morbidity or mortality in the foetus and young infants (for example various enteric bacteria and the Zika virus), could also be developed in the near future (Czerkinsky C and Holmgren J 2015), (National Institute of Allergy and Infectious Diseases 2017).

Conclusion

There are relatively few studies focusing on views towards maternal vaccination. There is also sparse research on healthcare professionals' views towards maternal vaccination, and most studies do not analyse vaccine concerns in depth, or analyse issues with accessing vaccination among women from ethnic minorities, and between various socio-economic groups. This may partly be why most healthcare policies and services are based on the needs of the ethnic majority. This can create or exacerbate inequalities in access to health care, with ethnic minority populations and women of lower socio-economic status usually receiving poorer levels of antenatal care than ethnic majority and higher socio-economic status women (Lindquist A, Knight M et al. 2013).

To counteract the knowledge gaps regarding vaccine hesitancy during pregnancy, and to inform context specific policies, there is a need to move beyond the narrow, risk/benefit framings dominant in public health research, and to understand how socio-political factors determine attitudes and access to vaccination, while considering how and why distinct vaccine concerns emerge in particular times and places. Qualitative analyses are essential for understanding this space where individuals and wider society subjectively develop ideas that help them understand the world as it appears to them to be (Schutz A 1970). This approach involves collecting evidence in the form of personal narratives and detailed accounts of vaccine experiences and perceptions from local populations. In this study, I aimed to provide an opportunity for women, including those who have often been marginalised within the healthcare service, to express their opinions about vaccination, and to speak in-depth about their experiences. Such an approach provides a deeper understanding of women's concerns around vaccination, and allows their expertise to be recognised and not de-legitimised.

I also aimed to understand perceptions of healthcare professionals around maternal vaccination, and the pressures and issues within the health system that may prevent them from recommending or providing the vaccines. This is an important area of research as there are far fewer studies analysing views towards vaccination among healthcare professionals than those that analyse views among parents. Additionally, it is important to understand healthcare professionals' perspectives towards maternal vaccination as they play a key role in recommending vaccination, and their views could greatly influence those of pregnant women in their care.

Finally, the development of new maternal vaccines presents the potential to further reduce maternal and neo-natal mortality and morbidity. For these vaccines to be of benefit, they must be available and accepted across population groups. Attempting to fully understand women's and healthcare professional's views towards maternal vaccination, and to each other, is key to informing policies that ensure vaccines are available and acceptable to all.

Chapter 3: Methods

In this chapter, I reflect on how my own social, academic and philosophical positions may have influenced the data collection and analysis for this study. I then outline the theoretical positions that have informed the study design and analysis. Details of the ethics approval process are provided, as well as an overview of the study site (Hackney) and the sites within Hackney where participant recruitment took place. Finally, I explain the methods used for participant recruitment and data collection.

Reflexivity

I approached the fieldwork and analysis for this study as an anthropologist with pre-existing positions and ideas. My positionality as a feminist and critical realist, who views social reality as historically and culturally constructed, and as partial and subjective, also underpinned the synthesis of my results. Throughout this study, efforts were made to maintain self-reflexivity and an awareness of the subjective nature of the data collection and analysis.

To keep this subjectivity at the forefront of my mind, I kept field-notes (Appendix 1); detailing my experiences and thoughts in relation to the fieldwork. This allowed me to remain aware of the role of my own experiences and viewpoints in conducting the research. Through re-reading my field-notes, it is evident that I was highly aware of my position as a White, middle-class educated woman without children. These identities became especially evident when recruiting and interviewing very young women, women suffering from past substance abuse, and women living under difficult circumstances (such as being homeless). I also felt slightly awkward and out of place among white middle-class mothers at parent-toddler groups, especially when I was asked where my baby was, by somebody who had not heard the leader of the group introduce me. This experience initially caused me to worry about my ability to understand participant's points of view, and about their ability to open up to me, if I was not in a similar 'life' situation to them. However, there are always power imbalances and differences between researcher and participant. While one can be aware of these differing positions when conducting qualitative research, such awareness does not create objectivity, and these positions inevitably affect the interpretation of data. Researcher-participant differences however, are not necessarily detrimental to the study,

in fact, such differences can cause some participants to be more open in their responses. For example, if the researcher and participant are of a different religion, the participant may be more open in their responses due to not being worried that the researcher would judge them for anything they say that might go against their religion.

As mentioned in the acknowledgements, I believe that my nephew's possible experience with meningitis affected my thinking about vaccination (in that it really brought home the importance of it), and thus made me more passionate about the importance of the research. Some participants asked about my views towards vaccination and I told them that I was pro-vaccine but could understand why pregnant women might have concerns about the vaccines, while reassuring them that I was not there to judge them. I was also open with participants about my connection with PHE, and explained that the research was being conducted to more fully understand vaccine hesitancy and issues with accessing vaccination, with the aim of informing policy to increase vaccination acceptance. This information was also included in the participant information sheet, and I was initially concerned that if participants believed that they were indirectly helping to increase vaccination acceptance through participating in the study, those who were against vaccination may decline to take part. However, nearly a quarter (nine) of the pregnant/recently pregnant interview participants had chosen not to receive both, or either the influenza or the dTaP/IPV vaccine during pregnancy, but still agreed to take part in the study.

Conducting the fieldwork sometimes influenced participant behaviour or perceptions around vaccination. To my knowledge, this influence was positive in terms of information-seeking. This was evident in an interview with a GP,

> RW: Do you use any NHS materials, like do you give women the leaflets about the vaccines?
> Dr. Marsh: in terms of the DTP [dTaP/IPV vaccine], I don't give them anything but maybe I should. Mm, I might start looking [laughs].

Most FGD participants were vocal about offering their advice and asking about maternal vaccination. They were also very interested in the research, asking me many questions such as, "Are you doing more groups like this at other surgeries?" (Chloe, age 35). Chloe also stated, "I came here, today, I thought ooh, vaccinations in pregnancy, I don't know about that! I'll go to that study!". She then said that she would bring the

topic of vaccination up in her consultation later that day. Chloe had not previously heard of maternal vaccination and neither Chloe nor Amy (another FGD participant), had previously considered receiving the influenza vaccine, but after hearing about it through the FGD, both wanted to look into it more,

> I've never considered having the flu vaccination, but I'm intending to start to have it. Because, as I said earlier, it, it's to protect you against potentially life-threatening [diseases], so it's something I will be looking into (Amy, age 37).

I also aimed to retain self-reflexivity in my analysis of the interviews, FGD and video-recording, and tried to be aware of any assumptions I was making about what participants were saying, so as not to impose pre-defined theories onto their narratives. I instead aimed to use theory to highlight the views and concerns expressed by the participants, and present them in a coherent way that I hoped would reflect their true meaning.

Theoretical underpinnings of the study

At the start of this PhD research, I aimed to analyse vaccine hesitancy through the lens of risk perceptions and notions of trust, as much of the literature on vaccine hesitancy does. Thus, these theories acted as a basis on which to start thinking about vaccine hesitancy during pregnancy, and informed the interview and FGD topic guides. However, through further reading on vaccination acceptance, and whilst conducting the fieldwork, I realised that theories of risk perception and trust would not sufficiently capture the nuance of concerns around maternal vaccination. It was evident that women had many concerns other than fears of side effects (which much risk discourse suggests), or pure distrust in vaccination. Women's backgrounds, social contexts, healthcare and vaccination experiences, and relationships with their healthcare professionals were the greatest influences on their views towards vaccination, and while notions of trust played a part in vaccine acceptance, the way that trust was formed and articulated by participants was complex. I was also conscious about working in partnership with PHE throughout the data collection and analysis. I did not want this to cause me to focus on aspects of vaccination concerns (such as fears of vaccine risks) that can be believed to be more easily changed by policy (such as through education campaigns), rather than analysing more complex aspects of vaccine hesitancy. While perceptions of vaccination risk can influence the creation and continuation of vaccine

concerns, they are part of a multiplicity of influences, and can thus be deductive when applied to the analysis of something as complex as vaccine hesitancy. For example, branches of the Tversky and Kahneman inspired risk perception area focus on individual perceptual or cognitive errors, pursuing the notion of the faultiness of human information processing (Tversky A and Kahneman D 1974). If used to analyse views towards vaccination, this framing assumes that if they decide not to vaccinate, the public have not followed information on risks and statistics, and thus they are portrayed as ignorant, irrational, or even believing in conspiracy theories, as the study by (Jolley D and Douglas KM 2017) does. This approach means that public health institutions assume that a key challenge for policy is to continuously educate the public towards a 'correct' understanding of 'real' risks (Leach M and Fairhead J 2007). They attempt to re-assure the public by "making the incalculable calculable" (Bostrom 1997). However, statistics are usually grounded at the population level, and so tell us little about deep-seated vaccine concerns, and overlook the possibility that people do not consider themselves and their particular foetus or infant as average, and so do not feel their calculations apply to them (Reich J 2016). Risk communication is sometimes so at odds with the ways people frame vaccine concerns, that not only does it not effectively reach the public, but can also perpetuate concerns.

Rather than being passive receivers of ideas from experts and the mass media, anthropologists argue that people form opinions and make decisions in highly social, emotive and symbolic ways (Mythen G and Walklate S 2006). Human thought, explanations and judgments are not constructed within individual minds, but in the "unceasing babble", the "permanent dialogue" that people have with each other and with institutions (Joffe H 2003). Thus, I argue that to gain an in-depth and more nuanced understanding of the complex ways that people feel and think about vaccination, rather than using risk perception models, it is important to consider the socio-political side of vaccination. This would include analysing whether patient-healthcare professional relationships are supportive; whether women feel confident, and are able to discuss, express their views, and ask questions about maternal vaccination; and whether women actually have access to vaccination.

I therefore found that drawing on insights from anthropological works that address diverse conceptualisations and practices around vaccination and healthcare, for example (Leach M and Fairhead J 2007) and (Mol A 2008); notions of governmentality and

biopolitics (Foucault M 1988); and theories of relational autonomy (Mackenzie C and Stoljar N 2000), better suited to critique notions of healthcare prevalent in neoliberal societies, which place importance on patient autonomy and choice, and ignore the social dimension of vaccination decisions. I also considered how framings around vaccination concerns, including concepts that link bodily, social and political dimensions, interact with and are shaped by those arising from institutions involved with vaccine development and delivery. This type of analysis provides insights into how and why public and policy perspectives on vaccination concerns have become so polarised.

Below, I outline the theoretical underpinnings of this study in more detail.

Self-governance and patient choice

One of the complexities of vaccine hesitancy analysed in this thesis is the fact that vaccines; which are by nature an intervention on the body, are produced within a political economy. As such, as Leach and Fairhead state, "at the needle point, the most global meets the most personal of worlds" (Leach M and Fairhead J 2007); the fragile boundaries between 'life' and 'politics' are transgressed, making it inevitable that concerns around vaccination arise.

In this thesis, I analyse such 'politics' largely in terms of self-governance, originating from Foucault's notions of governmentality and biopolitics (Foucault M 1976). Governmentality emphasises localised, routinised bodily constraints guided by the state and global institutions, and existing within, and emerging from families, communities and institutions, so that it comprises a form of self-governance centred on the body, optimising its capacities in the name of individual and collective life and health (Rabinow P and Rose N 2003), and integrating it into efficient systems within capitalist neoliberal market societies. A way in which this form of governance is achieved is through mechanisms linking science and disciplining institutions, leading to medicalisation, meaning that people accept science-based 'natural' classifications of themselves and their behaviour (Leach M and Fairhead J 2007). This type of governance is a form of biopolitics; the "explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (Foucault M 1976), especially through modern nation states, which regulate the quality, nature and norms of the human body through a shared understanding of what a 'good' person is in

a particular community (Hoy D 1991). Such self-regulation depends on an entrenchment of a sense of personal responsibility. For example, during pregnancy,

> [Pregnant] women develop a sense of personal responsibility and self-blame instead of social recognition… [They] are not *forbidden* [emphasis added] to smoke cigarettes or drink alcohol; rather they are shown the potentially harmful consequences of those behaviours (Queniert A 1992).

The instruments applied here are regulation and control, rather than traditional forms of discipline and supervision. This engenders a culture of negotiation, choice, and 'autonomous' decision-making, driven by the quest for self-actualisation and self-identity (Lemke T 2011). Such modes of control are directed at individuals in the most intimate details of their everyday lives, but also at social life as a whole (Lemke T 2011). In this way, "control extends throughout the depths of the consciousnesses and bodies of the population-and at the same time across the entirety of social relations" (Hardt M and Negri A 2000). The complexity of the self-governing individual is particularly apparent in pregnancy, as pregnant women must tread a fine line between exercising their will, and therefore establishing their status as autonomous individuals, while conforming to a 'natural' standard of behaviour considered suitable for pregnant women, in order to protect her foetus (Ruhl L 1999).

The idea that women should strongly govern their pregnant bodies arose in the late enlightenment era when, during the French Revolution, Rousseau espoused the importance of breastfeeding for passing on morals and notions of patriotism from mother to baby (Kukla R 2005). Through breastfeeding, it was believed that mothers could restore social harmony; returning the currently fractured body politic to its natural state. This meant that mothers embodied promises of the nurturing Republic and as such, were shouldered with the responsibility to properly manage their thoughts and bodies. Those who did not breastfeed were seen to be threatening the whole structure of the natural body politic (Kukla R 2005). In this way, nature was drawn on as a moral arbitrator and according to a physician in his 1872 pregnancy and child-rearing guide, "Natures laws cannot be broken without impunity"-punishment for not following nature's laws took the form of mothers' corrupting themselves and their foetus (Chavasse PH 1872). Little has changed in regards to the rhetoric around pregnancy today, especially with the re-emergence of neoliberal forms of governance in the West

in the 1980s. This has meant that pregnant bodies are intensely (self) governed; are increasingly held to high standards of perceived calculable and governable risk minimisation; and are expected to exercise extreme caution, restraint, and fear with regards to the safety of their foetus. Such modes of control are articulated by the portrayal of the woman's body as doubly at risk and she as dually responsible for two bodies (Lupton D 1999), constraining women as either responsible or reckless in terms of how they follow pregnancy advice. This advice contains an implicit bargain or insurance, that being responsible and following all the 'rules', will guarantee a desired outcome; a 'trouble-free' pregnancy and a 'healthy' baby (Ruhl L 1999). This level of self-regulation is much more prominent in neoliberal Western societies, compared to societies in other parts of the world. For example, within the Huichol community of North-Western Mexico, pregnancy is seen as a "normal, non-medicalised aspect of life", and so when pregnant, women usually carry on with their lives in the same way as prior to pregnancy (Gamlin JB and Hawkes SJ 2014).

In our society, where it is deemed liberating for people to be autonomous, independent, self-governing individuals, who are not "swayed" or influenced by external factors or social contacts; relations with others during pregnancy, and the capacity for re-assurance and caring on a real, human level, can be seen as unimportant. Instead, women are often presented with scientific facts, so that they can make rational decisions without the relational support of healthcare professionals. The interplay between the external features of biopolitics and modes of self-government is evident in the proliferation of various mediums of advice giving for pregnant women. This can be seen in health-related body-tracking software applications ('apps'), used for self-monitoring, self-quantification and normalisation; pregnancy books and manuals; and online information and guidance. For example, the website *Baby Centre,* list on their page *First Trimester: Your essential pregnancy to-do-list,* 23 things a woman must ensure she does during her first trimester. The instructions provided range from advice such as booking the initial midwife appointment, to largely cosmetic recommendations such as "Buy a maternity bra" (Baby Centre 2017), demonstrating that women's' bodies as well as their behaviour, should be controlled during pregnancy. Such advice is often ambiguous and conflicting; it often oscillates between alarmist statements about the prevention of birth defects, and 'reasonable' statements about the naturalness of pregnancy, which can make pregnancy overwhelming. It also increases women's feelings of guilt for anything that might be 'wrong' with her baby when it is born, as

they inevitably fail to meet the exacting standards set out for them. To be a truly 'responsible' woman in the vision of much advice means having a planned pregnancy, a level of education and motivation to sufficiently engage with pregnancy advice, and a general acceptance of medical authority. Providing she fits the profile of the 'responsible' mother-to-be, the pregnant woman must begin reforming her life the day she decides to try to conceive. If she takes six months to become pregnant and then breastfeeds for another six, this so-called temporary reform will occupy over 18 months of a woman's life per pregnancy; a significant demand that is rarely acknowledged (Ruhl L 1999).

This type of governance allows states and large corporations to negate social responsibility, and is happening at the same as the withdrawal of state funding for social support and healthcare programmes. This means that negative health outcomes come to be seen as the fault of individual and structural factors that cause ill health are not addressed (Owkzarzak J 2009). It must be acknowledged however, that where there is power, there is always resistance, and as analysed in my findings, there are many ways in which women resist the normative framings of biomedicine (Foucault M 1991).

Power relations exist between all entities, including between pregnant women and their foetus. However, in this thesis, the scope of discussion will focus on power dynamics between the state and patients; the state and healthcare professionals; healthcare professionals and patients; and between private corporations (such as pharmaceutical companies) and the state, healthcare professionals and patients.

Relational autonomy

Relational autonomy is a formulation of autonomy first applied by Mackenzie and Stoljar, which presents a way of thinking about autonomy that is social, or relational rather than individualistic (Mackenzie C and Stoljar S 2000), thus offering an alternative, more flexible conception of what it means to be a free, autonomous individual. It understands that dialogue, especially with healthcare professionals, which involves advice-giving, reassurance and support, is not an affront to individual autonomy, but allows autonomy to flourish (Walter JK and Friedman Ross L 2014). In this way, relational autonomy opposes the current neoliberal emphasis on the wholly self-governing individual, who is expected to possess the ability to access and acquire

skills on their own, and allows for an in-depth understanding of how people consider healthcare technologies and institutions, and how decisions are influenced by various social contacts.

Proponents of relational approaches to research are not new in the discipline of Anthropology. For example, Pierre Bourdieu believed that one should take into account the wider social contexts in which individuals are situated. This idea was demonstrated in his concepts of habitus-which describes how individuals' choices are influenced by the structures and institutions in which they are embedded, and the people that surround them (Bourdieu P 1977)-and social capital, which focuses more specifically on the importance of the acquisition of social networks to individuals' wellbeing (Bourdieu P and Wacquant LJD 1992). With regards to relational approaches to care, which stress the importance of the healthcare professional-patient relationship, and seeing the patient as human rather than object, Kleinman, writing in 1989 stressed the importance of taking into account patient contexts in diagnosis and treatment (Kleinman A 1989). The theory of relational autonomy takes relational approaches to care a step further, by tackling the concept of autonomy; arguing that individuals can have support from others (as with the relational approach), while still making decisions that feel autonomous. Relational autonomy accepts that people are deeply embedded in societies, with identities being formed within social relationships and shaped by intersecting social determinants such as race, class, gender and ethnicity (Mackenzie C and Stoljar N 2000), which define our values and decisions. Decisions are thus made in terms of interpersonal relations and mutual dependencies (Christman J 2004).

Vaccination is embedded within a set of moral and social contexts, and a set of bodily and wider political reflections. Thus, without attention to bodily experiences and the wider socio-political dimensions of vaccination, many aspects of people's concerns are lost and analysis remains 'thin'. For example, taking into account the wider socio-political context, researchers can ask why it was through resisting the polio vaccination that people in northern Nigeria expressed concern about USA imperialism (Ghinai I, Willott C et al. 2013). It is this wider interpretative and experiential context that shapes thinking and practice surrounding vaccination (Leach M and Fairhead J 2007).

Ethics approval

An ethics application received favourable opinion from the LSHTM Ethics Committee, reference 10429. An ethics application also received favourable opinion from the NHS Integrated Research Application System (IRAS), REC reference 15/LO/2189, IRAS project ID 186948. The IRAS application encompassed the application that was made to the NHS trust[6] for Hackney, through the North Central London Research Consortium (NOCLOR).

Only GP practices that recorded information about women who had experienced stillbirth and miscarriage were recruited, so that I could ensure that invitation letters were not sent to these women. Informed consent was obtained from participants prior to commencement of interviews, the FGD and the consultation video-recording (Appendix 1 and 2). Pseudonyms were assigned to each participant.

Study Site

Hackney, London (highlighted in red)

[6] An NHS trust is an organisation within the English NHS generally serving either a geographical area or a specialised function (such as mental health services) NHS Choices. (2016). "The NHS in England." Retrieved 15th August, 2017, from http://www.nhs.uk/NHSEngland/thenhs/about/Pages/authoritiesandtrusts.aspx.

The borough of Hackney, London was chosen as the study site as it has one of the lowest vaccination coverage rates in England (Screening & Immunisations Team NHS Digital 2016), and one of the lowest coverage rates among pregnant women in England. The most recent data shows that the maternal influenza vaccination coverage rate is 31% in Hackney (PHE 2017) and the maternal dTaP/IPV coverage rate is 27% (Byrne L 2015). Hackney is also very ethnically and socially diverse. Nearly 38% of Hackney residents were born outside the UK, with the largest migrant populations by country of birth being Turkish, Nigerian and Jamaican (Office for National Statistics 2014). Just over a third (36%) of Hackney residents described themselves as White British. The second largest group are Other White (16%), followed by Black African (11%) and Black Caribbean (8%). Hackney has the largest Charedi Orthodox Jewish population in Europe, which represents about 7% of the borough's overall population. At least 5% of the population is Turkish and other communities in Hackney include Chinese, Vietnamese, Eastern Europeans (particularly Polish), Western Europeans (particularly Italian, Spanish and French), Australasians and North and South Americans (LB Hackney Policy Team 2016). The main language spoken in Hackney is English, followed by Turkish and Polish (Hackney Council 2015). Thirty-nine percent of the population are Christian, 28% have no religion and 14% are Muslim (Hackney Council 2014). Choosing a study area with a diverse population was important because vaccination coverage rates in pregnant women tend to be lower in ethnic minority groups. A study conducted by Donaldson et al., on maternal dTaP/IPV vaccination uptake in London, found that uptake differed by up to 15% between ethnicities (Donaldson B, Jain P et al. 2015). Additionally, refugees and migrants meet a number of obstacles in accessing good healthcare, including not speaking English, a lack of awareness of the ways healthcare is delivered in the UK, experiences of racism, and having more pressing needs such as immigration issues, housing and employment. As a result, they may delay seeking healthcare. This may be a significant issue in Hackney, where there is a large migrant population (Hackney Council, City of London et al. 2012). Estimates of the proportion of Hackney residents who are not registered with a GP vary from 4% to 13% (Hackney Council 2014).

Hackney is an area of growing economic opportunity, however, this growth sits alongside significant deprivation, with persistent inequalities and child poverty, unemployment and welfare dependency in some areas (LB Hackney Policy Team 2016). Hackney was the eleventh most deprived local authority overall in England in

2015 according to the Index of Multiple Deprivation (LB Hackney Policy Team 2016). This means that Hackney residents vary widely in socio-economic status.

Recruitment sites within Hackney

I aimed to reach saturation by contacting 12 parent-toddler groups; 11 community centres and migrant support groups; four GP practices with median maternal vaccination uptake rates and a diverse patient population (according to 2012-2014 Hackney GP practice data provided by The Blizard Institute, Barts and The London School of Medicine and Dentistry (Robson J 2015)); and four heads of midwifery/immunisation in Hackney. Recruitment sites were spread across the borough, were all free to attend, and attracted women from a wide range of backgrounds so that information about attitudes and access to vaccination could be compared across various participant backgrounds.

An official letter (Appendix 4 and 5) explaining the study was sent by email to all potential recruitment sites[7], explaining the details of the study including the aim and potential benefits, and that recipients could contact me if they had any questions about the study. Recipients were asked to respond to me directly if they were happy to be involved in the study, by email or letter. If there was no response after two weeks, I telephoned the practice/organisation and asked to speak with the manager to explain the study and invite them to participate. I also offered to meet them in person to discuss the study in more detail if they wished.

The number of recruitment sites included in the study is provided in Section 2.

[7] Separate letters were sent to GP practices and heads of midwifery/immunisation (NHS sites), and parent-toddler groups and community centres and migrant support groups (non-NHS sites) because, as per NHS ethics guidelines, material sent to NHS sites was required to have NHS ethics approval and include the appropriate NHS logos.

Participant recruitment methods

Maximum variation sampling was used to recruit participants. This method is based on the principle of maximum diversity. Instead of seeking representativeness through equal probability, it is sought by including a broad range of extremes. This means that data gathered through maximum variation sampling can be more representative than those gathered through a random sample approach (Vitcu A, Lungu E et al. 2007).

Participant recruitment commenced in October 2015. For the recruitment of healthcare professionals and patients from GP practices and antenatal clinics included in the study, I sent two different versions of information sheets to the practice managers. One version was for healthcare professionals (Appendix 4), and one for patients (Appendix 5). Invitation letters for both healthcare professionals and pregnant women explained the study in detail and invited them to participate in an interview. My email address and telephone number were included in both versions of invitation letters and it was explained that recipients could contact me if they had any questions. Recipients were asked to respond if they wanted to take part in the study by emailing or telephoning me. Practice managers and GPs were asked if any of their patients did not speak English. If so, invitations could be translated. However, this turned out not to be necessary. In the invitation letter, it was also stated that the interview could be conducted in a language other than English if recipients preferred, with a translator present. I asked managers to send the relevant information sheet to all their healthcare professionals (doctors, nurses and midwives), as well as all their currently pregnant patients (in the second and third trimester as by then, women are more likely to have been offered both the influenza and dTaP/IPV vaccines), and all patients who had given birth within the past year. Women who both had and had not been vaccinated according to GP databases, were included. One GP practice agreed to recruit participants for a FGD, as well as for interviews, and provided a room at the practice for the FGD to take place. Once interviews had been conducted, this practice sent an additional invitation to pregnant women and women who had given birth in the past year, inviting them to take part in the FGD (Appendix 8). The manager of this practice also agreed to invite women to take part in the final aspect of the data collection; the video-recording of patient's consultations, when they were telephoned to organise their 16-week check. If the pregnant woman was interested in participating, an invitation letter was sent to them (Appendix 9). Like the invitation letter to potential interview participants, the letters to potential FGD participants and to

those whose consultation might be video-recorded, explained the study in detail. My email address and telephone number were included and it was explained that recipients could contact me if they had any questions. Recipients were asked to respond if they wanted to take part in the study by emailing or telephoning me.

For the recruitment of pregnant/recently pregnant women from non-NHS sites, with permission from group organisers, I sat in on sessions for parents held at parent-toddler groups and community centres. When the time was appropriate, I spoke to women individually, briefly explaining the study and inviting them to participate. If they were interested, I gave them the study information sheet (Appendix 7) and asked them to contact me if they wanted to take part. In some cases, a date and time for an interview was organised during these sessions.

With the agreement from GP practice managers and managers of the non-NHS sites, I also put up posters and provided leaflets at recruitment sites (see Appendix 10 and 11 for examples of the English versions of these), which included details of the study and my contact details. Posters and leaflets were translated into Turkish, Polish and Portuguese and were displayed in English as well as in one or more of the above languages where a study site had a high proportion of patients/service users speaking this language.

Inclusion and exclusion criteria for participants is provided in Appendix 12. The numbers and demographic details of the included participants are provided in Section 2.

Data collection methods

Informal piloting of interview questions was conducted with colleagues and feedback was positive. A formal pilot was not conducted due to the length of time it took for the NHS ethics approval process, so that when approval was granted, it was important to start the fieldwork straight away.

Data collection began in December 2015. The three methods used-in-depth interviews, a FGD and a video-recording of a consultation-encouraged participants to speak widely and openly about maternal vaccination. The data gathered through these methods was triangulated, with the interviews providing depth; the FGD allowing insights into the

social nature of vaccination decisions; and the video-recording providing an added example of how vaccination discussions may take place in consultations. Below I provide details of the chosen data collection methods and how they were applied to the study.

In-depth interviews

In-depth, semi-structured interviews were chosen as the main study method as they enable an insight into the subjectivity, voice and lived experience of individuals, and allow space and time for complex ideas and perceptions to be explored and understood. This method was preferred over structured interviews, which can limit the responses provided by participants (Atkinson P and Silverman D 1997). In-depth interviews may also allow participants to feel that they are able to speak more openly than for example, in a FGD, where more restrictions exist due to the social pressures that arise in group settings.

The theoretical underpinnings of this study outlined at the beginning of this chapter informed topic guide design (Appendix 13 and 14). As well as guiding and focusing the interviews, the topic guide familiarised translators with the type of questions asked.

Interviews with pregnant/recently pregnant women took place at a location most convenient to her (usually at her home or a local café), and a £20 gift voucher was given to thank her for her time. Interviews with healthcare professionals took place at their work place. Participants were asked to read and sign a consent form (Appendix 2 and 3), and were told that they could take a break or stop the interview at any point. Interviews did not have a time limit so that participants were able to respond at length and in depth to the questions. I consciously introduced various themes, which invited participants to engage with and position themselves in relation to them. I aimed to understand how participant's maternal vaccination perceptions and experiences relate to their wider socio-political context. For example, interviews with pregnant/recently pregnant women aimed to elicit details of,

- Their experiences of maternity care within the NHS[8]

[8] Active research and interest in birth often means that mothers also conduct research around vaccination at the same time. Leach and Fairhead (2007) therefore recommend exposing people's wider ideas and practices concerning childbearing. I did this by examining participant's wider pregnancy and labour experiences within the NHS,

- Their views towards and relationships with healthcare professionals
- Sources of maternal vaccination information
- Their views towards maternal vaccination
- Influences on their vaccination decisions.

Interviews with healthcare professionals aimed to elicit details of,

- Their views towards maternal vaccination
- How they approached the topic of maternal vaccination with their patients
- Whether they encourage maternal vaccination
- What they did if a patient was hesitant, or did not want to vaccinate.

Questions were phrased in a non-judgemental manner, were non-leading and open-ended, using phrases such as, "can you tell me about…?", so that participants were given the space for spontaneous answers and time for their explanations. Through active listening and understanding, I was able to identify topics for further exploration, and when appropriate, ask relevant follow-up questions. A detailed description of the interview format is provided in Appendix 15.
In all interview questions, influenza and dTaP/IPV vaccines were distinguished as there are differences in uptake, perceptions and ease of access between the two vaccines. Each interview was digitally recorded and transcribed in its entirety.

Focus group discussion

The FGD aimed to encourage open conversation and debate among a small group of pregnant/recently pregnant women; allowing a number of opinions, experiences and stories to be shared and discussed at once. In this way, and through exploring group dynamics and ascertaining if these dynamics influenced what was being said about vaccination, the FGD extended the findings of the in-depth interviews.

FGD participants were recruited through, and took place at one GP practice included in the study. The six participants sat in a circle in order to promote group discussion. After

exploring whether negative antenatal and birth experiences could affect engagement with health services and therefore can affect vaccination acceptance.

the consent form was signed by all participants (Appendix 3), using a topic guide (Appendix 16), five overarching questions were discussed relating to participants' maternity care experiences within the NHS, and their views towards maternal vaccination. I listened intently to the substance, as well as the interactive patterns of the discussion, following up with additional relevant questions where appropriate. The FGD was digitally recorded and transcribed in its entirety.

Consultation video-recording

Ideally I would have liked to use the method of participant observation; attending various healthcare appointments with women in order to gain an in-depth insight into their experiences, and of social norms or pressures to conform to certain behaviours, that are subconscious and less likely to be described in interviews (Opel DJ, Heritage J et al. 2013). However, due to patient confidentiality concerns, the NHS ethics committee believed it would be less intrusive if I video recorded consultations. Thus, in order to strengthen the findings of the interviews and FGD, a video recording of a consultation between a pregnant woman and her healthcare professional (both of whom had not previously been interviewed or involved in the FGD) at the patient's 16-week pregnancy check was conducted as a final study method.

The consultation was recorded using an i-pad owned by the GP practice, which is often used for recording consultations for training purposes. This meant that GPs were used to having their consultations recorded in this way. The patient and her GP signed consent forms before the commencement of the recording. Like sitting in on a consultation, through watching the recording after the consultation had taken place, I was able to observe aspects of the patient-healthcare professional interaction in context; how the GP approached the subject of maternal vaccination; and the patient's reaction to this. Although the whole consultation was recorded, due to the relevance to the study, only the vaccination discussion was transcribed.

Data management and analysis

Although qualitative research cannot be subjected to the same criteria as quantitative approaches, there are systematic methods and criteria for analysis of data, such as thematic analysis-which identifies, analyses, and reports patterns (themes)-that can be

applied rigorously to the data. Thematic analysis is often utilised when research is used in policy, and thus must be accessible to those outside of academia (Braun V and Clarke V 2014), therefore, it was deemed appropriate for analysing data in this study. Thematic analysis was used as a 'contextualist' method, characterised by theories of constructionism and critical realism. This approach acknowledges the ways that individuals perceive and make meaning of their experiences, and, in turn, the ways the broader social context impinges on these meanings, whilst retaining a focus on the limits of 'reality' (there is no singular, objective, universal truth, waiting to be uncovered through the application of the scientific method. Instead, there is a multiplicity of interrelated, subjective and often oppositional understandings (Taylor GW and Ussher JM 2001)). Therefore, thematic analysis conducted within a constructionist framework does not seek to focus only on motivation or individual psychologies, but to theorise on the socio-cultural contexts and structural conditions that enable individual accounts (Braun V and Clarke V 2014). Below I explain how thematic analysis was applied to the data.

All interview transcripts, the FGD transcript and the video-recording transcript, were imported into NVivo11; a qualitative data analysis computer software package. I initially read the transcripts several times to become familiar with the content. They were then organised and coded into manageable text segments, with the use of coding frameworks (Appendix 17). Different coding frameworks were used for interviews with healthcare professionals, patients, the FGD, and the video recording. Text segments could be classified under more than one code. The criterion for selection was not dependent on quantifiable measures, but in terms of whether it captured something important in relation to the overall research question. Data was independently coded alongside regular discussions with my supervisors. As the study began with some key questions, concerns and theoretical underpinnings, the coding frameworks were formulated both deductively (through pre-established theoretical concepts guiding the research questions), and inductively (on the basis of salient and recurrent themes identified in the data). This approach is suggested by Fereday and Muir-Cochrane, who argue that the method which balances inductive and deductive coding can demonstrate greater rigor in qualitative research (Fereday J and Muir-Cochrane E 2006). This form of thematic analysis overlaps with some forms of discourse analysis, where broader structures and/or meanings are theorised as underpinning what is actually articulated in the data (Braun V and Clarke V 2014). All transcripts were then re-read and any

relevant missed text added to codes and new codes added if necessary. To immerse myself within the data, I also selected three interview transcripts and the FGD transcript and re-read them a number of times, making notes and re-affirming my themes.

I re-read the text segments in each code and sub-code, and through extracting the salient, common or significant themes from each coding framework, data from the various methods of data collection were triangulated in order to obtain numerous levels of information, thus strengthening the quality of research. The content of each theme was summarised, supported with text segments. Comparisons were also made between the different themes. Finally, by bringing together (i) the deductions in the summaries of all the themes, and (ii) addressing the original research questions and the theoretical interests underpinning them, with arguments grounded in the themes identified (Attride-Stirling 2001), I was able to construct a cohesive analysis, exploring the significant themes, concepts, patterns and structures relating to maternal vaccination acceptance.

Below are examples of how the various transcripts were coded (see Appendix 17 for the full list of codes).

Pregnant/recently pregnant women's interview transcripts

Eighteen overarching data categories were derived on the basis of (a) the specific theoretical interests underpinning the study (b) recurrent or salient issues identified in the transcripts including experiences of care, social influences on vaccination decisions, convenience and information sources. For example, the category 'Convenience' included text segments such as, "In UK you have to register for GP for a general practice and whereas in Hong Kong you just go to any doctors really and the doctor will prescribe you medicine rather than you have to get the prescription to the pharmacy". The category 'Distrust' included text segments such as, "I don't know how um honest [healthcare professionals] can be basically".

Healthcare professional interview transcripts:

Eighteen overarching data categories were derived on the basis of (a) the specific theoretical interests underpinning the study (b) recurrent or salient issues identified in the transcripts including perceptions of maternal vaccination, the vaccine

discussion/recommendation, knowledge about the vaccines, vaccine administration, vaccine availability, vaccine information sources and 'legal talk'. For example, the category 'Vaccine administration' included text segments such as, "in my own practice, if I am available I will do it or my nurse will do it [vaccinate]". The category 'Vaccine availability' included text segments such as, "there is some flu [influenza] around but we haven't got any [vaccines] left".

FGD transcript

Eleven overarching data categories were derived on the basis of (a) specific theoretical interests underpinning the study and (b) recurrent or salient issues identified in the transcript including convenience, factors that would have increased maternal vaccination uptake, experiences of care, use of NHS materials, and social influences. For example, the category 'Negative experiences of care' included text segments such as, "I just felt quite alone". The category 'NHS materials' included text segments such as, "I feel like I've just got handed loads of leaflets".

Consultation video-recording transcript

Four overarching data categories were derived on the basis of (a) the specific theoretical interests underpinning the study and (b) recurrent or salient issues identified in the transcript including the maternal vaccination discussion, patient sentiments towards the vaccine recommendation, and times when the camera was noticed. For example, the category 'Patient sentiments' included text segments such as "it was very nice getting a call about [this consultation], its nice, like ah, its nice, to be looked after". The catergory 'Camera' included text segments such as, "Ok, I'm ignoring it".

Narrative analysis

Participants often volunteered information about their experiences during the interview, which I had not specifically asked for. Many relayed these experiences in the form of coherent stories. These narratives frequently touched on personal histories, birth events, the social life of motherhood and engagements with health professionals, as much as on understandings of vaccination. This may be because it is often easier for participants to tell the story of an experience, than to respond to questions or provide explanations.

Such stories and their intersections with other narratives may also have helped participants to situate themselves within the broader social, cultural, and medical worlds (Carson A, Chabot C et al. 2017). Because the content and linguistic expression used in narratives are influenced by both immediate and wider socio-political contexts, such narratives provide a useful way of working through sensitive or controversial topics. Labrov's method of narrative analysis was therefore used to analyse various participant narratives, in order to gain a deeper understanding of how participants made sense of negative experiences, and how vaccines made sense according to the wider socio-political context in which they were situated (Labrov W 2015). I started this analysis by using the transcripts to identify short stories offered by participants, and noting when they felt they needed to provide these. I analysed the orientation of the narrative (i.e. the time, place, situation and participants), and constructed a summary of the sequence of events. I then looked at the consequences of the events described, for the needs and desires of the narrator, as well as any resolution or statement of what finally happened or how the participant felt (for example, "So that was good"). Additionally, when I provide participant quotes in the thesis, I include details of when they paused and laughed (in brackets), as these moments themselves are important parts of narratives.

The second part of the thesis which follows, contains the results chapters, as well as a discussion of these results and strategies recommended to increase maternal vaccination acceptance.

Section 2: Findings

In this section, I provide details of the number of sites within Hackney included in the study from which participants were recruited, the number and details of participants recruited, as well as an overview of themes covered in the following chapters.

Recruitment

Study sites

Of the four GPs/practice managers contacted, three agreed to be involved in the study. The GP who declined said that this was due to time constraints. Through contacting four heads of midwifery/immunisation in Hackney, it was agreed that I could recruit participants from two community antenatal clinics. Out of 12 parent-toddler groups contacted, nine said that I could attend sessions in order to recruit participants and four out of 11 community centres and migrant support groups contacted agreed to be involved in the study (though letting me recruit participants directly at the study site, or by displaying posters and leaflets about the study). This amounted to 18 study sites across Hackney.

Interviews

Through recruiting from the above study sites, 71 pregnant and recently pregnant women showed interest in the study. However, 31 consequently did not respond to follow-up texts or declined to take part. After interviewing the remaining 40 women, I reached saturation and so stopped recruiting. The interviews with pregnant women lasted on average around an hour. Two participants (one who spoke Turkish and one who spoke Hebrew) required a translator.

Participants were between age 18 and 41, and from a wide variety of backgrounds. Fifteen out of 40 participants described themselves as White British, five as Black British Caribbean, two as Black British, two as Chinese, two as German, two as Nigerian, two as Orthodox Jewish, two as Turkish, and one each as Australian, British Brazilian, Italian, Lithuanian, Norwegian, Pakistani British, Somalian and South

African. Sixteen participants had not undergone higher education, nine had a Bachelor's degree and 15 had a master's degree.

Ten healthcare professionals were recruited from the three GP practices and two antenatal clinics included in the study. Due to healthcare professionals' time constraints, interviews lasted an average of 20 minutes.

The healthcare professionals interviewed were all female, between ages of 23 and 62, and had been in their current role for between six months and 35 years. Six participants were GPs, two were midwives and two were practice nurses. Five described themselves as White British, two as Black British Caribbean, two as British Indian, and one as Black British.

FGD

There were 11 positive responses to the FGD invitation letters. I also invited four participants I had previously interviewed to take part but these women declined due to having prior commitments. Six women in total were able to attend the FGD at the GP practice on the date suggested.

FGD participants were from a very similar demographic. They were between the ages of 32 and 37, five described themselves as White British and one as White and from the USA. Three participants had a Bachelor's degree and three had a master's degree. None of the participants identified with a religion.

The group closely adhered to the issues presented, and strongly held the same view towards vaccination throughout the discussion. This could have been due to the social desire to "fit in"; the social cohesion caused by the similar demographics of the participants; and the fact that some participants had had similar experiences and gave birth at the same hospital. For example, Thalia (age 34) and Amy (age 37) both spoke about how they were "stuck" in hospital when their babies had jaundice, and reminisced on how helpful their midwives were with breastfeeding. The FGD lasted 56 minutes.

More detailed interview and FGD participant demographics and for pregnant/recently pregnant women, maternal vaccination status, are presented in Appendix 18.

Video-recording

One pregnant woman agreed that her 16-week consultation could be video-recorded. This participant was age 34, White British and employed. The consultation lasted 21 minutes.

Fifty-seven participants were recruited in total.

In this thesis, I do not present detailed participant maternal vaccine uptake data. This is because uptake rates do not reflect, and can even mask women's views towards vaccination. For example, Lucy (age 27) was generally against vaccination in pregnancy and had various concerns about it, but accepted the dTaP/IPV vaccine as she worried about the consequences if she did not. On the other hand, Anetta (age 30) questioned why anyone would not vaccinate, but did not know about the vaccines as she was not offered them, and so did not receive them. I thus aimed to understand maternal vaccination acceptance in the context of participant narratives, rather than through statistics.

Overview of themes

Through pre-determined theories and the data analysis, I was able to deduce a number of broad themes for the focus of analysis. These were; 'How constellations of governance are embedded in vaccination discourse'; 'Socio-political influences on maternal vaccination acceptance'; and 'The effects of a relational approach to healthcare'. Below I outline these themes, which form the basis for the following results chapters.

How constellations of governance are embedded in vaccination discourse

This theme pertains to the frequent mention of, and strong sentiments towards the government and the NHS by participants, especially when asked if they trusted the maternal vaccination. Both the term 'government' and the 'NHS' were used

interchangeably by participants, or simply the term 'they' was employed when talking about the government or the NHS, especially in a pejorative sense. For example, "vaccination is just something *they* [emphasis added] want you to get". The government was often spoken about in a negative sense, and sometimes involved talk of funding cuts and the state of the NHS. The NHS was mostly spoken about positively, with regards to how much participants trusted its motives, because healthcare under the system is free. There was a general feeling of protectiveness and pride towards it, coupled with a fond understanding for the perceived disorganisation present within the NHS.

Socio-political influences on maternal vaccination acceptance

This theme is linked to the one above but focuses on how various socio-political contexts influence views towards maternal vaccination among specific population groups in Hackney. It analyses how the healthcare system and the state can (often unwittingly) exclude specific population groups from healthcare and produce inequities in access to and attitudes towards various healthcare technologies between population groups. It also analyses how the vaccination views held by women's social networks, as well as some women's intersecting stigmatised positions, influenced views towards the UK government, and as a government service, the NHS and vaccination.

The effects of a relational approach to healthcare

This theme encompasses sentiments both from pregnant and recently pregnant women about their GP, nurse or midwife, and from healthcare professionals about their patients. It analyses healthcare professional-patient relationships and how vaccination is discussed in consultations, capturing how this relationship (either positive or negative), affects women's pregnancy experiences, and their views and decisions around maternal vaccination.

Chapter 4: How constellations of governance are embedded in vaccination discourse

> *I really think that it has a big influence on your, um, behaviour, on your… opinion against, um, vaccinations… what the general message of the state is… what the hospital say… they have really a big influence I think* (Isleen, age 34).

Perceptions of maternal vaccination relating to 'the system' that provides them, and in turn, how current healthcare rhetoric portrays pregnant women and produces inequities in access to vaccination between populations, are the focus of this chapter. I use Foucault's concept of governmentality to capture the way in which traditional forms of care provided by the state have, in neoliberal societies, shifted to forms of self-care, and its associated cultures and values interpellated into patient consciousness. This form of governance involves a type of social control whereby only those decisions about the body that conform to social expectations and norms are considered rational or responsible (Memmi D 2003). The problems with this ideology are examined through an analysis of the relationships between the state and participants, and the everyday ways in which participants resist such forms of governance (Foucault M 1976). I also analyse how the interplay between these external features of biopolitics (Foucault M 1976), and modes of self-government are evident in the proliferation of various mediums of advice-giving for pregnant women. As the production of scientific knowledge and medicine is socially and politically situated, pregnancy advice today reflects the belief that women's bodies as well as their behaviour, should be (self) controlled during pregnancy. Advice provided during pregnancy often causes anxiety as women-especially those lacking financial security and social support-inevitably fail to meet the exacting standards set out for them. To be a truly 'responsible' woman in the vision of such advice, means having a planned pregnancy, a level of education and motivation to sufficiently engage with pregnancy manuals, and an acceptance of medical authority.

Along these lines, I analyse how the ideal of individuality and self-governance that places all responsibility of health on the pregnant woman-at the same as the withdrawal of state funding for social support and healthcare programmes-(the impact of which is also explored within this chapter)-means that negative health outcomes come to be seen as the fault of individuals. This allows states and large corporations to negate responsibility for addressing structural factors that cause ill health (Owkzarzak J 2009).

The effect that these structural issues (such as funding cuts to healthcare, and a lack of translators available for non-English speakers), have on perceptions and access to maternal vaccination, will also be analysed.

I highlight the underlying tensions existing in vaccination rhetoric; the push for autonomy and patient choice versus the desire of healthcare institutions for all patients to comply with vaccination advice by choosing to vaccinate. If women decide not to conform to generic models of biomedicine such as vaccination, or to ignore the scientific facts through which they are expected to make their own, informed vaccination decisions, they are alluded to as apathetic, ignorant, resistant to change, or 'hard to reach' (Leach M and Fairhead J 2007). This perception means that some women feel that they should vaccinate due to pressure from healthcare professionals, or to avoid judgement, but are not comfortable with this decision. In my analysis however, I do not situate the individual solely at the mercy of the power of 'the system'; I argue that where there is power, there is often resistance, and there are many ways in which women resist the normative framings of biomedicine (Foucault M 1991).

Ultimately, in focusing on how constellations of various forms of governance are embedded in vaccination discourse, I seek to gain an understanding of how wider socio-economic and political concerns influence maternal vaccination concerns, and in turn, why, as a government intervention on the body, vaccination can raise questions about wider socio-political concerns.

Notions of trust

Funded by a complex system of state and international agencies, as well as private companies, vaccines are involved in negotiations surrounding trade secrets, intellectual property, and procurement mechanisms. The free market model strengthens existing power imbalances between governments, pharmaceutical companies, healthcare professionals and patients, whilst reducing a relationship of care to one of market exchange, governed by dynamics of price and profit. Distrust in vaccination and the corporations and governments that provide them is therefore understandable.

'Trust' can be defined as an acceptance of decisions without questioning the rationale behind them (Löfstedt RE 2005). However, my findings demonstrated that when it

comes to vaccination, notions of trust and distrust are complex, context-specific and mean different things to different people. Individuals may express distrust when asked direct questions about whom or what they trust, while at the same time, still using or relying on certain technologies and institutions, even if they are ambivalent towards, or critical of them (some participants accepted vaccination, even though they were suspicious of it). In fact, Giddens argues that contemporary controversies regarding vaccination are not the causes of distrust, but consequences of wider structural phenomena (Giddens A 1990). If the concept of trust with regards to vaccination is to be meaningful, it therefore should be defined and understood in the specific context of analysis, rather than as a meta-framework for understanding vaccination rejection or resistance (Linden L 2016). Such an approach aims to understand the depth of citizens' relationships with the state, large corporations and technologies. These relationships are shaped through modes of governance; local understandings of health and certain vaccines; experiences of disease; both positive and negative experiences with maternal vaccination; their views towards other vaccines (such as childhood and travel vaccines); knowledge of extremely problematic past international pharmaceutical trials; and national and international political history. The term trust therefore, is used in this thesis to express a complex, embedded set of meanings that in everyday conversation (such as in participant interviews), cannot be articulated in full.

There are many differences between various vaccines, so it is worth considering why people are worried about vaccination in general. Attitudes towards the state (which regulates, recommends and distributes vaccines), easily translate into attitudes towards vaccination, in part because vaccination is largely aimed at the whole population (thus allowing for concerns such as that vaccination is a form of population control). Levine, writing for *NaturalHealth364* describes vaccination as a "bioweapon" and "war against the people" (Levine B 2012). The use of such emotive metaphors in vaccination 'talk' was evident as early as 1856, when a working class man who opposed compulsory vaccination argued, "they might as well brand us" (Gibbs J 1856), evoking the marking of cattle, slaves, and criminals. Through this articulation, the man equated his position to that of an item of property, disturbing human, slave and animal distinctions. Slavery was a frequent anti-vaccination analogy at this time, and was mobilised alongside a commentary about the human/object relationship, representing sentiments of a lack of autonomy. Since imprisonment was sometimes a consequence of vaccine refusal, the

bodies of those who resisted vaccination were constantly at risk of becoming property to be transferred from the individual, to the state (Durbach N 2000).

Participants in this study had mixed sentiments regarding government involvement in vaccination. When participants stated that they trusted vaccination, they often did not question vaccinating. When discussing NHS vaccination advice, Zoe (age 32) stated, "I take the advice given by the NHS as gospel… I trust the NHS, I trust that actually they're not going to give you something that's going to harm your child or harm you". Two participants used analogies comparing vaccination to other routine activities where the potential for harm is small, in order to illustrate their trust in vaccination,

> It's like brushing your teeth, something I'll just do, it wasn't I'm choosing to vaccinate or not, it's something I'll just do (Isleen, age 34).

> It's like someone saying you shouldn't use a pushchair [for infants]… you probably could find reasons why you shouldn't use a pushchair but I'm not going to research that (Carla, age 37).

Beth (age 22) even said, "I just have to do it". The importance of vaccination was emphasised; "it was not like making a dentist appointment, where you're more relaxed, but [you] say yes straight away". Beth also said that the dTap/IPV vaccine "is very strong and powerful… so… now [my son has] got that he can't get [pertussis]". A fear of the diseases prevented by vaccines was a common reason for vaccinating. For example, Margaret (age 41) recalled the effect that a video of a baby with pertussis had on her, and how that influenced her vaccination decision. Ava (age 26) felt so positively about vaccination that she stated she felt like running a marathon after receiving the influenza vaccine and the anti-D immunoglobulin injection (which protects pregnant women from rhesus disease (NHS Choices 2015)).

Many who vaccinated were reassured that vaccines were provided for a reason, especially because within the NHS, profit was not involved in vaccination,

> I know it sounds fairly naïve but I kind of generally trust that the NHS pretty much only gives you stuff that is very much proven to be useful to you, because apart from anything else, they don't have the funding to give you a whole load of random vaccinations that aren't relevant (Marika, age 35).

Cadenza (age 37) also stated that the fact that one did not have to pay for vaccination was important. Sentiments of trust in the NHS and vaccination were also reflected by

most healthcare professionals interviewed, “I trust the healthcare system here and the way in which vaccinations are developed” (Dr. Cooke).

However, such unequivocal notions of trust in vaccination were rare, with cognitive dissonance (Fishbein M and Ajzen I 1975) and nuance evident in many perceptions of vaccination. For example, after expressing concerns about vaccination, some participants defended their belief in vaccinating; “If I might add, if it was the difference between immunising and not immunising, we’d probably just immunise. I think it’s important to immunise” (Marigold, age 36), demonstrating the prevalence of suspicion or questioning of vaccination, over notions of pure trust or distrust.

Participants who did not grow up in the UK often compared the NHS with the healthcare system in their home country. Some felt that the standard of care under the NHS was not as high as that in their home country, or that they were not given as many ultrasound scans in the UK (participants from Germany, Israel, Italy, Jamaica and Japan expressed these sentiments), thus affecting their views towards the competence of the NHS and healthcare professionals. Some participants (from Germany, Japan, Nigeria and Pakistan) had not heard of maternal vaccination in their country of origin. This sometimes led them to not knowing much about maternal vaccination, questioning why the vaccines were offered in the UK, and believing that if the vaccines were not provided in their home country, they were not necessary,

> This made me feel a little bit strange… I think my sister [in Germany] didn’t have any vaccinations during pregnancy, I asked her and she said no, I was wondering like, “Should I? Should I?” (Bathild, German mother, age 35).

> RW: You said your-your husband was worried about [vaccine] side effects… Mahsa (Pakistani mother, age 31): He’s from Pakistan. Over there, they don’t have vaccinations… and the children are completely fine, so he has a completely different view about vaccinations… I grew up [in the UK] with vaccinations, everyone in my family, my siblings, have all had vaccinations, and nothing’s happened. My mum’s had vaccinations when she was pregnant, but, um… in Pakistan, they don’t really have these… it’s not like compulsory to get vaccinations done… and the kids don’t usually have them… It’s not really, kind of, like, put out there… they don’t know about all of that until the baby gets sick… then they’re informed… There’s not really a fear of, actual, the disease… it’s like, okay, if it’s happened, it’s going to happen… everything is in God’s hands… I have, um, like, family friends, like relatives and stuff, who haven’t had vaccinations. I mean, my husband, I don’t think he’s been vaccinated himself… I think that’s the reason why maybe he was not so much for

> vaccinations… I eventually decided to have the [dTaP/IPV] vaccination, because I grew up having vaccinations, and my mother had all the vaccinations, and so did my siblings. I guess the culture is different [to her husband's]. I do think that other women who are in the same… cultural background as me, um, or as my husband… there's loads of them who... haven't had vaccination, because they grew up back home, so... I think it's really important to have that kind of awareness for them, for vaccination to be discussed to them, in their language… possibly not in English.

Interestingly, while Mahsa received the dTaP/IPV vaccine, she said that she was not "convinced" to have the influenza vaccine because she believed it to be ineffective, and because she did not receive it in her first pregnancy and "was absolutely fine". Another mother who was a nurse, felt that vaccines, especially the influenza vaccine for healthcare professionals, were unnecessary, citing a variety of reasons; including being prone to catching influenza and hearing that the vaccine was ineffective. She believed that the government had ulterior motives for offering the vaccine-not due to a concern for nurses' health, but "to prevent them from going off sick" and thus preventing the NHS from being short of staff (Rafeal, age 34). Anna (age 34) expressed similar sentiments, saying that the childhood rotavirus vaccine was only given because it is "to do with money… to stop hospital admissions". For Tessa (age 26), a similar concern "just confirmed my beliefs that I do not trust everything they're telling me to take". Idda mentioned twice in her interview, that she thought she had more sceptical views towards vaccination than others in Norway (her country of birth). Idda was frustrated that people were "dogmatic" when it came to vaccination, with no critical thinking around it. She blamed this on being "fed" the idea that vaccines are important and safe. However, after explaining that she felt that she was being fed information, Idda contradicted herself by saying that she did not know anything about the influenza vaccine, "I just know that they want everyone to take it" (Idda, age 27). The metaphor of the population being "fed" information, as well as Idda's use of the abstract term "they", portray sentiments of being patronised by healthcare rhetoric, and a suspicion of an unidentifiable institution's motives for providing vaccination. These sentiments caused Idda to reject vaccination.

Personalised pathways of child health

> *A person is not the public writ small* (Poltorak M 2007)

Under neoliberal reforms to healthcare, since the 1990s, the NHS has adopted the rhetoric of patient choice, so that healthcare is personalised to meet the needs and desires of individuals. This was evident in interviews with healthcare professionals when asked how they spoke to women who were hesitant or declined to vaccinate,

> RW: Do you discuss the vaccines with your patients?
> Dr. Clark: Yeah. It's a conversation it's just where the emphasis of the conversation is… you're explaining that they exist, what they do-what the benefits are, why we give them, you know, asking them are they happy to have them, um, you know, obviously it's all… patient centred. And patient choice. And if someone is unsure then giving them time to go away, think about it, and come back.
>
> What I would say is that it's their personal choice based on the information they're given. It's not compulsory, but if you want to know a bit more about it… I direct them to the… NHS pregnancy pages… they can read more about it, or… Google whooping cough vaccination… and you can make your decision based on, on that… If they just completely refuse to vaccinate we have to respect their wishes… you just offer them the opportunity to, um, come back and discuss it another time, write a note on their records to discuss it when they're next seen… it's up to them… I'm not there to, to tell them what to do… I have to… guide them… if they're unsure (Midwife Renee).
>
> [I] just try not to make them feel… worse with anything I say or inferior-like you've made a bad decision. They're autonomous individuals (Dr. Cooke).

These narratives reflect the approach to care in healthcare settings in the West, where patients are expected to be completely autonomous and make their own decisions, often based purely on a plethora of internet advice. The ethic of patient choice, in which expert knowledge is not available for all, and the fact that often decisions related to healthcare take a lot of time and energy to make, shifts an enormous burden onto the patient under the guise of the 'gift' of choice. The ideal is also full of contradictions; while there is a constant push for active decision-making, this is coupled with a wish for patients to passively comply with medical advice, sometimes accompanied with exasperation and frustration at those who do not,

> There's a tendency not to be proactive about giving further information [about vaccination]… unprompted… and so… I know in general from my own experience that it's almost taken as a given that if they tell you about it and they tell you it's a good thing, that you'll just do it… as opposed to proactively looking to reassure you, if you haven't specifically asked… So if I had questions… "What are the known side effects or what are the risks?" and I'm confident enough to ask that, then they'd happily tell me… It's not like they were, uh, withholding [clears throat] anything, but they won't proactively

> volunteer the information… I'm pretty confident about asking questions… if there's something else I want to know about or I have a question about it… and… for some people, that might be more difficult… because…it is about, I guess, confidence and… some people don't want to challenge someone there and then (Isobel, age 40).

Unless they are marginalised, patients are not punished for failing to follow medical advice, but are encouraged to become independent and self-efficacious, with the assumption that such 'empowerment' will lead them to choosing what experts believe is correct (Reich J 2016). However, this logic is not applied to other areas of social life, such as school attendance, where very little choice is provided regarding attendance, and non-attendance leads to legal sanctions. In this way, ideals of patient choice can clash with patient expectations and lead to confusion,

> Tami (age 34): The doctor… said… I can have a choice not to take a vaccination… but I felt weird, why not to take the vaccination?
> RW: So the doctor said this after the midwife had already said you need to get these vaccines?
> Tami: Yeah… I felt weird because, yeah, a vaccination [is] a kind of mandatory thing for me… there's no reason why I'm not to take to protect my baby and myself… [the GP is] kind of like a, it's your right to say no… I've got a choice… it's a bit complicated. Yeah, confused me.

Despite the ideology that introducing patient choice into healthcare empowers patients and makes space for their desires, it in fact alters healthcare practices in ways that do not necessarily fit well with the intricacies of different people's healthcare needs (Mol A 2008),

> You are allowed choice… but I didn't really know what I was choosing… I signed up for something I didn't really know what I was signing up for… I would say that whole induction thing I felt quite ignorant about because you don't plan for it…I don't think they were giving… every option… you have to get induced at fourteen days late… in the NHS. And if you read the website… that is not necessary… they clearly are not allowed to say… "you just hang around'. So… I was slightly confused about… what NHS *doctrine* [emphasis added] is… I do 90% trust the NHS but… I'd watched a horrible show on induction so I … was trying to avoid it… So I just think we had clashing … objectives… They want a healthy baby and a healthy mum, and I want a healthy baby and a healthy mum with no undue pain... I did find that whole induction thing quite confusing… Everyone might be healthy at the end…but its… traumatic (Carla, age 37).

The above narratives demonstrate that the desire for patient choice has led to a tension between the emphasis on maintaining health at the population level, and citizen's individual rights to peruse their own health (Poltorak M 2007). Individualist notions of

healthcare also places burdens not only on patients, but on healthcare professionals, as it demands for personalised attention from healthcare systems and professionals (Reich J 2016),

> I heard with NHS delivery that you have to share rooms with up to 20 women and that you have to leave really soon after delivery… this made me a little bit…scared… I decided to deliver privately… NHS nurses do not have the time they could have to treat their patients a little bit more… individually (Bathild, age 35).

Along a similar vein, it was interesting that while there is no evidence to show that there are any medical benefits to receiving ultrasound scans during pregnancy (Kukla R 2005), participants were annoyed if they felt that they did not have enough scans. This may be because scans are increasingly routinised[9], and play a social or reassuring (Thomas GM, Roberts J et al. 2017), rather than medical role. However, they have also meant that pregnant women's experiences no longer construct notions of their foetus' health and growth. Rather, medical technologies of visualisation and laboratory test results, to which women have no access except through expert intervention and interpretation, are dominant sources of knowledge. In this way, the foetus has moved from the realm of private experience, to the status of the 'public foetus'. Images from scans enable us to 'see' the foetus as a distinct being; both dependant, but also separate from the mother, and therefore in an obviously liminal state (Ruhl L 1999). Through an ultrasound, the foetus can be normalised, individualised and surveyed, matching current desires for personalisation in healthcare. Such an individualist focus causes risk discourse to proliferate during pregnancy and thus induces anxiety and a heightened sense of responsibility on the part of pregnant women,

> The whooping cough [vaccine]... I'm just very careful about, I don't want to put... anything into my body that could damage [the foetus], so I'd be very careful, like any cleaning products... tried not to dye my hair; I was, you know, doing all sorts of things, and not using loads of perfumes or stuff on my skin. I just wanted to be really careful (Rebecca, age 29).

[9] All pregnant women in the UK are offered two scans via the NHS at around 12 weeks to 'date' the pregnancy, and 20 weeks for anomaly detection. Uptake for these scans is high: 89% for dating scans and 99% for anomaly scans. Redshaw M and Heikkila K (2010). Delivered with Care: A National Survey of Women's Experience of Maternity Care. Oxford, UK, National Perinatal Epidemiology Unit.

Women are chastised if their behaviour does not conform to what is understood as natural (Lock M and Kaufert PA 1998). As well as criticising women who do not take responsibility for eliminating toxins or chemical risks to the foetus, maternal bodies are criticised for being too young, too old, or too fat to be 'naturally' pregnant (Kukla R 2005). The importance placed on the notion of 'natural' pregnancy was evident when I asked participants if they had experienced any complications with their pregnancy or birth. Almost all mothers said "no", but then later, usually within a longer narrative, some participants (like Aldona, age 29) went on to describe a serious complication they had experienced. The fact that it was not mentioned at first may have been due to the acceptance that pregnancy is natural, and any issues should be bared without complaint.

This huge burden of responsibility placed on women during pregnancy can make healthcare decisions, such as around vaccination, so anxiety-provoking that personal concerns become paramount, leaving less space for wider social considerations,

> They're trying to build up a pool of immunisation… but… you've got to look at your individual child and prioritise him or her, so I do trust it but I've always got a mind on… what [healthcare professionals'] job is, and… if it's something I don't want to do... then I would challenge it (Marigold, age 36).

This phenomenon was also found in studies conducted by (Poltorak M, Leach M et al. 2005) and (Reich J 2016), alongside a parental desire not just for health on its own, but for *improved* health and developmental outcomes, beyond what the foetus would reach if left to develop 'on its own'. This desire is evident in online articles with titles such as "8 Pregnancy Tips to Make a Clever Baby", which opens with, "Call Mensa. You're building a super brain and we've got the best tricks for creating a smarter, happier baby" (Mother&Baby 2017). Practices used to 'improve' the foetus range from simply taking folic acid supplements, to playing Mozart for, and reading stories to the foetus. This self-governing approach to pregnancy reflects a shift from earlier acceptance of more authoritative and generalised childcare regimes visible in advice books from the 1940s (such as Dr. Spock's 1946 publication of *The Common Sense of Baby and Child Care*), to more individuated advice emerging since the 1970s, (such as Fletcher's 2017 book, *Happy Mum Happy Baby: <u>My</u> Adventures Into Motherhood* [emphasis added]). The social environment engendered by products like these, alongside policy narratives of 'patient choice' and a milieu of hyper-individualised market fundamentalism, provides

ample ground for parents to internalise pressures of parenthood and the judgement of others.

This means that vaccine hesitancy or refusal is not due to parents simply thinking and acting as self-centred individuals. In fact, through talking about vaccines, social relations and a sense of community can form among parents. Thus, opting out of vaccination can actually be part of an act of opting in to a community or shared belief, and so can be more about who one is and with whom one identifies, than about individual opposition or resistance (Sobo EJ 2016). For example, in some social circles, vaccinating is perceived as more controversial than not vaccinating. This was evident when a participant spoke about a friend who felt she was doing something different by choosing to vaccinate, and how this friend worried about how others would judge her 'controversial' decision,

> Some of the people I know, they know people who don't get vaccinated and… they find it a real conflict… I have been out to lunch with a few girls who feel they are bucking a trend or doing something a bit controversial by having a vaccination… I just think … of course you get kids vaccinated… Whereas [my friend] feels that, you know, these toxic people are telling her not to [vaccinate] when… she knows… like she has made a choice [to vaccinate] that other people will frown on. Of course I don't know anyone who would frown… it's just not my world (Carla, age 37).

However, as most healthcare institutions and professionals, and indeed members of the public, view vaccination as 'right', vaccination discourse reinforces the notion that vaccination is normal (Poltorak M 2007). This meant that some participants feared discussing hesitancy towards vaccination or anti-vaccine beliefs with other women, for fear of being judged for a perceived controversial opinion, "I know it's a contentious, uh, one, so it's not something I discuss publically a lot" (Kate, age 33). This fear is unsurprising given the way that some pro-vaccine mothers spoke about those who did not vaccinate,

> When it comes to vaccines, I generally think they're there for a reason, and I don't really understand why people wouldn't take them (Magda, age 33).

> I lived in Switzerland… the whole vaccination, uh, do or don't, um, during pregnancy… is a big topic with a lot of… parents, um, being totally against it, with quite weird arguments, like… "but back in the days, they didn't… have vaccination either", and I'm going, like, "yeah, but they... didn't have showers, central heating... so maybe think-think about that argument"… You've got all the hip-hipsters... who are going... "I go foraging on the weekend... I'm all

> organic, and I care about the environment"… we had these huge discussions in Germany with measles last year in-in berlin, where all the hipster Berlin parents… didn't want to vaccinate, um, and-and I think a few babies, or children died (Maddelin, age 34).

However, some participants, like Margaret, were clear that they did not adhere to social norms such as vaccination unreflectively,

> I probably did consider [vaccination] more, because… you know that pe-people refuse vaccinations because of that MMR thing probably, that, you know, that... refusing is an option… which is why-why I did think about it, because rather than just… do it like a sheep… vaccinations are a good thing… don't get me wrong, but just, yeah... and also, I suppose, as well… it's the first decisions you're getting to make about your child, so… it's practice (Margaret, age 41).

Such values of personal responsibility connect with ideas around personalised immunity. Many mothers judged their infant's health depending on interactions between environmental and nutritional factors; expressing concerns about allergies, eczema, asthma, and behaviour in terms of such interactions, building on the notion that the immune system must be strengthened through personalised nurturing, exposure to the world and good nutrition,

> I trained as a nutritional therapist, and I obviously read quite a lot about different things, and um, then I've... seen a homeopath as well, which I see regularly... Not that she's influenced me. And, to be honest, when I studied nutrition, it wasn't that people were saying vaccinations are bad-they were saying it's up to you to make your own decision (Rebecca, age 29).

The rhetoric of the immune system, which encompasses holistic notions of bodily health, has moved to the centre of cultural conceptions of health. The discussion of bolstering the immune system relates bodily processes to wider socio-economic transformations that emphasise an innovative, agile and ultimately, perfect body (Leach M and Fairhead J 2007). Yet, the sense that everything about an individual's health is connected to everything else, and that it is one's personal responsibility to manage and control these interactions, leads to a paradox of empowered powerlessness; "feeling responsible for everything but powerless at the same time" (Biss E 2015).

Such conceptions of personalised immune systems can also be partnered with social and racial prejudices due to some illnesses being perceived as relating to poverty or impoverished areas abroad. In this way, some white, well-educated, middle-class

participants did not see themselves as at risk from certain diseases, and thus not in need of some vaccines,

> Based on what it says... in the green [book]… with the BCG [bacillus calmette-guérin vaccine]... I needed to understand... what the risks were, whether it's about, it's a kind of a blanket vaccination, which is about catching particular groups of people, so therefore, you give it to everyone, in order to cover certain groups… and what it said was that, although the rates were higher in [certain boroughs]… it's about the children of parents who have come from areas, other countries, with high rates of TB [tuberculosis]… but there's very little evidence of, um, it being transferred through schools, um. So, based on that, I would have thought that I might not want them to have it... BCG [vaccine]… is one where, like my son's got a huge crater [scarring] in his arm, and it's *particularly* [emphasis added]… painful for him (Ruth, age 36).

> My understanding is of TB that you have to be in prolonged contact... with somebody living in the house, and I know that, obviously, they recommend it here because there's a lot of people coming from sub-Saharan Africa and all of their, where you know, grandma comes over and lives in the house-shouldn't really stereotype, but... when I spoke to the doctor, they said, "If you're not going to be in London for-for a long time… then maybe you wouldn't need it" (Rebecca, age 29).

A midwife also expressed the view that vaccines are more important for people within certain demographics, and separated herself from this group,

> Midwife Renee: I definitely think that, um, there's certain demographics of people that vaccinations are a really good idea for… if I was pregnant now, I wouldn't have any vaccinations… because I feel like, um, I've got a very good healthy diet, strong immune system… the environment that I live in is, is, uh, healthy and, um, I don't feel like I'm particularly at a high risk of contracting anything, and if I did, my immune system… would be able to cope with it… I think that also, um, I'm quite sensible… I feel like breastfeeding is quite a good, um, protection of babies and I feel like I'd be very sensible in terms of, um, where I was taking my baby… I wouldn't… take my new born around other children potentially who had illnesses and things like that.
> RW: You mentioned that it's important for certain demographics, which, which people do you mean?
> Midwife Renee: Yeah, I feel like... especially in Hackney where… it's a very deprived, borough, um, people on low incomes with poor nutrition and smokers, um, overcrowding to housing, squalid conditions, poor housing… with damp and dirty environments, they're the people po-potentially who have poor immunity. They might be at more risk of getting of getting unwell or their children being unwell (Midwife Renee).

These sentiments reflect a form of social Darwinism, which allows people of different 'quality' to be distinguished from each other (Biss E 2015); constructing social and

moral categories (such as a 'healthy' population which needs to be protected versus a 'dangerous' population which must be avoided), as well as norms and binary oppositions around social class, race and ethnicity (Crawford R 1994).

By comparing themselves with others who they perceived to be particularly at risk, participants also maintained a sense of low personal risk (Joffe H 2003). These individuals enacted imagined gated communities from which they could control social exposure to those they believed might carry disease (Reich J 2016). This was evident in Cadenza's assertion that, "Maybe [diseases are] dangerous but because we're always here [at home]… we're not that exposed, we're not that exposed" (Cadenza, age 34). This statement demonstrates that middle-class women trust their ability not only to maintain social distance from others who may carry disease, but also their ability to use their privilege to discern when exposure to others might happen and under what terms (Reich J 2016). Thus, while Mol suggests that in Western society, people are expected to be autonomous, but not at the expense of others (Mol A 2008), the above narratives demonstrate that in some cases, the opposite may be true. Individuals like the participants mentioned above, believe that they are able to keep their children away from 'foreigners', or poor people, who are thought to be 'in need' of vaccination, but they, with their unvaccinated children, do not consider themselves to be a danger to such people. As Mol states, "microbes and liberalism do not go well together. While in liberalism, every body counts for one, microbes make far wider calculations" (Mol A 2008).

Being a "good" patient

A 2016 study of vaccine acceptance among White and African Americans, found that if patients did not ask questions about vaccination due to feeling uncomfortable or patronised, they were often mistakenly read as implicitly trusting in vaccines, passively accepting them or complying, rather than possessing an informed realisation that they are safe (Quinn S, Jamison A et al. 2016). Such assumptions could have been made about participants like Lucy,

> The nurse that I saw… said to me… "when you get to a certain stage in your pregnancy... you can have a vaccine called the whooping cough"... She'd give me a leaflet to read up on it, but again, to me, that was quite a blur, because it didn't really... It's not talking so I didn't really understand it, to be honest. Um, and then the next appointment, she kind of said, "Well... Are you thinking about

> doing the whooping cough, um, vaccination?" Then a little bit more information came from that… and then when I did come for that appointment… I then decided, okay, I'll do the vaccine, but in my head I was still not 100% sure, but I kind of just went for it (Lucy, age 27).

This reluctance to vaccinate but going ahead anyway was evident when another participant accepted vaccination but believed that they were safe only because "there are so many people who are very willing and able to sue the NHS if they go wrong" (Carla, age 37). These narratives suggest that one can still vaccinate while voicing uncertainty tied to dealing with a wide variety of social and economic factors, pressures and implications for parental responsibility (Poltorak M, Leach M et al. 2005). Accepting vaccination can be seen as passive acceptance by healthcare professionals, especially among lower-income 'uneducated', 'unreflective' and 'ignorant' women, as demonstrated in Dr. Clark's narrative,

> I have two different groups of patients, you have patients… who are middle-classed, well-educated … who come in pretty much knowing their own decision, and whether that's right or wrong… It's sort, sort of two different conversations… in one… you're undoing some of the myths… whereas in the socially deprived you're… it's just a different… some don't know that they're available… So it, it's, it's informing them that they are… and for others will come… saying "well, when am I going to have my whooping cough [vaccine]?"... And some will just have no idea… if you're advising them to have something they will, they will take your advice… these are… stereotypes… whereas some of the others where you're undoing the myths… I find out… what's their ideas concerns and expectations. Find out why they're hesitant, have they got a bad family experience… where is that sort of hesitancy… based… then explore and try and talk to them about… whether that hesitancy is justified… and then give them some information and talk about why we do it (Dr. Clark).

Dr. Khatri, who distinguished between two types of patients (educated and non-educated), also made the assumption that educated women conduct more health-related research than non-educated women. She said that the majority of educated younger women knew about maternal vaccination, and so did not ask questions about them. According to Midwife Williams, those who had not conducted much personal research relied on GP advice "and say 'yes doctor… if you say, I am going to have it". Shiloh, a 19 year-old unemployed single mother educated up to high-school level, disproved the assumption that the importance of health-related research and vaccine questioning is higher among middle-class groups, with her frustration at those who did not question vaccination, "Some people don't do research… they hear it from someone which is part of a health team". In fact, according to Renn et al., lower-income, less educated people

show less trust with respect to the system or institutions in general than higher-income, more educated people, who express more confidence in the system (Renn O and Levine D 1991). Vaccination talk thus favours a questioning of vaccination over blind acceptance of official pro-vaccination advice (Poltorak M 2007).

Additionally, as patients' interactions with healthcare professionals are shaped by broader relations of power and authority, lower income women who have concerns about vaccination may feel less comfortable voicing concerns than middle-class women. This may be because their educational and social experiences have not given them the confidence or empowerment to have discussions with healthcare professionals whom they may experience as intimidating, patronising, or judgemental. This observation was made by Midwife Renee, "It's really difficult to know what [women's]… actual view is… when they're sitting in front of a health professional… because they don't want to be judged for… doing the right thing or the wrong thing". This may mean that assent rather than consent to being vaccinated is reached (Anspach R 1993). In a study by Murira et al., feeling patronised and intimidated in healthcare settings was experienced especially by young pregnant participants, who disproportionately received disrespectful care and felt ignored by healthcare professionals (Murira N, Ashford R et al. 2010). These sentiments were also expressed by Lucy,

> I asked something, it was… patronising… the attitude… how they came across with the answer-it was, like, mm, was I meant to ask you that?... it was more or less, well, because they're professionals, that I must understand that whatever they tell me, I must just take it on board… I think with me looking so young, I felt like I was patronised a lot. Um, there's one of the ladies that I used to speak to, and we were at the same stages of our pregnancy, and I felt like, when I heard her, um, midwife, kind of, give her information about certain things, I felt like… she wanted to give her advice, whereas with me it was, kind of, like, "well, you got yourself pregnant, so kind of deal with it and take the-take the leaflets and just read up and do your own, sort of, in-investigation"… it kind of felt like you just got shrugged off (Lucy, age 27).

Additionally, and as was also found in a study by (Bradley S, McCourt C et al. 2016), some women experienced attempts by midwives to assert their power and control, especially on how women physically behaved during labour,

> I had to have antibiotic during my labour, so they tried to put um, this… [intravenous drip]… and I said, "Please can you move it?" I said "it's hurting"… then they took me to the labour ward and then the midwives changed. So this

> midwife was explaining to another one saying, “Look she doesn’t want it here because it’s hurting her, you know but she needs antibiotics” and the other one she didn’t even listen. She was like, “Oh no, you have to get antibiotics done, this is not the question”. But you know I would’ve said to her but I was in so much pain that I couldn’t and then the other one said “Calm down you know she doesn’t refuse to have antibiotics, she just doesn’t want it here”. [The other one said], “it’s not up to her, we have to put it here”. But she was from the agency… it was madness… after you give birth like you’re holding your baby and then they say, “Oh you can’t hold the baby too much in the bed because it's dangerous, you have to put it in the cot in-case you fall asleep the baby might drop”. I said, “Okay like you know, if I feel like if I want to sleep...” [The midwife said] “No, you know, you have to put it” and I felt a bit like, please like it’s my child… I’m sure like you know I’m not that stupid… So some of them were like… not listening (Aldona, age 29).

The implicit power dynamics existing between the healthcare professional-who usually holds the professional knowledge and status (Nursing Times 2016)-and the patient, who is expected to unquestioningly accept biomedical knowledges, means that if women asked questions, healthcare professionals are sometimes annoyed or short-tempered, “The first-first nurse I saw was quite um, quite annoyed that I was even questioning whether or not I should I have [the BCG vaccine for my child]” (Ruth, age 36). In this way, some women may comply with vaccination because being silent, passive and accepting are perceived as being a “good patient” (Wortman C and Christine D-S 1979).

Healthcare professionals’ experiences of pressure to vaccinate

Nurse Thompson demonstrated the pressures she felt to vaccinate patients in order to keep her patients safe, and avoid any legal action taken against her if she did not, “There’s no way we’re going to give you a medication that will harm your baby… because we would be liable... there's a leaflet in [the vaccine box]… we both read it together” (Nurse Thompson). Midwife Williams voiced similar concerns, coupled with a fear of legal action taken against her if she did not offer vaccination. When asked if she believed that one maternal vaccine was more important than the other, she stated,

> I do think they're important… for the wellbeing of the baby and… the family… and also from the [NHS] trust’s point of view, it’s expensive… if we get sued and… if they felt that we haven't, you know, given them the proper information about it… so it’s, it’s two-fold really, you know, it’s for their benefit and also to protect… yourself and the Trust… We have interpreters, we… must have it because you're liable… if you haven't given them the correct information… if they don’t speak English, then how do you give them the correct information? Our notes get audit, so if it, if it comes up that you're not documenting

> [vaccination], you're not offering to the ladies, then it will be flagged up… and, um, there's also the fear as well that if something… happens… with a woman not getting that immunisation to her baby, they will trace those notes, and, and we're aware of that, so there's an element of fear… So I think midwives will [vaccinate]. They, they've got nothing to lose… because… you then put yourself in a vulnerable position if anything was to happen and you haven't, um, done that (Midwife Williams).

Such pressures and concerns are common in healthcare settings, where healthcare professionals must communicate with patients who hold a wide range of views on vaccination, or who have other, pressing concerns, in short spaces of time. These pressures have been exacerbated in recent years due to structural factors affecting the NHS, including severe financial pressures, which as of September 2017, show no sign of easing. Research by The King's Fund found that for neonatal care, there is often not enough staff within the NHS to meet staffing ratios recommended by the British Association of Perinatal Medicine (British Association of Perinatal Medicine 2010). This is also likely to be the case in other sectors of care. Staff shortages have been attributed primarily to problems with recruitment (due to funding cuts to training budgets). Relatively little is known about the impact of funding cuts on quality of patient care, as changes to quality of care are less visible than access to care. However, an increasing proportion of NHS staff are working additional hours and working unpaid overtime. This may explain why the number of voluntary resignations from the NHS associated with 'work-life balance', increased from 3,233 in the first two quarters of 2011/12, to 8,657 in the first two quarters of 2016/17 (Robertson R, Wenzel L et al. 2017). The extra pressures on staff is leading to low morale and increased sickness absence in some areas. This is particularly concerning given the well-established link between staff wellbeing and the quality of patient care. Interviews conducted by The King's Fund with healthcare professionals found that many services are operating on "goodwill", but that this goodwill is running out (Robertson R, Wenzel L et al. 2017). A lack of goodwill, possibly due to the pressures mentioned above, was experienced by some participants in this study in the form of distancing, or rudeness on the part of healthcare professionals,

> I had a-a really, really frustrating appointment and... left in tears… you have these blood tests… and I had a, um, an appointment with the midwife... I'd received… the kind of analysis, but not an explanation of what it meant, so... I was asking her to explain... whether or not this was okay... and she said that she

> didn't have time because it was, um, too late in the day... and I would have to make another appointment to-to run through it all (Ruth, age 36).

> [At] six weeks pregnant I started bleeding. [My GP] basically said to me well, one in five pregnancies ends in miscarriage… there's nothing I can do at this point, like, but I'll send you to the early pregnancy centre next week. So I spent four days over the bank holiday just crying… being really stressed out… I had no reassurance from the doctor whatsoever. Like, it was really horrible (Marika, age 35).

Often questions were not answered and no re-assurance provided. This may be due to time constraints, but also might be an act of self-preservation on the part of healthcare professionals that helps buffer them from emotional demands and work place pressures (Bradley S, McCourt C et al. 2016). For Mahsa (age 31), healthcare professionals being rude to her affected her whole experience of labour. This is significant considering that birth experiences could guide thinking about future vaccination. This will be explored further in Chapter 6.

Access inequalities

> [Imagine that you have to make a choice about what social order you would want to be born into] *behind a veil of ignorance…* [you] *do not know certain kinds of particular facts…* [You do not know your] *place in society,* [your] *class position or social status; nor* [do you] *know* [your] *fortune in the distribution of natural assets and abilities,* [your] *intelligence and strength… Nor, again,* [do you] *know… the special features of* [your] *psychology*…[You] *do not know the particular circumstances of* [your] *own society*… [you] *do not know its economic or political situation…* (Rawls J 1999).

If John Rawl's Original Position (above), is used to imagine a "veil of ignorance", people's overriding concern regarding healthcare would probably be to ensure that access is equal, no matter what position they are in (Biss E 2015). However, many women experience one of two extremes of care: too little too late, or too much too soon. Women often excluded from good quality care include adolescents and unmarried women, immigrants, women from ethnic and religious minorities, women living in poverty, and women living in fragile states (such homeless women and refugees). On the other hand, over-medicalisation of normal pregnancy and birth, which involves the routine use of unnecessary interventions such as caesarean section; induction or augmented labour; continuous electronic foetal monitoring; and episiotomy, is also common but not supported with evidence of its benefits, and may cause harm and raise

health costs. Over medicalisation also has a tendency to see the psycho-socio elements of care as unrelated to quality and safety (The Lancet 2016). A less 'clinical' approach to care was appreciated by patients,

> The midwife I had… was… very reassuring... she knew what she was doing… she was sweet… she stayed on for like an extra hour to help me with the baby and that was… really re-assuring because I knew her… the students they were like, we need to monitor her and [the midwife] was like "no, no… I've got this covered. I've seen all this before… I can tell that it's going fine just from my experience" and that made me feel very reassured. It wasn't just like, you know, a clinical procedure where every ten minutes they monitor the heartbeat and they just kind of left me to do it because they were confident that it was going alright… So that was really really great (Idda, age 27).

There are differing levels of ease of access to maternal vaccination for women across the UK, and thus vast differences in uptake between various GP practices and geographical areas (Robson J 2015). This is because there is no standardised delivery programme for maternal vaccination in the UK. However, people do not have access to healthcare based on geographical and organisational availability and affordability alone. Access to care is a function of the social and economic characteristics of the environment in which people live, and in today's neoliberal healthcare environment, the possibility to choose acceptable and effective services requires patients to be engaged in care (Levesque JF, Harris MF et al. 2013). For example, Dr. Henderson said that she told women at their 16 week check to write in their diaries that they needed a dTaP/IPV vaccine at 20 weeks, and to remind their GP or midwife about this. While this approach may be suitable for some, it places the responsibility of organising vaccination on pregnant women, some of whom may have other, more pressing health concerns,

> We had the business which was going all over the place, and [my husband] asked me to go back to work, and I think I was really struggling with postnatal depression, and my head was all over the place, and I was trying to just function every day, and I didn't do enough about [booking vaccination]. And then suddenly, I'm like… shit, [my daughter is] nearly three now... I didn't follow up with the rest of [the vaccines] (Rebecca, age 29).

While it should be taken into account that vaccination is not the immediate priority for health professionals working with women who have other health and social issues (Poltorak M 2007), there did not seem to be much help available from healthcare professionals to book vaccination appointments or provide women with information

about how to go about receiving the vaccines. Instead, there was an assumption that women would sort this out themselves,

> I recommend that… if they want to have a whooping cough jab they can have it between 20 weeks and 36 weeks and that they can have it at either at our whooping cough vaccination clinic or they can have it at their GP and they make the appointment themselves… If they want more information about it, they can look on the NHS website and very briefly I say it's a childhood illness, um, that can make babies, children very sick, and that it's the same vaccination that babies have when they're two months… And then will say like during around about maybe 26 to 30 weeks, I'll say, "Are you going to have the whooping cough vaccination? Have you had it?" (Midwife Renee).

It was evident that the time it took to schedule maternal vaccination and attend appointments, as well as how complicated it was to book appointments (especially if the participant was not fluent in English), greatly affected vaccination acceptance. Organising vaccination appointments was easier if the woman's GP practice or hospital was physically close to where they lived (as was the case for most participants), and if they could schedule midwife appointments at evenings or the weekend. One of the most important factors to accessing maternal vaccination was being able to receive vaccines at the point of recommendation, rather than having to make additional appointments, which often required taking time off work or arranging child-care,

> I was having a lot of appointments… so much time off work and feeling quite stressed about everything I needed to get done before I went on maternity leave and it just felt like one more thing to sort of take a half a day off work and go and sort out… I just didn't get around to it… It was a time and a convenience constraint… if they said, "You can have it done at the antenatal clinic"… I was always waiting for hours and if they said… have it done while you're waiting… then I would've absolutely have done it… I don't have any fears about being vaccinated or any problems with it… You're meant to have [the dTaP/IPV vaccine] done after 22 [weeks]. So... it was not really at the front of my mind at that point… I want someone to literally come to my house [to vaccinate me] (Hayley, age 34).

> It was time... if the midwife have it in her room and… in the next appointment I get it, it [would be] easy… It was difficult also with my language, also I have… a baby, and I couldn't take… I didn't get it (Talia, age 21).

> If they want you to get it why don't they just give it to you? why do you have to go and get it?... if the midwife gave it to you… and said "oh yeah you can get it here"… it might be a whole different story… but the fact that you have to go and like maybe get a GP appointment… and ask for it... (Julia, age 38).

> I think [my GP] mentioned [vaccination] in week 21, and then he didn't mention it at all afterwards… then it kind of just drifted out of my-my head, and then it was basically too late. And then I just tried not to think about it [laughs] So... It wasn't, like, I'm-I'm against it… I think what was also, so the midwife… didn't do the appointment, so it would've been going to, um, the GPs reception-receptionist, and I think... if probably the midwife said, "All right, we-we book you in on-on next Tuesday", then I would've just said yes.… Maybe on that day… it might've been very hot and I just wanted to get-get out… there was a queue at the-at the reception... and then you just-you just forget about it. So… if he'd have just said, "All right, let's book you in"… that would've been it. So, yeah, my, um, my fault… I really have issues with the non-vaccinators… So…that was-that was really just a silly timing-timing issue (Maddelin, age 34).

Midwife Williams was aware of the tendency for pregnant women to forget about vaccines provided towards the end of pregnancy, but which are usually mentioned at the beginning of the pregnancy, "[After] the gestational age where they can take [vaccination]… we'll be saying… "What, what have you decided?" we're… reminding them, because… sometimes you [mention it] in the beginning and they completely forget" (Midwife Williams). As well as discussed by women of various ages and backgrounds in the interviews (as shown above), the inconvenience of booking extra vaccination appointments was discussed at length in the FGD. As FGD participants were all white, middle-class women in their 30s, this sentiment demonstrates that the inconvenience of booking extra appointments influenced maternal vaccination acceptance even among women who were perhaps more able to take time off work or arrange child care. However, while an after-hours vaccination clinic was suggested by FGD participants for such appointments, participants were aware that this may only be beneficial to those with a "standard" office job,

> Sasha (age 32): I had to book with the nurse to do the vaccine but I had to book after I'd seen the midwife… I guess it would have been easier if the midwife could just give you the jab.
> Nicola (age 35): Yeah, yeah, just save people… an extra trip [all: yeah], you know, to the GP or the hospital, seems like such an unnecessary, especially when you're pregnant… you're trying to do all this appointments and things.
> Marika (age 35): Yes, there's a definite thing I think that people seem to assume that you didn't have a job from the time you were pregnant… My hospital is close to home… but I work in Bermondsey… as soon as I stopped cycling, I basically had to take half day off work every time I had an appointment.
> Sasha: Yeah I took half a day to make an appointment.
> Chloe (age 35): It takes me over an hour to get [to my GP practice] from work, so there's no point going back afterwards.

> Sasha: I tried to do it in lunch once, and it was just so stressful… Here they do like evening appointments… so I probably would have rather had an evening appointment for a vaccine rather than 6.00 in the morning.
> RW: Do you think that would have helped?
> Sasha: Personally, I don't know if it helped with the demographic of Hackney in general. I think the middle-class, working woman.
> Marika: It does really depend… what type of job you do and what position you're in. Like, I've I've worked at my practice for 10 years, so when I got pregnant I felt like I had quite a lot of slack, I could be like, no I need to go to these appointments… But actually, if I'd started a new job, I would have felt really awkward about the amount of time I had to take off.
> Chloe: It's quite frequent towards the end isn't it?, it's every few weeks that you feeling, oh, that's another one coming up. I've got another half day.
> Sasha: I mean like you're entitled to take it as leave, but… that's the law rather than reality.
> Chloe: [Some people] can't just take a day off work and…if they… went, "do you want [to be vaccinated] now?" I'd be like, "absolutely".
> Sasha: And [midwives] wouldn't forget to do it either, would they, because they would have to carry all these vaccines around with them (Chuckle).
> Chloe: I've got [an appointment] today, if they said to me now do you want it now, the vaccine, I would just absolutely say yes, but if they say to me, oh remember to book an appointment with your doctor, then it's another thing. (Except from FGD).

A study by O'Grady et al., analysing access to maternal influenza vaccination among Torres Strait Islander women in Australia had similar findings; women felt that vaccination was difficult to complete due to competing priorities. One participant said that vaccines should be given to women when they were at the clinic, which would save them from having to book extra appointments (O'Grady KA, Dunbar M et al. 2015).

Another oft-cited frustration with vaccination appointments, was long waiting times due to over-booking or staff shortages, without, as stated by Marika above, staff acknowledging how much their patient had been put out,

> It's so busy, it's so overbooked… it was a first come, first served, rather than an appointment system…. I didn't mind waiting antenatally. Postnatally, I had a really horrible time and I ended up walking out because… you can't really do it with a baby… there wasn't anywhere to breastfeed (Rafeal, age 34).

Some participants were frustrated with the lack of organisation within the healthcare system, "with… one arm not knowing what the other arm is doing" (Margaret, age 41). Even when women were very pro-active about getting vaccinated, often the process was so disorganised or so complicated that they did not end up receiving the vaccines,

> I don't love having injections, but… I was surprised when it wasn't a part of my general antenatal care, when it was something that I just had to organise and book, and then everyone seemed quite confused by it all… I don't remember the midwife discussing it with me… some staff on my-on my ward got suspected, um, pertussis, um, and I think it was at that point that I was, like, oh, I need to get it sorted. Um, but it wasn't clear, and I'm a nurse, wasn't clear where you... how you organised it, who did it, who you needed to call. I think the midwife did say, "Oh, you should just make an appointment with the GP"… but that was only when I asked… everything's laid out as a schedule of all your appointments and… like when you need blood tests at 28 weeks, the midwife does them... when you need an ultrasound, it's booked in, and… that's something that's just not clear. So, I think it makes [vaccination] feel a bit less… important (Rafeal, age 34).

When another mother tried to book an appointment to receive the dTaP/IPV vaccine, she was told it was too soon to book and to call back in two weeks. When she did this, no appointments were available, "I was, like, 'It's all right... I don't think my baby's likely to get whooping cough… in the next week, but it's just, you know, sort your appointment system out" (Margaret, age 41). Idda experienced similar difficulties,

> My GP surgery is really shit (chuckles)… not because of the doctor… they're just completely disorganised…. it was not like I was called in for vaccinations… it was just impossible to get an… appointment with my GP… I tried several times… they were like… not today, no space, can you come tomorrow? Oh no, we're not in today… then… I couldn't get through to them, I couldn't get an appointment. I was worried about whooping cough… because I didn't manage to get the vaccine at the time when I wanted to take it (Idda, age 27).

In some cases, vaccine shortages were even reported at practices and pharmacies. For example, Lucy stated,

> I think one of the doctors did say I can have it at the doctor's, but then there was a-a shortage of vaccinations for some reason, so ... after the 35 weeks, that meant I would've had to wait for a good couple of weeks before he was born to get it, so I was, like, no, well, there's no point in doing that, then, is there? So, I'd done it at the hospital (Lucy, age 27).

The narratives drawn on in this section have demonstrated that there are various structural factors that affect access to maternal vaccination, which are often beyond individual women's control. These factors can affect access to, and acceptance of vaccination more among certain demographics than others. This will be discussed further in the following chapter.

Views towards vaccination information

The primary means used by the NHS to persuade parents of the importance of vaccination, and thus encourage vaccination compliance, are educational strategies such as brochures and leaflets, media and websites (such as the NHS website: *NHS Choices*), and information and advice-giving by healthcare professionals, backed up by reminder letters and texts. A midwife-led helpline is also available. A tension exists with this information-based approach, in that in practice, women are not always seeking 'facts'; the ideal of scientific knowledge as rigorous truth presented in NHS vaccination information, but seek information from a variety of sources, including from friends and family and the media, and are influenced by personal experiences. However, when it comes to healthcare, personal or experiential forms of knowledge are often considered illegitimate. The kinds of knowledge considered authoritative tend to be from Western notions of science and can be universalistic, transcend the particularities of individual experience, and serve dominant social structures (Lock M and Kaufert PA 1998). In this way, science is shaped by socio-political conditions, not just evidence, and is therefore both fallible and corruptible (Kuhn TS 1970). For example, much of what has passed for science in the past 200 years, especially where women are concerned, has not been the product of scientific enquiry, so much as it has been "the refuse of science re-purposed to support already existing ideologies in the interests of women's oppression" (Laidler JR 2004). This has included scientific research which aimed to 'prove' that women are inferior to men (Saini A 2017). In this section, I analyse how women perceive vaccination information emanating from scientific research and the state; and the tensions between this advice, which women are expected to accept, and the sources from which women actually obtain advice.

Many participants used *NHS Choices* to access vaccine and other information related to pregnancy, as they saw it as reliable, thorough, up-to-date and non-biased. However, the vaccine information presented on *NHS Choices* was not always perceived to be sufficient,

> I would go onto *NHS* [*Choices*]… it never broke down... I wanted an actual, um, definition of things, whereas it never gave you that actual thing. It just was, kind of, like someone just blabbering on... it wasn't really information that was helpful (Lucy, age 27).

Some participants had seen posters in GP practices about maternal vaccination and most had also received leaflets about it. Sometimes these were perceived as informative, especially for first-time mothers and those whose first language was not English. While hospitals often employed translators (a service which was used by Sabah, Turkish participant), Tami, a Japanese mother stated that when it came to verbal information about vaccination, such as from healthcare professionals and in antenatal classes, she could not fully understand the information provided. According to Tami, this was because her midwife had a "very native English accent… speaking fast and using medical jargon". Tami also said she was too nervous to ask questions in the antenatal class as it was such a big group and she did not want to disturb the session, so tended to ask questions when it had finished. This meant that leaflets were very important for her, as well as conducting her own online research through *NHS Choices* so that she could "catch up". Midwife Williams was aware of the importance of materials such as leaflets for those who did not speak English,

> I think if we want to protect everyone and if every baby does count, [leaflets] need to be in every language… I know for other leaflets or other documents that we consider to be important, it is available in other languages (Midwife Williams).

On the other hand, white middle-class women in their 30s tended to find leaflets and *NHS Choices* to be lacking information or unnecessary (especially if they had been pregnant before). Some of these mothers felt "bombarded" with information,

> I remember getting a lot of leaflets from the health visitor… which I just ended up recycling because… if you need to know things nowadays you would just go and look it up I don't think you would go and find that leaflet (Anna, age 34).

> Marika (age 35): There's like periods in your pregnancy where they just bombard you with information and then other points where you don't feel like actually you've seen anyone in ages or gotten any information about anything and… it's the same like after the baby is born… the health visitor turns up, you've just come home from hospital you're like "Uh, I have just given birth, like, I got a baby, I don't know what I am doing" and they are literally just like… "here is a form about this, here is a form about this" (chuckle)… and here is like every single vaccination your child is going to have until they're five, and I am like…
> Nicola (age 35): This is so not what I'm thinking about right now… I am just trying to get through the next two hours.
> Marika: We gathered it all up and put in a corner and were like, we will deal with that later (excerpt from FGD).

Isleen (age 34) stated, “Sometimes you can be given too much information and you sort of feel like, “Oh, okay, yeah, I know this is a good thing. I don’t necessarily need to know why.” Isleen said she was busy during her pregnancy and felt that if she needed more information, she would look it up in her own time “when you’ve got a moment to… absorb the information”. The widespread use of the internet by women was evident in the statement by Nurse Anand,

> I always try to give the leaflet if they are asking. They will be looking all over the internet for information before they come. So most of the time, I haven’t recommended any website (Nurse Anand).

Nurse Anand’s apparent disapproval of women’s internet use to find vaccination information may be evidence of the tension existing between perceived ‘acceptable’ sources of information-such as from the NHS-and ‘unacceptable’ sources which can be found “all over the internet” and are thus beyond the control of public health institutions.

The most popular websites used by participants were *NHS Choices;* online blogs and forums; especially *Netmums* and *Mumsnet*; *Baby Centre*; *The MayoClinic*; and *Medscape*. These websites were used to access information on vaccination (usually related to possible side-effects rather than the diseases they aim to prevent), pregnancy, birth and breastfeeding. Participants sometimes also used apps and email updates, such as from *Boots, Bounty* and *Mothercare,* especially to track the development of their foetus. Some (such as Hayley, age 34), who worked in medical publishing, also accessed the medical literature through such websites as *PubMed* and *Medline,* which they found more useful than NHS leaflets.

Some women mocked the use of forums such as *Netmums,* criticising ‘incorrect’ information and the opinions of other users, “There’s a lot of crap out there… Johnny Briggs can sit in a house and write a load of crap” (Rebecca, age 29). Participants were also aware of the influence of the media in propagating anti-vaccination sentiment and so were careful about knowing the sources of the information that they were looking at,

> I used to read a website called *Natural News*, which... I don’t think is that great, um, and then there’s also *What Doctors Don’t Tell You*… I look at things, and if it’s got a research study behind it, then I’d look at the research study. If someone just says something, I’m not, obviously, going to take that as gospel... and, I

> think from studying nutrition myself… there's a lot of whacky people... it makes you look at... what's backing it up (Rebecca, age 29).
>
> I did… internet research, but… trying to stay on the, like, the NHS home page, and not going to mum forums… where they're all going a bit potty (Maddelin, age 34).

Despite such criticisms, the wide use of internet forums (often before seeking GP advice)-which, through their participatory nature, enabled women to discuss or just read about others' opinions towards pregnancy issues and vaccination-provided an extension to women's 'real life' social networks,

> Nicola: I read the leaflet and read some um, some websites, just for further information… there's a few like evidence-based, sort of, more researchy websites about pregnancy… not like, *Mumsnet* or anything, but like science-based ones (Chuckle).
> Chloe: Not people claiming it's going to give their babies autism.
> Marika: The terrifying black hole that is Google when you're pregnant.
> Chloe: Sometimes [websites] are useful though, and then you're like… oh yeah it's fine, other people have got it (excerpt from FGD).

Lucy even personified the internet as a best friend, even though it was acknowledged that this 'relationship' was not always healthy.

> Within my pregnancy, that internet became my best friend, and it gave me information I didn't really want to know, but it wasn't actually… the right information. So, I was always told not to always believe everything that's on Google, because it's not 100% accurate…so you never know if it's the truth (Lucy, age 27).

While some participants were aware of the lack of accuracy and reliability of the information found through 'Googling' ("nine times out of ten, you're dying" (Sarah, age 22)), when they were not accessing specific websites, participants would often use online search engines, tending to look at the websites that came up first. They also used search engines if they wanted to carry out further research on an aspect of pregnancy that they had heard about elsewhere (one participant did this after watching the television programme *One Born Every Minute*). Television programmes were also a source of information about the negative effects of vaccination. For example, Margaret (age 41) and Gabriela (age 19) learned through watching a documentary that the influenza vaccine, *Pandemrix*, caused cases of narcolepsy in Norway (Norwegian Institute of Public Health 2017). The documentary led Margaret to be wary of new

vaccines when she was considering childhood vaccination and Gabriela to think twice about receiving the maternal influenza vaccine. Shiloh (age 19) (who did not vaccinate during pregnancy), also reported watching a documentary in which pregnant women complained of problems after receiving maternal vaccination.

Some participants also accessed YouTube videos, especially about how babies develop in the womb and about birth. However, YouTube and social media sites (such as Facebook) were also often a source of information (both correct and incorrect) about negative outcomes of vaccination. For example, Zoe (age 32) did not receive the influenza vaccine as she believed it not to be necessary and was worried that it could cause influenza, as was stated by a Facebook post that she saw, and supposedly experienced by a friend of hers. Additionally, Tessa (age 27), saw a Facebook post that stated that the dTaP/IPV vaccine caused stillbirth. Tessa hesitantly accepted the vaccine, as she believed "it was the right thing to do".

Often, women who were hesitant to vaccinate conducted a lot of their own research and sought advice from friends and family, some of whom had experienced or knew someone who had suffered from suspected side effects from vaccination. This was something they saw as "personal information, and less formal" (Bathild, age 35). Some (like Lucy), who accepted the vaccines, felt that they would have liked more information and guidance in making their decision, possibly due to feeling pressured into vaccinating and not being comfortable with this decision. On the other hand, those (like Idda), who declined vaccination, felt that they needed less information, possibly due to their mind already being made up before vaccination was offered. Some women defended their decision not to conduct research into vaccination,

> Obviously, NHS and the healthcare system… thinks [vaccines] are safe... So… I wasn't looking at loads of research to say [vaccines] weren't safe... I didn't research very much, I was just, like, no, I don't want to do this (Rebecca, age 29).

Rebecca used homeopathy and "good nutrition" rather than following the standard healthcare model, and instead of vaccinating during her pregnancy, as "there's a lot of other approaches you can take",

> My friend who's vaccinated... her child's been ill consistently… I wouldn't say to do with the vaccines, but I gave [my first child], like, infant probiotics... I think that really helped, and I've used homeopathy for her, and I think that with myself… obviously, homeopathy... I've used quite a lot of homeopathy with [my children] (Rebecca, age 29).

Poltorak et al., found that using alternative medicine does not reflect a simple opposition between pro-vaccination and anti-vaccination views. The influence of alternative therapies may lie less in their specific theories than in the empathy and support that they give to the ideas of personalised immune systems and women's decisions, which engenders the confidence to make the best decision for them (Poltorak M, Leach M et al. 2005). Similarly, in a study on HPV vaccine communication in Sweden, Linden found that girls trusted vaccination information more if it included the face of somebody they knew (i.e. a school nurse). Therefore, Linden argues that it is not vaccination information itself that causes trust or distrust in vaccination, but the people connected to the information (Linden L 2016). This dynamic will be explored further in Chapter 6.

Another reason for deciding not to conduct research into vaccination may be due to a rejection of the effort required, and the anxiety provoked, by navigating the minefield of other parents' advice about vaccination; the perspectives of anti-vaccination campaigners; and often inaccessible texts on immunology (Poltorak M 2007). As Idda (age 27) expressed, "It was quite difficult… I was buried in literature and I went back and forth, over and over and over and I had lots of anxiety when it came to that decision". In this way, more knowledge does not ensure a greater degree of certainty or less ignorance but may increase concerns (Llupia A, Mena G et al. 2013), as "the more we know, the better we know what we don't know" (Luhmann N 1993). This was found in a study conducted by Scherer et al., which discovered that the more vaccination information people read, the more risk-averse they became. When general information about the Vaccine Adverse Events Reporting System (VAERS) data relating to the HPV vaccine was given to participants, their trust in the Centre for Disease Control and Prevention (CDC) slightly increased and rates of vaccine acceptance improved. However, when detailed VAERS reports were given to participants, levels of trust in the CDC and vaccination decreased. One reason for this could be that detailed VAERS reports increased the vividness of side effects, making participants more risk-averse, even when they judged that the vaccine did not cause the side effects. Another

possibility is that the medical terminology used in the reports made them seem complex and unclear (Scherer LD, Shaffer VA et al. 2016). The reports may also have been interpreted in a way that bolstered some vaccine hesitant participant's pre-existing beliefs about the severity of vaccine side effects. This phenomenon was found in a study conducted by Poltorak et al., where only mothers who looked at information about the MMR vaccine that supported a previously held position, ended up making a decision about vaccination that they felt happy with (Poltorak M, Leach M et al. 2005). This means that misconceptions about vaccination, vaccine ingredients and their dosage is common,

> I don't know the specific ingredients, but I know that formaldehyde[10] is in some of the vaccines, and my concern is of, you know, the baby is so vulnerable… formaldehyde is a poison (Rebecca, age 29).

Some participants also believed that the maternal influenza vaccine could cause influenza,[11] and many believed that the vaccine was not necessary,

> The reason why [my mum] said no because… I even said the same thing. Back in the times, where Romans… when peoples having kids there was no vaccinations… So why should there be vaccinations now?... Flus are everywhere, viruses are everywhere, so you can never take a needle and say you know oh that's going to protect me (Shiloh, age 19).

The availability and proliferation of a wide variety of information-which is endemic to late modern existence (Foucault M 1976)- meant that participants obtained information about maternal vaccination from a range of sources, but those which were seen as 'informal' sources (such as advice from friends and family), were often seen as more important than 'formal', 'science'-based forms of information. This has implications for how vaccination is best recommended, and will be discussed further in Chapter 6.

[10] Formaldehyde is used in the production of some vaccines to inactivate toxins from bacteria and viruses. It is an organic compound found naturally in the bloodstream. The amount of natural formaldehyde in a 2-month-old infant's blood (around 1.1 milligrams) is ten times greater than the amount found in any vaccine (less than 0.1 milligrams). Vaccine Knowledge Project. (2017). "Vaccine ingredients." Retrieved 28th June, 2017, from http://vk.ovg.ox.ac.uk/vaccine-ingredients.

[11] The influenza vaccine provided in pregnancy is inactivated and so cannot cause influenza. Oxford Vaccine Group. (2016). "Flu vaccine in pregnancy." Retrieved 19th May, 2017, from http://vk.ovg.ox.ac.uk/flu-vaccine-pregnancy.

Conclusion

In neoliberal societies of deregulation, where, according to Giddens, bodies are increasingly viewed as flexible and alterable, as well as subject to processes of knowledge formation (Giddens A 1990), healthcare is turning into a marketplace, where patients choose their care and so are perceived as 'customers' (Mol A 2008). This approach to healthcare highlights the tensions that exist between the NHS rhetoric of patient choice and their constant push for active decision-making around vaccination; and their wish for patients to passively comply, or choose to comply with biomedical advice (and therefore make the 'right' choice), in order to protect the population's health. In this way, the individualist approach to healthcare jars with the 'one size fits all' vaccination programme and the discourse of herd immunity; which seems impersonal, without much scope for patient's inclusion in decision-making processes.

Additionally, there are many factors influencing acceptance of, and access to vaccination relating to the socio-economic situation of individuals, and the structural features of the healthcare system, so that not all women have the financial, linguistic capabilities, and social support to conform to the individualist ideal of care. This means that, although everyone has a right to health care in theory, access may be restricted in practice (Levesque JF, Harris MF et al. 2013). Efforts to increase access to specific population groups however, should be taken with care. In healthcare settings in the West, healthcare professionals are frequently encouraged to pay attention to the impact of culture and ethnicity on the knowledge and behaviour of their patients. This has sometimes led to the "medicalisation of culture". Such an approach makes few allowances for people of divergent countries of origin who speak the same language; and socio-economic, generation and educational differences among people, denying the multiple ways in which people conceptualise health and their bodies. In blaming certain groups for not accessing various healthcare technologies such as vaccination, as some vaccination rhetoric does, the responsibility of healthcare institutions to ensure equal access to healthcare across population groups is masked. In many cases, as was demonstrated in this study, the inability to travel to medical facilities for example, accounts much more for apparent non-compliance than 'embedded cultural resistance' (Bhopal RS 2007).

Whilst the approach by healthcare institutions to increase vaccination acceptance is to provide patients with 'scientific' information in the form of risk/benefits, the majority of participants said that such information was either too simplified, or that they felt "bombarded" with information during their pregnancy. Instead, women use a variety of sources to access vaccination information, and many rely on their own experiential knowledge, which they can use as a basis for accepting or rejecting healthcare professional's recommendations (Lock M and Kaufert PA 1998). This means that vaccine hesitancy reflects highly sophisticated and nuanced forms of expertise grounded in everyday practice, knowledge and epistemology, which is produced by a community of people, in conditions of social interaction and communication (Wagner W, Farr R et al. 1999). Such knowledges are expressive of identities, concerns, interests, history and culture. Lohm et al., found in their study on pregnant women's experiences of the 2009 influenza pandemic, that women provided highly reasoned explanations for chosen healthcare behaviours, even if such behaviours differed from public health advice (Lohm D, Flowers P et al. 2014). However, such knowledges are often dismissed by healthcare institutions and professionals, with the assumption that vaccine questioning is due to misplaced priorities, is irrational and due to ignorance (Leach M and Fairhead J 2007). Such assumptions may be made especially of lower income and lower educated women, who are believed to passively accept vaccination. In reality, they may actually be hesitant to voicing their concerns about, or discussing vaccination, due to fears of being patronised or judged by healthcare professionals, or attracting the attention of government authorities.

The findings analysed in this chapter have demonstrated that in understanding those who are hesitant to vaccinate, it is important not only to focus on their views of science but its social and institutional embedding, and its forms of governance or control. These are axes that can alienate certain women from healthcare settings, and lead them to disengage with healthcare services (which in turn leads to stigmatisation by healthcare professionals and public health institutions), or to feel that they must arm themselves with information before consultations, in order to defend their healthcare decisions. This causes anxiety and places additional burdens of responsibility on pregnant women, whose bodies are already so thoroughly (self) regulated.

Chapter 5: How various socio-political contexts influence views towards maternal vaccination among specific population groups in Hackney, London[12]

> *Encounters with government vaccinators are never about immunization alone* (Greenough, 1995).

Chapter 4 analysed the broader perceptions of maternal vaccination relating to 'the system' that provides them, and in turn, how current healthcare rhetoric portrays pregnant women and produces inequities in access to vaccination between populations. I argued that implicit distrust in vaccination runs deeper than fears of vaccines themselves and are indicative of the socio-political context in which vaccines and those for whom they are intended, are situated. In this way, perceptions of vaccination that may lie at odds with biomedical rationalities make sense as part of these particular contexts (Leach M and Fairhead J 2007). In this chapter, I explore this idea further by analysing the concepts and metaphors participants use when talking about their vaccination views and experiences, and how their narratives integrate bodily and socio-political reflection. I focus on how current and historically located dimensions of governance, and social (especially familial) influences, can affect maternal vaccination acceptance, specifically among self-described Black British Caribbean participants[13], and compare the quite striking influences on their views towards vaccination, with those of participants from different backgrounds. The participants whose narratives form the main focus of this chapter, are five self-described Black British Caribbean mothers and one self-described Black/White British Caribbean midwife. The British Caribbean mothers were between 18 and 28 years old, four were educated up to secondary school level, and one had a Bachelor's degree. Three mothers were single and two were cohabiting. None of these participants had accepted the maternal influenza vaccine and only two had accepted the dTaP/IPV vaccine (one very hesitantly) during pregnancy. The British Caribbean midwife was aged 41 and had been practicing as a midwife for five years.

[12] An article based on the analysis included this chapter was submitted to Ethnicity and Health on 14th December 2017.

[13] The Black Caribbean population are normally known as people of African descent and were born in the Caribbean or originate from families which include people born in one of the Caribbean islands. The National Archives. (2017). "The Cabinet Papers: Immigration controls." from http://www.nationalarchives.gov.uk/cabinetpapers/themes/immigration-controls.htm.

Significant immigration from the Caribbean to the UK began in 1948 in response to demand for labour in the UK due to post-war reconstruction and economic growth (Law I 2008). When migration accelerated during the 1950s, relations between Black and White populations became tense and race riots occurred in London and Nottingham. Such incidents over the past 50 years have largely occurred in poor areas where people compete for scarce employment opportunities and housing (The National Archives 2017). The Black British Caribbean population still experiences incidents of racism, xenophobia, hostility, violence and practices of restriction and exclusion, and are more economically disadvantaged compared to other population groups, thus affecting their access to healthcare, including vaccination (Law I 2008). The latest data shows that the proportion of people who live in low-income households is 20% for White people and 30% for Black Caribbean people (The poverty site 2010). Employment in vulnerable sectors and concentration in poorer areas which offer fewer opportunities, as well as lower levels of individuals attending higher education institutions, have resulted in high long-term unemployment for this population. People from the Black Caribbean population are also overrepresented amongst the homeless and are less likely to vote in elections than White and other ethnic groups (Law I 2008). In Hackney, 20% of children live in poverty overall but Black Caribbean children have rates of poverty of 26%. Similar to national data, neonatal mortality rates in Hackney are higher among Black Caribbean infants (Hackney council 2014). Additionally, a 2015 study found that maternal dTaP/IPV vaccination uptake in London greatly differed by ethnicity. The highest uptake was among White women (30%) and the lowest (19%) among Black women, with the poorest uptake being seven percent among Black Caribbean women (Donaldson B, Jain P et al. 2015).

In order to meet its economic interests, the capitalist economy has created the major social axes of the modern world, including classes and racial groups (Solomos J, Findlay B et al. 1994). The hegemony engendered by the creation of such axes is not stable but is constantly reshaped by the operation of various socio-economic structures (Hall S 1980). These are social realities that Western researchers have often overlooked when investigating women's experiences (Kumar R 2013). Thus, the analysis in this chapter incorporates an intersectional approach that includes an examination of the inseparable and interdependent axes of ‘class’, as well as gender and ethnicity. Such an approach is crucial to analysing health inequalities as health is a multidimensional

construct and the intersections of identities can play oppressive, as well as “leveraging” roles (Joe W 2015). As Deborah Levenson-Estrada argues in relation to the class axis in a study of women union activists in 1970s Guatemala: "There is no ‘more important' or ‘prior' issue-class or gender-these are inside one another” (Levenson-Estrada D 1997). I therefore aim to consider how the intersections of the axes of class, ethnicity and gender among participants interviewed for this study influenced their attitudes towards, and access to vaccination, while through their narratives and the theories underlying this study, retaining a category of ‘ethnicity’ that is sufficiently coherent to form the basis of effective analysis (Scott H 2006).

Distrust in the organisations and healthcare professionals who promote vaccination

Distrust in the state and institutions that deliver and distribute vaccines has been linked to past experiences of coercive colonial health campaigns (Feldman-Savelsberg P, Ndonko FT et al. 2000), problematic actions by international pharmaceutical companies, and economic reforms that have weakened the accountability of health services to local populations (Leach M and Fairhead J 2007). According to Martin, due to the impact of colonial legacy, power and social inequalities in the woman-healthcare institution relationship, poor and black women may be more resistant to biomedical interventions (Martin E 1987).

Renee, a 41 year-old British Caribbean midwife (who was against vaccination in pregnancy herself) mentioned that more Black Caribbean than White women decline vaccination due to distrust in what the vaccines contain, as vaccination is “something that the government are putting in people”. This sentiment was evident in the narrative of one of the Black British Caribbean mothers interviewed, “They say there’s certain things in there… there’s more things when you look into it… there’s definitely some things that can be hurting you or your child… No one ever reads the small prints” (Shiloh, age 19). Tessa also had suspicions that the vaccines could affect various populations differently, and Samantha was sceptical of the need for the maternal dTap/IPV vaccination,

> I read a lot of things… about the way the, um, vaccines affect people and affect different cultures differently. Different races and things like that. And that concerned me (Tessa, Black British Caribbean mother, age 27).

> I've never heard about this whooping cough [vaccine] until I came to this country [from Jamaica]. All the other things I'm aware of and they're more… well-known… but this whooping cough one, I don't know anything, like too much about it, so I was a bit more reluctant to, yeah. And if it was that important it would be amongst the childhood vaccines, no? (Samantha, Black British Caribbean mother, age 28).

In many participant narratives, the term, "they" was used to mean the government or the healthcare system, but conjured connotations of a malevolent higher being, "When you're introduced to one needle, *they* [emphasis added] want to carry on calling you up after and… letting you go and take more and more and more… It's not right" (Shiloh, age 19). Distrust in vaccination then, may be about the unidentifiable and unaccountable "they" described so negatively throughout Shiloh's and other participant's narratives. Both Shiloh and Jane showed sentiments of suspicion and distrust in the healthcare system when they mentioned that they were sceptical as to whether healthcare professionals accepted vaccination themselves. Jane said that to feel at ease about vaccination, she would ask the doctor if she had received the vaccines herself, and "would have to see in personal writing that they have had this done" (Jane, Black British Caribbean mother, age 24). She also wanted to know how many people had been vaccinated since the vaccine was introduced. Shiloh stated that she did not trust healthcare professionals' advice and questioned the authenticity of the vaccines, as she believed healthcare professionals did not get vaccinated themselves, and wondered why she should. Tessa was also concerned that vaccination information provided by healthcare professionals comes from the NHS and is therefore biased,

> I feel like they've all been given the same information. It's all coming from the NHS… So they're all going to advocate taking vaccines… I feel like it's important to get it from someone who isn't part of the NHS as well (Tessa, age 27).

When individuals encounter perceived risks, they often unconsciously draw on ways of thinking, metaphors, and symbols that are acceptable to the groups with which they identify. Among historically oppressed groups, these ways of thinking can be used in forms of resistance and the struggle for recognition and justice (Anspach R 1979). For example, Shiloh used powerful metaphors, which have connotations of forced experimentation and covert violence, such as "guinea-pig" and "Russian roulette", to describe her concerns regarding the maternal vaccination,

> I just, I think that we're guinea pigs… I really feel like there's a guinea pig test done… And that's why I didn't, that's why I said no… we're guinea pigs to it… because it's like every time you have a child something new comes out… When I told my doctor that I didn't want [the vaccines], they was like it can help you in your pregnancy… they jab you… the percentage goes into you and a little percentage goes into the baby… So it's like, there's that one percent chance it can have that effect on the child… and it's one percent chance it won't, so you're just taking a Russian roulette chance… while taking it. That's why I didn't want… to have the vaccination (Shiloh, age 19).

The choice of the metaphors used by Shiloh is not arbitrary and is inseparable from the history and culture of the society in which Shiloh is situated; inevitably structuring thought and activities surrounding vaccination (Wagner W, Farr R et al. 1999). These thoughts and activities can in turn bolster the strength of such metaphors.

As in the UK, vaccines are provided by the government, the perceptions of maternal vaccination by British Caribbean participants, which included concerns about what the vaccines contain; fears about how they could affect various races differently; and metaphors with connotations of violence, could be linked to historical distrust in the UK government. This is plausible considering British-Caribbean colonialism, and that since the 19th century, women and ethnic minority groups especially, have experienced an increasing appropriation of their bodies as a site for medical experimentation, particularly in connection with pregnancy and childbirth (Feldman-Savelsberg P, Ndonko FT et al. 2000). Additionally, more recent forms of experimentation on Caribbean women with the contraceptive pill in the 1960s involved, "Caribbean women acting as guinea-pigs of one of the most revolutionary drugs in the history of medicine" (Oudshoorn N 2002). In the next section, I analyse how other identities that intersect with ethnicity, influenced these participants' acceptance of, and access to maternal vaccination.

Intersectionality and dealing with government authorities

Bourdieu's notion of habitus is useful to conceptualise the ways that choices, such as around vaccination, are both shaped and constrained by individuals' social position (particularly their ethnicity, gender and class), and are formed within the structural conditions within which people are located (Bourdieu P 1984). Thus, among certain populations, vaccine perceptions are largely influenced by the knowledge that vaccines are provided by a government and governmental authorities that harbour institutional

racism and often stigmatise young, pregnant, single women of lower socio-economic status (Solomos J, Findlay B et al. 1994) (Brand G, Morrison P et al. 2014), (Dillaway H and Brubaker SJ 2006), (Kelly DM 1996).

As discussed in Section 1, in Britain, vaccine hesitancy; the fear of attracting the attention of governmental authorities; and experiencing pressure to vaccinate, dates back to the 1800s. While anti-vaccination was a national movement after the introduction of the Compulsory Vaccination Act in 1853, it gained most support in working-class regions. The strongest support in London came from the working-class communities of Hackney, Mile End, and Tower Hamlets. In order to carry out smallpox vaccination, the most common method for vaccinators was to take 'lymph' directly from an infected infant's blister and then smear it into a cut made in another infant's arm. After 1871, a fine could be imposed upon parents who refused to allow lymph to be taken from their child for use in public vaccination. In this way, infants were "not only recipients of vaccine matter, but its incubators" (Durbach N 2000). It is unsurprising that this angered working class parents especially, who were less able to accept fines; meaning that their children more vulnerable to vaccination experimentation. In Gloucester ten years later, a policy of 'Vaccination or Starvation' forced working people to be vaccinated or become unemployed. Vaccination officers employed to track down resistant parents often held other Poor Law appointments. The Poor Law was despised by the working class as it forced all recipients of government relief into the workhouse, thus the fact that these employees were administering vaccination ensured it was immediately unpopular. Working-class anti-vaccinationists in 1871 consistently portrayed themselves as tracked, scrutinized, and policed (Durbach N 2000). These sentiments were not dissimilar to those of the participants mentioned in this chapter.

> I was signed on to Social Services… It was like they was just watching me, every move I was making with them…they was looking to see… if you're doing everything right… so it just felt not right… because of my past [domestic violence by ex-partner] and my ex-partner, he came [to the hospital] for the first time… because we both thought that was right… all of us… going to these appointments. And soon as I went there… [the hospital staff] called Social Services to say I came here with him… and then through that it just felt I had to go the clinic by myself after that (Shiloh, age 19).

As ethnic minority groups are often disproportionately represented in lower income groups, experiences attributed to ethnic differences could be confounded by socioeconomic differences (Lindquist A, Knight M et al. 2013). Thus, as young,

unmarried, unemployed Black Caribbean mothers, it is possible that the intersection of their socio-economic position, ethnicity, and gender had consequences regarding Shiloh and Jane's treatment by government services, which can see women with such identities as irresponsible and in need of management,

> I was told, if you don't... *make* [emphasis added] the child get all their injections that… they can… bring up, like, my background… see if I had a social worker, and social worker can get onto my case because... it's like I'm not protecting the child… that's what I was told by one of my midwives… she's the one that closed my case, after I told her, "yes, [my daughter] will get all her, um, injections"… These injections are new to me, so for me to just say, yeah, I'm going to give it to [my daughter], it's something that I was kind of being forced to do, without... thinking about it… and the same GP… she told me that you need to… and I-I felt intimidated, and I feeled under pressure because she was telling me that... these are the things that can happen if you don't get the child [vaccinated] (Jane, age 24).

Shiloh and Jane's narratives invoke notions of coercion and blackmail; Jane felt forced to vaccinate her daughter without having a chance to consider or discuss it. Here, the threat that the state would be involved in the form of Jane having a social worker "on her case" if she did not vaccinate her child, demonstrates one of the ways in which women are punished for failing to conform to ideologies of 'being a good mother'; through state-imposed disciplinary regimes (Salmon A 2010). This is the case particularly for women marginalised or discriminated against due to their ethnicity and socio-economic position. For example, in a study by Paltrow and Flavin, which analysed arrests of, and forced interventions on pregnant women in the USA, 16% of participants received threats of, or actual arrest; incarceration or increased prison time; institutional detention; or forced medical intervention, due to claims that they had not obtained prenatal care; had mental illness; gestational diabetes; or had suffered a pregnancy loss. Most cases were reported by healthcare professionals, social workers, the mother's hospital, and child protective services. Strikingly, healthcare professionals reported Black women at almost double the rate of White women, despite the fact that in most cases, there was no reported health issue cited in the allegation. Instead, concern for the health of the foetus was typically offered as a reason for increased scrutiny or detainment (Paltrow P and Flavin J 2013).

Observations of the way in which pregnant women are treated by various governmental authorities in my study, are not a critique of individual healthcare professionals, but

instead demonstrate that parents with few resources sit on the margins of society in these situations. They are less able to demand services, less likely to view providers as contributing advice rather than dictating behaviours, and are more likely to be reported to state agencies or social workers than privileged parents, who do not have to worry so much about these threats and thus have more choice in their vaccination decisions (Reich J 2016).

Similarly, for mothers without established social networks with other parents or family members, or who receive little support from healthcare professionals, the social relations of parenting are structured differently to those who have large social networks and support. In this way, social capital can play a large part in individuals' decisions to vaccinate and in their access to vaccination. According to Bourdieu, social capital is,

> The sum of the resources, actual or virtual, that accrue to an individual or a group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition (Bourdieu P and Wacquant LJD 1992).

Women with little social capital may feel excluded from the healthcare system. For example, participants whose first language was not English, would sometimes ask for advice about the vaccines-such as the names of the vaccines in their own language-from friends and family in their home country or who had also moved to the UK from their home country. One Turkish mother (Sabah, age 32), did not go to antenatal classes because she did not speak English, and instead went to informal Turkish-speaking groups to seek advice about vaccination. Because of a lack of translation services, such women may be excluded from some healthcare services. This was discussed in the FGD,

> Chloe (age 35): You have to be quite on the ball... its quite easy for you to slip through the net… You know the fact that I was not even really sure I was aware of [the vaccines]… But, to be quite on the ball.
> Nicola (age 35): Yeah it does makes you worry, like there's probably so many people that, that are less able to call… Or less on the ball or whatever… Or less aware…
> Chloe: They can't just take a day off work…
> Marika (age 35): I felt it was the same during pregnancy that, because I'm reasonably on the ball, English is my first language and lived in London my whole life. I was completely able to kind of navigate the system and be like, no I want this or I don't want this. And it did make me think that actually if you were, if English wasn't your first language or you weren't from the UK and you weren't

> even aware of what you're entitled to (FGD excerpt).

The White middle-class FGD participants may have been showing empathy for those who find it difficult to navigate the UK healthcare system; however, they use the phrase "on the ball" four times (by Chloe twice, Nicola once; and Marika once). This could be because they were sharing each-others language and metaphors. However, in the comparison with themselves being "on the ball", and non-English speakers not being so, the expression has patronising undertones, inferring that those who do not speak English, or who are not from the UK, are not perceptive or responsive. In a society where professional education and the ability to speak English are held in high regard, it is not surprising that the non-English-speaking women that these participants speak about, may feel patronised or that their concerns are dismissed in 'formal' healthcare settings (Bradley S, McCourt C et al. 2016).

Two English-speaking participants, who were both unemployed single mothers, also felt a sense of isolation from the healthcare system,

> Some people tell me that… there's [antenatal] classes… I never went to any, no-one ever told me about any classes and things like that… so I was a bit disappointed (Ava, White British mother, age 26).

> I'd moved… and then they said to me I have to sign up with another doctor's, but then the doctor's… said to me I had to have a bill to show that I was living there, which was really inconvenient... I felt like, as if, like, I wasn't a UK resident, like I'd just come here, and it was like I was just looking for a doctor's… I'd done basically everything myself (Lucy, Black British mother, age 27).

Lucy was made to feel so excluded that she reported being treated as though she was not a UK resident. This is an important observation considering that support from those working within healthcare was especially important if women had no family support,

> My labour was also quite horrific… it was quite traumatic. I had forceps delivery… it was really painful, because I was induced… straightaway they [healthcare professionals] don't care… I didn't have family support either, so it was really hard for me (Haleefa, Somalian mother, age 27).

The model of individualised healthcare, with its notions of complete patient autonomy, which expects patients to make decisions on their own, can lead to a sense of isolation and vulnerability during pregnancy. For one to make the autonomous, 'rational'

decisions expected of patients, certain minimal conditions are required, which enable the state of a 'well-functioning' individual (Buss S 1994). However, these minimal conditions are not available to everyone. Most women's decisions are impacted by gender and racial norms, other oppressive social conditions, and internalised oppression that undermine or erode their autonomy, which the hyper-individualised conception of autonomy does not capture. Therefore, for many women of lower socio-economic status, the individualised model of healthcare just places more burdens of responsibility on them, and can overwhelm their ability to make informed medical choices. This sometimes leads women to wanting to hand over certain decisions-such as about vaccination-to healthcare professionals. For example, a young unemployed Nigerian mother, who had recently moved to the UK said, "my first midwife… said just use NHS [website] otherwise its confusing, and I do. It's… just all so contradictory. Someone has got to make a decision for you" (Haadiya, age 19). In this way, there existed a strong desire for support in making healthcare decisions among marginalised women,

> I went in to be checked they said they're not sure if it was my waters [broke] and I'm saying to them, "It was my waters, I've done this before" and they was like, "We're not sure"… You expect when you're going into someone's care for them to say, "Right well this is what's happening". Not, "What do you want to happen?"… Because one doctor said they're going to induce me, the other one said, "No we're sending you home"… [They] wouldn't listen to anything I was saying. And then eventually a midwife, because I broke down in tears and I was like, "No-one knows what they're doing in here" and then um she was like, "What do you want to do?" and was like, "I don't know but I just want my baby to be safe". So she said, "Alright well what if I make the decision for you?" and I said, "Okay" and she said, "Right you're being induced". I said, "Alright"… She was lovely. I remember her (Ava, White British, unemployed mother, age 26).

Additionally, patients have different needs for support than in other situations in life where they are not patients, and where being 'autonomous' may be preferred. Patients need to be *cared* for; they want support-not to have to make decisions alone in vulnerable situations, and thus feel neglected. Sentiments of marginalisation and neglect during her pregnancy and the birth ran through Shiloh's entire interview. When she was asked if enough information was provided during her pregnancy, Shiloh stated, "I was just working off my own mind… I… had no help from doctors… I had to learn by myself". Shiloh felt that during her pregnancy, she was not a main priority; she experienced a lack of empathy from healthcare professionals and overall, felt neglected. She could not go to antenatal classes as she was moving house and did not know about

parenting classes, even though she would have liked to attend some, and felt alone unless her family was with her and defending her, "My mum, my sister was at work… I didn't have no one there until my auntie [said]… "she's in pain can't you give her a bit more… paracetamol?" (Shiloh, age 19). These sentiments of neglect extended to comments on the current state of the NHS and possible funding cuts,

> I've got a lot to say about __ Hospital (chuckle)… It ain't good (chuckle)… A lot of people who has had children there said the same thing… My cousin, which works there, she even said… they don't really care about their patients… there's no money in the NHS for the maternity ward…. they can't do anything… There's too much pressure on the doctors, too much pressure on the nurses, midwives… getting paid less… and it's going to mess up the NHS… it will go back to where people are having their kids at home themselves… my sister-in-law is having her baby and she signed up to… __ Hospital… and they've closed the Midwife bit down… So [she]… had to go all the way to Romford… to have her child… We can't do nothing unless, I've got a good way, kick Cameron[14] out… kick him out. Go back to the old times (Shiloh, age 19).

The above narratives show that when women fall into intersecting social categories in which members often face discrimination and oppression, experiences of poor care and marginalisation are exacerbated. These experiences can engender negative views towards governments and therefore government-funded healthcare systems, and thus vaccination. Such concerns can be intensified by negative family and community views towards the healthcare system, and can greatly influence vaccination decisions.

Family and community influences on vaccination decisions

Even with the current culture of individualism in the West, people rarely make vaccination decisions as single individuals. Perceptions and constructions are reproduced both in the public and private spheres; which include the family, governmental organisations, corporations and the media (Bourdieu P 1977), and individuals tend to be strongly influenced by members of their own reference groups. This means that they discuss vaccination with relatives, neighbours, friends, colleagues and religious advisers, drawing upon their advice and personal experiences (Caplan P 2000). For example, mothers who belong to a social group formed around their children's school, often develop nearly identical fears, concerns and questions or attitudes about vaccines that they did not hold prior to membership of the group

[14] David Cameron, UK Conservative Party Prime Minister at the time of data collection.

(Milligan G and Barrett A 2015). Discussions among people who decide not to accept any vaccines thus usually take place in specific settings, such as with alternative therapists or at antenatal groups. This was the case for Rebecca, who preferred to use alternative medicines rather than vaccination, and Idda, who attended National Childbirth Trust (NCT) classes,

> Of my antenatal group, over six of us, um, three have not vaccinated… and the other three have… I think in Hackney, as well, I think there's a lot more of, maybe people... think differently… in terms of within our group of people, I think there's certain... people who live in Hackney... I think people maybe think or question things a bit more (Rebecca, White British mother, age 29).

> I, uh, sought advice from the other mums at the NCT group and then listened to what they had done… I think most of them had [maternal vaccination]… At least 50% of them (Idda, White Norwegian mother, age 27).

When asked who made decisions about their health, all 40 women interviewed immediately and usually proudly, responded "me". However, later in the interview, when asked specifically if there was anyone or anywhere they would typically go to for advice regarding their health or vaccination, all participants mentioned friends or family members, (usually female family members such as sisters who already had children, mother-in-laws, mothers and aunts), as well as, or rather than their GP. For example, Shiloh reported that she and her mother made decisions about her health. While these answers seem to contradict each other, relational autonomy suggests that, due to the nature of 'society' and the idea that no-one is completely individual or untouched by others, one can engage with others in important health decisions and value their input, while still feeling autonomous. Often participants sought advice from these contacts not because they were looking for actual information, but because they wanted personally focused discussions and advice and to feel comfortable and cared for. This demonstrates that the source of advice can be more significant than its 'factual' content. Mothers value the informal, friendly and egalitarian quality of conversations with other mothers, where little heed is paid to people knowing more than others, or by having done more research. These conversations allow mothers to express what they regard as valued parenthood, their sense of responsibility, and their views of government institutions (Poltorak M 2007). Based on shared experience, where concerns are taken seriously, such interactions can increase feelings of autonomy, as they allow an in-depth exploration of vaccination and thus empower women to make the best decision for them (Walter JK and Friedman Ross L 2014).

In addition, ten participants had family members who were healthcare professionals, whose vaccine advice was trusted more than advice given by non-related healthcare professionals. Such advice often carried warnings not to vaccinate,

> My sister [who is a midwife]… informed me of the fact that… testing vaccines in pregnancy is really limited because obviously not many pregnant women are going to say, "Yeah sure… try me out with this, see what the side effects are", so that really put me off wanting to have anything… when you're told by doctors and nurses that you need to have that it's quite difficult to… argue unless you… have somebody, like I have my sister who is a midwife… I would've trusted my sister more for honest advice because… [healthcare professionals would] be promoting all the… injections… and I've read lots of stories of children being really unwell after having them… a doctor, a nurse wouldn't tell you that, they'd say, "Oh no of course you have to have that" (Anna, White British mother, age 34).

Another participant asked her grandfather (a retired doctor) and her stepmother (a paediatrician) for advice. When asking her grandfather about the influenza vaccination during pregnancy, he responded,

> You're not allowed to medicate pregnant women and especially vaccines… Don't get anything because there is no research how it will affect an unborn child, it needs to be studied for 20/30 years to know… if there is any effect… don't become a guinea-pig (Aldona, Lithuanian mother, age 29, quoting her grandfather).

Because this advice not only came from close family members, but family members who were also healthcare professionals, it was extremely influential.

Interestingly, participants with male partners tended not to seek advice from them as much as from their female friends and family members, and so in many instances, they were not engaged in vaccination decisions. Some women, actively excluded male partners or fathers from the decision-making process. For example, Rita employed a rather patronising attitude towards her partner's understanding of vaccination and pregnancy, illustrating that she herself was in control of her body,

> My partner doesn't factor in... I read, when I was pregnant… an article… this man is, like… "when my wife was pregnant, I discovered all the things she couldn't eat, so I had to cook her a special meal every night…" I'd have murdered him if he'd said anything like this… I know some people feel like it's their [partner's] baby. But, I don't…When it's inside me, it's my baby (Rita, White/Jewish British age 27).

However, the fact that male partners were not involved in vaccination decisions may not have always been the woman's choice, and may have sometimes placed an extra burden of responsibility on her, demonstrating the gendering nature of ideals of individual empowerment when it comes to pregnancy (Linden L 2016). For example, Rebecca recalled, "I don't really think I spoke to my husband about [vaccination] [Laughs]. Because, he's really busy" (Rebecca, White British, age 29).

While the above narratives demonstrate the importance of social influences on vaccination decisions for all participants, British Caribbean mothers in this study relayed family members' experiences and views towards vaccination more often and in more detail than other participants. For example, Shiloh said that her mother and aunt advised her against maternal vaccination because "when [my aunt] first came to the country 21 years ago… when she did take the flu jab, she constantly got sick" (Shiloh, age 19). Samantha and Jane relayed similar family experiences, and expressed how these experiences influenced their maternal vaccination decisions,

> Samantha (age 28): I've never had the flu vaccine, but I've had loads of friends, family have it, and it's always negative things. Like even my granddad, they call him for flu vaccines… and he's always grumbling afterwards of like feeling a bit like weak with the flu, and it's kind of like why would I have that if, if I've seen other people go through that? No… especially in a pregnancy as well. You already feel tired and weak.
> RW: you said you… ask your mum if you're not sure what to do. Did you discuss vaccination with her?
> Samantha: Yeah… she said "no, don't have it"… She's more like… natural health person, like not to do with medicated stuff… so she's… against that kind of stuff anyway… I had already made my decision, but… when you talk to her and she's… saying all of this kind of… add[s] to all the things you already thought of.
>
> Jane (age 24): [Healthcare professionals] asked me if I wanted the flu jabs. Um, I told them no, not after my aunty was ill, and my cousin was ill… my aunty advised me not to get the flu jab.
> RW: You said you had a discussion with your-your aunt about it... do you think… because she advised not to get it… you were influenced by her?
> Jane: Yeah… None of my family's got it. None of my family members mentioned anything about it… now, we're Jamaicans, we've got friends, we've got more relatives that's Jamaicans, I've heard it through... So, obviously… if I was [pregnant now], I would get it done because… I've heard it several times now.

Tessa also spoke about the decision of her niece's mother not to vaccinate her infant, and how this influenced her vaccination decision,

> Tessa: I've got a niece, and her mum and dad haven't given her any vaccines… and she's like s-, she's six, seven, now… and she's fine.
> RW: And do you think their decisions influenced yours about vaccinating?
> Tessa: Um, a little bit, yeah… I would say yeah (Tessa, age 27).

Additionally, while Shiloh's mother advised her against maternal vaccination, when she had previously encouraged her to have the relatively new HPV vaccine (introduced in 2008 (Department of Health 2011)), Shiloh decided to accept it,

> RW: Why do you think that you decided to have [the HPV vaccine] or that you accepted?
> Shiloh (age 19): Because it was a new thing out and it was to do with cancer… And my mum… I never had the choice to say no or yes… So my mum had, had to let me do it.
> RW: So your mum really encouraged you?
> Shiloh: Yeah.

Similarly, despite declining maternal vaccination, Shiloh, as well as some of the other mothers interviewed in this study were angry that their infants were too old to receive the new meningitis B vaccine (introduced in 2015 (Meningitis Research Foundation 2016)),

> I think the [vaccine] which I would have wanted my son mostly to get… which he never got because he was too old for it, was the… what's that one they was talking about on TV about yesterday?... one where you can lose your limbs during it… my nephew [had it]… the meningitis one. I would have wanted my son to mostly have that… But now they're saying that from… five months and under… I think it should be suitable for any child's age… Because… they say you never know when you're going to get it… So right now it's actually put me on a panic where when are they going to sign that paper to say… that kids can get it done, er-, late?... that came out after I had him… he was what, six months and we still couldn't get it… So it's like what am I meant to do? We were discussing me, my mum, my sister, were discussing it. Um, my sister asked the doctors… on TV they said you have to pay £95 to get the jab done… and you can't get it on NHS… Last night. It was constantly on the news from… six to ten o'clock in the evening (Shiloh, age 19).

The fact that Shiloh's mother had encouraged her to have the HPV vaccine, and the knowledge that her nephew had received the meningitis B vaccine, and the vaccine had featured in the news a lot around this time, could have normalised the vaccines and

affected their perceived safety and necessity. In contrast, the maternal dTaP/IPV and influenza vaccines had not been discussed in detail with Shiloh. Such differing views of various newly introduced vaccines demonstrate that concerns are not always about vaccines being new (in fact, Shiloh's narrative demonstrates that new vaccines are sometimes sought after). Instead, trust in vaccination and the healthcare system in general is strongly influenced by friends and family members' views and past experiences and stories, with, according to some participants mentioned in this chapter, older family members being very clear that they are against vaccination. This could influence younger family members' decisions to vaccinate, as observed by Midwife Renee,

> I used to work… in elderly care… and obviously [vaccination] was very much encouraged… And you would hear year-on-year people saying, "Oh, I had it last year, and I got really ill"… and I think maybe… [negative sentiment] is passed down from… people that have been vaccinated recently (Midwife Renee).

The strength of this influence was evident in the observation that Black Caribbean participants especially, preferred to adhere to and trust family advice and the advice of those within their community, over advice from healthcare professionals. Shiloh even perceived her mother and aunt to be more medically competent than her midwife, attributing the survival of her son to their intervention during the birth,

> Every time I went [to the hospital] there were problems… all they did was just check on the baby and send me home… I was vomiting… and went hospital. All they did was just tell me have rest, plenty of water… And that was it… My mum had to help me out of bed… my sister and her boyfriend… rushed me to the hospital… and then sent me back home telling me to rest. And I was back less than 24 hours into the hospital… and every time I asked for help they will be like oh don't worry someone's coming. And because of my mum, my sister was at work, it was like no, I didn't have no one there until my auntie came… to say that she's in pain can't you give her a bit more… paracetamol?... she's literally in pain… when I was in labour with him, I didn't feel like I was looked after… because… one of the midwives said to me oh the only time you take the gas and air is when you're in pain. I said… "I'm in fucking pain so shut the hell up"... They didn't concentrate on my pregnancy, all they were worried about [was]… your baby has a lot of hair… and my auntie was like… "can't you see that the coil is wrapped around his neck?… get the coil off his neck" if it wasn't for my aunt and my mum… he wouldn't be here (Shiloh, age 19).

On the surface, this narrative shows Shiloh's frustration at what she sees as the incompetency of her healthcare professionals. However, at its heart, lay her feelings of

neglect. Such negative birth experiences were widely shared between family members, and influenced views towards hospitals and healthcare professionals. Shiloh relayed the birth experiences of her aunt and sister, which affected her views towards a particular hospital,

> My cousin… come out with… a disability… at the time [my aunt] gave birth to him, they noticed a rash around his face… which wasn't part of when he came out. [My aunt] tried to take them to court and they said they've lost all the notes for him… so they didn't know what they can do, so they dropped the case… My sister, her waters broke, and no one noticed at the time she was… dilated… and… after having him, they noticed that she had… an infection… There's a lot people have had a lot of problems… [__ Hospital] is not a place to have kids, they just basically want you to give birth to your child and walk out… They don't bother trying to look first to see what they can do… to help… __ Hospital is one of the baddest hospitals within London (Shiloh, age 19).

The strong influence of family experience, knowledge and advice was also evident in Shiloh's statement, "I haven't heard no one [say], have you got the flu [vaccine]?" as a justification not to receive the vaccine, and Jane's comment that now that she had heard of the vaccine from Jamaican friends and family, she would accept it if she was pregnant again. This could be because for people to feel part of a community, particularly one that is very close-knit, individuals often conform to group values. Jane and Shiloh may then only have accepted vaccination with the approval of friends and family members.

Black Caribbean participants were generally more sceptical of the vaccines than older middle-class White participants, especially in the FGD. The six participants of the FGD were demographically homogenous. They were all white women living in Hackney, who were between the ages of 32 and 37 and educated up to Bachelor's or master's degree level. Four participants had received the dTaP/IPV vaccine, and all had accepted the influenza vaccine if they were pregnant during the influenza season. Nicola had been advised to vaccinate by her GP, nurse and midwife; Amy had had a discussion about the vaccines with a healthcare professional; Marika had received a letter from her GP (but had not had a discussion with a healthcare professional about vaccination); and Sasha (who was herself a GP), said that she received information about the vaccines while she was having it done, but that she did not need any information prior to this because she received the influenza vaccine for work every year. Thalia was not offered the vaccines but said that if she had been, she would have accepted them. Chloe (who

was eight months pregnant), had not heard about the dTaP/IPV vaccine but intended to bring it up at her next consultation. All FGD participants had very similar, positive views towards vaccination. When asked what they would say if a friend asked for their advice about maternal vaccination, four participants immediately responded,

> Marika (age 35): Do it.
> Sasha (age 32): Yeah I'd say just get it.
> Amy (age 37): Yeah.
> Nicola (age 35): Definitely, no reason not to, every reason to [chuckle] (FGD excerpt).

For some White interview participants, the power of family traditions and the intergenerational transfer of health practices emerged as significant source of such confidence in vaccination,

> Isleen (White Australian, age 34): I'm quite informed about my health, I think, um, with my mum being a nurse… and I think growing up in Australia too… we're very much about preventative health… So in terms of… immunisations… it was very much part of our dialogue when we were children… through my family and, and through the government. I feel like it was something that was always a priority… it wasn't a decision to make… it was like brushing my teeth. It's something that I'll just do… it wasn't a, "I'm choosing to vaccinate or not"… I wouldn't not do them…
> RW: What do you think are the most important influences on your decision to vaccinate?
> Isleen: Um, medical research… and probably my mum's influence too. My husband and I… have very similar values… he came from a very similar family… so being… vaccinated was very much… what we did.

Similarly, Beth, a 22 year-old White British participant had a good relationship with her midwife who advised her to vaccinate, and said that all of her friends had received maternal vaccination. Beth trusted vaccination, saying "I took every vaccination going". The extremely pro-vaccine views of the White middle-class FGD participants, as well as of Isleen and Beth, whose family members and other social contacts were positive about vaccination; and who received advice from these contacts, as well as healthcare professionals to vaccinate, contrasted greatly with the views of the Black Caribbean participants. This may be because the Black Caribbean women's intersecting identities, which have traditionally been oppressed and discriminated against, as well as family advice against vaccination, which possibly led to a lifetime of socially reinforced fear of vaccination (Quinn S, Jamison A et al. 2016), came together for these women and led to distrust in the organisations and healthcare professionals who promote vaccination. The

narratives of the participants in this study thus demonstrate that concerns around healthcare and especially interventions on the body such as vaccination, inevitably extend beyond the realm of medical interventions. Such concerns exist in the context of the social world of politics and are exacerbated by past histories and community experiences, as well as current experiences of marginalisation, stigmatisation and discrimination.

Conclusion

Among the British Caribbean women interviewed in this study, it is plausible that marginalisation, stigmatisation by the state, and family narratives came together to drive distrust in the UK government and thus vaccination. Family narratives of past negative experiences with vaccination both contributed to, and strengthened participants' levels of distrust, forming an interpretive framework and set of expectations of biomedical care (Comaroff J and Comaroff J 1991), which led the Black Caribbean participants mentioned in this chapter to resist vaccination.

Despite its negative connotations, refusal to vaccinate can represent a very sociable stance, as its immediate focus is on the well-being of one's immediate social relations (Sobo EJ 2016). Vaccination resistance can also be a form of political action, a movement for rights and recognition, and for rejecting specific normative structures and systems. Women therefore are not simply passive victims of medical influence; a very real agency exists concerning the health of themselves and their foetuses. Therefore, rather than treating subversive discourses only as "windows into the workings of power" (Urla J and Helepololei J 2014), which see people as victims of their circumstances, refusal should also be read as generative of local group relations. This is because in reality, resistance is manifold; dominated groups have complex social and political lives that support diverse oppositional activities. Thus, resistance extends far beyond acts or verbal proclamations. This makes vaccine resistance or hesitancy a complicated, multifaceted activity, something that the commonly used phrase vaccine refusal, with its focus on the rejecting aspect, fails to account for (Sobo EJ 2016). This was noted by midwife Renee when asked if she had many women who refused vaccination, "I don't even see it as refusing, I see it as choosing not to have it… it seems like… they've not got the right k-kind of language really to say refuse".

Currently, and despite the knowledge of how strongly family narratives can influence healthcare decisions, vaccination promotion material usually provides information about risks and statistics, focusing on rationality and weighing up costs and benefits. This suggests that hesitancy towards vaccination is due to ignorance, and can be overcome by increasing the population's knowledge of vaccines and the diseases they prevent, ignoring the complex reasons for vaccine hesitancy. Along this vein, social and structural factors influencing people's health-related attitudes and behaviours, such as ethnicity and socioeconomic status are often seen as 'barriers' to successful transmission of public health messages (Freimuth V and Mettger W 1990). In reality, vaccine decisions are based on much more than information and instead are influenced by a person's socio-political context (Slovic P, Finucane M et al. 2004). It is economic and social well-being that give a person the time and confidence to feel sure about their information sources and the various decisions they make. As German physician Rudolf Virchow famously stated,

> Medicine is a social science and politics is nothing else but medicine on a large scale. Medicine as a social science, as the science of human beings, has the obligation to point out problems and to attempt their theoretical solution; the politician, the practical anthropologist, must find the means for their actual solution (Weisenberg E 2009).

Therefore, meeting the healthcare needs of various population groups should be seen as a key responsibility of the healthcare service, not a problem of those groups (Bhopal RS 2007). In order to gain a better understanding of vaccine hesitancy, efforts should be made for an awareness of women's various intersecting identities, and how these influence views towards, and access to vaccination. This would help public health institutions and healthcare professionals to better acknowledge the differing levels of healthcare access, and varying perceptions of vaccination among women, and the means by which these differences find expression in constructing group beliefs (Crenshaw K 1991). Because the circulation of knowledge from a core of experts into the wider mass public involves the transformation of abstract and conceptual ideas into more accessible images, metaphors and habitual practices (Bauer MW and Gaskell G 1999), which are often used to create community, policy-makers and healthcare professionals should aim to deeply understand community rhetoric, understandings, aspirations and priorities about health and vaccination. Public health institutions should also reflect on their own framings and assumptions, and the knowledge, social and political values, and

commitments that they and the normative practices of biomedicine embody, and how these might be excluding women (Wynne B 2005). This would also shed light on why scientific and policy institutions represent pregnant women in the ways that they do.

A move towards a more holistic and context-specific approach to encouraging vaccination acceptance has been recently encouraged by the World Health Organization's (WHO) Tailoring Immunization Programmes (TIP) framework. This approach tailors immunisation services to specific communities and healthcare professionals (WHO 2017). With regards to caring for pregnant women, this approach would involve a core group of healthcare professionals to attend to women in order to understand the contextual features of their identity and experience, including key relationships with others, and the role the woman wishes herself and others to play in healthcare decisions. Healthcare professionals would then be more equipped to address questions and talk through any concerns raised by women, and recognise how their interactions and relationships with women can either enable or impair empowerment. In incorporating a broader conception of women's healthcare needs and desires in context, while engaging in a discussion about how vaccines make sense in their lives, this approach would mean that one-way information is replaced with dialogue that appreciates and understands the social processes around vaccination concerns (Poltorak M, Leach M et al. 2005). Such an approach fosters relationships of collaboration, addresses any circumstances that may hinder patient autonomy, and helps healthcare professionals to build trusting and close relationships with women, thus ensuring that she feels comfortable, taken care of, and in control. This means that healthcare professionals can be key in women's empowerment in vaccination decisions (Ells C, Hunt MR et al. 2011). The ways in which positive patient experiences within the healthcare system-engendered by this relational approach to care-can lead to greater levels of trust in policy-makers, public health organisations, and vaccination, will be explored further in the following chapter.

Chapter 6: A relational approach to healthcare[15]

Dr. Shaw smiled at the baby scan, stating, "It doesn't matter how many times I see this, I still think it's amazing… its phenomenal". Dr. Shaw clearly outlined what would happen in the consultation and initiated the vaccine discussion with Sophie, her patient, by saying that they would "have a little chat about vaccines and things like that. Is that kind of what you were expecting?" Sophie expressed how nice it felt to receive the call about the consultation and to be looked after. Dr. Shaw told Sophie that she could stop her if she had any questions. She said she would touch on the dTaP/IPV vaccine and asked if Sophie knew much about the infection and the vaccine. Sophie told Dr. Shaw how she had pertussis as a child and was given fish fingers. Both were able to laugh about this as an idea for a cure. Dr. Shaw explained why the vaccine was introduced; the dangers of an infant contracting pertussis; and when and by whom it would be administered. She asserted that it is rare to have any side effects from the vaccine, reassuring Sophie that "we keep an eye on you when we give it… but it's incredibly rare to have any kind of allergic reaction… you should be perfect; you won't notice anything". Sophie was able to ask questions during this discussion, which were answered confidently, and at the end of the discussion, expressed, "that makes perfect sense to me". Dr. Shaw finished the consultation by asking about the Sophie's mood, if she had a supportive partner, and telling her that she seemed clued up.

This snapshot of a consultation is from a video-recording of a sixteen-week check between a GP (Dr. Shaw), and her pregnant patient (Sophie, age 34), conducted in one of the GP practices included in this study. It demonstrates that from the start of the consultation, Dr. Shaw built a positive relationship with Sophie. She personalised the consultation and had a caring manner, showing genuine delight in the baby scan, while also asking about Sophie's emotional needs. She was able to make Sophie feel comfortable and at ease by sharing a joke. The question-answer format (i.e. "have you heard of pertussis"?) and the assurance that Sophie could ask questions, allowed for Sophie's participation in the vaccination decision process (Opel DJ, Robinson JD et al. 2012). The result of this approach was that Sophie felt cared for and confident in the

[15] A chapter based on the analysis included this chapter has been recently published: Wilson RJ, Chantler T, Lees S, Paterson P and Larson H (2017). The Patient–Healthcare Worker Relationship: How Does it Affect Patient Views towards Vaccination during Pregnancy? Health and Health Care Concerns Among Women and Racial and Ethnic Minorities. Kronenfeld JJ. Bingley, UK, Emerald Publishing Limited. **35**.

vaccine recommendation. This is an example of a relational, autonomous approach to healthcare.

In the previous chapter, I discussed the socio-political factors influencing pregnant women's access to vaccination and their vaccination decisions, focusing especially on the influence of social contacts on perceptions and decisions concerning vaccination. In this chapter, I critique the illusion of, and push for individual autonomy in healthcare settings today, and explore a more relational approach to healthcare, using the notion of relational autonomy to analyse how relationships with healthcare professionals affect pregnant women's vaccination decisions. Annette Baier argues that individuals are "second persons", who are "essentially successors, heirs to other persons who formed and cared for them" (Baier A 1985). Due to this social nature of human motivations, and the interdependent mutual support that we rely on, social capital (as mentioned in the previous chapter) and positive social relations, can enable individuals to be more autonomous than those who lack appropriate social relationships (Friedman M 1997). Similarly, positive relationships with, and support from healthcare professionals in making vaccination decisions is not an affront to individual autonomy, but can actually support it; women can at the same time agree with the healthcare professional recommendations, but claim the decision as their own, as it was guided by a trusted person with whom they have a good relationship (Kukla R 2005).

The first section of this chapter focuses on the healthcare professional-patient relationship and the social nature of vaccination decision-making. I then discuss how vaccine recommendations provided by healthcare professionals greatly influence vaccination acceptance, moving on to explore how vaccine discussions are influenced by a number of factors. These include healthcare professionals' own views towards vaccination; patients viewing GPs as time constrained, biased in their advice (due to their possible financial gain from meeting vaccination targets[16]), having a patronising or dismissive attitude; or due to the patient feeling intimidated. Finally, I explore the importance of support in making healthcare decisions, and how this contributes to patient's feelings of autonomy and empowerment. I conclude by making suggestions about how to improve vaccination acceptance through a more relational approach to

[16] Payment of £7.64 per dose of seasonal influenza vaccination for eligible patients is available to GP practices in England from NHS England. NHS England. (2014). "Enhanced services specification: Seasonal influenza and pneumococcal immunisation enhanced service." Retrieved 3rd August, 2017, from https://www.england.nhs.uk/wp-content/uploads/2014/06/flu-pneumo-immu-spec.pdf.

care, whilst acknowledging the difficulties of implementing this approach with the currently difficult financial state of the NHS.

The patient-healthcare professional relationship

> *I've been living here a long time but I've always stayed at the GP that's in Hackney that I've known since I was 15, so I went to see him [because] I need[ed] to change GPs… but I wanted to come and say goodbye* (Margaret, age 41).

In this section, I argue that improved patient-healthcare professional relationships can increase patient trust in healthcare professionals and their advice, and even increase healthcare professional's trust in their patients. If a pregnant woman is close to their healthcare professional, and that healthcare professional is recommending vaccination, they are more likely to have positive views towards vaccination.

Notions of trust however, are nuanced. The term is broad and greatly context-dependant. For example, most participants had very complex views towards healthcare professional's advice and maternal vaccination. Isobel (age 40), felt that advice was not always accurate for every person; that it changed over time; and that there was never a 100% correct answer, but still trusted the research on the vaccines. Marigold (age 36), Cadenza (age 34) and Idda (age 27), said that they trusted healthcare professional advice but wondered if they had an agenda to promote them, even if they were personally against vaccination; a sentiment also expressed by Rebecca (age 29), "I think that they have to [recommend vaccination], because that's their obligation… I do take it with a pinch of salt, because that's-that's their job, that's what they have to say". In this chapter, I therefore use the term 'trust' with regards to patient-healthcare professional relationships to imply close, understanding relationships, in which women feel respected and in turn have confidence in advice provided by their healthcare professionals.

Participants often had especially close relationships with their midwives. This close relationship was reflected on by Midwife Renee, when she stated "We see [women] for nine months… so… they do trust us". Additionally, a nurse relayed an experience where it was clear to her that her patient trusted her midwife more than her. During a consultation, this patient wanted to see the box that the vaccine was delivered in, so that she could later show it to her midwife and check that it was the correct vaccine, "she

wanted to make sure that… [laughs] I've given the right... [laughs]… medication [laughs]… she hasn't come back so it was right, it was right [laughs]" (Nurse Thompson).

Beth (age 22), said that her midwife concentrated on her needs, was very supportive and became her friend; always asking her how she was and what she had been up to, making her feel welcome, comfortable and respected. Beth trusted healthcare professional advice about vaccination "100%" and thought that there were no disadvantages to vaccination, or side effects. Another participant, Ava, also greatly trusted her healthcare professional's advice,

> My, um, doctor will always tell you about [the vaccine] before giving it to you anyway and then, um, he always says like, "Are you happy about this, like do you understand?" And I'm like, "Yeah", so yeah I'm quite happy, whatever my doctor says to have I'm like, "Okay then… when do I need to get them done?" (Ava, age 26).

Ava said she felt like running a marathon after receiving the anti-D immunoglobulin injection and the influenza vaccine. Although Beth and Ava both had negative birth experiences (Beth described an unexpected and unexplained forcep delivery and Ava felt that she was left on her own to make decisions when she arrived at the hospital to give birth), they still trusted healthcare professional advice, possibly due to their positive antenatal experiences and close relationships with their midwives. These close relationships were built through patients feeling cared for and reassured. Maddelin (age 34) expressed how reassured her midwife made her feel when her unborn baby was diagnosed with a possible failing kidney. The midwife told her that his friend's baby had a similar condition, that it was normal, and that everything would be fine. Some women also appreciated a tactile, familiar approach. Sabah, a 32 year-old Turkish mother said that she trusted advice about vaccination as during her caesarean, her doctor helped her, touched her and provided emotional support. Similarly, Haadiya stated, "I felt so happy that I had been taken care of so much… they explain everything in detail… before I was scared of giving birth… I was a bit at ease because of the nurse" (Haadiya, age 19). Haadiya also said she felt relieved that she had received the dTaP/IPV vaccine as her baby will be protected from pertussis, and stated, "I trust [healthcare professional advice] so much". Women who had similar positive experiences with healthcare professionals followed their advice as they felt they did not

need to question vaccination; they trusted that vaccines were provided for a reason. Magda (age 33) stated that healthcare professionals know better and she would not be able to forgive herself if she decided not to vaccinate and then something "went wrong".

Margaret highlighted the importance to women of midwife rather than doctor-led care, possibly due to midwife-led care engendering a more equal and informal patient-healthcare professional relationship, being more relaxed, and centred on women,

> It's confusing about when you actually go in, because they clearly thought I'd gone in too early… I wanted to be in… the midwife-midwife run one rather than the doctor one, and use the pool and everything, and they wouldn't-they wouldn't let me go, because I was… only, like, a couple of centimetres dilated… it's… like, well-well, what's the point in-in booking in and expecting this relaxing place if you have to be lying on some uncomfortable couch for hours getting stressed before you're allowed to go and relax... I had no idea-I thought... if that's where I was... giving birth, that's where my entire labour would be, once I arrived at hospital. So that, to me, was a big hole in the information I was given…. I thought I was doing what I was supposed to do…. it wasn't too early, because as it turns out I needed an emergency caesarean two hours later, but… the way they were acting when I got there…It was just…not a nice environment... at least I could be on one of those balls… my pain was worse than it needed to be (Margaret, age 41).

A German mother also preferred a midwife-led approach over doctor-led care (which is common in Germany), "it's quite cold because doctors usually tend to speak in doctor terms… a lot of Latin is used instead of just straightforward, okay, that's what it is" (Maddelin, age 34). An Australian and a South African mother also said that healthcare in their home countries was becoming over-medicalised and that they preferred seeing a midwife, as is usually the case in the UK. However, a hindrance to building close patient-midwife relationships was the fact that women often saw a number of different midwives during their pregnancy. When talking about giving birth, Marigold (age 30) said, "you didn't know who was going to be there on the night". Knowing who the healthcare professional was going to be would have been re-assuring, "you won't know anyone at the hospital so it's quite nice to have had a bit of [midwife] continuity" (Sasha, age 32). Julia expressed similar sentiments,

> When you actually come to give birth there's a whole load of new people who don't know you… and you're getting passed around… If you had that same midwife… or if there was someone who knew you, I think it would make quite a difference because you could at least trust what they had to say… at least trust one person when people are telling [you] different things (Julia, age 38).

Instead of having continuity and feeling reassured however, participants who did not see the same one or two midwives often felt let down,

> What I… found a little frustrating is… every single healthcare worker I came into contact with during my pregnancy was different… which because I'm… relatively familiar with the system, I… wasn't massively concerned… but nonetheless… I don't know if disheartening is the right word… it's not hugely satisfactory… I know that our birth rate is high in Hackney… but it was just a little disappointing (Isobel, age 40).

Experiences of mothers who saw the same midwife throughout their pregnancy and had a close and positive relationship with them, were very different to those who saw multiple midwives throughout their pregnancy,

> [My midwife was] really, really warm… I think because you see the same person and they come to your house, I guess you build, um, quite a good relationship with them over the course of your pregnancy, as opposed to if I just went and saw any old... a different person every week… I don't think I'd have the same kind of relationship with them (Kate, age 33).

> Because [midwives] visit me at home, it's quite a personal experience. It's the same midwife so she very much knows where I'm at… I feel like she's really been able to tailor it to, to me… than seeing a different midwife every week at the doctor's surgery or at the hospital… the continuity's just not there (Isleen, age 34).

Isleen accepted both the maternal dTaP/IPV and influenza vaccines. The above sentiments demonstrate the value that women place on healthcare professionals personalising their care, being friendly, honest and ultimately, caring. If healthcare professionals lacked these qualities, women often did not trust them. For example, Lucy (who had been introduced to her midwives as "Midwife 1 and Midwife 2") did not have a good relationship with either of her midwives, and this seemed to affect her whole birth experience, in which she felt unsupported and neglected. These experiences could have contributed to her distrust in healthcare professional advice, and thus her hesitancy to vaccinate. When asked how much she trusted healthcare professionals' advice, Lucy responded, "You're supposed to say 100%, in my eyes, because they are the health professionals. Like, they should know their stuff, realistically, but [if] you're not getting the right information, then you won't go for [vaccination]" (Lucy, age 27).

Whether a woman saw the same midwife throughout her pregnancy, or a different midwife at each antenatal appointment, was perceived as a "lottery", with no reasons given to women as to why this happens,

> It would've been nice to… stick with one person… because… one of the girls ... that was at the same stage [of] pregnancy… we used to have si-similar appointments together, and she would always have the same midwife and I was like, "Oh, how come do you always get the same midwife?" and she said to me, "I don't know, like, the lady that I always see has always been around". So, it's like, okay, that's a bit random. So, how did that one happen? And, when I… mentioned it to one of the midwives who wasn't actually my midwife... she kind of said, "Well… as long as you see a midwife, you should be kind of happy", and I was, like, "well, no, that's not what I'm asking you" (Lucy, age 27).

Healthcare professional-patient relationships also depend on the demographics, individual personalities, and varying abilities and approaches to care among healthcare professionals. For example, in this study, when there were significant differences in power dynamics between healthcare professionals and patients, some participants like Lucy, tended to prefer not to seek advice from their healthcare professional. Lucy was reluctant to "follow suit" with regards to vaccination, and although she was never 100% sure about her decision, she was persuaded to vaccinate by members of her antenatal group who happened to be nurses and had received the vaccines themselves. Lucy trusted the antenatal group nurses' advice more than that of her own healthcare professionals, who she felt patronised by. Lucy also sought advice from the leader of a parent-toddler group she visited, who she felt understood her concerns,

> [She's] been very, very helpful... she's got three kids of her own, so… with her experience... I felt comfortable with her advice... It was very reassuring; I didn't feel patronised by her... If she's not sure, she's not sure, but most of the time, when she is sure, it sounds… convincible… so... I can understand what she's saying and I can relate to it (Lucy, age 27).

The way that Lucy spoke about the parent-toddler group leader was very different to how she spoke about her healthcare professionals,

> You're putting your whole trust in these people… to make sure that you come through the other end perfectly fine… to make you at least feel comfortable… and say… I felt at ease; I felt comfortable. There was nothing like that (Lucy, age 27).

Honesty was seen as an important quality in anyone providing healthcare advice. If an advisor was honest, it did not matter if they did not have all the answers. It did not matter that the leader of the toddler-group was not a medic; she listened to Lucy and was not patronising, she had three children of her own and so could empathise. Cadenza (age 34) expressed similar sentiments, saying that she always asked for a certain health visitor as "she seems to talk straight", and Shiloh (age 19) appreciated when midwives admitted to not knowing something; trusting them for being open and honest, "My midwife concentrated on my needs… I can ask her anything. Any sort of problems… [and if she does not know the answer] she always says, "I don't know but I can see into it" and she'll get back to me… within that hour". On the other hand, when their healthcare professional was seen to be dishonest, participants were very scathing and viewed them as incompetent. When talking about a midwife who checked online through her mobile phone for an answer to her question, Lucy said she was "uneducated and sly". Lucy reported having so little trust in the competence of healthcare professionals that she worried that she had been given the wrong vaccine. This led to the fear that she would experience a negative side effect such as going into early labour. Additionally, Magda (age 33) was exasperated when she asked her midwife a question, saying that she "did not look properly… She knew less than… if I'd looked [it] up online" and Marika stated,

> I had a discussion with my midwife… about just things you can eat [during pregnancy] and frankly she was not as well informed as I was, having read the NHS website… she was like oh, you shouldn't eat this. And I was like, actually NHS, England says you can eat that, it's totally fine and you even appear not to have read your own guidance… so, I don't know if, if the midwife had said to me, let's have a discussion about whooping cough, I think I would have said, no I'll just go and do my own research, or I'll have it because I didn't totally trust that she had all the information. And if I was worried about something, I'd rather inform myself of it than rely on the like lottery of the random person that you've been given an appointment with (Marika, age 35).

A lack of positive healthcare professional-patient relationships was evident when participants expressed that healthcare professionals did not listen to their concerns or were dismissive, and that their consultations were rushed (thus hindering the ability for relationships to be built in the first place). For example, Hayley (age 34) stated, "I sort of had to fight my corner a bit in taking print-outs and stuff to get taken seriously". Lucy had a similar experience,

> There needs to be a lot more information, even like in antenatal classes-they never actually spoke about those vaccinations... Everything's a bit blasé, like, everything was rushed. I honestly think my pregnancy was rushed… Some [healthcare professionals] were more or less kind of brushing my concerns away… if you've got concerns about certain things in your pregnancy, and… it's your first pregnancy, you're feeling a bit, like, well, where do you go to for advice?... I just felt like everything, I had to do myself… like they're talking about now on the news, it's like they want people to not come into the hospital. That's what it felt like... if I did call them for information about the whooping cough, it was more or less, oh, just wait until your next appointment, which could be four weeks away (Lucy, age 27).

Experiences of concerns being brushed aside by healthcare professionals could be why some participants, such as Zoe (age 32) alluded to talking about their experiences during their interview as 'therapy". Zoe said that it was nice to be able to talk to me about her views as when you see a GP and they offer the vaccines, "you say yes or no and nobody asks why". Before the interview, Zoe felt that nobody had listened to her vaccine-related concerns.

Healthcare professional's vaccine recommendations

In an ethnographic study examining the ways that GPs come to their individual and collective healthcare decisions, Gabbay and Le May found that clinicians rarely accessed and used explicit evidence from scientific research directly, but relied on what the authors termed "mindlines", which are "collectively reinforced, internalised, tacit guidelines". These were informed through a range of informal interactions in "communities of practice" and mainly consisted of their own and their colleagues' experiences; interactions with each other, opinion leaders, patients, and pharmaceutical representatives; and resulted in socially constructed "knowledge in practice" (Gabbay J and Le May A 2004). Such an approach was evident among healthcare professionals in this study, who, despite all receiving information about the vaccines from NHS England, PHE, and the Green Book[17], worked in practices with specific cultures and modes of operating, which meant that forms of vaccine administration and recommendation varied between each practice.

[17] The Green Book contains the latest information on vaccines and vaccination procedures, for vaccine preventable infectious diseases in the UK.

DTaP/IPV and (if it is influenza season) influenza vaccines, should be recommended at pregnant women's 16-week check with her GP, and then at antenatal appointments with her midwife (NHS Choices 2016a), (NHS Choices 2016b). All six GPs and both nurses interviewed administered maternal vaccination (although one admitted that her practice had, at the time, run out of the influenza vaccine). Out of the two midwives interviewed, one was not trained to administer vaccines and the other did not administer them at the children's centre where she was based, as there was a specific vaccination clinic elsewhere. Two GPs said that the dTaP/IPV vaccine was given opportunistically (when they happened to see a patient, rather than booking them in for specific appointments), or that nurses normally administered this vaccine. Some GPs (Dr. Marsh, Dr. Henderson and Dr. Lawson) were frustrated that midwives and nurses in some areas were not trained to administer the vaccines, especially as they saw pregnant women most often,

> I think it's quite difficult to spend a lot of time discussing [vaccination] because we see them at the time they know they're pregnant right at the beginning. And there's a lot to cover and because we're not giving the whooping cough at that point, just say oh, you know, a new whooping cough will be, be offered to you later on… getting an anonymous letter, come in to see us [and have the dTaP/IPV vaccine] when they're seeing the midwife every... It just… doesn't make sense… [midwives] not giving the [dTaP/IPV] immunisations... it's crazy…I 'm not sure why [dTaP/IPV vaccination] can't be done in a consultation… with... our nurses… I don't understand that… the flu is a bit different because when during the flu season we have them and we can inject then. Sometimes we forget because it's a newer thing in antenatal, but often… I would promote it (Dr. Lawson).

Apart from one nurse who did not know whose responsibility she believed it should be to recommend and administer vaccines, all other healthcare professionals interviewed stated that it should be the responsibility of every healthcare professional to recommend and administer vaccines when there was the opportunity and if there was time. This was, according to Midwife Williams, because, "It helps to re-emphasise the fact that they've got the midwife and the doctor saying it… added proof that we are urging you to do this, um, and we think it's important". Dr. Henderson observed that sometimes the maternal vaccine recommendation may be missed due to certain healthcare professionals' believing that other healthcare professionals had already initiated the discussion, and so they do not need to remind women to vaccinate,

> I think there was probably a time when there was a case of we'd assume that… there'd be a number of antenatal appointments with the midwife who would probably bring [vaccination] up… it's sort of that thing of, never assume that somebody else is talking about it… 'cause they're possibly not (Dr. Henderson).

Participants also noticed this miscommunication, which contributed to sentiments of information being withheld, and perceptions of a chaotic care environment

> It would make sense that… whoever the health care professional is looking after the pregnant women… would just mention it every time, because if, if there's no like standard that its someone's responsibility then the midwife might think… oh, the GP probably told them and then so everyone thinks you've been… informed… if they just said "have you ever heard about whooping cough?" If everybody just said that (Nicola, age 35).

> I suppose I just couldn't get verbal… information... because there wasn't a lot of continuity of care-I didn't see the same midwife each time, so... she didn't have the time (Marigold, age 36).

> So I didn't have [the influenza vaccine], um, at the beginning I think I saw four different midwives because one was off sick and then, they handed over to someone else, so no one really mentioned it, it was all quite secretive… So I didn't have either immunisation… there was a lot of moaning about each other over my midwives (chuckles): "I am so stressed. I could barely fit you in" and then the next week it would be someone else saying, "oh I am so stressed, and so busy" and then someone else would go off sick, and it was all very up in the air (Thalia, age 34).

Most GPs said that they initiated the topic of vaccination at women's booking appointment[18] or at their 16-week check. Sometimes, a midwife or nurse had mentioned the vaccines before a woman saw her GP. However, some GPs seemed to have little faith in midwives' ability to administer or discuss vaccination,

> Some women are uncertain… I always say think about [it]… when they're six weeks pregnant I'll say… you've got till 28 weeks… read about it, talk, um, we can discuss it again. Oh, I'm not sure [I'd] say talk to the midwife… I really don't know how much they know about it (Dr. Lawson).

Most healthcare professionals said that they approached the maternal vaccination recommendation by having a conversation with women, explaining the dangers of the diseases the vaccines aim to prevent, and reassuring them of the safety of the vaccines.

[18] The first appointment women have when they find out that they are pregnant.

Dr. Marsh said that most women were happy to be vaccinated once she explained the importance of the vaccines,

> We always recommend the flu jab... You can't take so many medications when you're pregnant anyway, so you don't really want to get the flu if you can avoid it… and then just checking with them about allergies… I've never had anyone question the flu jab… I think more women agree to that than don't have it… with the pertussis one, when I talk about that I explain that… a few years ago there was a lot of pertussis around and babies were getting very sick. Especially when they're new-born because they don't have their first jab until two months old. When they get [pertussis]… they get really poorly and lots of them have to go to hospital and some babies died. So now that we give mums a boost with the injection that they've had before many times, just so that their levels are higher and they can pass it all to baby just before baby's born. And women I think then, when you say that to them, it's about sort of saving your baby's life in those first few months, they all seem to be quite keen and I think they take [the vaccine] much more readily (Dr. Marsh).

However, it was acknowledged that having a discussion about vaccination was sometimes difficult, possibly due to time constraints (the reasons for which are discussed in Chapter 4), "sometimes it is a bit difficult, isn't it? (chuckle) when they're coming they will be with a hundred questions" (Nurse Anand). This issue was also mentioned by Midwife Williams, and led her to sometimes only being able to offer women leaflets about vaccination, rather than having a conversation with them,

> At the start you give them all these different leaflets. Women are taking a lot of information in and it's hard for them to retain it all at once, so the leaflets I think is very valuable because… there's a reminder to them…so we… say "Please take the whooping cough," and it's, it's very short and sweet… and the leaflets are also good for… us as midwives because I've read the leaflet and it reminds me what I should actually be saying to the ladies as well… I am brief on it… I do rely on the, the leaflet because of the time factor… so… your first point will be saying, "Have a read of these, chew it over and come back to me" (Midwife Williams).

One of the mothers interviewed (Bathild, age 35) believed that because healthcare professionals sometimes did not discuss vaccination, leaflets were important in ensuring that women did not miss key information regarding the vaccines. However, if there was not time in a consultation to have a discussion about the vaccines, and leaflets were not available or provided (some healthcare professionals stated that their practice often ran out of the leaflets and at some practices they were not routinely given to women), vaccination may be merely briefly mentioned (if at all). Healthcare professionals who

did mention vaccination often did not seem to actively encourage it (even if previously in the interview they mentioned that they did),

> I'll give her the pros and the cons and the, and the benefits of it, and, um, let her go home, think about it and then to make a final decision… I tell her… if she wants to come back to have it done… no problem (Nurse Thompson).

> They weren't pushing [vaccination]… it wasn't a massive theme. It wasn't something that they kept, uh, bringing up. I think they would mention it every now and again… and say… it's advisable to have these vaccines but it's up to you… whether you have them or not, so. It's not the end of the world if you choose not to (Idda, age 27).

Dr. Cooke stated that the vaccine discussion is "more of a tick-box discussion rather than one that we invite" and is "part of going through all the things that are needed". Additionally, Dr. Khatri said that she routinely mentioned vaccination in consultations and then directed women to the internet, especially if their first language was not English, "they can Google it, they can get [an] informed decision, find out" and Midwife Rennee stated, "there's probably more information online than there is in a small leaflet". The lack of vaccine discussion also led some women to independently conduct their own online research; Kate (age 33), who did not vaccinate, said she conducted online research because "you cannot find vaccination information anywhere else" and Samantha and Lucy stated,

> This time I actually had [no recommendation]… I wasn't really too bothered because I know like from the first [pregnancy], but now I'm like looking on Google to find these things… because [my healthcare professional] just didn't even offer it (Samantha, age 28).

> I'm someone that wants to dig a little bit deeper... especially with the whooping cough vaccination, the lady that I saw for that, she was, like, "Well, if you don't want it, you don't have to have it", but the question was, was, what does it entail?... Because, I've never heard of it, to be honest, so I wanted her to, kind of, briefly explain to me, and her answer was, kind of, like, "Well, did you not get a leaflet?" But, sometimes a leaflet does not break down everything... and nor does Google… Midwife 2, said... "it's up to you if you want to do it", but again, this is where the advice, the information wasn't fed into me about those vaccinations. So, it was, kind of, like, leaflet, read it up, Google it, whatever you want to do, and then when you come back in, let us know… it was me that had to do the work in terms of, so, what does that vaccination do, exactly, apart from the fact that you've given me a leaflet, what exactly does it do?... how would it benefit me? How would it benefit my child?... the only thing I can remember is one of them saying to me… it was, um, highly contagious back in the day… some of the babies had whooping cough and they died… but they wouldn't have

> said that to me if I didn't, kind of, say, "Well, what is it?... what would you advise?"... So, I think that they left me to it (Lucy, age 27).

Lucy's sentiments here are similar to those of Ava, explored in Chapter 5-she did not want to be left to make decisions herself, but wanted advice and *care*. If healthcare professionals did not provide such care, women felt neglected,

> Within the first three months… you find out you're pregnant and… then you're left there… I felt like I was just on my own. I mean, when I first went to my doctor and I was all excited to find out I was pregnant, because I was accidentally booked in with my doctor, and not the nurse, I was basically told I was wasting her time… I just thought I was left on my own. Wasn't given any information and such about what to do, what to expect… I just felt quite alone up until that time (Amy, age 37).

Amy's repeated reference to feeling alone demonstrates how strongly she felt about this neglect. Ultimately, the importance of support in the first trimester of pregnancy was evident in the observation made in Chapter 5; that if women felt neglected during initial contact with maternity services, it affected their perception of care throughout their whole pregnancy.

The value that women place on direct contact and verbal discussions with trusted healthcare professionals was also evident when Mahsa stated that although she and her husband had read stories about traumatic side effects from vaccination on *Mumsnet*, Mahsa still decided to receive the dTaP/IPV vaccine, as she said she was more convinced by her midwife than these forums because,

> I was informed by a midwife, the one that I was… quite happy with, she discussed everything with me; she… discussed the whooping cough vaccine with me, and she encouraged me to take the whooping cough vaccine in my second pregnancy, which is why I took it (Mahsa, age 31).

This illustrates the greater importance of a relational approach to care-through which trust in healthcare professionals and their recommendations is engendered-over solely providing women with information that often does not do enough to reassure them. This relational approach was taken by Dr. Marsh. She stated that one of her patients had heard from pregnant friends who decided not to receive the dTaP/IPV vaccine, that the vaccine contains antigens other than pertussis, and was concerned about this. Dr. Marsh discussed the vaccine with her patient and said that in the end, she decided to receive

the vaccine, and was going to go and discuss it with her friends (in order to persuade them to receive it). Similarly, Dr. Cooke said that she would invite her patients for extra consultations if they had concerns and wanted further discussion about the vaccines.

The importance of a vaccine recommendation from a trusted healthcare professional was evident when Marigold (age 34) stated that if her GP had not said that maternal vaccination was a good idea (as hers had); she would not have accepted it. Similarly, most participants who did not vaccinate, stated that if a vaccine discussion had taken place, they would have accepted maternal vaccination. "I would have [accepted vaccination if it had been offered], because generally I trust health care professionals (Magda, age 33). Nicola also saw the importance of this recommendation,

> Medical staff tend to… provide the information, but don't try to sway you one way or the other… which is obviously a professional approach I suppose… Saying "yes she should definitely have [the vaccines], book your appointment"… makes you think, oh yeah, this is really important… they just don't mention it because they kind of don't think it's that important (Nicola, age 35).

The perception that healthcare professionals did not think vaccination was important is not surprising considering that some participants reported that their healthcare professional had a dismissive attitude towards vaccination,

> My midwife she laughed at [vaccination], she said well it's up to what you want to do... No one's stopping you… just do what you want to do…. because in later rounds [of vaccination], they will end up asking you does [your son] want the flu jab himself… So I said he's not really, uh, lose out. Just do what you want to do… I called [my GP] and he said he was fine with [not vaccinating] as well…. They just say "we're not here to force you, it's just your decision" (Shiloh, age 19).

As well as time constraints and possibly believing that maternal vaccination is not important; a lack of encouragement to vaccinate may be due to some healthcare professionals having their own concerns about vaccination. This was despite the importance the healthcare professionals interviewed placed on reassuring women of the safety of maternal vaccination, and all healthcare professionals interviewed who were pregnant when the vaccines were available, saying that they vaccinated. For example, Midwife Renee said that she would tell women that vaccines are recommended, but that she did not encourage them, going on to say,

> I'm not anti vaccine… I understand… the concept… it works for everyone that's vaccinated… but… I don't know how… it's going to affect immune systems… autoimmune diseases… in the future… they haven't been around for hundreds of years, have they?... Personally I've… read books on vaccinations and the dangers of vaccination, um, and I have lots of friends who are from the alternative school of, of thought like herbal practitioners… homeopaths, things like that… I get information from them. My own personal opinions are much more over on the sort of holistic, natural route… I've got friends who are, coming from that same… opinion… I'd probably more likely… listen to their views, especially if they're… well educated in the subject… It's not just like anecdotal, it's… people who are trained, qualified… Even though that's my personal opinion on vaccinations, that's not what I tell [my patients] (Midwife Renee).

Despite Midwife Renee saying that she does not convey her personal opinions to her patients, as demonstrated earlier in this chapter, some women have close and trusting relationships with their midwives. It would seem reasonable therefore, to assume that some level of vaccine hesitancy on behalf of midwives would be communicated to patients. This is significant considering that healthcare professional's vaccine recommendations and their views towards vaccination, can have a strong influence on their patients decisions. For example, Magda (age 33) said that she would have been put off vaccinating if a midwife was against vaccination as "that's who you're trusting".

Healthcare professionals also sometimes had misconceptions about the vaccines. This could be because, as Dr. Lawson stated, at the beginning of a vaccination campaign, healthcare professionals are sent a lot of information, but then not much information following that. This could be why Midwife Renee said she told women that the dTaP/IPV vaccine contains additional antigens to pertussis, but then demonstrated a lack of knowledge about the vaccine by asking me what these other components were. Nurse Thompson and Midwife Williams also seemed to lack knowledge about the vaccines,

> I have a element of trust, um, I, I don't really know more than that… I just have a element of trust… I wasn't good at chemistry… so I, I don't really understand that language very much anyway (Midwife Williams).

Nurse Thompson and Midwife Renee also admitted that not knowing much about the dTaP/IPV vaccine and pertussis led them to direct women to other sources for information,

> [I] probably should [know]… since I'm, I'm advising you to have it but… I do say to them, "Go and look on the NHS website or I'll give you a leaflet if you want more information… I don't know the actual information as to how ef-, how effective it is… it's crossing the placenta so it's, there will be some… I don't know, dilution I suppose, or it's not going to be as effective as, um, if the baby has it at whenever, two months, but I don't know the facts (Midwife Renee).

Midwife Renee was also unclear about which vaccines protected the infant and which protected the mother, saying that she had never seen pertussis in an adult, or influenza in a baby, and therefore questioned the necessity of the vaccines. However, she asked me if the information she had provided in our interview was correct and whether the maternal influenza and dTaP/IPV vaccines are live (attenuated), demonstrating that she was concerned about her lack of knowledge around vaccination.

If healthcare professionals lack understanding about vaccination-a relatively complex intervention- it is understandable that patients also have knowledge gaps and misperceptions. However, solely making more vaccination information available to healthcare professionals may not change their perceptions towards vaccination. The fact that there are misconceptions about the vaccines among healthcare professionals (even if they care for women with the diseases the vaccines aim to prevent), and that healthcare professionals influence each other's views about vaccination, is unsurprising considering the findings of the study by Gabbay and Le May mentioned at the beginning of this chapter. The study found that sometimes information relayed to GPs by the Department for Health was regarded with scepticism. When describing guidelines, or "mindlines", clinicians said that they were grown from people who are trusted, and from experience (rather than information coming from the NHS), and could be shared and tested with these people, thus leaving room for flexibility (Gabbay J and Le May A 2004). For example, a mother interviewed, who was also a nurse, was greatly influenced by her colleagues with regards to her views about the influenza vaccine,

> Working in a hospital, the doctors are so sneery about the vaccine... I'd get vaccinated again as a pregnant woman. I wouldn't get vaccinated again as a healthcare worker… because I think I've been influenced by the, the doctors I work with, and they're feeling that… we're not a vulnerable group... I'm not sure there's the evidence to back up that sickness is reduced if you vaccinate... when you have a year like last year where it's... only effective against a third of cases... it shouldn't influence you, but personal experience, you actually get flu, you think… is there a massive point in this?... I'm definitely influenced by doctors… When we've had really fluey years, I've seen really sick pregnant women… with flu… I didn't really realise how vulnerable you are in

> pregnancy… You can go your whole life being fit and healthy and fine, then you're pregnant, and you're suddenly, like, a little bit broken… and then I did understand about the whooping cough vaccine, although it's a hard sell... when it's got everything else in it as well… I've nursed pregnant women who've been very poorly with flu, flu related pneumonias… you remember the swine flu year... there were pregnant women that died… I remember a lot of women coming in quite poorly then. So, yeah, no, I definitely do think it influenced me… My only feeling is that vaccination in pregnancy doesn't have the same public health benefits, as in terms of, herd immunity, and the eradication of diseases... flu and whooping cough [vaccines] have got different benefits (Rafael, age 34).

However, it must be noted that healthcare professionals' concerns about maternal vaccination were not always due to misconceptions or a lack of knowledge, but were also about disagreeing with how vaccines are promoted or provided. For example, Midwife Renee was concerned about why the dTaP/IPV vaccine is marketed as the 'pertussis' vaccine, when it contains other antigens. To her, this contributed to patient distrust in the vaccine, "that… is really, actually really important information and that is why people… say things like, "Oh, they're putting stuff in us and we don't know". Additionally, Dr. Khatri, was not "convinced" of the efficacy of the influenza vaccine-a reasonable concern considering that not all cases of influenza illness are averted by vaccination (vaccine effectiveness in adults is typically 50%–60% (CDC 2015). She said that this made her question the vaccine, an apprehension that was also shared by Midwife Renee. Additionally, Dr. Lawson, a 58 year-old GP who had been practicing for just under 20 years, was concerned about the tetanus component of the dTaP/IPV vaccine, and that too many tetanus vaccines are given to patients,

> I think it's, it's difficult… to explain why we have to, to give a combined immunisation… I think also if they're pregnant again and they're advised to have it again, aren't they?... That's really difficult because we say they shouldn't have too many tetanus… and so I do worry about that… that doesn't quite make sense. If they've already had their five tetanus, we're going to possibly increase the side-effects… I would be a bit concerned about that… and also having, I can't remember now, is it three, it's combined with three or four… whooping cough, tetanus, diphtheria and polio… I think that's within a year sometimes, two of them… when somebody asks us it's quite difficult… whether it can increase your side-effects and it does… with tetanus, you know, you get nasty reactions if you've had more than five tetanus jabs… that's a concern (Dr. Lawson).

On their web page entitled, *Tetanus shots: Is it risky to receive 'extra' boosters?*, the Mayo Clinic states, "It's usually OK to receive an extra booster of the tetanus vaccine" (Mayo Clinic 2017). However, I was unable to find more detailed information about the

effects of receiving a number of tetanus vaccines throughout a lifetime. Such concerns therefore should not be dismissed as they may not have been disproven, and represent healthcare professional's own expertise and opinions, which could differ from dominant scientific explanations.

Like the women interviewed, most (including GPs) viewed the dTaP/IPV vaccine as more important than the influenza vaccine, as regarding the dTaP/IPV vaccine, "we're considering the health of the child" (Dr. Khatri). Dr. Khatri also believed that when she vaccinated pregnant women against influenza, they still became infected, sometimes suffering more severely than they would have done without the vaccine. These perceptions could not only be due to a lack of information, but to what healthcare professionals believed which vaccines the NHS deems more important. For example, Midwife Williams had never seen a leaflet about the maternal influenza vaccine (thus believed there were not any), and so thought that the NHS emphasised the importance of the dTaP/IPV vaccine more than the influenza vaccine,

> I do notice that there is, um, um, whooping cough leaflets but not flu vaccine leaflets, so it, that in itself suggests maybe there's… more emphasis on the, the whooping cough because we clearly have a whooping cough vaccine [leaflet] with a pregnant lady but we don't have a flu one, or if we do have I've never seen it (Midwife Williams).

Fadda et al., found that patient confidence in vaccination decisions is related to the perceived importance of this decision (Fadda M, Galimberti E et al. 2016), and so if healthcare professionals do not convey the importance of vaccination, patients may feel that it is unnecessary, and not vaccinate. However, the relaxed approach to the vaccination discussion was seen as positive to Idda (age 27). While she did not vaccinate during her pregnancy, she appreciated that, "the midwives… were very… level headed… they didn't try to push me to accept but they… took me gently through it because they didn't want to make me feel pressured". Women who were not pressured to vaccinate usually did vaccinate, expressed positive sentiments towards healthcare professionals and vaccination, and were engaged with the healthcare system, "To me [vaccinating] just felt like the law. Not… being asked constantly… to be vaccinated against things… you think when you are [recommended the vaccines], then it's probably a good idea" (Ruth, age 36). Similarly Beth (age 22), said she was happy that, "They didn't pressure me or anything, it was all optional, so I took every vaccination going and it was fine, it agreed with me. Perfect".

However, Rebecca (who did not vaccinate during her pregnancy), had the opposite experience, feeling pressured when her GP continuously called to advise her to vaccinate, and when other healthcare professionals kept recommending the vaccines and assuming that she would accept them,

> Whenever I went to the health visitor, she'd ask me about [vaccination], and… it does make me feel a bit like, do I want to go and see the-see them sometimes, because they're going to bang on about this? And… my friend, who's not vaccinated at all, in Hackney... is concerned about going to the doctor because of what they'll say... judgement, and also being pushed, and… when I went to the doctor for [my daughter's] first check, they were, like, "Right, so we're going to do the TB right now". I'm like, "what? I didn't agree to that. I don't know what's-what's happening… no, no, no, I didn't know that it was going to be a vaccination today", and he said, "Oh, yes, that's what we're doing". I said, "Well, I'm sorry, I just need to think about it" (Rebecca, age 29).

Rebecca said that at this point she was back at work and "didn't have time to look into the rights of the mum". In using the language of 'rights', Rebecca felt she needed to be prepared to defend herself in interactions with her GP, who would judge her and "bang on about" vaccination. This led Rebecca to question whether she wanted to go and see her GP, thus disengaging with the healthcare system around the issue of vaccination. Similarly, Samantha avoided healthcare professionals' judgement regarding her vaccination decision by giving the impression in discussions with them that she would think about having the vaccines, but had already decided against them. This was because her mother had advised her against vaccination, and she was concerned the influenza vaccine could cause influenza,

> I made [my decision] there and then as soon as [my healthcare professional] told me… I did say to her I would go home and consider it, but there and then, as soon as she told me, I was just like… I don't think so (Samantha, age 28).

Similar findings were made in a study conducted by Reich, where one mother refused to go to public health clinics because of their insistence on vaccination. This mother said she felt she was seen as a delinquent for not vaccinating and so instead found doctors who were flexible about vaccination (Reich J 2016).

The narratives of participants explored in this section demonstrate the disconnect between how patients and healthcare professionals view the vaccination discussion and

how it should be approached, with healthcare professionals often being perceived as either too persistent in their recommendations, or not having enough of a discussion about the vaccines. Midwife Barbara acknowledged that most women just wanted to know more about the dTaP/IPV vaccine, and some were not clear about why they were expected to receive it when the aim is to protect the foetus. Another GP acknowledged that some women try to "put off" having the influenza vaccine because "they're not prepared mentally to have an injection at that point... we spring it upon them and they've come for something else" (Dr. Marsh). This observation highlights the value of healthcare professionals not merely recommending vaccination or providing a leaflet, but discussing it and guiding women in their decision, while giving them time to think about it, and the opportunity to come and discuss it again later. Women may then feel more supported, prepared and thus empowered in making vaccination decisions, rather than pressured, rushed, and anxious.

Ultimately, the contrasting experiences and desires of participants with regards to the vaccine recommendation and discussion, demonstrate the underlying tension explored in this chapter; between the responsibility of healthcare professionals to maintain a healthy population (through recommending and administering vaccination), and allowing patients to exercise personal choice and participate in their healthcare.

Empowerment

> *If we ask ourselves what actually enables people to be autonomous, the answer is not isolation, but relationships-with parents, teachers, friends, loved ones* (Nedelsky 1989, 12).

Empowerment is an essential component of autonomy but women's perceptions about their agency in vaccination decisions have often been neglected as possible drivers of their vaccination behaviour (Fadda M, Depping et al. 2015). According to Kabeer, empowerment is the process by which individuals acquire an ability to make strategic life choices. The ability to exercise choice incorporates three inter-related dimensions: resources (with regards to vaccination, this would include social capital and access to healthcare and vaccination); agency (processes of discussion, negotiation and decision making); and achievements (well-being outcomes) (Kabeer N 1999). Thus, the social nature of empowerment means that it is only possible in healthcare settings when one is close to and can trust their healthcare professional and the advice that they provide.

Nichols et al., found in their examination of young mothers' birth narratives, associations between birth satisfaction and mothers' sense of agency and experiences of positive support (Nichols T, Brown M et al. 2014). Similarly, in a study on parent's MMR vaccine decisions, Fadda et al., found that the majority of parents reported feeling competent and, consequently, autonomous when they could obtain vaccination-related information and guidance from an expert whom they could trust (Fadda M, Galimberti E et al. 2016). These sentiments were reflected in my study; if women were close to their healthcare professionals, trusted their advice and had support from them, they were more confident about their care and more empowered to make decisions that were best for them,

> My midwife… was really, really good, bubbly, had a laugh, my partner would come there and she would make my partner feel shy… and no one makes him feel like that and I felt like I took control with her… I discuss [vaccination] with her but I make all the decisions (Beth age 22).

> I felt…confident… I knew what was happening. I knew what was coming next, like I knew that [my midwife] was going to be calling the hospital to make my appointment… and she had everything organised. I felt like I didn't need to chase up on anything or…do that myself (Isleen, age 34).

However, this relational approach was often lacking. For example, Idda (age 27), stated that while healthcare professionals were in general very pro-vaccine, there was no scope for discussion. In cases like this, the implicit message given to women who turn to healthcare professionals for advice is that they are on their own, and should be able to think clearly about the decision. The consequence of this is that the burden of making decisions is carried exclusively by the pregnant woman (Wendler D and Rid A 2011). This lack of support in making healthcare decisions led participants to feeling unclear about their options and even neglected,

> I think you have to go with your instinct… [there] needs to be a lot more… one to one… communication… especially with pregnant women… there needs to be… more… understanding between one another… "I've understood what you're saying, and what you're saying to me doesn't make me feel like I have to go to somewhere else to get another opinion" ... to make someone feel like they have to do their own investigation… it's like being at school…this is different. This is to do with an unborn… human (Lucy, age 27).

> They forgot about the anti-D [immunoglobulin injection], someone didn't read my notes… my midwife was really hands on and then she um she… moved to

> another place… then I had another midwife and then from thereon on hardly saw or heard of my midwife and then trying to get in contact with her was really hard…So it was constantly that I would have to go to the hospital or ring the delivery suite for any advice and… it just really went downhill…. couldn't get hold of her, she kept cancelling my appointment… I got rushed to the hospital, they left me for nearly two hours before checking me and then when I did they were really… horrible to me. I ended up in tears… I've got no-one with me and they wouldn't charge my phone… I was just crying my eyes out (Ava, age 26).

Ava was given conflicting advice and asked to make decisions herself. Her response was, "I'm not the doctor, I don't know what's best for me and the baby… no-one knows what they're doing in here". As discussed in Chapter 3, in today's society, it is deemed liberating for people to be autonomous, meaning that they are independent, self-governing individuals, who are not "swayed" or influenced by external factors or social contacts. However, as demonstrated in the above narratives, ironically, the pressure placed on individuals to be autonomous, runs counter to the whole idea of choice and autonomy.

Notions of individuality in healthcare settings-where patients are also customers and may be required to manage their doctors and make difficult decisions on their own, as autonomous individuals-are also exclusionary and may mask, or give excuses for forms of neglect. The individualist approach causes relations with others, and the capacity for reassurance and caring on a real, human level, to be seen as unimportant. Women in this study were clear that they did not want to be left to make difficult decisions alone and some wanted healthcare professionals to make healthcare decisions for them. As shown in Ava's narrative, in such situations, patients are not worried about losing their autonomy, or being 'bossed around' but want to cared for by others. Indeed, pregnant women are considered vulnerable members of the population, and as such, are patients during their pregnancy. Patients, are 'troubled' by their body; they therefore have different needs for support than in other situations in life, where being 'autonomous' may be preferred. They could die if they are left alone, and so have to "bracket a part of who they are" (Mol A 2008)-the part that *needs* support-from a perceived notion of the autonomous self,

> When I was in hospital, I was really bad, my husband was there because … normally I'm very able to say for myself "this is what I want, this is what I need", can't really do that in labour, it's the one time, you really need an advocate… particularly being in hospital after our baby was born where we had

> no continuity or care. I needed [my husband] to be able to go and say, well she hasn't had any medication (Marika, age 35).
>
> They told my hubby to go home… I was feeling pains… I couldn't do anything on my own… And when he left I was expecting someone to be close so that if I should press the bell, uh, that I needed help or something… I would be able to get… help on time, or the second day was when my hubby left I was still on my own for hours… I was so depressed. I needed to use the toilet; I didn't see any help… I was pressing the bell, nobody came… I even broke down, I started crying because… I didn't even know what to do. I almost… pass urine on… the bed. I didn't see anybody… to come and help me… I was at breaking point, I was so angry… they instruct my husband… to go home… at least someone's supposed to be close by so that… if I need something they'll be able to assist me… they never asked me what I wanted… they didn't help in any way to… remove the pain… they didn't do their job (Anetta, age 30).

The above narratives demonstrate that notions of choice (which arise within market economies), in asking simply for a limited set of decisions to be made (i.e. do I purchase this product or that one?), do not always fit well within the healthcare setting (McNally D 1993). Unlike market transactions, the process of caring is open-ended and does not have clear boundaries (Mol A 2008). Care, like any social service, is a process which involves many different actors (and power imbalances-something which is dangerous if care becomes marketised[19]), adapting to each other and working together on shared tasks over time.

The push for patient autonomy and choice also seems futile when it sits alongside high levels of bureaucracy in hospitals, which prevents personalised care. This was noted by Chloe (age 35), "It's funny isn't it because they say, you know, say that [labour] affects every woman differently… but then you come to the hospital and they treat you all the same". Similar sentiments were expressed by Julia,

> The way they presented it was that we had all these options [for birth]… and then... I turned up in labour the midwife who was there... was like oh you can't do that, no, no, no and then there was other ones saying different things because they had all these different midwives... and then the head midwife came and she was like yes of course you can… so I was really confused. My water broke and I had spontaneous rupture of membrane…and she was saying you have to take... intravenous antibiotics... and the midwife there said oh if you've had, um, intravenous antibiotics you can't ... you're not allowed to have a natural birth... the head midwife then came to talk to us… and she said oh no that's absolutely ridiculous of course you can… and then the [other] midwife wrote on our notes that we had refused to take antibiotics and that we had refused our medication

[19] With the possible loss of patient protection, and issues with accessing care.

> and so the doctors came and they was like why have you refused the medication?… So there was like a lot of confusion... there wasn't much choice about what I was allowed… I did have a natural birth in the end but I really had to fight for it because they wanted to give me an emergency C-section… and then, um, they lost my notes and then they tried to give me medication I wasn't on and it was a bit of a nightmare… I ended up having to stay an extra nine hours while they found my notes again because… the doctor walked off with my notes... they all got filed all over the place… the whole hospital part ... it was just a bureaucratic nightmare basically and, um, very inefficient and actually slightly dangerous… when you're a slightly kind of vulnerable state... you need to know that you're safe… and I had to keep trying to be aware of everything that was going on (Julia, age 38).

Julia however, had a very positive post-birth experience in Hampshire, which greatly contrasted with her negative experience in London,

> I had all my post birth care in… Hampshire… they were amazing there… I was breastfeeding [my baby] and I was having problems... so I rang up the birth centre there and they were like oh come in and they basically they… said oh we're going to keep you in and take you through a number of feeds… until you're completely ready and then they looked at him and they said oh he's got a little bit of a tongue tie we've got three midwives who specialise in tongue ties… we'll book you in for [the operation]… we wanted to make sure you had it done because if you went back to London you'd have to wait six months before having it… And the health visitor came and she stayed for an hour… It was like a completely different experience, everybody had time, everyone wanted to make sure that you were really well cared for, that you were happy… I felt very respected and listened to… I felt really good… felt very positive… they had all the specialised midwives… that came round through the night and helped everyone breastfeed (Julia, age 38).

Julia's very different experiences at different hospitals, and the effects that these experiences had on how she felt while she was there-on edge and in danger at one, versus respected and listened to at the other-demonstrate the importance of emotional support and kindness in such a stressful situation as birth. For Lucy, this emotional support could even have taken the form of being offered a cup of tea; a simple gesture of comfort and hospitality,

> I went into labour and they kept sending me back… the midwives… just sat there, and it was kind of, like, "well, we don't-we don't really have space for you right now, so you have to go home"… Everything was just so rushed... it wasn't structured really nicely to the point where I'd be, like, "I had a happy time and a happy birth"… even after the birth, no one explained to me why [my son] was in the, um, intensive care bit. They whisked him straight away, and didn't let me… bond a little bit with the baby, and the nurse that took him was… like, "Hurry up, hold, let's go"… Even the aftercare was horrible, because…

> there was no breakfast… no lunch… no dinner… I've just had a baby that I do intend to breastfeed… the midwife that was on the ward, probably saw me once the whole time that I was there. Other than that, I was beeping for her… even when they discharged me… there was just nothing… it was, like, go home, and even though I was going back every day… there was no... your child's still in hospital, so why is it that the mother of that child doesn't get that, sort of, "do you want a cup of tea?"... I know everyone's rushed off their feet, but… I'm sitting there all day and there's no…. emotional support, no one spoke to you- again, leaflets. So, I could've turned round and said, "I don't like to read, so could you explain it to me?" [laughs] (Lucy, age 27).

Emotional support, especially in making decisions, could prevent the phenomenon of 'omission bias'; the favouring of potentially harmful omissions over less harmful acts. When this happens, people choose to take the course of inaction (such as not vaccinating), rather than one they see as a risky (such as vaccinating), even though when it comes to vaccination, inaction is more risky than taking action. The phenomenon arises because it is often perceived that one is more responsible for the consequences of one's actions than for the consequences of one's inactions, and so the former would cause more blame and regret (Asch DA 1994). Omission bias has been shown to be equally strong whether decisions are made by physicians, patients, or a public health officials deciding for many patients (Ritov I and Baron J 1990).

As discussed in Chapter 4, decisions that have to be made during pregnancy are especially anxiety-provoking due to the immense pressure placed on women to protect their foetus, and so omission bias may be especially obvious around maternal vaccination. For example, Sim et al., found that pregnant women felt the vaccination decision during pregnancy to be distressing, leaving them to choose the "least worst" option in the context of a difficult set of choices (Sim J, Ulanika A et al. 2011). Additionally, compared to other vaccines, those provided during pregnancy (especially dTaP/IPV), are aimed at protecting the foetus and thus raise questions about responsibility. The decision also entails many contradictions- women may fear vaccination, yet at the time of birth and during her child's infancy, interventions (such as episiotomy) are rarely questioned, without regard for the possible burdens to both foetus and mother that such interventions may bring (Lyerly AD, Mitchell LM et al. 2009). Such contradictions were evident in in the way that Shiloh (age 19) for example, did not want to vaccinate during her pregnancy, but like many mothers, did not worry about giving her infant Calpol (a brand of children's paracetamol).

Douglas asserts that in today's society, we are ready to blame any death or illness on somebody else. We ask, "who's fault", then "what compensation?" (Douglas M 1994). However, this was not the case among women in my study. Rather than blaming others, women instead internalised a sense of responsibility-they themselves were to blame for any harm caused by diseases or vaccines. This acceptance of personal responsibility was manifest in some women's recurring statements that if something went wrong with their pregnancy after either not vaccinating or vaccinating, they would be, or were, angry or annoyed with themselves. For example, when I asked Tessa (age 27), who was hesitant to vaccinate, what finally made her decide to accept the maternal dTaP/IPV vaccine, she stated "Um, I think it was just the effects of what would happen if you did get whooping cough… and how bad that would be… and how bad [guilty] I would feel".
Additionally, Shiloh (age 19) said,

> Shiloh: If I didn't take nothing, I can just put it down to what I've ate… Or what I've done. That's what you need to understand… if I take all these injections I won't know what hurt [my son]… I only took one and that was the anti-D [immunoglobulin injection]… And it's the least I know if anything was going to happen to me or my child, it would be the anti-D… or food.
> RW: how would you feel if you had the vaccine and your child became ill?
> Shiloh: I would be annoyed with myself.

These narratives demonstrate that women worry that it is their responsibility to accept vaccines to protect their infant against diseases, but that at the same time, feel it is their responsibility to reject vaccines to protect their infant against possible side effects of vaccination (Poltorak M, Leach M et al. 2005). This means that personal and social reflections on the implications of vaccination do not stop with the act of deciding to vaccinate or not. In the immediate weeks and even years after the decision, parents may be aware of possible side effects of vaccination or disease, and express either relief that nothing serious happened, or worry that any problematic aspects of their child's development could have been caused by their vaccination decision,

> I was in labour for so long… I feel like they didn't help with... I think if they tried to get him out soon enough, instead of just trying to make me relax all the time, then maybe he might not have been ill. But there were so many… things that I-I'm thinking of, why was he ill, then? Was it me? Was it-was it what I did in the pregnancy? There's so many things I could think of… I was thinking to myself, um, is [receiving the dTaP/IPV vaccine] the reason why he… didn't really breastfeed very well... you think of so many things (Lucy, age 27).

> Kate (age 33): I looked a bit on-online as well, about the risks and stuff.

> RW: About the risks of the vaccine, or the disease?
> Kate: Well, probably the vaccine, actually. I don't really think I looked at the risk of the disease [Laughs]. Probably should've done... We kind of felt nature must've done something right, there must be an in-built immunity that will develop over time, and hopefully protect her. And, it's not a decision that we made lightly... we might regret it in a few years' time, and we felt, either way, if something happened to her, we would regret whatever decision we made.

Additionally, when discussing the influenza vaccine, Haleefa (age 27) stated that she felt "down" because she did not receive the vaccine during pregnancy. The vaccine was not recommended and she mentioned that healthcare professionals "did not care". Haleefa's sentiments and those of the participants above, are of regret and disempowerment, often caused by feeling alone in making vaccination decisions, as well as anxious about, and blaming themselves for any consequences of the choices they made, regardless of what that choice was. Such concerns meant that some mothers expressed that they may not accept vaccines during future pregnancies, even if they had received them in their current or most recent pregnancy.

A more relational approach to care would mean that patient-healthcare professional relationships are supportive, and that women feel confident, competent and empowered; and able to discuss, express their views, and ask questions about their healthcare. It would appreciate that healthcare decisions are usually (and can be better) made with the support from others and would allow space for a deeper and more nuanced understanding of the complex ways that people feel and think about vaccination.

Conclusion

It appeared that personal relationships with, and support from healthcare professionals were often as, or more important to pregnant women than perceptions of expertise. Despite this, a study by Rapley found that rather than offer advice to patients, GPs offered answers based on the language of 'evidence' of the latest research-based science. The approach of merely reporting information, and offering neutral answers was not satisfactory for patients (Rapley T 2008); a finding that was also evident in my study-only one participant (Celia, age 32), said that statistics and risk influenced her decision to vaccinate. Additionally, while Rafael (age 34) said that she trusted the NHS was following evidence-based practice and meta studies, and that she followed these rather than her feelings, earlier in our interview, she said that she decided not to accept

the influenza vaccine due to personal experience of believing she had caught influenza from the vaccine (rather than meta studies). This demonstrates that vaccination decisions are based on much more than risk rhetoric, even if, according to the neoliberal approach to healthcare-which emphases the personal behaviour and self-responsibility of citizens-the risk rhetoric may seem the most obvious and rational approach to decision-making (Lupton D 1999).

The individualist rhetoric of prenatal care simultaneously casts pregnant women as responsible for the care of herself and her foetus, while supporting a subtext (from patriarchal views that women are emotionally irrational) that invokes the opposite-the irresponsible woman who endangers the health of her foetus. The individualist approach to care is the result of the neoliberal marketisation of care, which invokes a version of autonomy that suggests that individuals should be self-sufficient, with views, thoughts and decisions being generated 'from within', with the premise that people exist apart from their social relations (Rapley T 2008). This conceptualisation of autonomy fails to capture the reality of pregnancy, which is both collective and individual in nature (Ruhl L 1999). Women face many influences on their decisions during pregnancy, which reach beyond the immediate space of a single consultation; including from family, friends, healthcare professionals, religious institutions, and government agencies. In addition, there exists parent organisations and self-help groups which, as opposed to biomedical frameworks, represent collective subjects that remove the borders between the public and experts, and between active researchers and the passive beneficiaries of technological progress (Heath D, Rapp R et al. 2004). It was even evident that prenatal and birth experiences, which included dealings with hospital bureaucracy and various healthcare professionals at such a stressful and vulnerable time, shaped vaccination decisions.

Pregnant women are especially influenced by close female family members to whom they approach for advice, possibly due to feeling listened to by such women, and not judged. This advice has a great influence on pregnant women's vaccination decisions, and their own decisions in turn can influence the vaccination decisions of other family members. In this way, even refusing vaccination can be social. Individuals and collectives refuse affiliations, identities, and relationships in ways that intersect with staking claims to the sociality that underlies all relationships, and so such refusal is not just as a response to authority, or a version of resistance. It may also signal a deliberate

move toward one belief, practice, or social group, and a move away from another (McGranahan C 2016).

Different conceptions about what empowerment means might be a contributing factor to vaccine hesitancy (Fadda M, Galimberti E et al. 2016). The responsibility granted to women during pregnancy through the notion of patient choice, and the expectation to follow the 'rules' for a healthy pregnancy, creates an illusion of control, but ironically, due to the unpredictable nature of health and bodies, such responsibility rarely allows women to control their birth outcome. Empowerment to most women in this study did not mean wanting to 'take control', but involved having support in decision-making. In fact, women can feel more in control of a decision when it is made with a medical professional with whom they have a close relationship (Mendick N, Young B et al. 2010). However, a study by Donaldson et al., in London, found that only 24% of respondents had discussed maternal dTaP/IPV vaccination with their GP and 62% were not offered the vaccine (Donaldson B, Jain P et al. 2015). This is an important finding considering that in my study, pregnant women (despite their contrasting opinions towards vaccination), were much more likely to vaccinate if they received a recommendation from a healthcare professional, especially from a midwife with whom they were close. However, while some participants in this study had a close relationship with their healthcare professionals and felt that their concerns were addressed, in many cases, good patient-healthcare professional relationships and understanding of the woman's social context was lacking, and concerns brushed aside. This meant that some women felt neglected, which led to frustration, disappointment and to distrust in healthcare professionals and their vaccination advice.

To address this, an ongoing partnership should be developed between the clinical team, the patient and her family (Rapley T 2008). This would make women feel more in control of their care, and less like a bystander, thus reducing the potential for omission bias. It is important that healthcare professionals understand the influences on women's decisions, engaging in a dialogue about how vaccines make sense in their lives, and ultimately incorporating a broader conception of women's needs in context. This would mean that they are better equipped to discuss any concerns brought about by various influences. Healthcare professionals may also then notice that partners are not being involved in such decisions, thus affecting their ability to provide advice and support, and could engage them in such discussions, unburdening pregnant women from making

healthcare decisions on their own. The approach to care where relationships with the same healthcare professionals are built over time would engender understanding and trust between healthcare professionals and pregnant women.

A relational approach to care would require a change in how maternity care is perceived, with a move away from dehumanised, bureaucratic institution-centred maternity care, which, as demonstrated by the narratives in this chapter, can have a negative impact on the utilisation of services, towards a more woman-centred, personalised conceptualisation of care (Bradley S, McCourt C et al. 2016). Such an approach would entail a move from the top-down approach to vaccine information provision, towards a greater depth of engagement not only by healthcare professionals towards patients but also by public health institutions towards healthcare professionals. It would mean that concerns (such as those expressed by Dr. Lawson about the tetanus vaccine), and differences of opinion, could be openly discussed, and the benefits and importance of vaccination fully understood by healthcare professionals.

The difficulty in addressing vaccine hesitancy with this approach to healthcare however, is that it requires the same one or two healthcare professionals (ideally midwives), to spend time with women and to invest effort into vaccination discussions and their own learning about vaccination. This is problematic in the UK's current care environment where, as discussed in the previous chapter, the NHS has seen a slowdown in funding growth since 2010/11. There is sparse literature on the impact of these financial pressures on healthcare staff but there is a danger that they are leading to a dilution in the quality of care. Research by the King's Fund found that NHS services are often being run on 'goodwill', with many staff working overtime, which can lead to low staff morale and poor quality services. Many of the cuts that have been made, such as to numbers of staff, will negatively affect future care practices (Robertson R, Wenzel L et al. 2017). This is especially significant in the area of maternal and neonatal health, where consequences of poor care or neglect are not immediately visible, and effects can be long-term.

Additionally, while (Ishola, Permalloo et al. 2013) found that in general, London midwives support vaccination of pregnant women, one of the midwives in my study was personally against vaccination. The relational approach to vaccine discussions may not increase vaccination acceptance in these circumstances: if a trusted healthcare

professional is advising against vaccination, or not actively recommending it because of personal views against it, it is likely that women will trust their advice and decide against vaccination. However, a relational approach to healthcare would remedy other very serious issues with service provision (such as the negative experiences some women had with healthcare professionals being rude, or feeling rushed; which affected other aspects of their healthcare, and their engagement with the system in general). A more conversational approach, rather than the pressure to hit vaccine targets, may also provide a necessarily relief of stress on behalf of the professionals, and so may incidentally (along with other factors discussed in Chapter 8), increase vaccine uptake among the majority of the population.

Attention to the social dimensions of healthcare professional-patient encounters and pregnant women's encounters with public health institutions, enables an in-depth understanding of their experiences of vaccination and highlights what are often key points in the shaping of vaccine concerns (Leach M and Fairhead J 2007). The features of a relational approach to care can not only lead to greater patient satisfaction, less symptom burden, and lower rates of referral (Little P, Everitt H et al. 2001), but could also increase levels of trust in vaccination and thus create higher rates of vaccination acceptance. A vaccination decision that is shared with a healthcare professional could also lesson future sentiments of blame and regret. Thus, to feel empowered does not mean that pregnant women must make decisions on their own.

Chapter 7: Discussion

> *Apart from a few small tribes in the South American rain forest, every community on earth experiences influence from practically all others* (Azuonye IO 1996).

In this chapter, I discuss how the theories underpinning the study enriched the analysis of the data. I then summarise how the findings respond to the original research questions, and what they reveal about vaccination acceptance during pregnancy in Hackney. Finally, I detail the limitations of this study; what the study can contribute to the both the field of medical anthropology and to vaccination policy in the UK; and ideas for further research.

Contribution of theory to the study

In order to add depth and relevance to the analysis of the data collected for this study, I drew on insights from anthropological works that address diverse conceptualisations and practices around vaccination and healthcare, for example (Leach M and Fairhead J 2007) and (Mol A 2008); notions of biopolitics and governmentality (Foucault M 1988); and theories of relational autonomy (Mackenzie C and Stoljar N 2000).

Through the notion of governmentality, I analysed the pressure placed on women to protect their foetus in every way possible, and the way that this pressure is exercised-not through direct domination or oppression, but instead through neoliberal forms of governance, the aim of which in healthcare settings, is for patients to internalise notions of individuality and self-care (Foucault M 1988). This approach, evident in the rhetoric of patient choice and the plethora of pregnancy manuals and apps, assumes a "rational individual" who has the time and access to resources that enable a woman to be a "good" mother, and thus turns pregnancy into 'work'. Women who do not conform to this model are criticised and blamed by other parents, healthcare institutions, and healthcare professionals (indeed also often by themselves), for any adverse pregnancy outcomes (Leach M and Fairhead J 2007). The ideology sees women's bodies as mere vessels in which the foetus is carried, and leads some women to feeling that the safety of their foetus is considered more important than their own health. For example, Cadenza (age 34) stated, "the baby is fine, but how about me?" and Carla (age 37), explained that there are some "pressure points" where you do not trust the NHS. For

her, this pressure point was induction. Like Cadenza, she felt that the NHS was only worried about the baby being alive and "if the mother's in a bad way, it's not a big deal", using the graphic imagery of being "ripped to shreds" when talking about her view that there are too many forced inductions within the NHS. One of the main arguments presented throughout this thesis therefore, is that individualised models of healthcare are not only a form of self-governance, but also do not account for the social nature and the importance of support in making healthcare decisions during pregnancy.

This latter argument was formulated based on the importance of social influences and relationships to pregnant women's vaccination decisions. The notion of relational autonomy (Mackenzie C and Stoljar N 2000) was used alongside a criticism of the notion of patient choice (Mol A 2008), to analyse and suggest an approach to healthcare that supports and cares for pregnant women, while at the same time, respecting their autonomy. The concept allowed for an effective analysis of how popular notions of individuality and personal choice around healthcare-which place sole responsibility to make choices on individuals-adversely affects the ability of women to make choices with which they are comfortable. I argued that if women have support in the form of close relationships with healthcare professionals who understand their social situation, and these healthcare professionals recommend vaccination, women are more likely to trust their advice. This approach would lead to more empowered decisions, as women would feel that they fully understand their options, and would be reassured, and not pressured into making decisions that they were not comfortable with and may regret later (thus affecting later interactions with healthcare services). This means that support from healthcare professionals can engender feelings of autonomy, rather than reduce it.

Research question 1: What ideas, norms, beliefs and experiences concerning maternal vaccination prevail among pregnant/recently pregnant women from various backgrounds and identities?

When analysed in depth, it is evident that views towards vaccination are influenced by local and global political situations, and so can provide a basis for wider socio-political reflection. Through analysing the themes 'How constellations of governance are embedded in vaccination discourse', and 'How various socio-political contexts affect vaccination decisions' it was evident that women of various backgrounds receive and engage in healthcare in different ways. While I did not set out to analyse the extent to which individuals' intersecting identities could play a part in vaccination access or

acceptance, the strong influence of socio-economic factors on women's vaccination decisions was an unexpected and major finding of the research, and so was explored in further detail in the analysis of the data.

Pregnancy is full of contradictions. Neoliberal notions within healthcare systems in Western nations conceive individuals as autonomous beings, meaning that pregnant women should be responsible for self-care and conducting their own health research. However, women's bodies, as (according to risk rhetoric), irrational and unpredictable, must at the same time, be located under the surveillance of the public domain in order to make them more manageable (Kukla R 2005). Pregnant women are regarded as irresponsible if they do not live up to the standards set by popular pregnancy manuals, the media and healthcare institution advice (Ruhl L 1999). Thus, truly 'free' choice, without judgment or influence from others, is virtually non-existent. Such pressures can engender increased anxieties about the safety of the foetus, and may persuade women to take measures undesirable for them, for the 'protection' of their foetus, as experienced by Carla,

> When you're pregnant… I hated yoga and it was just like "You've got to go to yoga. I've got to go to yoga"... whereas if it was just yoga for me [I wouldn't do it]… I just was very aware that [the baby] was… 50% not mine so… my husband has an input into this girl's life even when it was in me, was what I thought (Carla, age 37).

These pressures also cause women to conduct vast amounts of personal research, which can lead them to incorrect and confusing online information, and which may be easier in the UK for higher income women who speak English.

The negative effects of such pressures placed on women, versus the importance of protecting the foetus or future child, especially when it comes to vaccination, can cause maternal-foetal conflict with regards to foetal rights (Post LF 1996). In most societies, a pregnant woman's right to autonomy and freedom of action prevail over rights of the foetus. For example, under European law, the foetus is generally regarded as an in utero part of the mother and thus its rights are held by the mother (Kurjak A and Chervenak FA 2006), and current law in the UK usually precludes either prosecution or compensation for pre-birth injury after a child is born (Wilkinson D, Skene L et al. 2016). However, as harm to the future child allows the possibility of legal action in third

party cases, it could be argued that if the pregnant woman injures her foetus in-utero or after it is born (through her behaviour while pregnant-such as not vaccinating), the award of compensation for injuries to the child later (such as contracting pertussis) should be considered. The argument for mandatory vaccination in such a case is compelling as the injury caused by not vaccinating could be very serious; the risk that it will occur during an outbreak of pertussis for example, is high; and the vaccine could prevent it (Wilkinson D, Skene L et al. 2016). However, omission bias arises in this argument; as previously discussed, deciding not to take action (such as vaccinating) to prevent injury is often perceived to be less harmful than deciding to take an action that may cause injury to a child. Additionally, preventing in-utero harm might require major infringements on the bodies of pregnant women. For example, in the USA, pregnant women have been detained or had their behaviour restricted under court order in order to protect a foetus; and in the USA and the UK, women have been compelled by court orders to undergo a caesarean section in the interests of the foetus (Wilkinson D, Skene L et al. 2016). In the New South Wales Supreme Court on the refusal of medical treatment, the judge left open the possibility that a court might override a woman's refusal of treatment to protect a foetus. The judge stated, "There may be a qualification [on the general need for consent] if the treatment is necessary to save the life of a viable unborn child" (Hunter and New England Health Service 2010). Finally, one could ask where the line is drawn when monitoring women's behaviour; in order to prevent future harm, it could also be argued that women's actions or omissions around conception, and even before conception are monitored in order to prevent any harm to children she may have. The obligation to prevent harm to future children may thus require significant sacrifices on the part of parents, prospective parents, and wider society and is worth more detailed discussion in similar studies (Wilkinson D, Skene L et al. 2016).

Vaccination decisions are also greatly influenced by how women access different information; the sources of which depend on when and how, in various social processes, they encounter them (Poltorak M 2007). A lack of knowledge about maternal vaccination was common among participants, but the reasons for this differed between socio-economic groups. Middle-class women who were citizens of the UK tended to believe that they had all the vaccination information that they needed; indeed some even

felt overwhelmed by such information from leaflets and online research[20]. However, some women who were more marginalised, especially those whose first language was not English (such as Japanese mother Tami; Turkish mother Sabah; and Orthodox Jewish mothers Talia and Meira), found it difficult to understand verbal vaccination information, especially if their healthcare professional had an accent or used medical 'jargon'. Some women, like Tami, were embarrassed about asking for clarification. Sabah even avoided antenatal clinics due to not speaking fluent English. Additionally, Talia had a baby to look after, and so could not attend vaccination appointments. This means that low-income, non-English-speaking women are at risk of being excluded from some healthcare services, and thus may not be un-vaccinated out of choice. Such experiences contrast with the middle-class White British women in the FGD, who, all except one were aware of maternal vaccination.

Marginalised or lower income groups also often face the assumption by healthcare professionals and public health institutions that they are unreflective and ignorant, and either 'refuse' to vaccinate, or passively comply with vaccination advice. What on the surface may look like refusal or passive compliance could actually be the result of a number of other complex but invisible factors, including opposing the institutions that promote vaccination, and anxiety in making such healthcare decisions. For example, pressures to conform to a certain model of pregnancy, and the desire for more supportive approaches to care, may cause some mothers to resist the normative rhetoric of pregnancy and thus to disengage with the healthcare system. This may be especially true for marginalised and historically dominated or oppressed groups (such as those previously living under colonial administration), who have complex cultural, political and religious lives that may support opposition to normative biomedical frameworks. This may be why the Black British Caribbean women in this study-at the intersection of a class and race that has historically been discriminated against-while having access to information about vaccination, were hesitant to vaccinate. These women had fears that the vaccines were "something that the government are putting in people" (Midwife Renee), and worried that vaccines can affect different populations differently.

[20] Almost all participants across various backgrounds stated that they wanted a verbal conversation with their healthcare professional about vaccination, however, as discussed, this tended to be more for reassurance than information.

Others may find the responsibility placed on them to make various important healthcare decisions overwhelming, and so hand over such decisions to healthcare professionals (as was the case in this study for Ava, age 26). Like Lucy (age 27), women can also feel patronised or intimidated by certain healthcare professionals and may not feel that they can voice their concerns due to facing judgement. These sentiments are especially true for women of intersecting identities that traditionally face discrimination, such as being young, single, low-income, and/or from a non-white background. Instead of engaging with the healthcare system, these women may instead engage with 'alternative' forms of healthcare, or seek advice from their own communities. For example, like all the women in this study, British Caribbean women were strongly influenced by family member's views and advice about vaccination. However, while White participants tended to have family traditions of vaccinating, Black Caribbean participants reported that family members advised them against vaccinating. The strong influence of family members exists because, despite the pressure for women to educate *themselves* on all aspects of their pregnancy, choices are formed within the structural positions within which individuals are located, and are shaped and constrained by individuals' social positions (Bourdieu P 1984). According to Marx,

> The manifestation of a [person's] life-even when it does not appear directly in the form of a social manifestation, accomplished in association with other [people], is therefore a manifestation of social life… Though a [person] is an individual... [they are] equally the whole… the subjective existence of society as thought and experienced (Marx K 1844).

This means that, as well as resistance to normative biomedical frameworks, deciding against certain healthcare interventions such as vaccination, can also be described as "opting in" (Sobo EJ 2015), as it allows one to feel part of a certain group, and so builds community. However, the "opting in" (to a community) approach to vaccination, may be easier among middle-class women who have the financial and social capital to be able to avoid attracting authorities' attention for making the 'controversial' decision not to vaccinate. This means that they have more choice when it comes to deciding whether to vaccinate, delay vaccination, or pay to receive separate vaccines which are normally combined (such as the MMR vaccine). For example, Jane, a young, single, unemployed Black British Caribbean mother was threatened with the involvement of social services when the health visitor found out that her daughter was not vaccinated. On the other hand, Rebecca, a middle-aged, married, self-employed White British

mother who refused vaccination for both her children, faced no such threats. Similar distinctions between how different social groups are able to make vaccination decisions are demonstrated in White, middle-class women's' notions of 'the personalised immune system'. Such women may decide not to vaccinate as they believe that they are not at risk of diseases, due to the perceived ability to separate themselves from those who are 'different' to them and thus carry vaccine-preventable diseases. These actions have the effect of further defining boundaries between social categories (Biss E 2015).

Through this research question, I explored the pressures placed on women during pregnancy through modes of self-governance; how these pressures affect vaccination decisions; and how the various dynamics of maternal vaccination differ depending on social context. This question thus went deeper than a 'thin' analysis of fears of side effects, perceptions of risk, and a focus on the White majority, in order to enable an understanding of how various intersecting identities can affect access to, and utilisation of healthcare services, in particular, maternal vaccination.

Research question 2: What ideas, norms, beliefs and experiences concerning maternal vaccination prevail among healthcare professionals?

Like most women interviewed, healthcare professionals were generally pro-vaccine. However, during their interviews, it became apparent that some held fears, mild but valid concerns, or misconceptions about the vaccines. For example, similar to many of the women interviewed, both a GP and a midwife were concerned that the influenza vaccine could cause influenza and worsen symptoms. They were also not convinced of the vaccine's efficacy. The same midwife was concerned about the fact that the dTaP/IPV vaccine contained antigens other than against pertussis, and another GP was concerned about the tetanus antigen of the dTaP/IPV vaccine; worrying about the effects of receiving too many tetanus vaccines during a lifetime. Additionally, one mother who was a nurse, believed that the influenza vaccine was only provided so that healthcare professionals did not "go off sick", rather than to protect pregnant women; thus believing that the government had ulterior motives for promoting vaccination. Most healthcare professionals also believed that the dTaP/IPV vaccine was more important than the influenza vaccine. I was surprised that one healthcare professional, a midwife, was personally against vaccination in general, and lacked knowledge about maternal vaccination and the diseases it prevents. NHS vaccination leaflets were an

important source of vaccine information for another midwife. However, one GP said that little vaccination information was provided when specific vaccination campaigns had finished. Healthcare professionals therefore may lack sufficient information about maternal vaccination.

Almost all healthcare professionals interviewed said that it should be the responsibility of GPs, nurses and midwives to recommend and administer the vaccines. While the two midwives interviewed said that they were trained to administer vaccination, two GPs and a practice manager at one of the study sites said that many midwives are not trained to administer vaccination. This issue caused frustration among GPs and pregnant women alike, as it meant women having to book extra appointments with GPs or nurses to receive the vaccines, which was inconvenient or forgotten, leading to under vaccination. Both GPs and women also mentioned the issue of miscommunication around maternal vaccination; there was a concern that this led to healthcare professionals believing that another healthcare professional had recommended vaccination, but in reality, nobody had, and so some women did not receive any recommendation.

Such oversights, neglect, or poor care may also be explained by the fact that since 2010, the NHS has seen a slowdown in funding growth. NHS providers and commissioners ended 2015/16 with the largest aggregate deficit in NHS history, of £1.85 billion; a threefold increase on the previous year. This has placed disproportionate strain on providers (Dunn P, McKenna H et al. 2016), meaning that appointments are shorter or less frequent as fewer staff are employed. For example, between September 2009 and September 2014, the number of senior district nurses in England fell by 30% (Robertson R 2016). A survey of district and community nurses in England, conducted by the Royal College of Nursing in 2013 revealed that the vast majority (77%) felt that their workload was too heavy, and 83% felt that there were not enough nurses to complete work. Seventy-five percent of nurses therefore reported that necessary activities were left undone because of a lack of time (Ball J, Philippou J et al. 2014).

This means that access to healthcare such as vaccination, is not just affected by women's own identities and characteristics, but also by those of healthcare

professionals[21] and the organisation within which they work. Time constraints placed on healthcare professionals due to funding cuts within the NHS may affect their approach to care, including how much time they are able to spend with women discussing vaccination and any concerns they may have; prioritising what are perceived as more pressing matters in consultations; and how they relate to patients (possibly coming across as distant or rude). For example, a number of pregnant/recently pregnant participants reported grievances that related to such pressures and time constraints, ranging from, not receiving letters with appointment dates, and having to wait for long periods of time for scans; to being driven to hospital in a police car when in labour because no ambulances were available. Other mothers had very traumatic birth experiences due to there being no space for them in the hospital, feeling rushed, not listened to, and being in a chaotic care environment. For example, when Ava (age 26), went to hospital to give birth and received conflicting advice, she stated, "I was saying, 'send me to another hospital I don't feel safe'".

Healthcare professionals may also distance themselves from patients because they know that they are going to be liable if they give the wrong advice, and so have to practice a more cautious medicine. This is a result of the introduction of patient laws introduced in response to calls for more equal power dynamics between healthcare professionals and patients in an era of patient-customers, where patient choice is paramount (Mol A 2008). This means that healthcare professional-patient relationships are based on a form of contractual agreement and the fact that patients are not equal to healthcare professionals (not due to being subordinate, but as being vulnerable or ill), is dismissed. Thus, healthcare professionals' manners have to be formal and distant, and they resort to objective probabilities to explain the choices available for women, asking what they want rather than providing advice.

Distancing on the part of healthcare professionals may cause women to feel that they are excluded from decision-making processes and can leave them feeling anxious, invisible and powerless, relegating them to the role of bystander in their care,

> I would've felt more comfortable if a midwife, instead of focussing on the person that was training... they got more of the information and advice and

[21] For example, the demographics of some healthcare professionals may influence their vaccination recommendation (i.e. those practicing for longer may not perceive the need for a relatively new influenza vaccine).

> details than what I got. So… when she was explaining it to me, it wasn't like she was explaining stuff to me, it was more or less to the other person in the room… So, I was, like, I was the third-a third person there… it was a bit annoying… then she would be like, "Oh, you know, if there are any other concerns, you can call us", so in other words, you can't ask us now, just call us. So, yeah, I didn't really like that, to be honest (Lucy, age 27).

An understanding of healthcare professionals' views towards vaccination, as well as their experiences working within the healthcare system aids in understanding why patients may have the views that they do about vaccination, and may receive poor care. This is important to understand because negative experiences could lead women to disengage with the healthcare system and thus not be aware of, or resist vaccination. It is also important to understand the effects of neglect and poor care now; as such issues could worsen with the inevitability of further cuts in funding and staffing within the NHS. This will make maternity care increasingly institution, rather than woman-centred (Bradley S, McCourt C et al. 2016), and has consequences for patient's ability to feel that they are supported and able to make healthcare decisions with which they are comfortable.

Research question 3: How do ideas, norms and beliefs about maternal vaccination differ between healthcare professionals and pregnant/recently pregnant women?

Most healthcare professionals asserted that they recommended the maternal influenza and DTaP/IPV vaccines to pregnant women. However, when, later in the interview, they were asked about their recommendation specifically, it often became apparent that they did not actively recommend the vaccines, but merely mentioned them. This may be why many women interviewed said that they had not received a vaccine recommendation,

> My sister in law sent me an article about a month before I was due, that was about… a woman had gotten flu-like a couple of days before labour and… that made the baby very ill. So she sort of said to me… maybe if you've got the opportunity… go have the vaccine. Other than that, I wouldn't have known that there was any possibility (Marika, age 35).

Additionally, Nicola (age 35) stated, "I think [vaccination] just definitely sounds like its being under publicised". While the women interviewed were not the patients of the healthcare professionals interviewed, as women were recruited from a broad range of backgrounds across Hackney, sentiments expressed could be representative of those

across the borough. This is an important finding considering that most women said that they would have accepted vaccination if it had been offered and discussed by their healthcare professional.

Most healthcare professionals also stated that they reassured vaccine hesitant women of the safety of the vaccines, and offered to discuss vaccination further with them if they had any concerns. However, according to the women interviewed, this rarely happened, especially if they did not initiate the conversation themselves. Instead, women stated that they were often handed leaflets (despite most healthcare professionals saying that leaflets were not routinely given to women), or advised to conduct online research. Almost all women interviewed stated that they would have liked to have a more in-depth, verbal conversation with their healthcare professional about their concerns, rather than just being given information about vaccination. For example, Lucy (age 27) expressed the want for healthcare professionals to take time to discuss her concerns and ask her what she was comfortable with "so that they can actually understand you as a person". This sentiment was also found in a study by Hilton et al., on school nurses' experiences of delivering the UK HPV vaccination programme; when parents telephoned nurses with concerns related to the vaccines, parents were generally seeking reassurance rather than information about the pros and cons of vaccination (Hilton S, Petticrew M et al. 2006). However, in my study, instead of feeling reassured by their healthcare professionals, many women, especially if they were young, single and/or unemployed, reported feeling judged by them, or that their concerns were dismissed. This may be why most participants asked for, and trusted advice from female family members and friends, over that of their healthcare professionals.

Possibly due to the currently popular individualised model of healthcare, allowing for patients' choice in their vaccination decisions was important to all healthcare professionals interviewed. This was also found in a study by Poltorak; when discussing the MMR vaccine, healthcare professionals felt more comfortable giving a range of information from which parents could make choices, than providing direct advice (Poltorak M 2007). However, as discussed in Chapter 4, due to public health institution's (and indeed the population's) need for high vaccination rates, and varying social positions of individuals, completely hassle-free, free choices are not an option for all women. Therefore, despite the NHS ideology of patient choice, there simultaneously exists the desire for 'good' patients who passively comply with vaccination advice. This

contradiction is also evident in the scientific literature; the authors of a study on patients' "adherence-related" beliefs about prescription medicines suggest that understanding patients' perceptions of treatment necessity and their concerns, is essential to support informed choice and optimal adherence to treatment (Horne R, Chapman SC et al. 2013). The language of adherence directly contradicts the language of choice used in the same sentence. It illustrates that while academics, healthcare institutions and healthcare professionals are expected to use the rhetoric of patient choice, healthcare policies come from healthcare institutions, and what they really need and indeed strive for, is adherence to medical interventions; a phrase that does not invoke notions of free choice.

In summary, through this research question, I found that views towards vaccination, and some vaccination concerns existing among both pregnant/recently pregnant women and healthcare professionals, are surprisingly similar. However, the way that healthcare professionals discuss vaccination is often very different to how pregnant women expect or desire it to be discussed. This expectation gap (which involves a lack of expected discussion or reassurance), could be a key point at which vaccine hesitant women decide not to vaccinate.

The final research question; *Research question 4: How could factors influencing vaccination acceptance articulated through this research inform strategies to improve maternal vaccination acceptance?* will be analysed in the following chapter.

Limitations

In-depth interviews

Maximum variation sampling can sometimes lead to certain population groups being omitted from studies. However, participants for this study were recruited from three GP practices, sixteen community antenatal clinics, nine parent-toddler groups and four community/migrant support centres across Hackney, all of which were free to attend. These included specialised parenting groups, for example for young parents, and for pregnant women with alcohol or drug addiction (although no women from the latter group wanted to participate in the study), and so participant demographics varied greatly. I also aimed to recruit some women from the traveller community in Hackney,

as immunisation leads and midwives had told me that this population had low vaccination acceptance rates. However, I struggled to recruit from this community, possibly and understandably, due to the community's scepticism of those linked to government authorities (Richardson J 2007).

I aimed to include the perspectives of male partners towards maternal vaccination, as my literature review showed that very few such studies have been conducted to date. One study that did analyse partners' influence on women's vaccination decisions found that close family, especially partners and husbands can influence a woman's decision to vaccinate (Meharry P, Colson E et al. 2013). Additionally, a 2014 study in the UK found that more than a third of fathers and male partners directly sought out information about pregnancy and birth when their partner was pregnant (Redshaw and Henderson 2015). Therefore, in the initial conception of this study, it was decided that when I visited women's homes to conduct the interviews, if they had male partners also at home, or any other family members over the age of 18, I would ask if they would also be happy to be interviewed. However, there was usually nobody else at home other than the participant when I conducted the interviews. In one case, the participant's husband was at home but was working, and so I did not feel I could ask for his participation. There were also time constraints and I was concerned about having too much data to be analysed effectively for an anthropological study.

A small number of healthcare professionals were interviewed due to difficulties in recruiting such a busy and time constrained cohort. This also meant that their interviews were shorter than interviews with pregnant/recently pregnant women. However, enough information gathered in order to effectively inform the findings of the study.

Additionally, all healthcare professionals interviewed happened to be women. This may be because I only interviewed healthcare professionals who saw pregnant women, and healthcare professionals who are women might be more likely than male healthcare professionals to see pregnant women (due to either healthcare professional or patient preference). Nurses and midwives are also known to be disproportionately women (Staffing Industry Analysts 2016). Interviewing only women however, meant that I was not able to ascertain male healthcare professional's views towards vaccination.

All participants, but healthcare professionals especially, may have been guarded in their responses if they had vaccine hesitant views because they were aware that the study was being conducted in partnership with PHE. However, one quarter of pregnant/recently pregnant women interviewed were hesitant to vaccinate but were keen to talk about their views, and two GPs and one midwife interviewed were very open about their concerns regarding vaccination.

Focus group discussion

Only one FGD was conducted due to time constraints. More FGDs would have allowed for comparison between groups.

Participants were all of a very similar demographic, possibly due to middle-class, white women being more able to take time off work to participate in research studies. This may have meant that more varied attitudes towards vaccination or access issues, which may be experienced by women outside of this demographic, were not discussed. Such homogeneity could also have led to heightened perceptions of social norms, which may have meant that experiences were less detailed as participants may have assumed that certain aspects of their experiences were uniform and therefore did not merit attention. Heightened perceptions of social norms could also have led to views being modified, censored or constrained-a danger that also comes with the emergence of a group ideology. This could have been the case in the FGD as most participants were very vocal with their pro-vaccination views. For example, it was difficult to hear much about the experience and views of one participant (Thalia, age 34), as often when she spoke, she was cut off by members of the group who were more dominant in the discussion and who were more likely to offer their opinions and speak about their experiences without prompt. It is possible that Thalia's views differed from the rest of the group, but due to their strong presence, it could have been intimidating to express these. Additionally, Thalia left halfway through the FGD as her baby was crying and so there was less opportunity to hear about her views of, and experiences with vaccination.

However, the point of an FGD is not to find objective truths but to examine the normative understandings present within certain groups. Additionally, despite the homogeneity of the group, the collective interaction of the FGD generated different insights compared to the interviews. For example, the three participants below seemed

to accept vaccination without question and without feeling the need for a discussion with their healthcare professional about the vaccines or the diseases they aim to prevent,

> Sasha (age 32): I think it was through my work that I knew… why they were encouraging [vaccination]… But, it seemed like a good enough reason.
> RW: And those who did have a conversation about it, did [healthcare professionals] talk about the diseases?
> Amy (age 37): I don't remember going into that much detail but I think at that point in time, all you want to do is protect your baby don't you? So, I think you hear… the positives about it and then your automatic response is I'll have it, I just want to protect my child.
> Nicola (age 35): Yeah same here, just like, I guess you just kind of think, its bad… they didn't actually say, ok, these are the signs of whooping cough… It felt like I kind of knew what I needed to know.

These sentiments contrasted with the majority of interview participants, who at least wanted a discussion about the vaccines with their healthcare professionals, or (like Lucy, age 27), wanted a lot more information about the vaccines before they accepted them.

Consultation video-recording

The Hawthorne effect (Mayo E 1949) may have occurred with this method, as the GP being video-recorded knew that the study was analysing vaccine discussions and so could have been more likely to bring up vaccination in the consultation. However, Pringle et al,. studied the consulting behaviour of four GPs whilst they were either aware or unaware of their consultations being video-recorded and found that consulting behaviour was not be affected by their awareness of the recording (Pringle and Stewart-Evans 1990). It could also be argued that patients' behaviour may be changed if their consultation is recorded. However, it has been found that video-recorded consultations are of little consequence to patients (Martin and Martin 1984), and such patients are no less satisfied with their consultations than other patients (Campbell, Sullivan et al. 1995). In another study, around 70% of patients who consented to recording agreed on a post-consultation questionnaire that they 'forgot' about the presence of a video-camera during their consultation (Coleman 2000).

The NHS ethics committee and I believed that recording the consultation through an i-pad (which is often used by GP practices to record consultations for training purposes), would be less intrusive than if I observed the consultation in person. It was explained to

potential participants that only the principal investigator would see the recording. However, when a member of the practice staff telephoned women to organise their 16-week check and to ask them if they would like to participate in the study in the form of having their consultation video-recorded, they often told him that they were worried that the recording could end up online. Therefore, only one consented to having her consultation recorded.

Thematic approach to data analysis

Many disadvantages of using the thematic analysis approach to analyse data depend more on poorly conducted analyses or inappropriate research questions, than on the method itself. The flexibility of the method, which allows for a wide range of analytic options, did mean that trying to decide what aspects of the data to focus on was difficult. However, because I used existing theoretical underpinnings, I was able to focus the analysis and anchor the analytic claims that were made.

Another disadvantage to the thematic analysis approach is that unlike narrative approaches to qualitative research, it does not as easily allow the researcher to retain a sense of continuity and contradiction through individual interviews (Braun V and Clarke V 2014). However, I aimed to portray the significance of the contradictions and consistencies existing throughout participant narratives especially in context in Chapter 5, where I focused on a small number of participants, and so an in-depth analysis of their accounts was feasible.

Relational autonomy

Whilst a relational approach to theorising the data provided an in-depth understanding of the importance of close healthcare professional and patient relationships to vaccination acceptance, when it comes to making recommendations for policy, there is a flaw to this approach. For it to work, healthcare professionals must have positive views towards vaccination, and want to recommend them. However, as was found in this study, some healthcare professionals are personally against vaccination. This means that whilst women who have close relationships with their healthcare professionals are likely to trust pro-vaccination advice, they are also likely to trust advice if it is against vaccination or if vaccination is portrayed as unimportant. Therefore, when used in

vaccination policy, before a relational approach to care is suggested, it must be ensured that healthcare professionals receive appropriate training on the importance of maternal vaccination and how to discuss the vaccines with pregnant women, and have an opportunity to discuss their own vaccination concerns with other healthcare professionals.

This approach also requires funding for longer consultations and training for healthcare professionals. These measures will be difficult to implement due to current issues of underfunding and staff shortages within the NHS.

Conclusion

One of the targets of the UN Sustainable Development Goals (SDGs) is to reduce the global maternal mortality ratio to less than 70 per 100,000 live births. However, globally, over six million children under the age of five died in 2013 and more than half of these deaths were due to conditions that could be prevented or treated with access to simple, affordable interventions such as vaccination (WHO 2014). Mortality reduction in new-born infants under one year of age has been gradual, especially in various African countries (Lawn JE, Blencowe H et al. 2014), declining on average at three percent per year since 1990 (UNICEF 2015). The relative proportion of new-born deaths now accounts for about 44% of the total under-five mortality, and are projected to make up 55% of all under-five mortality by 2035 (Sobanjo-Ter Meulen A 2015). Women's access to, and acceptance of maternal vaccination, which prevents life-threatening diseases in new-borns, is therefore essential.

In this study, I aimed to recover modes of understanding that better grasp the ways that people think about and experience vaccination. This is because if the benefits of vaccination are to be experienced equally across the population, understanding vaccine hesitancy and issues in accessing vaccination is vital. Only then can the gulfs between the public and public health institution's views of vaccination be overcome. An in-depth understanding of views towards, and differing levels of access to maternal vaccination among women in Hackney, was achieved through conducting in-depth interviews, an FGD, and a video-recording of a consultation, through which I accessed the views of

those both providing and receiving vaccination. Anthropological theories were then applied to a qualitative thematic and narrative analysis of the data.

I considered women's views and experiences of wider socio-economic and political dimensions that influence perceptions towards, and access to maternal vaccination, as well as their broader perspectives on pregnancy and their birth experiences and how these related to their vaccination decisions. I also analysed bodily and social dimensions to vaccination concerns that exist among family members, communities and healthcare professionals. This gave me an insight into how vaccine decisions are made; the narratives making clear that decisions are not made as autonomous individuals, but as communities and societies. Such societies extend beyond family and immediate group ties, to parent-toddler groups, social media networks, and internet forums, which allow space for discussion, questioning, and most importantly, empathy and understanding.

I found that intersecting identities also play a large part in pregnant women's access to vaccination, as well as in their vaccine choices. If a woman is on a low-income, she may not be in a position to take time off work, or organise childcare to attend vaccine appointments. Some women also may not have sufficient English to book vaccine appointments. On the other hand, historically dominated groups may resist vaccination as a way to resist government control and normative frameworks of biomedicine. Additionally, young, low-income women from ethnic minorities may unwillingly accept vaccination due to a fear of attracting attention from government authorities if they refuse or question vaccination.

Access and attitudes towards the healthcare system, and thus vaccination, can be further affected by the state of the NHS and women's interactions with individual healthcare professionals, meaning that most healthcare professionals interviewed did not have in-depth conversations about the vaccines with women. Individual healthcare professionals however, should not be blamed for this. Discussions take time, something that is in short supply within the NHS due to immense financial pressures and scarce resources. This means that individual healthcare professionals are not able on their own to make the changes suggested in the following chapter, but must be supported by NHS England and PHE.

Severe time constraints translate into chaotic care environments, where women do not feel that they are respected, or where they experience neglect. These experiences can have negative consequences for how women perceive the healthcare system and health technologies, such as vaccination in general. These issues, as well as the complexity of vaccine hesitancy, means that there are large gaps between what healthcare institutions assume women want (i.e. leaflets or a brief mention of the vaccines), and what many women interviewed expressed what they actually needed (in-depth discussions and reassurance). There are also contradictions between what public health institutions say to patients-'your health, your choice' (a notion that has become the holy grail of healthcare provision in many contexts) and what, in reality, they expect-'you should vaccinate to protect yourself and the rest of the population'. In trying to maintain vaccination uptake rates, but also respecting patient choice, frontline healthcare professionals have to manage the contradictions of various healthcare approaches with their patients. Such contradictions also make patient's decisions difficult, as they are expected to be autonomous, in control, and therefore 'on their own' in making them. For pregnant woman, there is the added pressure of making the correct decisions to protect her foetus: the responsibility of which is expected to be all hers. Potential hazards she is expected to avoid include those which have no scientific evidence of harms (such dying her hair during pregnancy), but also those caused by structural factors that individuals cannot control (such as poverty). Thus, women tend to feel guilty when such harm is caused, even though it is likely to be beyond her control. It is unsurprising then, that having to make a choice about vaccination during pregnancy can be anxiety provoking, or is avoided altogether.

This study was the first to provide an in-depth analysis of attitudes towards maternal vaccination in Hackney, and is also (to my knowledge), the first anthropological study analysing views towards maternal vaccination. The findings will therefore add depth and context to the knowledge on views relating to the relatively newly introduced maternal vaccines not only in Hackney, but in the UK in general, where only 12 other scientific studies to date been conducted, mostly focusing on the influenza vaccine and using quantitative approaches. In its application of an in-depth anthropological analysis, this study moved beyond previous studies on maternal vaccination, not only to understand what concerns women had about the vaccines, but also how these concerns may have come about. I linked these concerns to wider socio-political contexts in order to move the discussion of vaccine hesitancy away from the dry reporting of fears of side

effects, into an area where there was space for the exploration of nuance in participants' accounts. This approach allowed for an in-depth understanding not just of perceptions relating to vaccination, but also of healthcare professionals, and the healthcare system overall, as well as the government within which it is situated. The approach also allowed issues in accessing vaccination to be understood as complex and dependent on a variety of factors, rather than only on a woman's individual characteristics.

The findings have allowed me to suggest practical guidance for increasing maternal vaccination acceptance, which is often lacking in anthropological studies on vaccination. One of the main suggestions based on the findings is to promote policy which does not overwhelm women with statistics about vaccine efficacy, but which takes a more relational approach to healthcare. This approach understands the social context and lived experiences of each woman, moving away from the simplistic language of removing barriers to accessing healthcare. Such language betrays the normative assumptions that underlie Western models of biomedicine; that change is always good, and that 'barriers' should be removed. It engenders stereotypical assumptions that perceive certain population groups to be the cause of any difficulties they may have in accessing care. The 'barriers' and 'difficult to reach populations' reported as preventing optimal vaccine acceptance are actually less important to maintaining optimal vaccination rates than the socio-political contexts that give rise to vaccination concerns (Checkland K, Harrison S et al. 2007).

Due to time constraints, this study was unable to gain the perspectives of family members and friends who influenced pregnant women's vaccination decisions. As social contacts had such a large influence on vaccination decisions, it would be beneficial for future studies on maternal vaccination acceptance to conduct interviews with such influencers to gain an added dimension to understanding vaccination perceptions and access to vaccination in context. There is also a need for more studies exploring if and how women's male partners influence their vaccination decisions. While this study found that most women's vaccination decisions seemed not to be influenced by their male partners, a deeper exploration involving directly interviewing partners, would engender an understanding of their perceptions of the vaccines and whether they would like to be more involved in vaccination decisions. Such findings could affect how healthcare institutions and professionals involve partners in vaccine discussions, and at whom they target vaccine promotion materials. Similarly, it would

be beneficial to ascertain male healthcare professional's views towards maternal vaccination, and whether they recommend the vaccines.

It may also be beneficial for additional FGDs to be conducted with pregnant/recently pregnant women from varying demographics, in order to understand in more depth, how people from various backgrounds discuss vaccination with each other. For example, the study found that Black British Caribbean women had particular concerns about the vaccines. This requires deeper exploration among more women from this population, in a variety of areas across the UK. Specific questions could be asked about discrimination and intersecting identities, in order to more deeply understand how these factors influence vaccination perceptions, and if their concerns reflect those of the Black British Caribbean women interviewed in Hackney.

Based on the findings of this study, the recommendations made in the following chapter could be relevant not just to increase acceptance of currently available and future maternal vaccination in Hackney or the UK, but in countries that have yet to introduce the vaccines. Prior to vaccine introduction, these recommendations may help to allay concerns, prevent misconceptions from spreading, as well as advise on the best vaccine delivery methods to ensure equal access to vaccination across populations.

Chapter 8: How factors influencing vaccination acceptance articulated through this research could inform strategies to improve maternal vaccination acceptance

This research was conducted with support from PHE to increase access to, and acceptance of maternal vaccination in England. My role as a medical anthropologist was to critically engage with PHE's vaccination policies, which are situated within the normative model of biomedicine, whilst acknowledging the benefits of vaccination and providing policy recommendations. Translating research into policy is usually complex and rarely linear (Hawkes S, Zaheer HA et al. 2012), but the nature of critical anthropology makes direct recommendations especially difficult to make. In this chapter however, I take into account the socio-political specificities in the lived reality of pregnancy and healthcare in order to provide anthropologically informed recommendations about how to increase acceptance of, and access to vaccination through improving patient-healthcare professional relationships and healthcare institution rhetoric around pregnancy; including friends and family members in vaccination discussions; and ensuring equal access to vaccination across population groups.

It must be noted that the public, and especially vaccine hesitant women, as individuals who are normally open to discussing vaccination, should be the target of efforts to increase vaccination acceptance, rather than vocal deniers. This is because when individuals have strong beliefs about something, they often hold onto these beliefs, even when the evidence for them is refuted (Milligan G and Barrett A 2015).

Patient-healthcare professional relationships

> *"… during the birth, when the violence to my body was greatest… Everything that happened to me in the hospital… I experienced at that time as aglow with humanity. Alarms were sounded for me… ice chips were held to my lips. Human hands were in me and in everything that touched me"* (Biss E 2015).

The top-down approach to vaccination policy currently pursued by PHE, jars with the currently popular individualised notion of healthcare and the rhetoric of patient choice. Greater public involvement in decisions around vaccination policy and programmes should move away from expectations of compliance, to concordance. This requires a collaborative communication approach with patients (Department of Health and Human

Services and CDC 2009), which allows space for individuals' own definitions of health-which are relative, dynamic and strongly linked to personal experience-without removing them from the broader social context (Lupton D 1995). This would enable healthcare institutions and professionals to learn from patients. Such an approach could take the form of PHE creating working groups where healthcare professionals, concerned publics, and social science academics are invited into the design process of vaccination campaigns. A similar approach, with a focus on "patients as partners" was conceptualised and brought together as a programme by the King's Fund, and has been implemented by a number of NHS Trusts since September 2016 (Seale B 2016). The programme is viewed favourably by those who have been involved with it. For example, Julia Briscoe, Patient Experience Lead, Barts Health NHS Trust, and Sally Edwards, Chair, Whipps Cross Patient Panel state on the web page dedicated to the impact of the approach,

> We are embedding the collaborative pairs work within our patient experience and engagement strategy. Barts Health NHS Trust is large and spread across several sites and this approach ensures that the patients' voice is embedded at the most fundamental level (The Kings Fund 2016).

As demonstrated in my study, good communication is a precondition for good care. While healthcare professionals should of course be knowledgeable and provide advice based on scientific evidence, it is also important to build relationships with pregnant women, to be kind, attentive, persistent and forgiving, and to make sure that the various people and activities involved in her care are attuned to each other (Mol A 2008). Pregnant women desire a less medicalised and more relational approach to care, which requires open, trusting patient-healthcare professional relationships. These relationships could be built through greater transparency in healthcare practices, and training healthcare professionals to be more empathetic and to encourage dialogue when recommending vaccination. This is important because even the way in which the topic of vaccination is initiated can significantly affect patient's vaccination decisions (Opel DJ, Robinson JD et al. 2012). An example of a positive approach to a vaccination discussion was that used by the GP in my study whose consultation was video-recorded. Dr. Shaw employed a participatory approach to the vaccination discussion, which invited her patient into the conversation, while also asking her about wider aspects of her wellbeing. In contrast to Dr. Shaw's participatory consultation format, Opel et al., found that GPs also often use a presumptive format, involving asserting a position

regarding vaccination (for example, in my study, Ava (age 26), said that her healthcare professional stated, “Right, are we going to get the vaccinations?”). Such an approach may be used by some healthcare professionals due to the fear that a “discussion would open up a can of worms” (Davis TC, Fredrickson DD et al. 2001). However, this format constrains women’s participation because it merely licenses their acknowledgement of the recommendation, thereby requiring them to actively resist the proposal as a precondition for starting a discussion (Opel DJ, Robinson JD et al. 2012). The presumptive approach may thus only be beneficial in certain situations. For example, if it is used by healthcare professionals who have an established relationship with their patient and use their prior understanding of that patient's desired communication style and vaccine attitudes to determine that a non-participatory initiation of the topic of vaccines is appropriate (Opel DJ, Robinson JD et al. 2012). Healthcare professionals can pragmatically involve pregnant women in the vaccination decision-making process by having an open and non-judgemental manner and allowing space and time for questions. An example of a relational, participatory approach to structuring the vaccination conversation with vaccine hesitant women in consultations is as follows,

1. Healthcare professionals should introduce themselves to their patient and explain what they can expect from the consultation
2. Explain what the maternal dTaP/IPV (and if relevant), the influenza vaccines are and why they are important
3. Check the patient’s decision making role preference (i.e. involving her to the extent that she desires to be involved)
4. Explore expectations and any fears surrounding vaccination
5. Provide personalised information and reassurance based on the patient’s concerns (acknowledge or be honest if an answer to a patient’s question is not known)
6. Discuss potential options for moving forward (such as having time to think about the decision and coming back to discuss it further if necessary. Do not pressure her to vaccinate[22])
7. Check the patient’s understanding of information and her expectations of possible options

[22] When employing a relational, caring approach to encouraging vaccination, a balance between the two poles of neglect and dictating advice should be found so that healthcare professionals avoid coming across as paternalistic or pressuring women to vaccinate.

8. Support the patient to make a decision.

(Adapted from (Elwyn G and Charles C 2001)).

Communication experts could video-record consultations and provide healthcare professionals with feedback on their communication style. Various styles and approaches can then be experimented with and applied to different patients depending on their individual characteristics and preferences.

A relational approach would also require more midwife continuity, so that the same one or two healthcare professionals spend more time with women over the course of her pregnancy, in order to build trusting relationships and enable any concerns to be discussed fully. As midwives usually have close relationships with pregnant women, they should also be more involved with vaccine programmes and promotion. They should receive training so that they understand the importance of vaccination; have the chance to discuss any concerns they themselves may have with maternal vaccination; and ensure that they can manage the very high expectations of both the system and the demands and questions of patients. Ishola recommends that employers issue clear and specific information, direction and guidance about maternal vaccination to midwives (Ishola, Permalloo et al. 2013). More research is also needed to ascertain the number of midwives who are not trained to administer vaccines, and these midwives should then receive the correct vaccine administration training so that women can receive the vaccines when they are recommended, rather than having the inconvenience of having to book extra appointments to receive them. Such training is essential because the practice of midwives is likely to become more important under the emerging health service framework in England, with the growing shift away from hospitals and GPs to community-based services such as separate midwife-ran maternity services, leading to greater roles, responsibilities and influence for frontline staff (Ishola, Permalloo et al. 2013). Along these lines, discussions should be had with healthcare professionals about trends towards growing privatisation within the NHS, and its implications for vaccination.

Women especially require more contact during their first trimester, when participants in this study sometimes felt neglected, and when women may need support with experiences of miscarriage. An approach that is currently used for women with *high risk*

pregnancies[23], which involves healthcare professionals spending more time with women, could be beneficial for all pregnant women. This approach was seen as very positive for Anna who had a high-risk pregnancy,

> The appointments were… half an hour long and they were very intimate and personal and I would generally see… the same people so it kind of felt like a nice kind of journey… They would kind of have this small group, um, which kind of supports you through… so yeah it was really good care… they were always really supportive and… quite often I would have my older son with me and they were very sweet with him… I'm very pro-NHS I think it's an amazing thing… very positive… they listened and kind of didn't brush aside any worries I had and very supportive. I'd love to get that again whether I will I don't know (Anna, age 34).

A more relational, personalised approach to care at the beginning of pregnancy is also important because the first contact a woman has with the healthcare service during pregnancy could influence her entire perception of healthcare throughout her pregnancy. In spending more time with women, healthcare professionals would understand them and their social context more broadly, as well as how they themselves influence women's vaccination decisions, and would be more easily able to identify specific vaccination concerns. This would engender a move away from an emphasis on autonomy, to an understanding of patients' lives as a whole, and how they can be improved with support from others, meaning that healthcare can be tailored to women's needs while actively strengthening their confidence in their healthcare decisions (Bradley S, McCourt C et al. 2016). It must be noted that tailoring does not need to be so individualised that it is inefficient to the healthcare service. In fact, a method of "mass customisation" can be employed where individuals can be grouped according to their expressed preferences, and methods of personalisation can be systematised (Sobo EJ 2009).

Healthcare institution rhetoric

Attention to the contextual and dialogical ways that gulfs emerge between patient and policy worlds suggests ways towards bridging the gulfs that exist between healthcare professionals and patients (Leach M and Fairhead J 2007). Those deemed to be

[23] A high-risk pregnancy is one that threatens the health or life of the mother or her foetus National Institutes of Health. (2017). "What is a high-risk pregnancy?" Retrieved 2nd August, 2017, from https://www.nichd.nih.gov/health/topics/pregnancy/conditioninfo/Pages/high-risk.aspx..

responsible for risk (such as those deciding not to vaccinate), are often seen as deviant (Mythen G and Walklate S 2006), as was the case in this study when Jane was threatened with social services when she considered not vaccinating her daughter. The blaming of women, especially, like Jane, who already face various difficulties and discrimination due to their socio-economic position, does little to encourage them to vaccinate. In missing the ambiguous, processual, and particular character of women's histories and experiences, not only are their perspectives misunderstood and thus some women become alienated, but flawed and ineffective policies are introduced, thus perpetuating the problem. For example, the current focus on presenting the public with copious amounts of information based on 'scientific facts' in order to increase vaccination acceptance, assumes public ignorance and a lack of rational thinking, and contributes to the stereotypes often applied to vaccine hesitant women by healthcare institutions and professionals. While success stories about controlling disease through vaccination are seductive, partial accounts conceal complicated histories, mask problematic collaborations with capitalist entities such as pharmaceutical companies as well as failures in science, and ignore external social, political, and institutional factors that affect healthcare (Graham J 2016). Instead of being presented with abstract statistics with which they are expected to make probability calculations in order to make decisions, most pregnant women want verbal discussions, which include reassurance and empathy. A narrative or 'story telling' approach from some*one*, which generates emotions, can thus be more effective in encouraging vaccination acceptance than presenting 'facts' verbally or through some*thing*, such as leaflets. This is because in reality, decisions and dilemmas occur socially and often do not account for clear certitudes and scientific explanations (Lemke T 2011). Most women ask friends and family for advice or search online if they require pregnancy-related information. Vaccination promotion materials should therefore be used as a supplement to more in-depth and personalised vaccination discussions.

Along a similar vein, the use of alternative therapies should not be dismissed in negative terms, as they are often used alongside vaccination and the therapists involved can be an important source of support. This means that if women engage with alternative therapists, they should be discussed, and their role understood in vaccine conversations. Similarly, the emergence of parental networks and mobilisation around vaccination should not be written off in negative terms, simply as problematic, but should be understood as a complex phenomenon and a means of building community. In this way,

at a time where individualist notions of healthcare are popular, and where patients believe that they are the experts of their own health, the positive elements of vaccine decision-making should be acknowledged and built upon, and information presented in a way that affirms self-worth or core values. It should acknowledge the value of women's expertise; their dedication to their and their foetus' health; their commitment to good parenting and active health seeking; and what they already do to protect their and their foetus or infant's health.

Whilst acknowledging and accepting the need to work within a healthcare system and society that takes an individualist approach to healthcare, healthcare professionals should remind women of the community benefits of vaccination and how the diseases that vaccines aim to prevent could affect her whole family and others she is close to. For example, discussions with especially white, middle-class women who assume that they can avoid certain populations in order to avoid disease, and thus vaccination, should address the danger of this approach, not only to themselves, but the populations that they aim to avoid. Along this vein, the language of herd immunity used with regards to vaccination should be reconsidered. When used in respect to public health, the term 'herd' conjures images of herds of sheep or cattle blindly following orders. This blind acceptance of authority is one of the fears that some vaccine resistance is based on. Such language is also too abstract and insensitive to relate to particular women and their infants, and dismisses women's individual perspectives. A more appropriate term to explain that optimum vaccination rates are necessary to protect the whole population, may be 'community immunity', as rather than conjuring images of herds of cattle lined up to be injected, it conveys the idea of caring for others within the community.

Organisations that do not support their healthcare professionals are unlikely to prioritise respectful care for women (Bradley S, McCourt C et al. 2016). It must be taken into account that health systems constraints such as underfunding (as currently faced by the NHS), can frustrate the workforce and undermine healthcare professionals' performance and professionalism, as well as their sense of 'good will', as such constraints are a source of considerable distress. Given the well-established link between staff wellbeing and the quality of patient care, maintaining a healthy workforce as the NHS goes through this period of intense pressure is therefore particularly important.

Involving friends and family members in vaccination decisions

> *No one takes a decision… without consulting neighbours, family, work friends. These are the support group that will help if things go wrong.* (Douglas M 1994).

Due to the overwhelming influence that family members and friends had on participant's vaccination decisions, it is important that maternal vaccination promotion material reaches a wider public than just pregnant women. Participants in a study conducted by Linden, on HPV vaccine acceptance in Sweden, believed that including relatives in vaccination campaigns engendered a more caring approach to encouraging vaccination acceptance (Linden L 2016). The Black British Caribbean women in this study relied especially on family members' advice when making healthcare decisions. However, these family members often had negative views towards the vaccines. In order to increase vaccination acceptance, family members must have positive views towards vaccination, which could be achieved through involving them in vaccine discussions and decisions as much as possible (for example if they attend consultations with the pregnant patient), if of course, this is what the patient wants. Including family members in vaccination decisions in this way could dispel traditionally held familial misconceptions about the vaccines, possibly making it less likely that they will try to persuade the pregnant woman against vaccination[24], and would enable such contacts to feel more included in her healthcare. This approach may even lead to friends and family members encouraging vaccination, which my findings suggested, had a positive influence on perceptions towards vaccination,

> Isleen (age 34): [People] are always advocating that… we should be vaccinated against [pertussis], so that always rings in my mind… thinking of a tiny baby coughing itself to death… I remember my friend saying that… you should get [the flu vaccine]… we get a free one… during pregnancy. But… I've not actually had flu jabs before… so I …did it because I was pregnant… It's not something that I religiously do.
> RW: How did you feel when your, your friend recommended the, the flu vaccine?
> Isleen: Um, I remember thinking, oh, that that's probably a good idea.

[24] However, I would also argue that it is beneficial to include friends and wider social contacts in such campaigns, so as not to assume the trope of the family as the main 'care unit' in anyone's life.

Additionally, the parents of women who are currently offered maternal vaccination are of a generation that pre-dates it, and so participants often reported that their mothers had told them that pertussis and influenza are common childhood diseases that both they and their children survived. It is thus especially important that women's parents are aware of the maternal vaccine recommendations, and the importance of the vaccines.

A study by Frew et al., found an inverse relationship between being married and vaccinating, suggesting that pregnant women who are single, as the primary providers for themselves and their unborn child, may exert more control over the health of themselves and their foetus, and thus may be more likely to vaccinate (Frew PM, Saint-Victor DS et al. 2014). In my study, even women who had male partners tended not to seek advice from them as much as from their female friends and family members, and so in many instances, they were not engaged in vaccination decisions and thus could not offer support in making such decisions. Efforts should therefore be made to include male partners in vaccine discussions through encouragement to attend appointments (if this is what their pregnant partner wants). Partners and other influential family members should also be targeted more by vaccination promotion material. Currently, the NHS maternal vaccination promotion leaflets and posters contain a photo of a pregnant woman (on her own) on the front page, with the leaflet for influenza vaccination entitled, "Flu, *your* pregnancy and *you"* [emphases added] (PHE 2015). The lack of representation of other social contacts in these materials, and the emphasis of the effects of influenza only on the individual pregnant woman, excludes others invested in her and her infant's health, and who greatly influence decisions around such matters.

Access

Due to the many socio-political and economic factors that can create inequalities in access to healthcare, medical technologies aimed at improving population health can be homogenising in the way that they are used and practiced, yet partial and unequal in their operation or effect (Biehl J and Petryna A 2013). This means that programmes need to be developed that aim to change factors that engender inequalities, rather than default to strategies of individual risk management, which blame individuals for inequalities in access to healthcare (Owkzarzak J 2009).

Health promotion in the West is a middle-class movement dominated by those from English-speaking backgrounds. While their appeals to normative models of biomedicine and self-control may strike a chord with others of similar socio-economic and cultural backgrounds, different social groups receive and interpret health promotional discourses in different ways (Lupton D 1995)[25]. It is therefore not fair to allude to any particular religious group, ethnicity, or 'class' as resistant to vaccination. While language or cultural 'barriers' are often blamed for under-vaccination, it is more productive to examine communication issues that could lead to a lack of knowledge, misconceptions or distrust in healthcare professionals or vaccination that arise within the healthcare system. Even English speakers report communication challenges when trying to navigate the NHS. The fault for low vaccination uptake rates among certain groups is thus more likely to lie within the healthcare system and its failure to engage certain population groups 'appropriately'. For example, it was previously assumed that the Charedi community in North London had systemic religious or cultural objections to vaccination, but it has recently been shown that this is not the case (PHE 2016). Instead, in my study, the two Orthodox Jewish participants faced structural barriers to accessing vaccination. One was not able to attend the vaccine appointments due to having another baby at home to take care of, and the other did not understand what maternal vaccination was for, due to it being explained in English without a translator present. Therefore in targeting health messages at specific groups, public health institutions should be wary of creating or perpetuating stigmas or fuelling racism, which can ensue from associating them with problems that they are perceived to cause for health care systems. Incriminating culture can also lead to a disengagement with the healthcare system, which is especially dangerous with regards to vaccine discussions, because vaccination is often the first opportunity for recent migrants to be integrated into local services (Bhopal RS 2007). Instead, efforts should be made to gain an understanding of how pregnant women in particular social and political settings engage with healthcare and vaccination, and how varying levels of access to care are perceived and interpreted by them (Leach M and Fairhead J 2007). To address issues of miscommunication, existing translation services should be enhanced so that they are more widely available and maternal vaccination leaflets should be translated into a variety of languages. Additionally, technical terms used in medical settings and in vaccination promotion

[25] It must not be assumed however, as neoliberal notions of risk management often do, that non-Western or poor women are not rational, and so there is not point appealing to them on the basis of a shared form of responsibility. In reality, most women want what is best for their infants Ruhl L (1999). "Liberal governance and prenatal care: risk and regulation in pregnancy." Economy and Society **28**(1): 95-117.

materials should be translated into lay language that is culturally appropriate, appreciating that health understandings are flexible, and taking into account the socio-political contexts in which women are situated.

An equitable healthcare service would meet healthcare needs across the population, and ensure uniformity in access, use, and quality at the point of delivery, through flexibility as well as standardisation in the organisation of services. This would mean that women experience predictability and consistency in the care that is provided. IT systems should provide prompts to identify when pregnant women are eligible for the vaccines, so that reminder letters can be sent (only one GP interviewed mentioned that such prompts were available at her practice). If time allows, GPs should also call women to discuss vaccination directly with them. A pregnancy-vaccine helpline could also be established, so that women can find accurate information and reassurance about maternal vaccination at any time. For example, some women and healthcare professionals in this study were concerned that patients were not normally told that the maternal dTaP/IPV (or 'pertussis') vaccine also contains tetanus and diphtheria antigens, and did not know why these components were included. It is important that women are clear about what exactly the vaccines offered immunise against, so that they do not feel that information is being hidden from them. Additionally, maternal vaccination should be made more visible. Jane (age 24) said that because maternal vaccination was not frequently mentioned on the news or in newspapers, it was not something she felt she needed to receive. Additionally, Mahsa (age 31) stated that information about maternal vaccination should be shown on television, otherwise many women do not know how important they are. The belief in the importance of positive media attention regarding vaccination was also shared by Dr. Clark, who believed that because the dTaP/IPV vaccine had been on the news, it was considered more important by women than the influenza vaccine.

As was recommended by many participants in this study, the maternal dTaP/IPV and (in influenza season), the influenza vaccine, could be recommended at a particular point during a woman's pregnancy, and administered together at the same appointment in which they are recommended, in order to save healthcare professionals time, and for the convenience of the pregnant woman. However, it is important that in the influenza season, women do not delay receiving the influenza vaccine until 16 weeks of pregnancy (the time from which the dTaP/IPV vaccine should be provided). If they

become pregnant during the influenza season, they should have the vaccine as soon as possible (NHS Choices 2016b). Additionally, after-hours vaccination clinics held at GP practices would be beneficial for women who work during the day and cannot take time off. Waiting times for appointments should also be reduced in maternity care in general, in order to make it easier for, and to encourage all women to attend appointments. This issue could be helped with budget increases to ensure that the recommended staffing ratio is met at all times. Finally, through better information systems that produce data on access to healthcare, as well as experiences of care among various population groups, services could promote and monitor equity in access to and quality of healthcare, as well as utilisation of health advocacy services (Bhopal RS 2007).

Ultimately, GP practices and antenatal clinics should have specific but aspirational targets for maternal vaccination. This could involve having a 'vaccine champion'-a member of staff who oversees and creates enthusiasm for vaccination campaigns, and encourages improved communication about vaccination between healthcare professionals. This could be somebody like Midwife Williams,

> I encourage [vaccination] because I do believe in it, and… I've got some leaflets and… I went to [management], I said, "Look, we do need more leaflets." I was the one that requested that when they run out".

Most of the suggestions mentioned in this chapter require additional funding to be directed at providing longer consultations and the training of healthcare professionals towards a more relational approach to care. The need for budgets to take account the implementation of the above measures is of utmost importance as it would mean that healthcare service are tailored to meet the needs of local populations, ensuring that pregnant women feel that services are working with them rather than parallel to them. Ultimately, this would lead to a consistent, high level of care for everyone, and thus increased levels of vaccination acceptance.

Conclusion

One of the key issues I faced as a critical medical anthropologist conducting research to inform policy, was how to balance a critique of biomedicalisation, whilst not losing sight of the real medical benefits of maternal vaccination. I aimed to achieve this balance by conducting research that demonstrates the complex reasons for vaccine

hesitancy and inequitable access to vaccination, and analysing the issues within the healthcare system that contribute to this, while engaging productively with science, medicine and healthcare professionals.

I have provided recommendations that encourage a questioning of the dominant framework of biomedicine and how this shapes PHE's approach to providing healthcare, which is not suitable for all women. I have argued that healthcare institutions, healthcare professionals, and academics should promote more personalised modes of healthcare, and uncover the ways in which public health landscapes are configuring and being configured by novel articulations of patient choice, rights and responsibilities. This would involve more ethnographic engagement in healthcare settings, allowing the space for dialogue with women, and the telling of their stories and experiences. Such an approach would allow for "alter-narratives" (Linden L 2016), which include wider conceptualisations of healthcare and vaccination across various communities, and thus upset predominant, normative articulations of healthcare, so that vaccine hesitancy can be more deeply understood.

The relational approach to healthcare, which requires support and close relationships between healthcare professionals and patients, would engender an understanding of women's experiences and perceptions in context, and enable women to be more involved in healthcare decisions. It would provide a first step in addressing the assumptions and normative frameworks underlying healthcare provision, which, whether due to resistance to such frameworks, alienation, or discrimination within the healthcare system, is excluding women from healthcare interventions such as vaccination. Following this, a move should be made away from moralising individual behaviour and encouraging individual women to change, to addressing the deeper, structural conditions that affect women's and their broader collectives', choices and actions.

If the full benefits of vaccination are to be experienced by the majority of pregnant women, instead of expecting them to unquestioningly comply with healthcare programmes, policy-makers and healthcare professionals should include a wider variety of views in definitions of science and evidence. This would create a more open, democratised and pluralistic healthcare system. It would mean that care is shared rather than individualised, and would reduce the focus of responsibility placed on pregnant women, who's bodies undergo more regulation, quantification and public scrutiny than

any other bodies (Kukla R 2005). Overall, we should trust that in decision-making, pregnant women usually have their and their foetus' best interests at heart, and would often just like a little support in navigating the complex and contradictory world of pregnancy.

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Appendices

Appendix 1 Field Notes

8th February 2016

I am a little late starting this (I did my first interview in December but I have just started to do a lot more interviews). I will note down observations that come to me while recruiting people for my fieldwork, and interviewing them.

Today I visited Daubney Children's Centre, a group for young parents. I felt strange talking about my research as they were laughing and joking and I was left feeling a bit foolish as an outsider, a privileged researcher, not involved in their jokes.

In general, it feels as though the women have really opened up to me. It is interesting, however, that often, when a question is asked such as, "did you have any health complications during your pregnancy?" They will often say no but then later on in the interview, they may mention quite a serious health complication, which they were admitted to hospital for.

10th February 2016

This morning I went to a parent-toddler group. I feel awkward going to speak to mothers while they are with their babies and both today and yesterday, two women asked where my baby was. I feel like some kind of posh researcher, not being able to understand what it is like to have children.

Until now, I have been explaining the study very briefly to the women, asking if they would like to participate and then taking their contact details. I would then text her the next day to ask where and when would be best for her to meet and if there was no reply, to send another text a week later. Only around half the women however, responded to my text, even though they had said they were interested when I met them. Today, after I explained the study and if they agreed they would like to participate, I asked there and then what time and date would be best for them so we could both put it in our diaries. I would then text them the day before we met to check that it was still ok to go ahead and this worked much better.

18th February 2016

I've found that some participants are not very reliable. I had planned to do four interviews today and two of the participants cancelled, saying that they had forgotten about it.

11th March 2016

Yesterday I went to a group for pregnant women and mothers who have dealt with substance abuse. One of the mothers I recruited is living in a hostel. It is quite difficult asking a woman in that position to participate in an interview. I also got into a debate with a woman who was there showing the mothers how to make juice and healthy food. I was angry because she was telling them about seven day juice diets, which I think is irresponsible advice to give to a pregnant woman. I did not mention anything however, as it is not my place to do so. At the end of the session, she asked about my research and as soon as I said the word 'vaccine', she rolled her eyes and proceeded to tell me that a good diet can cure or prevent anything. I told her that a good diet would not cure or prevent polio. We did however leave on good terms.

Today a participant who did not turn up to our interview texted me to ask if we could change the location of our re-scheduled interview. I had suggested Stoke Newington as it is close to me, in case she did not turn up again but she text to ask if we could meet in Shoreditch instead. I felt she probably would do the same again and replied to say that I did not have time to go to Shoreditch so maybe it was best to leave it but thanking her anyway. I felt slightly guilty but I am sure she would have not turned up again and I have already done thirty-two interviews with ten more lined up-that will be forty-two and my target is fifty. I still have to recruit women from GP practices and antenatal clinics (the NHS IRAS ethics approval still has not come through and I started it in September 2015). I also now want to focus on recruiting Turkish women, as this group makes up a large proportion of the population in Hackney and I do not have any Turkish women involved in the study yet. I would also like to recruit more women whose first language is not English.

Yesterday, I went to an Alevi Community Centre to take my poster and leaflets, which I had been translated into Turkish. I had put a photo of a woman in a veil on it as I want to speak to women from a wide range of backgrounds. However, when they saw it, the people in the office at the community centre said that their religion did not agree with

women wearing a veil, so people would wonder why they put it up. I felt extremely stupid and agreed to get some posters done with a different picture. I gave them the English version in the mean-time and they gave me a leaflet about Alevism!

20th March 2016

Yesterday, I did three interviews at the Alevi community centre. For the first one, I had a translator who is a friend of a friend. She is Turkish and said that being there was like being in a Turkish village. I felt a bit awkward being there and not understanding a lot of what people said, however, everyone was extremely friendly. The next two participants I recruited there and then and interviewed them that afternoon.

22nd April 2016

I met with the manager of one of the GP practices included in the study to talk more about what the study would involve. He spoke at length about the problems within the system-such as that community midwives from one of the main hospitals in Hackney use the practice but the hospital does not pay the practice for the space. According to the manager, midwives are also not trained to administer the vaccines or recommend them (training takes 90 minutes) and the manager did not know why but suggested that perhaps it is an excuse not to give it because midwives are against vaccines saying, "Everyone treads on eggshells around midwives". The manager stated that the fact that some midwives do not vaccinate is not challenged through the Clinical Commissioning Group (CCG). Additionally, there is still no leaflet explaining that the vaccine is now offered at 20 rather than 28 weeks. According to the manager, GPs and nurses at his practice administer the vaccines but there is a disconnect between them. The manager stated, "You have to be aware that this is a political minefield". He also stated that people feel that the main hospital in Hackney is very good apart from its antenatal unit.

11th May 2016

One of the GPs I interviewed responded when I asked if she used NHS materials, such as leaflets, "Oh, maybe I should start doing this". Also, when I was interviewing an Orthodox Jewish woman, she said she had not heard much about the vaccine during pregnancy, so did not vaccinate. She asked one of the breast-feeding drop-in women about the vaccines, who explained it to her in Hebrew. This participant said she would have received the vaccines if she had known about them, and asked me if you can have

them after pregnancy, so was obviously willing. Hopefully now she knows, she would get them in the next pregnancy.

12th May 2016

I interviewed another midwife today. It was interesting as she and her friends were into natural medicine. She said she did not say this to patients-that even though she recommended vaccination, she herself would not have them if she were pregnant. When I asked what she did if a patient refused to vaccinate, she said she did not like the term 'refuse' and said it would be better terminology to say 'those who choose not to vaccinate'. I felt slightly chastened. She also said that more Afro-Caribbean's do not vaccinate due to distrust of what is in them and due to distrust in the government. This actually has also been reflected in some of the interviews I have done with Afro-Caribbean women and I want to explore the distrust in government aspect more with regards to British Caribbean relations/history.

6th June 2016

One patient agreed that her 16-week consultation could be video-recorded but many who were asked refused and said they would rather I was in the room than video-record the consultation. This was interesting because the NHS ethics committee did not want me to sit in on consultations as they saw this as intrusive. However, the administrator who booked the consultations said that women had told him that they were afraid that the recording would end up on the internet.

Appendix 2: Consent form for healthcare professionals

NHS National Institute for Health Research

Homerton University Hospital NHS Foundation Trust

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

INFORMED CONSENT FORM

Study title: Vaccination in Pregnancy: Attitudes and Access, Hackney: an in-depth qualitative analysis

	Please initial box
1. I confirm that I have read and understand the participant information sheet dated 11th February 2016 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that I may be asked if one of my consultations with a patient can be videotaped but that I can decline to take part in this part of the study if I wish and still take part in an interview. Videotaping is optional, please tick the box to state whether you would like your consultation to be videotaped or not **Yes** I would like one of my consultations to be videotaped ☐ **No** I would not like one of my consultations to be videotaped ☐	
4. If I do take part in an interview, I understand that these will be audio recorded and that the recording will be shared with the Chief Investigator (Rose Wilson) and a transcriber only.	
5. I agree to be quoted anonymously in publications or reports released on the study.	
6. I agree to take part in the above study.	

_____	_____	_____
Participant's Name	**Date**	**Signature**
_____Rose Wilson_____	_____	_____
Principal Investigator's Name	**Date**	**Signature**

Vaccination in Pregnancy: Attitudes and Access, Hackney Consent form for HCW version 2, dated 11th February 2016. LSHTM Ethics Ref: 10429

LSHTM Contacts:

Rose Wilson, Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Population Health, LSHTM, Keppel Street, London, WC1E 7HT. Tel: 0207 927 4740 Email: rose.wilson@lshtm.ac.uk. Principal Investigator: Rose Wilson. This study has been approved by the London School of Hygiene & Tropical Medicine's Research Ethics Committee and is funded by the National Institute for Health Research.

1 copy for participant; 1 copy for Principal Investigator

Appendix 3: Consent form for pregnant/recently pregnant women

NHS
National Institute for Health Research

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

INFORMED CONSENT FORM

Study title: Vaccination in Pregnancy: Attitudes and Access, Hackney: an in-depth qualitative analysis

	Please initial box
1. I confirm that I have read and understand the participant information sheet dated 11th February 2016 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that I may be asked if one of my consultations with a healthcare worker can be videotaped but that I can decline to take part in this part of the study if I wish and still take part in a focus group discussion. Videotaping is optional, please tick the box to state whether you would like your consultation to be videotaped or not **Yes** I would like one of my consultations to be videotaped ☐ **No** I would not like one of my consultations to be videotaped ☐	
4. I agree to be quoted anonymously in publications or reports released on the study.	
5. I agree to take part in the above study.	

_____	_____	_____
Participant's Name	**Date**	**Signature**
_____Rose Wilson_____	_____	_____
Principal Investigator's Name	**Date**	**Signature**

LSHTM Contacts:

Rose Wilson, Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Population Health, LSHTM, Keppel Street, London, WC1E 7HT. Tel: 0207 927 4740 Email: rose.wilson@lshtm.ac.uk Principal Investigator: Rose Wilson. This study has been approved by the London School of Hygiene & Tropical Medicine's Research Ethics Committee and is funded by the National Institute for Health Research.

Vaccination in Pregnancy: Attitudes and Access, Hackney Consent form for patients version 2, dated 11th February 2016. LSHTM Ethics Ref: 10429

LSHTM Contacts:

Rose Wilson, Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Population Health, LSHTM, Keppel Street, London, WC1E 7HT. Tel: 0207 927 4740 Email: rose.wilson@lshtm.ac.uk. Principal Investigator: Rose Wilson. This study has been approved by the London School of Hygiene & Tropical Medicine's Research Ethics Committee and is funded by the National Institute for Health Research.

1 copy for participant; 1 copy for Principal Investigator

Appendix 4 Study invitation letter for GPs and heads of midwifery/immunisation

NHS
National Institute for Health Research

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Vaccination in Pregnancy: Attitudes and Access, Hackney study

London School of Hygiene & Tropical Medicine
Keppel St
London
WC1E 7HT

11th February 2016

Dear XXX

I would like to invite your practice to take part in a research project aimed at understanding issues affecting vaccine uptake among pregnant women in Hackney.

Background

Maternal vaccination is effective at preventing illness in pregnant women and new-borns, however, uptake of such programmes has been low in Hackney, especially among some ethnic minorities. Barriers to vaccination are complex and vary depending on context and population.

This study aims to determine attitudes and access issues affecting uptake of vaccines provided in pregnancy in Hackney, with a focus on uptake rate by ethnicity.

The research

The study is part of a PhD, as a partnership between Public Health England (PHE) and London School of Hygiene & Tropical Medicine (LSHTM).

Your practice has been chosen because it has an average uptake rate for Hackney and a variety of patients from different ethnic groups.
In each GP practice (four have been chosen), we are planning to interview around five healthcare workers. These will include doctors, nurses and midwives. We will also interview around five women who are pregnant or have given birth to a live new-born within the last twelve months. We will provide interpreting services where necessary.

What is required of practices?

We would like to ask you to conduct a patient database search to identify all your currently pregnant patients who are aged over 18, in their second or third trimester and all patients

over 18 who have given a live birth in the past year from when we start the interviews. We would ask you to exclude all women who have suffered a miscarriage.

We would then request that practice staff post/email a participant information sheet to those patients meeting the eligibility criteria. In addition, we would ask you to send one reminder to non-responders two weeks later.

We would also request that you give an invitation letter to participate in the study to all your healthcare staff. We will provide all study materials, envelopes and postal costs. We plan to start interviewing and conducting focus groups in March and April 2016.

Finally, we would ask if leaflets and a poster explaining the study can be put up in the practice waiting room (supplied by us).

Who is funding and supporting the research

The research is funded by the National Institute of Health Research (NIHR) and adopted to the NIHR portfolio. It is hosted by City and Hackney CCG and supported by Public Health England (PHE) and the London School of Hygiene & Tropical Medicine (LSHTM).

Next Steps

If you have any questions about the study, please contact Rose Wilson at rose.wilson@lshtm.ac.uk or on 07788 100 571.

If you are interested in taking part, please complete the attached "Expression of Interest" form and return by e-mail. Submitting an expression of interest does not commit you in any way.

After receiving your completed form, I will contact you to confirm that you would like to take part in the study and to arrange a meeting, where I can give you the invitation letters for participants.

If you are not interested in taking part please email me at rose.wilson@lshtm.ac.uk and I will know not to contact you again.

Thank you so much for considering to be a part of this study and I look forward to hearing from you.

Yours sincerely,

Rose Wilson

PhD candidate, London School of Hygiene & Tropical Medicine

NHS
National Institute for Health Research

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Expression of Interest Form

Practice name _____

Many thanks for expressing an interest in the Vaccination in pregnancy: attitudes and access, Hackney study.

Please provide the following details to assist with the set-up of study procedures:

Practice Research Contact

After receiving this form, Rose will contact you to arrange a time to visit your practice to give you invitation letters to pass on to healthcare staff and registered pregnant/recently pregnant patients.

Contact details:

Best person in the practice to contact _____

Their contact phone number _____

Their contact e mail _____

Best times to contact them _____

Please return the completed form either by email to: **rose.wilson@lshtm.ac.uk**
or by post to:
Rose Wilson,
London School of Hygiene and Tropical Medicine,
Keppel St,
London,
WC1E 7HT

Appendix 5: Study invitation for parent-toddler groups, community centres/migrant support groups

Vaccination in Pregnancy: Attitudes and Access, Hackney study

London School of Hygiene & Tropical Medicine
Keppel St
London
WC1E 7HT

1st December 2015

Dear XXX,

My name is Rosie and I am a PhD student at the London School of Hygiene & Tropical Medicine (LSHTM). My thesis is part of a project funded and undertaken by the National Institute for Health Research (NIHR), in partnership with Public Health England (PHE). My research focuses on understanding factors influencing vaccination uptake during pregnancy. As part of my thesis, I am presently conducting a qualitative study in order to listen to the views of pregnant women and healthcare workers, with a specific focus on Hackney.

I have decided to focus the research in Hackney as preliminary research and studies have shown that the area has relatively low vaccination rates compared to other boroughs of London. Therefore, I would be interested in learning more about how pregnant (and recently pregnant) women in Hackney experience healthcare during pregnancy and how it has shaped their decision-making process, especially with regards to healthcare-related measures such as vaccination in pregnancy. As I am looking for participants for this part of my research who are willing to engage in an open conversation about the above points, I would like to ask you if you would be willing for me to invite some of the mothers attending your group to participate in the study. I am seeking to address the above points by having a short conversation with new mothers/pregnant women, to ask if they would like to be interviewed. If the mother would like to participate, the interviews would take place at the most convenient time and location for her (not at that moment or in your group session). If the mother would not like to participate, this is fine and I will thank her for her time.

The research protocol has been reviewed and approved by the ethics committee at the London School of Hygiene and Tropical Medicine.

I would really appreciate your support with this as I hope that it can help us to understand reasons for low vaccination uptake rates in pregnancy in Hackney.

I am more than happy to come and chat to you in person about this and please do not hesitate to contact me if you have any questions. You can respond to this letter either by email, phone or post:

Email: rose.wilson@lshtm.ac.uk

Telephone: 07788100571

Address: Rose Wilson
London School of Hygiene & Tropical Medicine
Keppel St
London
WC1E 7HT

Thank you for considering to be a part of this study and I look forward to hearing from you.

Yours sincerely,

Rose Wilson

PhD candidate, London School of Hygiene & Tropical Medicine.

Appendix 6: Participant information sheet for interviews with healthcare professionals

Vaccination in pregnancy: attitudes and access, Hackney

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Homerton University Hospital NHS Foundation Trust

NHS National Institute for Health Research

Dear potential participant,

We would like to invite you to take part in this research study entitled Vaccination in pregnancy: attitudes and access in Hackney. This academic study is part of a PhD and looks at attitudes and access issues affecting vaccination uptake among pregnant women in Hackney.

Before you decide whether you would like to take part, it is important for you to understand why the study is being carried out and what is involved in participation. Please take some time to read the information in this information sheet carefully and discuss with others if you wish.

Why are we carrying out the Vaccination in pregnancy study?

Recently there has been a renewed focus on vaccines administered in pregnancy to provide protection to the mother, foetus and newborn infant. However, uptake of these vaccines in Hackney is low. We know that advice from maternity healthcare professionals regarding vaccination is highly valued by pregnant women so we want to find out your opinions about immunisation during pregnancy.

We are interviewing people and video recording some consultations to help understand the reasons behind such a low uptake.

Do I have to take part?

Whether you decide to take part in this study is entirely up to you. If you decide you want to but later change your mind, you can withdraw at any time and any information that you have previously supplied will be destroyed.

Your GP surgery/antenatal clinic has received information about this study and has agreed to participate.

What will happen if I say no?

Taking part in this study is voluntary. If you decide not to participate, this will not affect your legal rights in any way. You are also free to change your mind at any time without giving a reason.

What will happen in the interview?

When you arrive, you would sign a consent form stating that you understand what is involved in your participation in the study and are willing to take part. We would also ask your permission to make an audio recording of the interview and take written notes. The interview will be a relaxed and informal chat about your background, such as number of years you have been practicing, your attitudes to vaccination and any barriers you perceive to pregnant women receiving vaccination. You will not have to receive any vaccinations during the interview. Interviews will usually take an hour but can be longer if you wish.

There are no right or wrong answers to the questions – the aim of these interviews is to learn your real thoughts and views of the subjects discussed.

Will my consultation be recorded?

During the interview, healthcare workers will be asked if a consultation with their patient can be video recorded. If you agree to this, we will ask you and the patient to sign an informed consent form. The purpose of the recording is to understand how vaccination is discussed. It will be relatively unobtrusive (the recorder will be attached to the ceiling of the consultation room) and so it is not expected that it will disrupt the consultation in any way. Video recorders can be turned off at any point during the consultation and recordings will only be viewed by the Chief Investigator (Rose Wilson) and will not be shown to anyone else (even your employer). Only a small number of consultations will be recorded

and if you do not wish for one of your consultations to be recorded, you can still take part in the interviews.

Who else would be told of my involvement in the study?
Your participation in the study would remain confidential. We won't discuss the content of your interview/video recording with your employer.

What will happen to the information we collect?
The audio recording and any video recordings would be transcribed and stored in strict confidence in a locked drawer and in password-protected computer files as required by the Data Protection Act, at the London School of Hygiene and Tropical Medicine for analysis. Only the Chief Investigator and a transcriber will have access to this information (the transcriber will not see the video recordings), all of which will be anonymised using a unique study number. All information collected will be destroyed at the end of the study.

Are there any possible advantages to taking part in the project?
In the short-term it is unlikely that you will receive direct medical benefits. However, the main advantage is that you will have the opportunity to share your views about vaccination, helping us in our efforts to understand more about attitudes and access issues to vaccination which lead to low vaccination uptake of pregnant women living in our communities, and how this might be improved for future generations.

What are the disadvantages or risks of taking part in the study?
As this is a qualitative research study and does not involve any interventions; we do not anticipate any risks to you as a result of your participation.

What are the costs of the study?
There are no financial costs to you participating in the study.

How will I find out the results of the study?

The findings from the study will be published in scientific journals and may be presented at academic conferences. We would send you a summary of the results once they have been analysed.
None of these publications or presentations will identify individual participants.

Who is organising and funding the research?
The study is funded by the National Institute for Health Research (NIHR), is being carried out in partnership with Public Health England (PHE) and is sponsored by the London School of Hygiene and Tropical Medicine (LSHTM). Rose Wilson is Principal Investigator of the study.

This project has received NHS REC and R&D approval and approval from the London School of Hygiene and Tropical Medicine (LSHTM) Ethics Committee.

If you wish to take part or have any questions about the project or just want to know more about the work we are conducting please contact Rose Wilson at rose.wilson@lshtm.ac.uk or text/call 07788 100571. Alternatively you can complete the attached form and return it in the pre-paid envelope provided.

Thank you for considering taking part in this study.

Yours sincerely,

Rose Wilson

Principal Investigator

London School of Hygiene & Tropical Medicine

Vaccination in pregnancy: attitudes and access, Hackney

Reply slip

You can either **email** us at: rose.wilson@lshtm.ac.uk

OR

Telephone us on: 07788 100 571

OR

Complete this **reply slip** and return in the enclosed pre-paid envelope

Name and job title	
Your address (including post code)	
Phone number(s) Home Mobile (and best time to call)	
Email address	

Please **contact me**. I realise that this is not a commitment to taking part in the study.

Please indicate preferred method of contact. Please tick:

o Email o Phone

OR o I do not wish to be included in this study.

If we do not hear from you, we will assume that you do not want to take part in the study. However, you are still welcome to tick the 'No' box below and provide feedback if you wish.

Appendix 7: Participant information sheet for interviews with pregnant/recently pregnant women

Vaccination in pregnancy: attitudes and access, Hackney

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NHS National Institute for Health Research

Dear potential participant,

We would like to invite you to take part in a research study entitled Vaccination in pregnancy: attitudes and access in Hackney. This academic study is part of a PhD and looks at attitudes and access issues affecting vaccination uptake among pregnant women in Hackney.

Before you decide whether you would like to take part, it is important for you to understand why the study is being carried out and what is involved in participation. Please take some time to read the information in this sheet carefully and discuss with others if you wish.

If you have experienced a miscarriage and we have contacted you in error, please accept our sincere apologies. If receiving this letter has distressed you in any way, please contact the Miscarriage Association helpline on 01924 200 799.

Why are we carrying out the Vaccination in pregnancy study?

Recently there has been a renewed focus on vaccines administered in pregnancy to provide protection to the mother, foetus and newborn infant. However, uptake of these vaccines in Hackney is low. We are conducting focus group discussions and video-recording some consultations to help understand the reasons behind this low uptake.

Do I have to take part?

Whether you decide to take part in this study is entirely up to you. If you decide you want to but later change your mind, you can withdraw at any time. Whatever you decide, your medical care will not be affected in any way.

Your GP surgery/antenatal clinic has received information about this study and has agreed to participate.

What will happen if I take part?

If you agree to take part, we will arrange a time and place which is convenient for you, most likely your GP practice or a community clinic in Hackney.

What will happen if I say no?

Taking part in this study is voluntary. If you decide not to participate, this will not affect your legal rights in any way. You are also free to change your mind at any time without giving a reason.

What will happen in the interview/focus group discussion?

When you arrive, you would sign a consent form stating that you understand what is involved in your participation in the study and are willing to take part. We would also ask your permission to make an audio recording of the interview. We will also take written notes during the interview. The interview will be a relaxed and informal chat about your background, your experience of the healthcare you have received during your current/recent pregnancy and your attitudes to vaccination.

The focus group discussion gathers six or seven people together from similar backgrounds or experiences to discuss a specific topic of interest. The group of participants is guided by a group facilitator who introduces topics for discussion and helps the group to participate in a lively and natural discussion amongst themselves. In this case, the group will consist of pregnant and recently pregnant women. There are no right or wrong answers to the questions – the aim of these focus groups and interviews is to learn your thoughts and views on the subjects discussed. The focus group discussions will be confidential and nothing discussed should be repeated outside of the group.

You are invited to take part in the study whether you have been vaccinated or not. You will not have to receive any vaccinations discussion. Discussions will usually take an hour but timing can be flexible.

Will my consultation be recorded?

If you agree to participate in the study, you may be asked if a consultation with your healthcare worker can be video recorded. If you agree to this, we will ask you and your healthcare worker to sign an informed consent form. The purpose of the recording is to understand how vaccination is discussed. It would be relatively unobtrusive (the recorder will be attached to the ceiling of the consultation room), so it is not expected that it will disrupt the consultation in any way. You can request for the recorder to be turned off at any point during the consultation. Recordings will only be viewed by the Chief Investigator (Rose Wilson) and will not be shown to anyone else. Only a small number of consultations will be recorded and if you do not wish for one of your consultations to be recorded, that is fine. You would still be able to take part in an interview or focus group discussion if you wish.

Who else would be told of my involvement in the study?

Your participation in the study would remain confidential. We won't discuss the content of your interview with anyone.

What will happen to the information we collect?

The audio recording and any video recordings would be transcribed and stored in strict confidence in a locked drawer and in password-protected computer files as required by the Data Protection Act, at the London School of Hygiene and Tropical Medicine for analysis. Only the Chief Investigator and one transcriber will have access to this information (the transcriber will only have access to the audio

recordings), all of which will be anonymised using a unique study number. All information collected will be destroyed at the end of the study.
You can withdraw from the study at any time and if you do so, information we have already collected from you will be destroyed.

Are there any possible advantages to taking part in the project?

In the short-term it is unlikely that you will receive direct medical benefits. However, the main advantage is that you will have the opportunity to share your views about vaccination, helping us in our efforts to understand more about attitudes and access issues to vaccination which lead to low vaccination uptake of pregnant women living in our communities and how this might be improved for future generations.

What are the disadvantages or risks of taking part in the study?

As this is a qualitative research study and does not involve any interventions, we do not anticipate any risks to you as a result of your participation.

This project is sponsored by the London School of Hygiene and Tropical Medicine (LSHTM) and has received ethics approval from the LSHTM Ethics Committee.

What are the costs of the study?

There are no costs to you participating in the study. You will be given a **£20 voucher** to thank you for your time and commitment if you decide to participate. If you decide to withdraw from the study at any point, this would not affect your receipt of the voucher.

How will I find out the results of the study?

The findings from the study will be published in scientific journals and may be presented at academic conferences. We would send you a copy of the papers once they have been published. None of these publications or presentations will identify individual participants.

If you wish to take part, have any questions about the project or just want to know more about the work we are conducting please contact Rose Wilson at rose.wilson@lshtm.ac.uk or text/call 07788 100571. Alternatively, you can complete the attached form and return it to: Rose Wilson, London School of Hygiene & Tropical Medicine, Keppel Street, London, WC1E 7HT

Thank you for considering taking part in this study.

Yours sincerely,

Rose Wilson

Principal Investigator

London School of Hygiene & Tropical Medicine

Vaccination in pregnancy: attitudes and access, Hackney

Reply slip

You can either **email** us at: rose.wilson@lshtm.ac.uk

OR

Telephone us on: 07788 100 571

OR

Complete this **reply slip** and return it to: Rose Wilson, London School of Hygiene & Tropical Medicine, Keppel Street, London, WC1E 7HT

Name	
Your address	
Phone number(s) Home Mobile (and best time to call)	
Email address	

Please **contact me**. I realise that this is not a commitment to taking part in the study.

Please indicate preferred method of contact. Please tick:

o Email o Phone

OR o I do not wish to be included in this study.

If we do not hear from you, we will assume that you do not want to take part in the study. However, you are still welcome to tick the 'No' box below and provide feedback if you wish.

Appendix 8: Participant information sheet for FGD

Vaccination in pregnancy: attitudes and access, Hackney

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NHS National Institute for Health Research

Dear potential participant,

We would like to invite you to take part in a research study entitled Vaccination in pregnancy: attitudes and access in Hackney, by taking part in a focus group discussion with around six other pregnant women. This academic study is part of a PhD and looks at attitudes and access issues affecting vaccination uptake among pregnant women in Hackney.

Before you decide whether you would like to take part, it is important for you to understand why the study is being carried out and what is involved in participation. Please take some time to read the information in this sheet carefully and discuss with others if you wish.

If you have experienced a miscarriage and we have contacted you in error, please accept our sincere apologies. If receiving this letter has distressed you in any way, please contact the Miscarriage Association helpline on 01924 200 799.

Why are we carrying out the Vaccination in pregnancy study?

Recently there has been a renewed focus on vaccines administered in pregnancy to provide protection to the mother, foetus and newborn infant. However, uptake of these vaccines in Hackney is low. We are conducting focus group discussions and video-recording some consultations to help understand the reasons behind this low uptake.

Do I have to take part?

Whether you decide to take part in this study is entirely up to you. If you decide you want to but later change your mind, you can withdraw at any time. Whatever you decide, your medical care will not be affected in any way.

Your GP surgery/antenatal clinic has received information about this study and has agreed to participate.

What will happen if I take part?

If you agree to take part, we will arrange a time and place which is convenient for you, most likely your GP practice or a community clinic in Hackney.

What will happen if I say no?

Taking part in this study is voluntary. If you decide not to participate, this will not affect your legal rights in any way. You are also free to change your mind at any time without giving a reason.

What will happen in the focus group discussion?

When you arrive, you would sign a consent form stating that you understand what is involved in your participation in the study and are willing to take part. We would also ask your permission to audio record the discussion. We will also take written notes during the discussion.

The focus group discussion gathers six or seven people together from similar backgrounds or experiences to discuss a specific topic of interest. The group of participants will be guided by a group facilitator (Rose Wilson) who will introduce topics for discussion and help the group to participate in a lively and natural discussion amongst themselves about their views towards vaccination during pregnancy. In this case, the group will consist of pregnant and recently pregnant women. There are no right or wrong answers to the questions – the aim of these focus groups and interviews is to learn your thoughts and views on the subjects discussed. The focus group discussions will be confidential and nothing discussed should be repeated outside of the group.

You are invited to take part in the study whether you have been vaccinated or not. You will not have to receive any vaccinations discussion. Discussions will usually take an hour but timing can be flexible.

Will my consultation be recorded?

If you agree to participate in the study, you may be asked if a consultation with your healthcare worker can be video recorded. If you agree to this, we will ask you and your healthcare worker to sign an informed consent form. The purpose of the recording is to understand how vaccination is discussed. It would be relatively unobtrusive (the recorder will be attached to the ceiling of the consultation room), so it is not expected that it will disrupt the consultation in any way. You can request for the recorder to be turned off at any point during the consultation. Recordings will only be viewed by the Chief Investigator (Rose Wilson) and will not be shown to anyone else. Only a small number of consultations will be recorded and if you do not wish for one of your consultations to be recorded, that is fine. You would still be able to take part in an interview or focus group discussion if you wish.

Who else would be told of my involvement in the study?

Your participation in the study would remain confidential. We won't discuss the content of your interview with anyone.

What will happen to the information we collect?

The audio recording and any video recordings would be transcribed and stored in strict confidence in a locked drawer and in password-protected computer files as required by the Data Protection Act, at the London School of Hygiene and Tropical Medicine for analysis. Only the Chief Investigator and one transcriber will have access to this information (the transcriber will only have access to the audio recordings), all of which will be anonymised using a unique study number. All information collected will be destroyed at the end of the study.
You can withdraw from the study at any time and if you do so, information we have already collected from you will be destroyed.

Are there any possible advantages to taking part in the project?

In the short-term it is unlikely that you will receive direct medical benefits. However, the main advantage is that you will have the opportunity to share your views about vaccination, helping us in our efforts to understand more about attitudes and access issues to vaccination which lead to low vaccination uptake of pregnant women living in our communities and how this might be improved for future generations.

What are the disadvantages or risks of taking part in the study?

As this is a qualitative research study and does not involve any interventions, we do not anticipate any risks to you as a result of your participation.

This project is sponsored by the London School of Hygiene and Tropical Medicine (LSHTM) and has received ethics approval from the LSHTM Ethics Committee.

What are the costs of the study?

There are no costs to you participating in the study. You will be given a **£20 voucher** to thank you for your time and commitment if you decide to participate. If you decide to withdraw from the study at any point, this would not affect your receipt of the voucher.

How will I find out the results of the study?

The findings from the study will be published in scientific journals and may be presented at academic conferences. We would send you a copy of the papers once they have been published. None of these publications or presentations will identify individual participants.

If you wish to take part, have any questions about the project or just want to know more about the work we are conducting please contact Rose Wilson at rose.wilson@lshtm.ac.uk or text/call 07788 100571. Alternatively, you can complete the attached form and return it to: Rose Wilson, London School of Hygiene & Tropical Medicine, Keppel Street, London, WC1E 7HT

Thank you for considering taking part in this study.

Yours sincerely,

Rose Wilson

Principal Investigator

London School of Hygiene & Tropical Medicine

Vaccination in pregnancy: attitudes and access, Hackney

Reply slip

You can either **email** us at: rose.wilson@lshtm.ac.uk

OR

Telephone us on: 07788 100 571

OR

Complete this **reply slip** and return it to: Rose Wilson, London School of Hygiene & Tropical Medicine, Keppel Street, London, WC1E 7HT

Name	
Your address	
Phone number(s) Home Mobile (and best time to call)	
Email address	

Please **contact me**. I realise that this is not a commitment to taking part in the study.

Please indicate preferred method of contact. Please tick:

o Email o Phone

OR o I do not wish to be included in this study.

If we do not hear from you, we will assume that you do not want to take part in the study. However, you are still welcome to tick the 'No' box below and provide feedback if you wish.

Appendix 9: Participant information sheet for consultation video-recording

Vaccination in pregnancy: attitudes and access, Hackney

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NHS National Institute for Health Research

Dear potential participant,

We would like to invite you to take part in a research study entitled Vaccination in pregnancy: attitudes and access in Hackney. This academic study is part of a PhD and looks at attitudes and access issues affecting vaccination uptake among pregnant women in Hackney.

Before you decide whether you would like to take part, it is important for you to understand why the study is being carried out and what is involved in participation. Please take some time to read the information in this sheet carefully and discuss with others if you wish.

If you have experienced a miscarriage and we have contacted you in error, please accept our sincere apologies. If receiving this letter has distressed you in any way, please contact the Miscarriage Association helpline on 01924 200 799.

Why are we carrying out the Vaccination in pregnancy study?

Recently there has been a renewed focus on vaccines administered in pregnancy to provide protection to the mother, foetus and newborn infant. However, uptake of these vaccines in Hackney is low. We are conducting focus group discussions and video-recording some consultations to help understand the reasons behind this low uptake.

Do I have to take part?

Whether you decide to take part in this study is entirely up to you. If you decide you want to but later change your mind, you can withdraw at any time. Whatever you decide, your medical care will not be affected in any way.

Your GP surgery/antenatal clinic has received information about this study and has agreed to participate.

What will happen if I say no?

Taking part in this study is voluntary. If you decide not to participate, this will not affect your legal rights in any way. You are also free to change your mind at any time without giving a reason.

Will my consultation be recorded?

If you agree to participate in the study, you may be asked if a consultation with your healthcare worker can be video recorded. If you agree to this, we will ask you and your healthcare worker to sign an informed consent form. The purpose of the recording is to understand how vaccination is discussed. It would be relatively unobtrusive (the recorder will be attached to the ceiling of the consultation room), so it is not expected that it will disrupt the consultation in any way. You can request for the recorder to be turned off at any point during the consultation. Recordings will only be viewed by the Chief Investigator (Rose Wilson) and will not be shown to anyone else. Only a small number of consultations will be recorded and if you do not wish for one of your consultations to be recorded, that is fine. You would still be able to take part in an interview or focus group discussion if you wish.

Who else would be told of my involvement in the study?

Your participation in the study would remain confidential. We won't discuss the content of your interview with anyone.

What will happen to the information we collect?

Video recordings would be transcribed and stored in strict confidence in a locked drawer and in password-protected computer files as required by the Data Protection Act, at the London School of Hygiene and Tropical Medicine for analysis. Only the Chief Investigator will only have access to the audio recordings,

all of which will be anonymised using a unique study number. All information collected will be destroyed at the end of the study.
You can withdraw from the study at any time and if you do so, information we have already collected from you will be destroyed.

Are there any possible advantages to taking part in the project?

In the short-term it is unlikely that you will receive direct medical benefits. However, the main advantage is that you will be helping us in our efforts to understand more about attitudes and access issues to vaccination which lead to low vaccination uptake of pregnant women living in our communities and how this might be improved for future generations.

What are the disadvantages or risks of taking part in the study?

As this is a qualitative research study and does not involve any interventions, we do not anticipate any risks to you as a result of your participation.

This project is sponsored by the London School of Hygiene and Tropical Medicine (LSHTM) and has received ethics approval from the LSHTM Ethics Committee.

What are the costs of the study?

There are no costs to you participating in the study. You will be given a **£20 voucher** to thank you for your time and commitment if you decide to participate. If you decide to withdraw from the study at any point, this would not affect your receipt of the voucher.

How will I find out the results of the study?

The findings from the study will be published in scientific journals and may be presented at academic conferences. We would send you a copy of the papers once they have been published. None of these publications or presentations will identify individual participants.

If you have any questions about the project or just want to know more about the work we are conducting please contact Rose Wilson at rose.wilson@lshtm.ac.uk or text/call 07788 100571.

Thank you for considering taking part in this study.

Yours sincerely,

Rose Wilson

Principal Investigator

London School of Hygiene & Tropical Medicine

Vaccination in pregnancy: attitudes and access, Hackney

Reply slip

You can either **email** us at: rose.wilson@lshtm.ac.uk

OR

Telephone us on: 07788 100 571

OR

Complete this **reply slip** and return it to: Rose Wilson, London School of Hygiene & Tropical Medicine, Keppel Street, London, WC1E 7HT

Name	
Your address	
Phone number(s) Home Mobile (and best time to call)	
Email address	

Please **contact me**. I realise that this is not a commitment to taking part in the study.

Please indicate preferred method of contact. Please tick:

o Email o Phone

OR o I do not wish to be included in this study.

If we do not hear from you, we will assume that you do not want to take part in the study. However, you are still welcome to tick the 'No' box below and provide feedback if you wish.

Appendix 10: Poster for recruitment sites

NHS City and Hackney

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NHS National Institute for Health Research

If you are pregnant or have given birth in the past 6 months, you are invited to take part in a research study: Vaccination in pregnancy: attitudes and access in Hackney.

We would like to interview you, at a place convenient for you, to ask about your attitudes to the flu and whooping cough vaccines provided during pregnancy and any access issues you may have had to getting them.

You will be given a £20 voucher to thank you for your time if you decide to participate in the study.

Uptake of vaccination in pregnancy in Hackney is low. This study aims to understand why this is.

If you are interested in participating in the study or have any questions, please contact rose.wilson@lshtm.ac.uk or on 07788 100 571

Appendix 11: Leaflet for recruitment sites

Page 1:

If you are pregnant or have given birth in the past 6 months, you are invited to take part in a research study called

Vaccination in pregnancy: attitudes and access in Hackney.

We would like to interview you, at a place convenient for you, to ask about your attitudes to the flu and whooping cough vaccines provided during pregnancy and additionally, any access issues you may have had to getting them.

You will be given a £20 voucher to thank you for your time if you decide to participate in the study.

What is the purpose of this study?

Uptake of vaccination in pregnancy in Hackney is low. This study aims to understand why this could be.

If you are interested in taking part in the study or have any questions, please contact rose.wilson@lshtm.ac.uk or on 07788 100 571

NHS City and Hackney

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NHS National Institute for Health Research

Do I have to take part in the study?

Whether you decide to take part in this study is entirely up to you. If you decide you want to but later change your mind, you can withdraw at any time.

Whatever you decide, your medical care and legal rights will not be affected in any way.

Your GP surgery/antenatal clinic has received information about this new study and has agreed to participate.

What will happen in the interview?

When you arrive, you would sign a consent form stating that you understand what is involved in your participation in the study and are willing to take part.

We would also ask your permission to make an audio recording of the interview. This audio recording would be transcribed then transferred to a password-protected computer, as required by the Data Protection Act, at the London School of Hygiene and Tropical Medicine for analysis. We will also take written notes during the interview.

The interview will be a relaxed and informal chat about your background, your experience of the healthcare you have received during your current/recent pregnancy and your attitudes to vaccination.

You are invited to take part in the study whether you have been vaccinated or not. You will not have to receive any vaccinations during the interview and your answers will be anonymised.

Interviews will usually take an hour but timing will be flexible.

If you decide to withdraw from the study at any point, this would not affect your receipt of the voucher.

Public Health England

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NHS England

Appendix 12: Inclusion and Exclusion criteria for participants

Inclusion criteria for pregnant/recently pregnant women:

- Living in Hackney and/or receiving healthcare in Hackney, London
- Currently pregnant or been pregnant in the past year (from when ethics approval is confirmed)
- Fully understands the study after reading the participant information sheet and has signed the consent form
- Is over the age of 18

Inclusion criteria for healthcare professionals:

- Any doctors, nurses and midwives working in the GP practices and antenatal clinics included who have regular contact with pregnant patients
- Fully understands the study after reading the participant information sheet and has signed the consent form.

Other:

- Anyone influencing a patient's decision to vaccinate (such as partner or family member)
- Fully understands the study after reading the PIS and has signed the consent form
- Is over the age of 18.

Exclusion criteria for pregnant/recently pregnant women

- Anyone not living or receiving healthcare in Hackney, London
- Anyone who is not currently pregnant, or who gave birth over a year before study commencement
- Anyone who has suffered a miscarriage or infant death in their most recent pregnancy
- Anyone who is not capable of understanding the study and thus providing informed consent
- Anyone who does not sign the informed consent form
- Anyone under the age of 18.

Exclusion criteria for healthcare professionals:

- Anyone not working in Hackney, London

- Anyone who does not have regular contact with pregnant women
- Anyone who is not capable of understanding the study and thus providing informed consent
- Anyone who does not sign the informed consent form.

Appendix 13: Topic guide for healthcare professionals

Name/participant number	
Job title	
Place	
Date	
Time	
Email	
Telephone	

Age	
Gender	
Do you have any children?	
Vaccinated if/when pregnant	
Ethnicity/nationality	
Country of origin	
Religion	
How long have you been in your role?	
Notes	

Can you please tell me about your views generally on vaccinations during pregnancy?

- Are you aware of the vaccines currently recommended for pregnant women in the UK?
- Where do you get information about vaccination from?
- Do your colleagues share information with you on vaccinations provided in pregnancy?
- What are your views about the efficacy of vaccines provided in pregnancy?
- What are your views about the safety of vaccines provided in pregnancy?
- Do you feel the same way about both the pertussis and influenza vaccines?
- Do you think either one vaccine is more important than the other?
- Are you aware of the complications/symptoms associated with pertussis and influenza and the age at which people are usually affected?

- Have you ever heard or read anything which has worried you about vaccinating during pregnancy?

Please can you tell me about how you approach the topic of vaccination with a pregnant patient?

- Do you recommend vaccination?
- (If they do) What is the main reason for this?
- (If not) Please can you explain why not?
- Do you administer vaccines?
- Do you discuss vaccination with your patients?
- How do you bring up the topic of vaccination with your patients?
- How do you use NHS materials?
- Do you encourage your patients to vaccinate?
- If a woman is hesitant to vaccinate, what do you do?
- If a woman refuses to vaccinate, what do you do?
- Whose responsibility do you think it should be to recommend vaccination?
- Whose responsibility do you think it should be to provide vaccination?
- Do you know if your colleagues recommend vaccines for pregnant women?
- To who do you refer a woman who wants more information about vaccination or wants to be vaccinated?

I have no further questions, is there anything we have not discussed that you would like to tell me more about?

Is there anything you would like to ask me?[26]

[26] For all topic guides, ample space was provided under each question for my notes. These spaces have been omitted for the versions included in the thesis in order to save space.

Appendix 14: Topic guide for pregnant/recently pregnant women

Name/participant number	
Place	
Date	
Time	
Email	
Telephone	

Age	
Gender	
Ethnicity/nationality	
Country of origin	
Age when moved to UK (if applicable)	
Religion	
Language spoken the most at home	
Language used to read	
Education	
Employment	
Marital status	
Number of children	
Ages of children	
Pregnant or new mother	
How many months pregnant	
Any health complications during pregnancy	
Family members/friends present	
Immunisation status in pregnancy	
Use of complementary medicine/alternative medicine	
Notes	

I'd like to start off with a conversation about your experience with the health care system since you have been/when you were pregnant.

- How do you feel you are being taken care of?
- Did you mostly see doctor/midwife/nurse/other?
- Do you feel respected/listened to by your doctor/nurse/midwife?
- Do you feel at ease with your doctor/nurse/midwife?
- Coming away from your last appointment, how did you feel?
- Do you look at leaflets from your GP?
- (If applicable) Does the healthcare you receive here differ from where you were living before?
- How?

It would be helpful to hear about your experiences of using the antenatal clinic. Could you start from when you were first directed to it?

- Were you clear about what to expect from visits to the antenatal clinic?
- How easy was it to access the clinic?
- How did healthcare staff at the clinic make you feel about your pregnancy?
- Did you go to any other parenting groups?
- Did you feel like you received enough information?
- What kind of information did you want?

Can you tell me who normally makes decisions about your health?

- Who do you typically ask if you're not sure what to do?
- Where else would you go for advice?
- Is there a specific internet source you go to?

Can you please tell me about your experience of vaccination?

- Did you know you should be vaccinated during pregnancy?
- Please tell me how you learned that you should receive vaccinations during your pregnancy?
- How did you feel after you were told this?

- Did your HCW discuss vaccination with you?
- Did your HCW encourage you to get vaccinated?
- Do you remember which vaccines they recommended?
- Do you know what the vaccines protect against?
- Did you accept both of the vaccines?
- How easy was it to access the centre where the vaccines were administrated?
- (If only one) Why did you accept that one but not the other?
- Do you think either one vaccine is more important than the other?
- If so, why?
- Was the decision made just as any other health-related decision would be?
- On what grounds did you decide to/not to vaccinate? (was the decision an active and considered choice or simply following advice?)
- Was the decision difficult or fairly straight forward to make?
- What do you think are the most important influences to your decision to vaccinate?
- Did you seek any special advice?
- From where?
- How did you feel emotionally after you received the vaccine(s)?
- Have you had any other vaccines yourself?
- Have your other children been vaccinated?
- Have you ever heard or read anything which has worried you about vaccinating during pregnancy?
- Do you feel the same way about both the whooping cough and influenza vaccines?
- Can you describe what a 'bad reaction' would be (if respondent says 'bad reaction').
- What would this mean?
- How much do you trust the advice on immunisation given by your HCW?
- Have you heard any positive messages about vaccination during pregnancy?
- Do you think other people in your situation would have the same experience as you?
- What do you think may make your experience different from others within your community?
- Would you recommend vaccination in pregnancy to friends/relatives?

I have no further questions, is there anything we have not discussed that you would like to tell me more about? Is there anything you would like to ask me?

Appendix 15: Interview format

Stage 1: Arrival and introductions

Stage 2: Introduce the research, seek informed consent and explain aims and objectives of the research, its purpose and what I would like to cover. Explain that taking part is voluntary and set out the arrangements for confidentiality and disclosure. Explain that the interview is not a survey with a series of questions and short answers/options for participants to choose from but that the aim is to hear their views and experiences in their own words.

Stage 3: Begin the interview. Ask for demographic/contextual information. Then use follow-up questions to put the interviewee at ease, e.g. ask how long have they lived in the area.

Stage 4: During the interview. Keep overarching research questions in mind, decide what to follow up on and how to phrase questions. Exercise judgement on length of time given to any topic.

Stage 5: Once all questions have been asked and it seems that no new information will identified, signal the approach of the end. Ask for any final thoughts or comments.

Stage 6: After the interview, thank the participant and explain what happens next with the data and reporting. If the participant would like any more information on vaccination or their or their patient's health in general, for healthcare professionals I will advise that they contact Vanessa Saliba or Joanne Yarwood from PHE, and for pregnant women, I will direct them to the NHS choices website or advise that they speak to their healthcare professional.

Interview format adapted from Ritchie and McNaughton et al. (2014).

Appendix 16: Topic guide for focus group discussion

1. How was your healthcare whilst pregnant?

2. Tell me about your maternal vaccine decision

Prompts: Did you receive the vaccines?

Why

Why not

Specific side effects

Do you feel the same about both vaccines?

3. Did your healthcare professional recommend the vaccines

Prompts: Did they have a discussion with you about them?

Did they encourage you to vaccinate?

Did they discuss the diseases which the vaccines aim to prevent?

Did they listen to your concerns/questions?

4. Did you seek any special advice?

Prompts: From friends/family/partner

From the internet

Specific sites

5. What would you say if a friend asked your advice on whether to receive the vaccines?

Appendix 17: Coding frameworks

1: Coding framework for interviews with healthcare professionals

Name	Sources	References
Administration	9	13
Availability	1	1
Discussions	10	17
Encourage	8	10
Hesitancy	10	24
Refusal	10	19
Time	2	6
Importance	10	13
Incorrect or contradiction with another or something previously said	6	12
Lack of knowledge	2	9
Legal	2	5
Length of time practicing	9	9
Metaphor	1	1
My influence	1	1
Necessity efficacy	10	13
Own pregnancy vaccination	9	12
Patient	5	9
Concern	5	12
Convenience	2	2
Willing	2	5
Places they refer patients	5	8
Friends family	2	2
NHS leaflet	7	13
Availability	3	3
NHS website	6	10
Other professional	6	7
Other website	6	10
Responsibility	0	0
Administer	7	8
Midwives	6	10
Time	2	3
Recommendation	7	8
Midwives	6	10
Source of vaccine info	9	10
Suggestions	6	13
Vaccines	0	0
Distrust	2	5
Trust	10	22

2: Coding framework for interviews with pregnant/recently pregnant women

Name	Sources	References
Convenience	3	4
Availability	2	2
Difficult to access	9	16
Easy to access	27	39
Inconvenient	3	3
Inconvenient (flu)	2	6
Inconvenient (pertussis)	1	5
Language	3	5
No time	4	8
Waiting time	9	22
Distrust	3	3
HCW or HCW advice	15	41
Metaphors	10	29
NHS	7	9
Vaccine	9	16
Factors which would have or did increase uptake	11	23
HCW	0	0
Labour and antenatal	18	76
Trust & Distrust	40	289
Information	28	70
HCW recommendation	40	253
Internet and apps and TV news	38	150
Language	4	7
NHS materials	38	140
Knowledge of diseases	6	8
Negative experience of care	3	5
Confusion	21	73
Negative sentiments towards HCW	32	142
Negative sentiments towards NHS	17	41
Negotiating the health care system	16	58
NHS & The system	0	0
Access	36	116
Labour and antenatal	23	81
Trust & Distrust	29	123
NHS materials	38	136
Own recommendation	9	10
Positive experience of care	6	8
Positive sentiments towards HCW	39	173
Positive sentiments towards NHS	20	46
Relational autonomy	6	47
Risk	21	46
AEFI	16	33
Autism	8	12
Avoided risk during pregnancy	8	13
Childhood vaccines	27	81

Hate needles	3	4
Impurity	4	6
Influenza	6	10
AEFIs	16	27
Impurity	2	2
Inconvenient	2	6
New vaccine or not tested	3	7
Not necessary	20	41
New vaccine or not tested	6	9
Not necessary	16	26
Omission bias and balance with not being vaccinated	14	28
Pertussis	9	21
AEFIs	10	16
Impurity	4	4
New vaccine or not tested	3	4
Not necessary	10	13
Self-care	3	5
Food	5	5
Massage acupuncture or physiotherapy	9	22
Research	20	40
Vitamins	10	11
Social influence	5	8
Conflicting advice	9	12
Country of origin	20	69
Friends family partner	40	216
Job education baby centre antenatal classes mums	14	34
Social influencers	15	28
Conflicting advice	9	12
Country of origin	20	69
Friends family partner	40	213
HCW recommendation	40	228
Internet and apps and TV news	37	135
Job education baby centre antenatal classes mums	10	24
Trust	3	4
HCW or HCW advice	30	66
NHS	5	12
Vaccine	27	80
Influenza	13	32
Pertussis	23	58
Protection	17	44
Vaccine	3	5
Availability	2	2
Trust & Distrust	40	416

3: Coding framework for FGD

Name	References
Convenience	0
Availability	1
Language	2
No time	3
Distrust	0
HCW or HCW advice	1
Factors which would have increased uptake	7
Negative experience of care	0
Confusion	4
Negative sentiments towards HCW	8
Negative sentiments towards NHS	5
Negotiating the health care system	1
NHS materials	6
Own recommendation	2
Positive experience of care	0
Positive sentiments towards HCW	6
Positive sentiments towards NHS	4
Risk	2
AEFI	1
Influenza	0
AEFIs	1
Not necessary	1
Metaphors	5
Self-care	0
Research	1
Social influencers	1
Conflicting advice	1
Friends family partner	6
HCW recommendation	14
Internet and apps and TV news	4
Trust	0
HCW Advice	2
NHS	1
Vaccine	9
Influenza	5
Pertussis	2
Protection	3

4: Coding framework for consultation video-recording

Name	References
Camera	1
HCW and patient interaction	0
Caring	4
Human and relaxed	2
Patient sentiments	0
Health care	1
Study	1
Trust vaccine	1
Vaccine	0
Administration	1
Discussion	2
How brought up	2
Info about disease	1
Side effects	1

Appendix 18: Participant demographics and vaccination status of pregnant/recently pregnant women

Pregnant women

Participant	Age	Ethnicity	Religion	Education	Employment	Marital status	Primiparous /multiparous	DTaP/IPV	Influenza
Anna	34	White British	None	Bachelor's	Unemployed	Married	Multiparous	N	N
Margaret	41	White British	None	Bachelor's	Employed	Co-habiting	Primiparous	Y	Y
Tami	34	Japanese	Buddhist	Master's	Unemployed	Married	Primiparous	Y	Y
Hayley	34	White British	None	Bachelor's	Employed	Married	Primiparous	N	N
Maddelin	34	German	None	Bachelor's	Employed	Co-habiting	Primiparous	N	N/a
Magda	33	White British	None	Bachelor's	Employed	Co-habiting	Primiparous	Y	N/a
Lucy	27	Black British	Catholic	GCSE	Employed	Single	Primiparous	Y	N
Anetta	30	Nigerian	Christian	Bachelor's	Unemployed	Married	Primiparous	N	N
Bathild	35	German	None	Bachelor's	Unemployed	Married	Primiparous	Y	Y
Celia	32	White British	Catholic	Master's	Employed	Married	Primiparous	Y	Y
Ava	26	White British	None	GCSE	Unemployed	Single	Multiparous	Y	Y
Shiloh	19	Black British Caribbean	Christian	NVQ	Unemployed	Single	Multiparous	N	N
Caera	18	White/black Caribbean	None	GCSE	Unemployed	Single	Primiparous	Y	N/a
Sarah	22	White British	None	GCSE	Employed	Single	Primiparous	Y	N/a
Gabriela	19	White British	None	High school	Unemployed	Single	Primiparous	Y	Y
Isleen	34	Australian	None	Master's	Employed	Married	Multiparous	Y	Y
Rebecca	29	White British	Christian	Bachelor's	Employed	Married	Multiparous	N	N
Ruth	36	White British	None	Master's	Employed	Co-habiting	Multiparous	Y	N/a
Cai	34	Chinese	Christian	Master's	Unemployed	Married	Primiparous	Y	Y
Haadiya	19	Nigerian	Muslim	GCSE	Unemployed	Married	Primiparous	Y	Maybe
Tessa	27	Black British Caribbean	Christian	High school	Employed	Cohabiting	Primiparous	Y	N
Carla	37	White British	Catholic	Master's	Employed	Married	Primiparous	Y	Y

Samantha	28	Black British Caribbean	Christian	Bachelor's	Employed	Single	Multiparous	N	N
Jane	24	Black British Caribbean	Christian	High school	Unemployed	Single	Multiparous	N	N
Kate	33	South African	None	Master's	Employed	Married	Primiparous	N	N
Haleefa	27	Somalian	Muslim	Master's	Unemployed	Married	Primiparous	Y	N
Talia	21	Orthodox Jewish	Orthodox Jewish	High school	Unemployed	Married	Multiparous	N	N
Meira	23	Orthodox Jewish	Orthodox Jewish	High school	Employed	Married	Multiparous	N	N
Rafeal	34	White British (ethically Jewish)	None	Master's	Employed	Co-habiting	Primiparous	Y	Y
Beth	22	White British (Irish)	Catholic	NVQ	Unemployed	Single	Primiparous	Y	Y
Mahsa	31	Pakistani British	Muslim	Master's	Unemployed	Married	Multiparous	Y	N
Julia	38	Chinese/English	None	Master's	Unemployed	Single	Primiparous	N	N
Isobel	40	White British	None	Master's				Y	Y
Marigold	36	British/Brazilian	Christian	Master's	Employed	Married	Multiparous	Maybe	Y
Sabah	32	Turkish	Muslim	High school	Unemployed	Married	Multiparous (4 children)	N	N
Ezgi	30	Turkish	Muslim	High school	Unemployed	Married	Multiparous	N	Y
Idda	27	Norwegian	None	Master's	Student	Co-habiting	Primiparous	N	N
Cadenza	34	Italian	Christian	High school	Employed	Co-habiting	Multiparous	N	N
Zoe	32	Black British	Christian	Master's	Unemployed	Single	Multiparous	Y	N
Aldona	29	Lithuanian	None	NVQ	Unemployed	Married	Multiparous	N	N

FGD participants

Participant	Age	Ethnicity	Religion	Education	Employment	Marital status	Primiparous /multiparous	DTap/IPV	Influenza
Sasha	32	White British	None	Masters	Employed	Married	Primiparous	Y	Y
Nicola	35	White USA	None	Masters	Employed	Co-habiting	Primiparous	Y	Y
Chloe	35	White British (Irish)	None	Bachelors	Employed	Married	Primiparous	N	N
Amy	37	White British	None	Bachelors	Employed	Married	Primiparous	Y	Y
Thalia	34	White British	None	Bachelors	Employed	Single	Primiparous	N	N
Marika	35	White British	None	Masters	Employed	Married	Primiparous	Y	Y

Healthcare professionals

Participant	Age	Ethnicity	Religion	Recommend vacc.	Encourage vacc.
Dr. Lawson	58	White British	None	Y	Y
Dr. Marsh	23	White British	Christian	Y	Y
Dr. Cooke	29	White British	Christian	Y	Y
Midwife Williams	51	Black British	None	Y	Y
Dr. Henderson	32	White British	None	Y	Y
Dr. Khatri	62	British Indian	Hindu	Y	Y
Nurse Anand	46	British Indian	Christian	Y	Y
Nurse Thompson	40	Black Caribbean	Christian	Y	Y
Midwife Renee	41	Black/white Caribbean	None	Y	N
Dr. Clark	33	White British	Catholic	Y	Y