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**FACTORS AFFECTING EXPOSURE TO  
HEALTH PROMOTION ABOUT  
HPV VACCINE IN ENGLAND AND  
VARIATIONS IN UPTAKE OF THE  
HPV VACCINE IN SECONDARY SCHOOLS  
IN THE WEST MIDLANDS**

by

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**A thesis submitted in partial fulfillment of the requirements for the  
degree of  
Doctor of Philosophy in Health Sciences  
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# ABBREVIATIONS

|          |   |
|----------|---|
| ACIP     | Advisory Committee on Immunization Practices                                |
| BME      | Black and minority ethnic   |
| CCG      | Clinical Commissioning Groups   |
| CDC      | Center for Disease Control and Prevention                                   |
| CINAHL   | Cumulative Index to Nursing and Allied Health Literature                    |
| CRB      | Criminal Records Bureau   |
| CQC      | Care Quality Commission   |
| DE       | Department of Education   |
| DG SANCO | Directorate General Health and Consumers Affairs, European Commission       |
| DH       | Department of Health  |
| ECDC     | European Center for Disease Prevention and Control                          |
| EFTA     | European Free Trade Association   |
| EMA      | European Medicines Agency   |
| EU       | European Union  |
| FSM      | Free school meal  |
| GOR      | Government Office Region  |
| GP       | General Practitioner  |
| HBM      | Health Belief Model   |
| HEA      | Health Equity Audit   |
| HIV/AIDS | Human Immunodeficiency Virus Infection / Acquired Immunodeficiency Syndrome |
| HPV      | Human papillomavirus  |
| HSRG     | Health Services Research Group  |
| HWB      | Health and Wellbeing Board  |
| IMD      | Index of Multiple Deprivation   |
| JCAHO    | Joint Commission for Accreditation of Healthcare Organizations              |
| LA       | Local Authority   |
| LAT      | Local area team   |
| LGA      | Local Government Authority  |
| LSOA     | Lower Super Output Area   |
| MMR      | Measles, Mumps and Rubella  |
| NHS      | National Health Service   |
| NICE     | National Institute for Health and Care Excellence                           |
| NRES     | National Research Ethics Service  |
| OECD     | Organisation for Economic Co-operation and Development                      |
| ONS      | Office for National Statistics  |
| PCT      | Primary Care Trust  |
| PHE      | Public Health England   |
| PSHE     | Personal, Social and Health Education                                       |
| RR       | Relative risk   |
| RSPH     | Royal Society for Public Health   |
| SAP      | School Address Postcode   |
| SCA      | School Catchment Area   |
| SHA      | Strategic Health Authority  |
| STIs     | Sexually Transmitted Infections   |
| UK       | United Kingdom  |
| UN       | United Nations  |

|        |  |
|--------|--|
| US     | United States  |
| VENICE | Vaccine European New Integrated Collaboration Effort |
| VLPs   | virus-like particles                                 |
| WHO    | World Health Organization                            |

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# **DECLARATION**

I hereby declare that this thesis is my own work and that this thesis has not been submitted for any other degree at another University.

Corina Mihaela Chivu

June 2014

“To know that we know what we know,  
and to know that we do not know what we do not know,  
that is true knowledge.”

Copernicus

# ABSTRACT

**Background:** In 2008, the health departments of the United Kingdom implemented a routine and catch-up HPV immunization programme in schools to reduce the incidence of cervical cancer. European studies conducted from 2007 to 2012 showed inconsistent results on HPV vaccine uptake in relation to ethnicity and girls' age.

**Aim:** To examine the relationship between area deprivation and the take-up of informative materials related to HPV vaccination in secondary schools in England. Another aim was to investigate the association between uptake of HPV vaccine and area deprivation, ethnicity and religion and to explore the views and experiences of girls, teachers and health providers on the HPV vaccine to understand how mechanisms of programme delivery, strategies and practices contributed to HPV vaccine uptake in a city in the West Midlands.

**Methods:** Secondary data about uptake of professionally developed teaching materials by 4,750 schools in England was employed to explain the relationship between the take-up of the materials and the level of social deprivation of the area within which the school was located using logistic regression. Other secondary data about uptake of the third dose of HPV vaccine by year 8 girls in a city in the West Midlands was used to explain the variability of uptake across 20 schools between 2008 and 2012. Analytic statistics included simple and multivariate linear regressions. Qualitative data was collected through 47 semi-structured individual interviews with nine nurses, four school staff and 34 year 8 girls as well as through non-participant observations in 12 secondary schools between February and September 2013. Thematic analysis identified major themes related to the school context of implementation of the HPV vaccine programme as well as facilitators and barriers to uptake of HPV vaccine in the city of the study.

**Results:** Of all secondary schools in England invited to receive the HPV educational materials, 1,395 schools (30.17%) responded. These schools were in the largest quintile of school size as well as maintained schools. After controlling for other covariates, it was found that schools in the least deprived quintile had 1.31 the odds of requesting materials compared with the schools in the most deprived areas (95% CI=1.05-2.53).

Deprivation of school address postcode remained statistically significantly associated with uptake of HPV vaccine after controlling for ethnicity, school type and academic year. Similarly, the academic year 2009/10 remained statistically significantly associated with uptake of HPV vaccine adjusting for geographic and school factors. Deprivation of school catchment area was no longer statistically significantly associated with uptake of HPV vaccine when the other variables were held constant and the same was true for the association between ethnicity and uptake.

Thematic analysis showed that school based HPV vaccination programme was accepted by most of the schools in the city of study and was delivered by a mobile clinic aiming to vaccinate all eligible girls. Chasing up the consent forms and communication with the parents were the most challenging activities in the HPV vaccination administration. However, they were essential for a high HPV vaccine uptake. The manner in which the school staff and nurses sought parents' and girls' consent before and on the day of vaccination was often very persuasive and not entirely ethically justified. The HPV vaccine was poorly promoted in the school environment because of tight curriculum for compulsory subjects and the lack of adequate staff. A number of other influences affected girls' choices about receiving the vaccine. The family played the most important role for daughters' emotional support as also did the provision of information to help girls understand and make their own decision about the vaccine. The interactions with friends and nurses were beneficial for girls' confidence and feelings on the day of

vaccination. Girls' fear of injection caused by their poor knowledge, rumors spread by peers and parental negative attitudes about HPV vaccine were major obstacles to uptake before and on the day of vaccination. The main parental reasons for vaccine refusal were lack of understanding of the information about HPV vaccine, which they received from the school, their inadequate information, obtained from sources other than health professionals, their misconceptions about the safety of the vaccine and their religious beliefs related to their daughters' sexual activity in the future.

**Conclusion:** The impact of the HPV vaccination education campaign suggests differential level of exposure due to unevenly distributed requests for the materials across England. At local level, the HPV programme was not equally well implemented across the schools in the city. This was mainly due to school factors, including the location as well as the organization of delivery. The findings highlight the need for further investigation of factors associated with uptake of HPV vaccine to guide health policy and public health interventions for effective implementation of the HPV vaccination programme in all schools.

# CHAPTER 1: INTRODUCTION

I am a public health specialist and a medical doctor from Romania. Before this doctoral programme, I graduated a Master in Public Health course at the Braun School of Public Health and Community Medicine in Jerusalem, Israel. Further, I started a Doctorate in Public Health at Brunel University in the UK, which was interrupted in the mid-year 2009 because both supervisors moved to Monash University in Malaysia. Subsequently, I was awarded a Postgraduate Diploma in Public Health for partial doctoral study at Brunel University that helped me to strengthen my knowledge and to hone my research competence. Later, I transferred the research element of the work in Brunel University, which was completed there, to the University of Warwick. While I was doing my PhD at the University of Warwick, I registered with the General Medical Council and with the Faculty of Public Health, as a Fellow, in the UK in 2011.

My interest in the topic of this research began at Brunel University when I undertook the placement at the Royal Society of Public Health (RSPH) to evaluate its national education campaign to support teachers, school nurses and health professionals in introducing and raising awareness of the HPV vaccine in secondary schools. This public health programme was launched two months before the implementation of the national HPV immunization programme for the first time in the UK. Based on my previous work, which was a systematic review about interventions to increase awareness, knowledge about, and folic acid uptake before and during pregnancy, carried out during my Master's research, I was thinking, at the end of the placement, of designing my doctoral research around evidence related both to knowledge about the HPV vaccine and to factors associated with uptake. It was possible to put my idea into practice taking the opportunity of the implementation of HPV vaccination, which followed immediately after the education campaign of the RSPH.

## 1. 1. Background

Human papillomavirus affects a high proportion (70%) of sexually active women and men during their lifetime, usually shortly after sexual debut. (Cutts et al., 2007) Almost all cervical cancer cases are linked with genital infection with HPV (Wheeler, 2008) (Department of Health, 2008b). Two HPV types (16 and 18) are thought to be responsible for 70% of cervical cancer cases worldwide (Tota et al., 2011; European Centre for Disease Prevention and Control, 2008; Department of Health, 2008b).

Across Europe there are wide health inequalities in cervical cancer (European Cervical Cancer Association, 2009). Health inequalities refer to disparities in the health achievements of individuals and groups (Kawachi et al., 2002) due to free choice, unavoidable factors (i.e., biologic or genetic) or external environment (World Health Organization, 2012a). Ethnic inequalities in health are largely a consequence of socioeconomic differentials (Cooper, 2002; Nazroo and Williams, 2006) such as lower family income and education (United Nations Research Institute for Social Development, 2006). Areas with high concentration of ethnic groups seem to have fewer health services although they are most needed (Whitehead, 1992) and a worse environment (Bartley, 2004). Inequalities in access to cancer screening for people from ethnic minority groups were reported in several studies conducted both in the UK and in the US (Szczepura et al., 2008). The main reasons were attributed to language barriers, a lack of knowledge about screening services (Szczepura, 2005; Thomas et al., 2005), individual's cultural values and beliefs, individual's misconceptions about perceived risk (Thomas et al., 2005), inaccurate screening registers (Szczepura, 2005), a lack of recommendations by health care professionals (Szczepura, 2005), poor attitudes of GPs (Thomas et al., 2005), and lack of local access to services (Thomas et al., 2005).

The European Medicines Agency licensed a quadrivalent and a bivalent HPV vaccine which are safe (World Health Organization, 2009), effective (Lu et al., 2011) and cost-

effective (Westra et al., 2011) for prevention of cervical cancer for females aged 9 to 26 (D'Souza and Dempsey, 2011; Chaturvedi, 2010). In Europe, the vaccine was implemented at national level based on evidence related to existence or lack of cervical cancer screening and vaccine acceptability by adolescents and their parents as well as by health professionals (World Health Organization, 2008). Schools have been deemed a good medium for HPV vaccination because of other immunization programmes already in place and presumably because of existing education programs about HPV vaccine (Ramet et al., 2011). Equitable delivery of health services does not guarantee equality of uptake (von Wagner et al., 2011).

This thesis is based on two pieces of empirical work. I carried out the first study at Brunel University between October 2007 and June 2009 and based on the findings of that work I undertook the second study at the University of Warwick between October 2011 and June 2014.

### **Research questions**

1. Is there an association between uptake of educational materials about HPV vaccine by secondary schools and area level, social deprivation in England?
2. Is there an association between uptake of the HPV vaccine by secondary schools in a city in the West Midlands and area deprivation, ethnicity or religion?
3. What are the mechanisms, strategies and practices that influence uptake of HPV vaccine?

## **1. 2. Overview of the Thesis Structure**

This thesis comprises eight chapters.

In the first section of Chapter Two I present a review of literature on the epidemiology of sexually transmitted infections with special emphasis on infection with Human papillomavirus. The next section presents information about the theory of vaccines with a focus on herd immunity. Particular aspects of the vaccine such as effectiveness, cost-effectiveness, doses and adverse effects are mentioned in relation to HPV vaccine. Finally, some strategies to improve vaccination rates are presented. The last section contains a description of the HPV vaccination programme in Europe, including the context of HPV vaccination and the method of its delivery to target populations. The literature review refers to the European context because this research is conducted in the UK. Another reason is that the HPV vaccination policy developed at European Union level has been implemented differently at country level.

Chapter Three is divided into two parts. Part one presents the conceptual framework of the “right to health” and part two presents the conceptual framework of evaluation of quality of care. In part one, first, I introduce the concept of right to health. Then, I present and discuss the concept of access to health services. Because this concept is mostly related to the utilization of health services, I focused the discussion on barriers to access to health care among different ethnic groups mostly in the UK.

Part two of this chapter presents a conceptual framework of evaluation of quality care. Firstly, I discuss an equity concept and then I provide full details about the relationship between equity and access. Secondly, I introduce the concept of health inequality and then I focus the discussion on the explanations of health inequalities and ethnic inequalities in health. In the next two sections, I present equity in health service delivery and equity in access to health care with a particular example of equity in access to vaccination.

Chapter Four presents three sections, including health promotion and models, a scoping literature review related to awareness and knowledge about HPV vaccine and a national study based on a mass campaign distributing teaching materials about HPV vaccine to secondary schools in the UK. The first section introduces the concept of health promotion, approaches to health promotion and three categories of models related to individual, interpersonal and community health behaviour. In the next section, I present the findings of scoping literature review. In the last section, I describe a national study, which is an evaluation of a mass campaign using printed materials for use in formal education in the secondary schools. Then, I present an evaluation approach to this HPV education programme based on quantitative research, which addressed research question 1. I also present the methodology of the study including data sources and the techniques which I used for data analysis. Finally, I present the results of the study including descriptive and inferential statistics.

Chapter Five includes two sections, one that describes the city of the study and another one that provides details about the methodology of the study.

The first section, which presents the health profile of the city of study, is structured in three parts. Part one contains statistical data about the population including aspects of demography, ethnicity and employment. Part two gives information about area deprivation and part three presents health programmes provided since 2008 with special emphasis on sexual health services.

The second section of this chapter contains two parts. In part one, I present the research design and the justification for doing a case study, and I also mention the philosophical

position of the researcher. In part two, I discuss the methodology based on mixed methods research, providing details about its rationale, purpose, design and mixing strategies.

In Chapter Six, I describe the methods and the results of the quantitative component of mixed methods which addressed research question 2. First, I describe my methods including data sources and the techniques which I used to prepare the data for analysis. Second, I provide a detailed description of the methods of analysis, including descriptive and inferential statistics, and lastly I present the results of the study.

In Chapter Seven, I describe how I obtained ethical approval for the qualitative component of the mixed methods research in schools which addressed research question 3. Then, I describe my methods of data collection: individual face-to-face interviews and non-participant observation. Next, I present how I collected data, including the recruitment of the participants, the conduct of the interviews, the transcription of the interviews, reflexivity and the procedures to minimize possible researcher effect and researcher bias and thematic analysis and in the end, I present the results.

In Chapter Eight, I summarise the main findings from each section of the thesis in relation to the original research questions, highlight the strengths and limitations of the present study, discuss the relationship between the findings and the results of previous research, discuss the implications for policy, practice and future research, and end with a broad conclusion.

## **1.3 Summary**

In this chapter, I have presented the introduction to this thesis and information underpinning the basis of the present study. I also presented the description of the origin of my interest in the research topic, and the structure of the thesis. In the next chapter, I will present the literature review related to HPV and HPV vaccine and the delivery of the HPV vaccination programme in Europe.

## **CHAPTER 2: LITERATURE REVIEW**

The literature review is presented in three sections, including general aspects about HPV and the HPV vaccine as well as about the delivery of the HPV vaccination programme in Europe.

In this section, first I present a review of literature on the epidemiology of sexually transmitted infections with special emphasis on infection with Human papillomavirus. Then, I present information about the theory of vaccines with focus on herd immunity. Particular aspects of the vaccine such as effectiveness, cost-effectiveness, doses and adverse effects are mentioned in relation to the HPV vaccine. Finally, some strategies to improve vaccination rates are discussed.

### **2.1 Epidemiology of sexually transmitted infections**

Sexually transmitted infections (STIs) (World Health Organization, 2011b) or sexually transmitted diseases (STDs) (Shim, 2011) are infections that are spread primarily through person-to-person sexual contact (World Health Organization, 2011b). STIs are a public health problem and economic burden (World Health Organization, 2007; Da Ros and Schmitt Cda, 2008; Shim, 2011). Almost a million people have been estimated by WHO to acquire STIs, including the human immunodeficiency virus (HIV) every day (World Health Organization, 2007). Most affected people are in developing countries (World Health Organization, 2007; Shim, 2011). However, trends in STIs have increased in developed countries due to changes in sexual behavior and increased travel (World Health Organization, 2007). Young adults (15-24 years old) account for 50% of all new STIs (Da Ros and Schmitt Cda, 2008). Their high risk is associated with unprotected sex with an infected partner (Shim, 2011), higher susceptibility to infection (e.g. women (Low et al., 2006)), short term sexual relationships and difficult access to

prevention services (Workowski and Berman, 2006) (i.e., screening) (Da Ros and Schmitt Cda, 2008). STIs are caused by over 35 pathogens represented by bacteria, viruses and parasites (World Health Organization, 2011b; Shim, 2011). The virulence of the pathogen and the duration of infection determine the spread of STIs (Low et al., 2006). Some STIs are asymptomatic (e.g. herpes simplex virus type 2, HIV, hepatitis B, gonorrhoea) and difficult to control (Da Ros and Schmitt Cda, 2008); therefore, they are disseminated further (Anderson and Garnett, 2000). STIs are under-reported (Da Ros and Schmitt Cda, 2008). In addition, STIs can have severe long-term consequences (e.g. infertility, cervical cancer, ectopic pregnancy) (World Health Organization, 2012b).

Human papillomavirus (HPV) is considered the commonest agent of STIs (Kim et al., 2011). It has been estimated that 15-20% of people with STIs have HPV (Da Ros and Schmitt Cda, 2008).

Human papillomavirus vaccination and/or HPV testing as well as screening for cervical cancer are complementary (European Centre for Disease Prevention and Control, 2008) public health interventions put in practice for primary and secondary prevention of cervical cancer, respectively.

### **2.1.1. Epidemiology of human papillomavirus infection**

More than 100 human papillomavirus (HPV) types have been identified (Wheeler, 2008) but approximately 40 HPV types infect the anogenital region (Pandhi and Sonthalia, 2011; Haupt and Sings, 2011). There are 15 HPV types associated with an increased risk of various cancers of cervix, vulva, vagina, penis and anus, and some cancers of the head and neck (Department of Health, 2008c; Tota et al., 2011; Chaturvedi, 2010; D'Souza and Dempsey, 2011). Among “high-risk” types there are

oncogenic HPV-16 and HPV-18 which are associated with cervical cancer (Castellsague, 2008; Schiffman et al., 2005). Several other carcinogenic HPV types (31, 33, 35, 45, 52, and 58) have been found which have a similar structure to the HPV-16 and HPV-18 types (Pandhi and Sonthalia, 2011). There are 12 types with “low risk” including HPV-6 and HPV-11 types which are associated with genital warts (Castellsague, 2008; Ramet et al., 2011) and warts in the throat (D'Souza and Dempsey, 2011).

Human papillomavirus affects a high proportion (70%) of sexually active women and men during their lifetime, usually shortly after sexual debut (Cutts et al., 2007). 30% of women are infected within two years after start of sexual activity (Department of Health, 2008c). The peak incidence of HPV infection occurs between the ages of 14 and 24 years (Pandhi and Sonthalia, 2011).

Almost all cervical cancer cases are linked with genital infection with HPV (Wheeler, 2008; Department of Health, 2008b) and HPV types 16 and 18 are thought to be responsible for 70% of cervical cancer cases worldwide (Tota et al., 2011; European Centre for Disease Prevention and Control, 2008; Department of Health, 2008b).

Human papillomavirus is a common virus that is easily spread during vaginal, anal and oral sex (Tota et al., 2011), between heterosexual (Burchell et al., 2011) and homosexual partners (Graham and Mishra, 2011) even when the infected partner has no signs or symptoms. A person can be infected with one (Burchell et al., 2011) or less often with more than one HPV type (Cutts et al., 2007). It is possible to acquire HPV even if sexual contact happens only once and even if a condom is used (Cutts et al., 2007; Tota et al., 2011). However, the risk of infection is lower in women whose

partners use a condom or who are circumcised (Cutts et al., 2007; Tota et al., 2011). Another reported mode of HPV transmission is from mother to child in the case of vaginal delivery (Tota et al., 2011).

The acquired HPV infections can be asymptomatic (Kerkar et al., 2011) and 90% of new infections with HPV disappear within two years (Department of Health, 2008c) (Tota et al., 2011). Also, up to 30% genital warts disappear in the short term after infection even without treatment (Department of Health, 2008c).

It has been shown that cervical cancer develops under circumstances of persistent infection with HPV type (Chaturvedi, 2010) as HPV-16 or HPV-18 (Ramet et al., 2011). There are various factors thought to increase the risk of persistent HPV infection or development of cancer such as increasing age and immunosuppression as well as infections with multiple HPV types (Ramet et al., 2011).

The period between infection with HPV and the development of cervical cancer varies from one year to one decade (Department of Health, 2008c; Pandhi and Sonthalia, 2011; D'Souza and Dempsey, 2011).

## **2.2 Vaccine**

The World Health Organization (WHO) defines a vaccine as “any preparation intended to produce immunity to a disease by stimulating the production of antibodies” (World Health Organization, 2011a).

### **2.2.1. HPV vaccine**

Two HPV vaccines have been licensed in the US (Chaturvedi, 2010), in Australia and in Europe (European Centre for Disease Prevention and Control, 2008). The vaccine

made by Merck and licensed by European Medicines Agency (EMA) in 2006 (World Health Organization, 2008) is a quadrivalent vaccine which protects against HPV types 16, 18, 6 and 11 (Joint Committee on Vaccination and Immunisation, 2008b). The other vaccine made by GlaxoSmithKline and licensed by the EMA in 2007 (World Health Organization, 2008) is a bivalent vaccine, offering protection against HPV types 16 and 18 (Joint Committee on Vaccination and Immunisation, 2008b). By October 2007, 38 countries of the European Region licensed the quadrivalent vaccine but only 30 countries approved the bivalent vaccine (World Health Organization, 2008). Both vaccines are made from the major protein of the viral-coat of HPV called virus-like particles (VLPs) which imitate the structure of HPV but do not contain any HPV DNA (Department of Health, 2008c). These VLPs in the vaccine attach to human cells and stimulate the immune system to produce antibodies (Chaturvedi, 2010). The two vaccines differ not only in valency but also in substances added to the vaccine (Ramet et al., 2011) to increase the body's immune response. Currently it is known that the duration of vaccine-induced immunity is "at least" 5 (Wheeler, 2008) – 6 years (Department of Health, 2008a).

### **2.2.2. Effectiveness of vaccine**

Vaccine effectiveness is a measure of vaccine efficacy (see below), reflecting the potency to reduce disease in a population in the "real world" (Weinberg and Szilagyi, 2010).

### **2.2.3. Herd immunity**

Herd immunity (Kim et al., 2011), herd effect or herd protection (Goncalves, 2008) is the most effective way to control a disease through vaccination (Bonita et al., 2006). Vaccine is given to individuals with high risk of infection with a pathogen and who are

most likely to transmit the infection forward (i.e., children) (Smith et al., 2011). At individual level, vaccination protects immunized person through acquired immunity (Smith et al., 2011) against bacterial or viral disease (Kim et al., 2011) and infectiousness (Fine et al., 2011). At population level, vaccine reduces human to human transmission of infectious disease (John and Samuel, 2000) and indirectly protects unvaccinated people (Kim et al., 2011; Brisson and Edmunds, 2003; Smith et al., 2011). Indirect protection is the result of vaccine's effect on transmission (Fine et al., 2011). Some unvaccinated people are those thought not to respond to vaccines (i.e., elderly) or those who have medical reasons (i.e., immunosuppressed) (Smith et al., 2011) or those who refuse the vaccine (Fine et al., 2011). There is evidence that high-risk groups (i.e., elderly) who have suboptimal immune response to the vaccine could be protected indirectly by vaccinating those who respond well to vaccine (i.e., children) (Kim et al., 2011; Smith et al., 2011). Parents' refusal to vaccinate children could increase their risk of infection through contact with other members of the community (Fine et al., 2011).

The induced herd immunity could be influenced by vaccine efficacy, duration of protection and vaccine coverage (Brisson et al., 2011; John and Samuel, 2000). Herd immunity is important because vaccine efficacy is not 100% (Yip et al., 2007). Therefore, the proportion of the population to be vaccinated should be determined taking into consideration vaccine efficacy (Yip et al., 2007). Vaccine efficacy is best measured by double-blind, randomized, clinical controlled trials. It is expressed as a proportionate reduction in disease attack rate<sup>1</sup> (Bonita et al., 2006) between the unvaccinated and vaccinated study cohorts. It can be calculated from the relative risk<sup>2</sup>

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<sup>1</sup> The term "attack rate" is often used instead of incidence during a disease outbreak. It can be calculated as the number of people affected divided by the number exposed

<sup>2</sup> Relative risk is the ratio of the risk of occurrence of a disease among exposed people to that among the unexposed

(RR) (Bonita et al., 2006) of disease among the vaccinated group according to formula  $(1-RR) \times 100$  (Weinberg and Szilagyi, 2010).

Herd immunity could decline over time because of the waning vaccine-induced immunity. Under these circumstance the vaccine coverage should target higher levels (Kim et al., 2011; Fine et al., 2011) than if immunity is lifelong (Scherer and McLean, 2002). Loss of vaccine efficacy due to new strains of the infectious agent (Kim et al., 2011; Scherer and McLean, 2002) could be addressed using regular booster vaccine (Fine et al., 2011).

The coverage rate necessary to stop transmission of infection depends on the basic reproductive number (Andre et al., 2008) whose symbolic expression in literature is  $R_0$  and defined as the average number of new infections caused by one infected individual in an wholly susceptible (non-immune) population (Garnett, 2005; Scherer and McLean, 2002) at the start of a new outbreak (Fine et al., 2011). The effective reproductive number is the product of basic reproductive number and the proportion susceptible in the population (Garnett, 2005; Scherer and McLean, 2002). There is a mathematical formula  $(1 - 1/R_0)$  based on the basic reproductive number to express the herd immunity threshold which is used as a target for immunization coverage (Fine et al., 2011).  $R_0$  must exceed 1 for an infection to persist (Bogaards et al., 2011; Anderson and Garnett, 2000).  $R_0$  could be different between populations (Fine et al., 2011); therefore, vaccine coverage could vary geographically (John and Samuel, 2000). Also,  $R_0$  is different for different diseases (Scherer and McLean, 2002). The magnitude of  $R_0$  influences the speed and the scale of spread of infection (Anderson and Garnett, 2000). The higher the basic reproductive number, the higher the coverage should be to achieve herd immunity (e.g. measles) (Andre et al., 2008). Herd immunity is low when the proportion of vaccinated people is under a certain threshold (Gay, 2004); as a result the transmission of infection continues in the community (Kim et al., 2011). Incidence of infection

declines if the proportion of vaccinated people is higher than the herd immunity threshold (Fine et al., 2011; Kim et al., 2011). This means that each case should generate on average less than one other case (Scherer and McLean, 2002). An infection could be eliminated if there is no sustained transmission in the population, even if the vaccine coverage is less than 100% (Andre et al., 2008; Wallinga et al., 2005). Herd immunity has been significant in the eradication of smallpox, in the reduction of pertussis, in influenza protection and the prevention of pneumococcal disease (Kim et al., 2011).

One of the consequences of increased herd immunity is the shift in the age of infection. The more immunized individuals in a cohort, the less likelihood that infection is transmitted in the population (Brisson and Edmunds, 2003). But the non-vaccinated people from that cohort accumulate in older age groups when they become fully susceptible to infection if they were exposed (Fine et al., 2011). There is evidence of cases of measles and pertussis in older age groups (Fine et al., 2011) in developing countries (Brisson and Edmunds, 2003). Infections in older age are more severe (e.g. polio, hepatitis A, mumps (Brisson and Edmunds, 2003) and rubella in the first trimester of pregnancy (Fine et al., 2011)).

The level of vaccine-induced herd immunity depends on several factors:

- type of vaccine used [live attenuated or inactivated (Kim et al., 2011)]
- force of transmission of infection in the community (John and Samuel, 2000; Garnett, 2005)
- pattern of mixing in heterogeneous population (Fine et al., 2011)
- distribution of vaccine (Fine et al., 2011)
- immunity in the population (Fine et al., 2011).

### **2.2.3.1. Pattern of mixing in heterogeneous population**

A range of factors place some people at greater risk for STIs such as cultural values (sex roles, norms for sexual behavior (Adimora and Schoenbach, 2005)), lack of information about STIs transmission, lack of adult supervision (especially of boys), the number of sexual partners (Da Ros and Schmitt Cda, 2008) and sexual mixing by ethnic origin, age and country (Adimora and Schoenbach, 2005; Testa and Coleman, 2006; Liljeros et al., 2003). Men are more often the primary source of STIs than women. Therefore, transmission rates from men to women are higher than from women to men (Low et al., 2006). Individuals with no partners or individuals in long-term monogamous relationship (Adimora and Schoenbach, 2005) (e.g. Asian men and women in California (Mocello et al., 2008)) are least likely to propagate STIs (Adimora and Schoenbach, 2005). Mixing between people occur within sexual networks which characterize structural and temporal links between individuals through sexual relationships (Low et al., 2006). A group of individuals with high-risk behavior represents a core group (Gesink et al., 2011). Mixing “like with like” could limit the spread of infection to the core group with highly sexually active individuals (Anderson and Garnett, 2000). A particular concern represents concurrent sexual partnerships defined as sexual relationships that overlap over time (Adimora and Schoenbach, 2005). This kind of network spreads the STIs more quickly than sequential partnerships (Adimora and Schoenbach, 2005). The spread and persistence of STIs could be influenced by the number of simultaneous partners and with the number of sex acts with each partner (Anderson and Garnett, 2000).

Sexual networks play a key role in the transmission and persistence of STIs in population (Adimora and Schoenbach, 2005) due to several determinants such as individual factors (e.g. uncircumcised men (Da Ros and Schmitt Cda, 2008)), demography (Low et al., 2006) (e.g. scarcity of men (Adimora and Schoenbach, 2005)),

young age, single marital status (Fenton et al., 2005)), health-seeking behavior within networks (Fenton et al., 2005), poverty (Adimora and Schoenbach, 2005) (Low et al., 2006). Spatial patterns of STIs are influenced by neighborhood-level of sociocultural factors and/or local sexual partner selection (Gesink et al., 2011). For example, black people tend to choose other black persons as sex partners (Adimora and Schoenbach, 2005). This could be the consequence of social segregation in schools (as seen in the US) which influences the social and sexual networks of adolescents (Adimora and Schoenbach, 2005). Patterns of sexual networks among black people (e.g. Black Caribbean and Black African men and women in the UK (Fenton et al., 2005)) could promote faster dissemination of STIs than in white population (Adimora and Schoenbach, 2005). This is because of early sexual debut (before the age 16 years old) (Testa and Coleman, 2006), repeated change of partners (Anderson and Garnett, 2000) and mixing between individuals with low risk of STIs and people with high risk of STIs (Turner et al., 2004).

A study on sexual health knowledge, attitudes and behaviors among black and minority ethnic youth in London revealed that Asians, especially females, aged 15-18 years old hold more conservative attitudes about sex in comparison with White adolescents. Despite this fact, a small proportion of teenage Asians (males and females) experienced sexual relationships (e.g. anal sex) (Testa and Coleman, 2006).

#### **2.2.4. Effectiveness of HPV vaccine**

Vaccination of one sex against STIs could indirectly protect the other sex (Garnett, 2005). Studies showed that vaccination should target individuals with the highest prevalence of infection (Bogaards et al., 2011). Herd effect of HPV vaccine has been estimated through modeling analyses (Brisson et al., 2011). Herd effect of HPV vaccine

has been observed in real life context in Australia where HPV vaccination programme of girls aged 12 years produced herd immunity in males (Haupt and Sings, 2011; Brisson et al., 2011; Bogaards et al., 2011). Herd effect seems to be greater for HPV types 6 and 11 in comparison with HPV types 16 and 18 (Brisson et al., 2011).

Ideally, females should be vaccinated before the onset of sexual activity, when they may be exposed to HPV for the first time (Wheeler, 2008; Cutts et al., 2007).

It has been shown that vaccine-induced immunity is stronger than the immunity acquired by natural infection (Pandhi and Sonthalia, 2011). The vaccine has been found to produce a stronger immune response in young adolescents than in women over 15 years (Keam and Harper, 2008; Joint Committee on Vaccination and Immunisation, 2008b).

Immunogenicity studies have indicated that it is safe to administer HPV vaccine at the same time with other types of vaccines (Pandhi and Sonthalia, 2011).

Bivalent and quadrivalent vaccines are safe (World Health Organization, 2009), effective (Lu et al., 2011) and cost-effective (Westra et al., 2011) for prevention of cervical cancer for females aged 9 to 26 (D'Souza and Dempsey, 2011; Chaturvedi, 2010). No vaccination trials have yet been conducted in children less than 9 years old (Saslow et al., 2007). Quadrivalent vaccine is also safe and effective for males aged 9 to 26 (D'Souza and Dempsey, 2011; Chaturvedi, 2010). The US as well as the UK do not administer routinely vaccine to males (D'Souza and Dempsey, 2011; Department of Health, 2008a) because the direct benefit to males is not certain (i.e., what proportion of penile and anal cancers might be prevented).

Both vaccines protect against persistent infections and precancerous cervical lesions produced by HPV types 16 and 18 (Lu et al., 2011). Only quadrivalent vaccine protects additionally against most genital warts in females and males and cancers of the vulva,

vagina, and anus (D'Souza and Dempsey, 2011). It is not known if bivalent vaccine protects against these other anogenital cancers as it has not been tested for this purpose in the trials (D'Souza and Dempsey, 2011). Both vaccines also offer “cross-protection” against other infections caused by HPV types 31, 33 and 45 (Pandhi and Sonthalia, 2011; Wheeler, 2011) conditional upon immunization with three doses (Wheeler, 2011).

It is thought that about 30% (Lexchin et al., 2010) of cervical cancers are not prevented by the vaccines (Department of Health, 2008b). Therefore, it is important for both vaccinated and unvaccinated women to be screened for cervical cancer (Department of Health, 2008b). The Advisory Committee on Immunization Practices (ACIP) in the US recommended that women with abnormal cervical screening test results should be vaccinated, if they meet eligibility criteria, presuming that the HPV vaccine may protect them against “high-risk” HPV types to which they have not yet been exposed (Haupt and Sings, 2011; Joint Committee on Vaccination and Immunisation, 2008b). In addition, women with a history of HPV infection in the past can be vaccinated (Haupt and Sings, 2011) if they have no DNA marker of active HPV infection at the time of vaccination (Pandhi and Sonthalia, 2011; Haupt and Sings, 2011).

HPV vaccines do not treat existing active HPV infections (Cervical Cancer Action, 2009; Chaturvedi, 2010), do not treat abnormal cytology and do not prevent other sexually transmitted infections (STIs).

### **2.2.5. Cost-effectiveness of HPV vaccination**

The cost-effectiveness of HPV vaccine is determined by the magnitude and treatment cost of the cervical cancer, vaccine effectiveness and uptake (Cutts et al., 2007).

HPV vaccination costs include the actual cost of the HPV vaccine as well as administration and invitation costs (Rozenbaum et al., 2010). The actual cost of the

HPV vaccine in Europe ranges from €97 (Dee and Howell, 2010) to €118 (de Kok et al., 2009) per dose. In the US the price of the HPV vaccine is about \$130 per dose (Graham and Mishra, 2011). A Dutch study found that the administration cost of the HPV vaccine is €7.50 and invitation cost is €6.00 (Rozenbaum et al., 2010). The Health Protection Agency (HPA) showed that the administration cost of the HPV vaccine in the UK is £3.56 (Department of Health, 2008b).

A cost-utility analysis of adding HPV vaccine to the Irish cervical screening programme concluded that the quadrivalent vaccine is more cost effective than the bivalent vaccine (Dee and Howell, 2010). In November 2011, the Department of Health decided to move to the quadrivalent vaccine in September 2012 (Salisbury, 2011).

Studies which have explored the cost-effectiveness of adding HPV vaccination to the current cervical cancer screening programme have different results. HPV vaccination was considered to be potentially cost effective in Ireland (Dee and Howell, 2010) and Slovenia (Obradovic et al., 2010), but not in the Netherlands (de Kok et al., 2009). A few studies have shown that cost-effectiveness depends on vaccine price (Westra et al., 2011) and extent of long-term protection by vaccination (de Kok et al., 2009). For example, in the UK the HPV vaccination is cost-effective if protection lasts 20 years or more (Department of Health, 2008b). Cost-effectiveness is low if both females and males are vaccinated (Haupt and Sings, 2011). A cost-effectiveness analysis in the Netherlands pointed out that HPV vaccination is highly effective in girls aged 12 years and declines in older cohorts up to the age 30 years old (Westra et al., 2011). Vaccinating girls is more cost effective than vaccinating boys (Pandhi and Sonthalia, 2011; Brisson et al., 2011). Low coverage with HPV vaccine of females (as in the US (Haupt and Sings, 2011)) increases cost-effectiveness of HPV vaccination in males (D'Souza and Dempsey, 2011).

### **2.2.6. Doses of HPV vaccine**

It is necessary to administer three doses of vaccine (Wheeler, 2011). The Centers for Disease Control and Prevention (CDC) recommends that the second dose is given one to two months after the first, and the third dose six months after the first dose (Department of Health, 2008c). People who started vaccination with one type of vaccine but cannot complete the three doses with the same vaccine, could benefit from vaccination with the other type of vaccine i.e., one dose of quadrivalent vaccine and two doses of bivalent vaccine or two doses of quadrivalent vaccine and one dose of bivalent vaccine (Department of Health, 2008c). In fact, two doses of bivalent vaccine allow for the development of a level of immunity similar to vaccination with three doses (Wheeler, 2011)

### **2.2.7. Adverse effects of HPV vaccination**

Before licensing, the safety of both vaccines was studied in clinical trials in over 25,000 people females and males for the quadrivalent vaccine (Lexchin et al., 2010) and over 30,000 females for the bivalent vaccine. Several agencies (in the US, Europe, Australia and WHO) have monitored the safety of vaccines (Cervical Cancer Action, 2009). The adverse effects of the two vaccines reported are mostly mild (Ramet et al., 2011; Haupt and Sings, 2011) (Table 1).

**Table 1.Side effects of HPV vaccines**

| Vaccine      | Common  | Rare  |
|--------------|---|---|
| quadrivalent | <ul style="list-style-type: none"> <li>• pyrexia</li> <li>• erythema, pain, swelling, bruising, pruritus at the injection site</li> </ul>   | <ul style="list-style-type: none"> <li>• respiratory, thoracic and mediastinal disorders</li> <li>• bronchospasm</li> <li>• urticaria</li> <li>• blood clots in the heart, lungs, and legs</li> </ul> |
| bivalent     | <ul style="list-style-type: none"> <li>• headache</li> <li>• nausea, vomiting, Diarrhea and abdominal pain</li> <li>• itching/pruritus, rash, urticaria</li> <li>• myalgia, arthralgia</li> <li>• pain, redness, swelling at the injection site</li> <li>• fatigue, fever (<math>\geq 38^{\circ}\text{C}</math>)</li> </ul> | <ul style="list-style-type: none"> <li>• dizziness</li> <li>• induration, local paraesthesia at the injection site</li> </ul>   |

Some categories of people are excluded by the ACIP from receiving HPV vaccines such as pregnant women (Lu et al., 2011; World Health Organization, 2009) or those who could develop a life-threatening allergic reaction to HPV vaccine (World Health Organization, 2009) .

### **2.2.8. Successful strategies to improve vaccination rates**

There are several strategies to tackle the inadequate delivery of preventive services. Some are patient-related strategies (e.g. reminder and recall systems), others focus on providers (e.g. reducing missed opportunities, provider prompts) and others use a system-wide approach (e.g.financial interventions) (Jacobson and Szilagyi, 2005). Patient-related strategies as well as those focused on providers have improved vaccination coverage in children, adolescent and adults (Jacobson and Szilagyi, 2005; Task Force on Community Preventive Services, 2000).

Patient reminder and recall systems represent successful strategies to improve vaccination uptake in all types of primary care settings (Jacobson and Szilagyi, 2005; Task Force on Community Preventive Services, 2000) in developed countries (Jacobson and Szilagyi, 2005). These systems could be delivered through telephone, letters, postcards and face to face patient care (Jacobson and Szilagyi, 2005). The choice of the system is dependent on computer systems (Cockman et al., 2011), staff, accuracy of patient telephone numbers, and patient responsiveness to each type of reminders (Jacobson and Szilagyi, 2005). The most effective systems are those sent by telephone (Jacobson and Szilagyi, 2005). Repeated reminders appear to be more successful than single reminders (Jacobson and Szilagyi, 2005). Patient reminder and recall interventions could be used alone or as part of a multicomponent intervention (Task Force on Community Preventive Services, 2000). An example of a multicomponent intervention is a home-visiting intervention which includes education, assessment of need, referral and provision of vaccination in patients' homes (Task Force on Community Preventive Services, 2000).

There is strong evidence that physician reminder systems for preventive care are effective at increasing vaccination coverage (Task Force on Community Preventive Services, 2000). These systems could be delivered in patient charts (e.g. checklists or flowcharts), by computer or by mail as single reminders or as part of a multicomponent intervention (Task Force on Community Preventive Services, 2000). Nurse standing orders have been shown to be more effective than physician reminders to improve the uptake of vaccine when it is offered in hospital (Dexter et al., 2004). Other provider-related strategies that improve immunization rates include provider assessment and feedback based on performance evaluation of providers via retrospective data on delivering one or more vaccinations (Task Force on Community Preventive Services, 2000).

The next section contains a description of the HPV vaccination programme in Europe, including the context of HPV vaccination and the method of its delivery to target populations. The literature review refers to the European context because this research is conducted in the UK. Another reason is that the HPV vaccination policy developed at European Union level has been implemented differently at country level.

## **2. 3. Description of HPV vaccination program in Europe**

Relevant research evidence is based on a literature review which, included:

- Reports of relevant organizations (i.e., WHO, CDC, DH, ONS)
- Published articles and editorials in different databases: Medline (OVID), Web of Science (former Web of Knowledge), Embase, CINAHL
- The review included studies performed in Europe between 2007 to 2012 which addressed uptake of the HPV vaccine.
- Relevant textbooks

### **2.3.1. Cervical cancer incidence and mortality rates**

Cervical cancer is the second commonest type of cancer in women aged 15-44 years in the European Union (EU) (European Centre for Disease Prevention and Control, 2008) (European Cervical Cancer Association, 2009). Across Europe there are wide health inequalities (European Cervical Cancer Association, 2009) in cervical cancer, according to an analysis by the International Agency for Research (IARC) on Cancer in 2008 (Table 2 (GLOBOCAN, 2008)).

**Table 2. Age standardized incidence and mortality rates by cervical cancer/ 100,000 population by country**

| Age standardized rates by cervical cancer | Country     | Age standardized incidence rates per 100,000 | Country     | Age standardized mortality rates per 100,000 |
|---|-------------|--|-------------|--|
| <b>Highest</b>                            | Romania     | 23.9   | Romania     | 11.8   |
|   | FYR         | 22   | FYR         | 9.9  |
|   | Macedonia   |  | Macedonia   |  |
|   | Bulgaria    | 21.9   | Serbia      | 9.2  |
|   | Lithuania   | 21   | Lithuania   | 8.3  |
|   | Serbia      | 20.9   | Latvia      | 7.3  |
|   | <b>UK</b>   | <b>7.2</b>                                   | <b>UK</b>   | <b>2</b>                                     |
| <b>Lowest</b>                             | Switzerland | 4  | Switzerland | 0.9  |
|   | Finland     | 4.5  | Finland     | 1.2  |

Cervical cancer incidence and mortality rates are higher in countries which lack (King et al., 2008) or which have ineffective screening programmes (Tota et al., 2011) (e.g. in Eastern Europe (World Health Organization, 2008)) where the introduction of vaccination is conditional upon vaccine cost. Cervical cancer rates are lower in countries with a good infrastructure, well organized screening programs (e.g. Finland, the Netherlands, the United Kingdom (European Centre for Disease Prevention and Control, 2008)) and resources to fund the vaccine (King et al., 2008; World Health Organization, 2008).

Cervical cancer age-standardised incidence rates by Strategic Health Authorities (SHA) in England showed that the rates were lower than the national average in the south and east of England but higher in the north and the Midlands. Data between 2005 and 2009 showed that five SHAs had higher rates than the national level (8.7%) including North East (11.3%), Yorkshire and The Humber (10.7%), East Midlands (10.4%), North West (9.9%) and West Midlands (9.6%). Four SHAs (London, South

East Coast, East of England and South Central) had lower rates than the national level, ranging from 6.8% to 8% (Trent Cancer Registry et al., 2012).

The introduction of the HPV vaccine has raised hopes of making an impact on cervical cancer incidence and mortality in “hard to reach groups” (e.g. women from lower socioeconomic groups and minorities) that have had low access to organized screening programme (European Centre for Disease Prevention and Control, 2008; Marlow et al., 2008; European Cervical Cancer Association, 2009).

### **2.3.2. Context of HPV vaccination**

The introduction of the HPV vaccine in Europe was the result of collaboration between scientific societies, the European Centre for Disease Prevention and Control (ECDC), insurance funds and civil societies. The EU actions in favor of vaccination were supported by the European Council, and the European Public Health Alliance as well as a group of policy makers against cervical cancer established by the European Cancer Patient’s Coalition and the European Cervical Cancer Association (Laurent-Ledru et al., 2011). In 2008 the World Health Organization (WHO) and ECDC issued strategic papers to guide the introduction of HPV vaccine (World Health Organization, 2008; Sakou et al., 2011). At the national level, introduction of HPV vaccine has been recommended by a variety of national advisory body, health councils and professionals groups (World Health Organization, 2008) and decided by boards of health and vaccination committees (King et al., 2008; Jeannot et al., 2011; Dahlstrom et al., 2010; Kumar and Whynes, 2011). The vaccine has been implemented based on evidence related to burden of disease (King et al., 2008), safety (Ramet et al., 2011), efficacy, effectiveness (anticipated impact on precancerous and cancerous lesions) and cost-effectiveness of vaccine (King et al., 2008), existence or lack of cervical cancer

screening and vaccine acceptability by adolescents and their parents as well as by health professionals (World Health Organization, 2008). Austria has been reluctant to introduce HPV vaccine in the national immunization programme on the grounds that cervical screening appears more cost-effective than vaccination (Graham and Mishra, 2011).

In each country, various patients' and women's groups have taken actions to support policy makers and to involve healthcare professionals in the implementation of vaccine as well as to inform people about and to build public trust in vaccination (Laurent-Ledru et al., 2011). Furthermore, introduction of the HPV vaccine was facilitated by a European integrated collaboration effort within European Commission DG SANCO project called VENICE<sup>3</sup> which created a web-based network for exchange of experience between European countries (EU Members and Iceland and Norway) from 2006 to 2008 (King et al., 2008). In July 2010, a survey (VENICE 2 project) on HPV vaccination status in Europe was conducted within the ECDC (Dorleans et al., 2010). All the 27 EU countries as well as Iceland and Norway participated in the study (Dorleans et al., 2010). Eighteen countries have integrated routine HPV vaccination into the national immunisation schedules (Dorleans et al., 2010). Eleven countries have not introduced HPV vaccination into the national immunisation programme due to financial constraints (Dorleans et al., 2010).

European countries have adopted vaccination policies, which vary in relation to target population, vaccine delivery strategies and health services infrastructure (King et al., 2008). Target populations have been decided according to WHO recommendations e.g., that the vaccine should be given before sexual debut (European Centre for Disease

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<sup>3</sup> Vaccine European New Integrated Collaboration Effort

Prevention and Control, 2008) and the age for starting vaccination should be in accordance with national data on sexual behavior (World Health Organization, 2008). A global perspective on sexual behavior in 59 countries worldwide indicated that most adolescents start their sexual activity around the ages 15-19 years (Ramet et al., 2011). In addition, ECDC suggested that countries should consider the acceptability of vaccine to targeted girls and their parents as well as the feasibility of delivering the vaccine in determining the age of the target population. Subsequently, two target populations were established. Most countries decided to adopt a primary target population, which includes girls at the age just before sexual debut for routine vaccination. The other target population was referred as the 'catch-up group', comprising birth cohorts who start to be vaccinated at the time of programme implementation but whose age is older than the age of girls vaccinated routinely (European Centre for Disease Prevention and Control, 2008, p. 26). Of eighteen European countries which implemented routine immunization, nine countries decided to introduce a catch-up programme (Dorleans et al., 2010).

### **2.3.3. Target populations for HPV vaccine**

The recommended age ranges for the primary target population (routine cohort) for HPV vaccination in European countries included either one age group or several birth cohorts as presented in Table 3 (Dorleans et al., 2010). France decided to offer the vaccination to girls aged 14 years, reasoning that at this age the discussion about sexually transmitted infections (STIs) and their prevention would be much easier than at younger ages (Lutringer-Magnin et al., 2011).

**Table 3. Age ranges for the primary routine vaccination strategy by country**

| <b>Age groups</b> | <b>Country*</b> |
|-------------------|-----------------|
| 11 years old      | Italy           |
| 10-12 years old   | Sweden          |
| 11-12 years old   | Slovenia        |
| 12 years old      | Denmark         |
|                   | Latvia          |
|                   | Luxemburg       |
|                   | Netherlands     |
|                   | Norway          |
|                   | Romania         |
| 11-14 years old   | Spain           |
| 12-13 years old   | UK              |
|                   | Ireland         |
| 13 years old      | Portugal        |
| 14 years old      | France          |
| 12-15 years old   | Greece          |
| 12-17 years old   | Germany         |
| 12-18 years old   | Belgium         |

\* The country has HPV vaccination in the national immunization schedule

Source: (Dorleans et al., 2010)

Nine countries initiated a catch-up immunization schedule for adolescents/ young adults aged 13 to 24 years (World Health Organization, 2008; Dorleans et al., 2010). But, age ranges for catch-up vaccination were heterogeneous as shown in Table 4 (Dorleans et al., 2010).

**Table 4. Age ranges for catch-up vaccination strategy by country**

| <b>Age groups</b> | <b>Country</b>     |
|-------------------|--------------------|
| 13-16 years old   | Netherlands        |
| 13-18 years old   | UK                 |
| 15-17 years old   | Denmark            |
| 17 years old      | Portugal           |
| 13-18 years old   | Luxemburg, Belgium |
| 12-24 years old   | Romania            |
| 14-17 years old   | Italy              |
| 24 years old      | Italy              |
| 15-23 years old   | France             |

Source: (Dorleans et al., 2010)

Routine and catch-up HPV vaccination strategies were introduced and integrated in the national immunization programme in European countries at different times as presented in Table 5 and in Figure 1 (Dorleans et al., 2010).

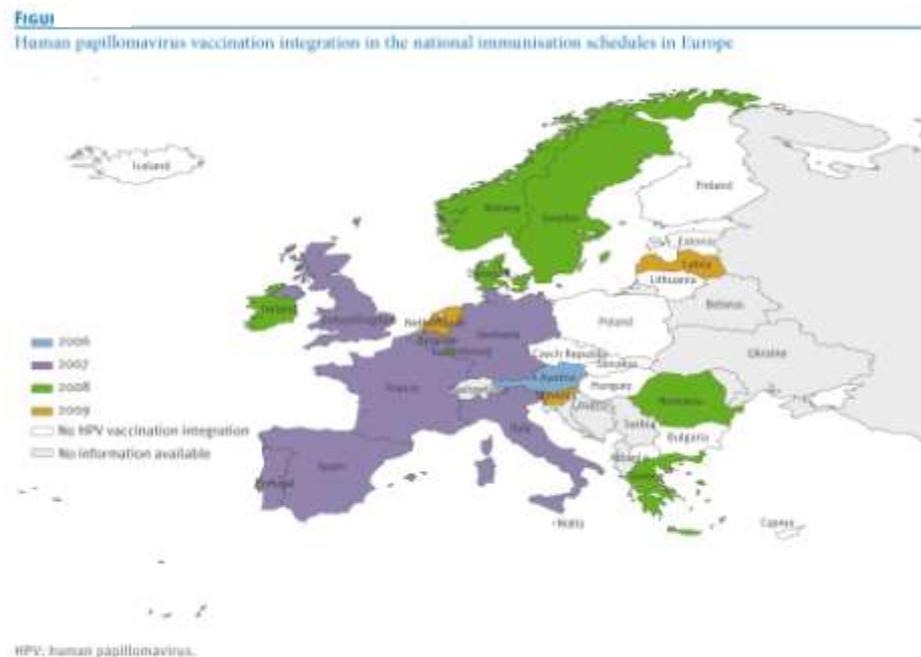
**Table 5. Start of HPV vaccination by year, by country and by cohort in Europe**

| Year                              | 2007  | 2008  | 2009   | 2010                              |
|-----------------------------------|---|---|--|-----------------------------------|
| <b>HPV vaccination by country</b> | Belgium* (Lefevere et al., 2011)                            | Belgium** (Dorleans et al., 2010)                           | Netherlands** (Rondy et al., 2010)                         | Netherlands* (Rondy et al., 2010) |
|                                   | France*, ** (Woodhall et al., 2007) (Dorleans et al., 2010) | Denmark** (Mortensen, 2010)                                 | Denmark* (Mortensen, 2010)                                 | Sweden* (Rondy et al., 2010)      |
|                                   | Germany* (Mosina et al., 2010)                              | Luxembourg*,** (Tozzi et al., 2009) (Dorleans et al., 2010) | Norway* (Mosina et al., 2010)                              | Ireland* (Dorleans et al., 2010)  |
|                                   | Italy** (Dorleans et al., 2010)                             | Italy*, ** (Tozzi et al., 2009) (Dorleans et al., 2010)     | Italy** (Dorleans et al., 2010)                            | Italy** (Dorleans et al., 2010)   |
|                                   |   | Romania* (Mosina et al., 2010)                              | Slovenia* (Dorleans et al., 2010)                          | Romania** (Dorleans et al., 2010) |
|                                   |   | Spain* (Mosina et al., 2010)                                | Portugal*,** (Mosina et al., 2010) (Dorleans et al., 2010) | Latvia* (Dorleans et al., 2010)   |
|                                   |   | Switzerland* (Mosina et al., 2010)                          |  |                                   |
|                                   |   | UK*, ** (Kumar and Whynes, 2011) (Dorleans et al., 2010)    |  |                                   |
|                                   |   | Greece* (Tozzi et al., 2009)                                |  |                                   |

\* for routine cohort, \*\* for catch up cohort, () = reference

In Italy catch-up vaccination was introduced from 2007 to 2010 depending on the region.

**Figure 1. Human papillomavirus vaccination integration in the national immunization schedules in Europe**



Source: (Dorleans et al., 2010)

### **2.3.4. HPV vaccine delivery**

Many European countries have introduced HPV vaccination into their childhood immunization programmes (Ramet et al., 2011; Forster et al., 2010). Different approaches have been chosen for implementation. Some countries decided to offer HPV vaccination in the public sector while others chose to deliver HPV vaccination in the private sector (Dorleans et al., 2010). In Italy, Spain, Switzerland and England the delivery system have followed strategies decided at local level (European Cervical Cancer Association, 2009; King et al., 2008; Kumar and Whynes, 2011). The HPV vaccine has been provided for the routine cohort through schools, health services and/or through health professionals and in public health clinics and some of the countries which adopted these strategies are shown in Table 6 (European Cervical Cancer Association, 2009; Dorleans et al., 2010). Norway and Sweden delivered HPV vaccine only in schools (Mosina et al., 2010). In Latvia, Romania, Spain, and UK, HPV

vaccinations were performed both in school and in public health clinics (Dorleans et al., 2010). The nine countries with catch-up campaigns delivered the HPV vaccine through public health infrastructures, private sector and/or schools (Dorleans et al., 2010).

**Table 6. HPV vaccine for routine cohort in public sector by country**

| <b>Public sector</b> |                                       |                              |
|----------------------|---------------------------------------|------------------------------|
| <b>Schools</b>       | <b>Health professionals' practice</b> | <b>Public health clinics</b> |
| Spain                | Italy                                 | Italy                        |
| Belgium              | Belgium                               | Spain                        |
| Sweden               | Netherlands                           | Netherlands                  |
| Ireland              | Denmark                               | Denmark                      |
| Norway               | Portugal                              | Portugal                     |
| Slovenia             | Luxembourg                            | UK                           |
| UK                   |                                       | Latvia                       |
| Latvia               |                                       | Romania                      |
| Romania              |                                       |                              |

It was assumed that adolescents could be targeted more easily in schools than in health facilities (Ramet et al., 2011) because just a few teenagers visit health providers given their “good health” (Sakou et al., 2011). Schools have been deemed a good medium for HPV vaccination because of other immunization programmes already in place and presumably because of existing education programmes about HPV vaccine (Ramet et al., 2011). In France the vaccine has been provided by general practitioners (Lutringer-Magnin et al., 2011) where it has been given on demand (European Cervical Cancer Association, 2009). In Germany, Greece, Luxembourg, and Spain, family information about HPV immunization is sent by health professionals by letter which invites families to request the vaccine for their daughters (European Cervical Cancer Association, 2009). Other countries have used combined delivery systems. For example, in Geneva between 2007 and 2009, the vaccination programme was delivered by the School Health Service, by pediatricians, gynecologists, internists and general practitioners (GP) in

private practice and by a vaccination centre in Geneva University Hospital (Jeannot et al., 2011).

Fifteen European countries have offered routine HPV vaccination free of charge to girls in different age groups. Table 7 presents some of these countries.

**Table 7. Routine HPV vaccination offered free of charge by girls' age group and by country**

| <b>Girls' age group</b> | <b>Country</b>  |
|-------------------------|---|
| girls 11/12 years old   | Sweden (Sundstrom et al., 2010)<br>Italy (World Health Organization, 2008)  |
| girls 12 - 15 years old | Belgium (World Health Organization, 2008) (Mortensen, 2010)<br>Denmark (World Health Organization, 2008) (Mortensen, 2010)  |
| girls 12 - 16 years old | Netherlands (Rondy et al., 2010)  |
| girls 12 - 17 years old | Germany (European Cervical Cancer Association, 2009) (World Health Organization, 2008)<br>Luxembourg (European Cervical Cancer Association, 2009) (World Health Organization, 2008) |
| girls 12 - 18 years old | United Kingdom (World Health Organization, 2008)  |
| girls 11 - 19 years old | Switzerland (Jeannot et al., 2011)  |
| girls 12 - 26 years old | Greece (European Cervical Cancer Association, 2009)   |

() = reference

Austria has offered routine HPV vaccination fully at the expense of the vaccinee (Dorleans et al., 2010). France has covered only 65% of the vaccine cost (King et al., 2008) and Sweden has reimbursed up to 50% of the cost for girls aged 13-17 years old (Sundstrom et al., 2010).

The next section shows uptake of the HPV vaccine across Europe based on a literature review.

### **2.3.5. Literature review about HPV vaccination uptake in Europe**

I took a systematic approach to the following literature review including a comprehensive systematic search of databases, systematic application of exclusion and inclusion criteria and systematic narrative synthesis of findings. This was not a formal systematic review because of lack of dual study inclusion/exclusion and data extraction. In addition, I did not undertake hand searching of key journals, or searches of conference proceedings or theses.

Four electronic databases were searched: Medline, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and ISI Web of Knowledge/Science. A comprehensive search strategy was developed using the following indexing terms (MeSH) to search Medline and Embase: ‘papillomavirus vaccines.mp. or exp Papillomavirus Vaccines/’, ‘human papilloma virus vaccines.mp.’, ‘human papilloma virus.mp.’, ‘hpv.mp.’, ‘exp Vaccination/ or exp Mass Vaccination/ or vaccination.mp.’, ‘exp Immunization/ or immunisation.mp. or exp Immunization Programs/’, ‘immunization.mp.’, ‘vaccin\*.mp.’, ‘great britain.mp. or exp Great Britain/’, ‘exp Europe/ or europe.mp.’, ‘uptake.mp.’. I used similar search terms in both Medline and Embase. The terms and search strategies used were adapted accordingly for the other two databases, CINAHL and Web of Knowledge/Science. The search strategy for each database is presented in Appendix 1 (including Table 1, Table 2 and Table 3). Abstracts were saved using EndNote basic X7. There were no restrictions placed on the language of publication.

The PRISMA<sup>4</sup> flow diagram in Appendix 1 depicts the flow of information through the different phases of this review. It maps out the number of records identified, included and excluded, and the reasons for exclusions. The review inclusion criteria were in

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<sup>4</sup> Preferred Reporting Items for Systematic Reviews and Meta-Analyses

relation to the populations, interventions, outcomes and types of studies. Inclusion criteria in relation to outcome and interventions were uptake of HPV vaccine (both quadrivalent and bivalent vaccine) provided in any setting (public/private healthcare sector as well as public/ private education sector) in Europe. Only studies conducted in Europe were considered for review because of several reasons. European countries introduced the HPV immunization programme almost at the same time around 2007 – 2008. The implementation of the HPV programme was supported by exchange of experience between European countries. The UK is part of Europe and it was intended to make a comparison between the HPV programme rolled out in the UK and the other European countries. Studies were eligible if HPV vaccine uptake one dose or two doses or all three doses in young women aged 9-26 years were reported. The searches were carried out between 2011 and 2012 and included literature dating from 2007 to 2012. The search was limited to 2007 because the HPV vaccination programme was firstly implemented in some European countries at that time. No restrictions were set according to study design. Both quantitative and qualitative studies were included.

The review exclusion criteria were in relation to any country which implemented the HPV vaccination programme but was not in Europe (for example, the US, Australia, Canada and the developing countries in other parts of the world).

Studies reporting attitudes/intention to receive the HPV vaccine were excluded as well as those studies related to awareness/knowledge about HPV vaccine, epidemiology of HPV infection, genital warts, cervical cancer, cervical cancer screening, only HPV vaccine, HPV vaccine and boys, cost effectiveness of HPV vaccine and modeling analyses, HPV vaccine and media, STIs, vaccination/immunization, sexual health.

Study selection was conducted in two stages: Initially, I assessed titles and abstracts of all identified studies according to the above mentioned inclusion criteria. Then, I included and I assessed twelve relevant full texts in English. The review is based on

these twelve studies of uptake of HPV vaccine in Europe. I undertook a narrative synthesis because of heterogeneity of study design, participants, and outcomes.

Some studies reported vaccination rates while others looked at the factors associated with the uptake. A summary of HPV vaccination uptake across European countries indicates that the uptake of one or more doses of HPV vaccine by routine and catch-up cohorts at local and national level varied from 4% to 81% between 2007 and 2010 (Table 8) although WHO recommended coverage of 70% of the target population (World Health Organization, 2008).

**Table 8. Uptake of HPV vaccine in European countries by dose, by age group and by year**

| Location                                       | Number of doses | Proportion of vaccinated girls/adolescent females | Age range  | Year                 |
|--|-----------------|---|--|----------------------|
| Portugal (Dorleans et al., 2010)               | Not reported    | 81%<br>56%  | 13 years old<br>17 years old                       | 2009<br>2009         |
| United Kingdom (Dorleans et al., 2010)         | Not reported    | 80%   | 12-13 years old                                    | 2009                 |
| Denmark (Dorleans et al., 2010)                | Not reported    | 32%<br>58%<br>73%                                 | 13-17 years old<br>12 years old<br>15-17 years old | 2009<br>2010<br>2010 |
| Italy (Dorleans et al., 2010)                  | Not reported    | 56%   | 11 years old                                       | 2009                 |
| Belgium - Flanders (Lefevere et al., 2011)     | 1 dose          | 53%   | 12-18 years old                                    | 2007-2009            |
| Netherlands (Rondy et al., 2010)               | 1 dose          | 49.9%   | 13-16 years old                                    | 2009                 |
| Switzerland - Geneva (Jeannot et al., 2011)    | 3 doses         | 41.6%   | 11-21 years old                                    | 2007-2009            |
| France - Paris (Rouzier and Giordanella, 2010) | 3 doses         | 43%   | 14-23 years old                                    | Not reported         |
| France (Lutringer-Magnin et al., 2011)         | Not reported    | 38%   | Not reported                                       | 2008-2010            |
| Norway (Dorleans et al., 2010)                 | Not reported    | 30%   | 12 years old                                       | 2010                 |
| Luxemburg (Dorleans et al., 2010)              | Not reported    | 17%<br>29%  | 12 years old<br>13-18 years old                    | 2009<br>2009         |
| Sweden (Dahlstrom et al., 2010)                | Not reported    | 13%   | Not reported                                       | Not reported         |
| Greece - Athens (Sakou et al., 2011)           | Not reported    | 11.9%   | 11-19 years old                                    | Not reported         |
| Austria (Schneider, 2010)                      | Not reported    | 4%  | Not reported                                       | Not reported         |

( )=reference

The review presents the results of studies which addressed common determinants of HPV vaccine uptake.

Two studies showed a significant association between age and the HPV vaccine uptake [1 dose (p-value=0.000) (Rondy et al., 2010) and 3 doses (p-value<0.001) (Rouzier and Giordanella, 2010)]. A study (Lefevere et al., 2011) reported that the hazard of HPV vaccination (1 dose) was higher for older girls (20 years old) ( $HR^5=19.39$ ; CI=17.47-21.52) than younger girls (13 years old) ( $HR^1=0.23$ ; CI=0.20-0.25). However, two studies (Fagot et al., 2011; Jeannot et al., 2011) showed lower HPV vaccine uptake (3 doses) in catch-up cohorts than in routine cohorts.

Four studies using correlation and multivariate analyses reported a significant association between ethnicity (measured by UK Census or country of birth) and low HPV vaccine uptake (1-2 doses) in routine and catch-up cohorts (Rondy et al., 2010; Roberts et al., 2011; Widgren et al., 2011; Kumar and Whynes, 2011). Two out of four studies showed imprecise effects of ethnicity because of small number of participants (Roberts et al., 2011; Widgren et al., 2011). One study out of four (population based) (Rondy et al., 2010) found a significant association of low HPV vaccine uptake (1 dose) and ethnicity (measured by country of birth). The lowest uptake was reported for girls having both parents born in a different country than the country of residence (p-value=0.000).

Four studies found a significant association between uptake of HPV vaccine and uptake of MMR (Rondy et al., 2010; Roberts et al., 2011; Widgren et al., 2011; Kumar and Whynes, 2011). Only one out of four studies (Rondy et al., 2010) adjusted for confounders and showed that the likelihood of HPV vaccine uptake was 6.26 higher for

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<sup>5</sup> HR = Hazard Ratio, Reference group: girls aged 17 years

those who have received a previous MMR<sup>6</sup> (NHS Choices, 2013a) (measles, mumps and rubella) than those who have not received it (CI=5.87-6.68; p-value=0.000).

Two studies showed a significant association between low uptake of the HPV vaccine (2 doses) and deprivation (measured by IMD) in routine (Roberts et al., 2011) and catch-up cohorts (Kumar and Whynes, 2011). Similarly, one study reported a significant association of low HPV vaccine uptake (1 dose) and socioeconomic level (based on income estimation at postcode level) (p-value=0.000) (Rondy et al., 2010). Another study found that the hazard of the HPV vaccination (1 dose) was higher for girls with a higher socioeconomic level (based on median income of the neighborhood) (HR=1.10; CI=1.07-1.12) (Lefevre et al., 2011).

Included studies were critically appraised according to Cochrane methodology to identify the strengths and the factors which may have introduced bias or limited the generalizability of the results. The strength of the studies came from the use of an HPV vaccine register (Rondy et al., 2010; Widgren et al., 2011), the measures to increase response rate (Rondy et al., 2010), the techniques to increase the validity of the findings [i.e., triangulation (Mortensen, 2010)], the adjustment for confounders (Rondy et al., 2010; Lefevre et al., 2011; Roberts et al., 2011; Widgren et al., 2011; Chadenier et al., 2011) and large sample size including eligible girls for the HPV vaccine (between 435 and 4.2 million).

Methodological problems included variation in reported HPV vaccine uptake: unknown dose (Mortensen, 2010; Sakou et al., 2011; Dorleans et al., 2010), 1 dose (Rondy et al., 2010; Lefevre et al., 2011; Widgren et al., 2011), 2 doses (Roberts et al., 2011; Kumar

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<sup>6</sup> MMR is a vaccine that protects against three infectious diseases – measles, mumps and rubella. The vaccine is given routinely to children in two doses and is administered as a single injection. The first dose is administered when babies are 12 and 13 months old and the second dose is given to pre school children aged 3- 5 years. In case of measles outbreak it is recommended that MMR vaccine should be given to babies who are over 6 months old to older children and adults.

and Whynes, 2011; Brabin et al., 2008), and 3 doses [(Rouzier and Giordanella, 2010; Fagot et al., 2011; Jeannot et al., 2011; Chadenier et al., 2011). Some studies were conducted soon after the start of the programme (Roberts et al., 2011; Brabin et al., 2008) and reported the initiation of HPV vaccination with one-two doses although WHO guidelines indicate that three doses are effective. Reporting of the HPV vaccine uptake rates varied e.g. using reimbursement data (Rouzier and Giordanella, 2010; Lefevre et al., 2011; Fagot et al., 2011), a local health authority dataset (Chadenier et al., 2011), a PCT<sup>7</sup> (Roberts et al., 2011; Kumar and Whynes, 2011; Brabin et al., 2008), or a state health office (Jeannot et al., 2011), introducing the possibility of bias. Reimbursement data might not indicate the actual uptake. The use of aggregate data (Rondy et al., 2010; Kumar and Whynes, 2011) could introduce an ecological fallacy.

There was inconsistency of classification of ethnicity across studies because of insufficient data (not recorded in health system) or different definitions across countries (Rondy et al., 2010; Roberts et al., 2011; Widgren et al., 2011). Varying measures of socioeconomic level were used based on area indicators (Rondy et al., 2010; Lefevre et al., 2011; Roberts et al., 2011; Kumar and Whynes, 2011; Brabin et al., 2008). No study measured socioeconomic level by individual income, education or occupation.

Although studies were large, some findings could not be generalized beyond the study population because of limitations of datasets [missing data, loss of follow up for 3 doses

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<sup>7</sup> Primary care trusts (PCTs) were organizational structures of NHS and were responsible for management, delivery of and access to health and social care services to people in their geographic area according to people's needs. PCTs controlled 80% of the NHS budget (NHS Choices, 2013b). It planned and purchased healthcare services for local populations (NHS England, 2014). A range of services were provided at primary care level through GPs, dentists, opticians, pharmacists, screening, mental health services, NHS walk-in centres, NHS Direct, patient transport (including accident and emergency). PCTs commissioned hospital services also.

There were 152 PCTs in England. In April 2013, they were replaced with 211 Clinical Commissioning Groups (CCG) (NHS England, 2014). and local area teams (LATs). which have taken the responsibility to commission hospital and community NHS services for the people in their area (NHS Choices, 2013b).

(Rondy et al., 2010; Fagot et al., 2011; Widgren et al., 2011)] or participants' low response rate (Roberts et al., 2011).

In summary, the quality of included studies limits the conclusions which could be drawn about the determinants of the HPV vaccine uptake and their effect size. There were inconsistent results related to the association between the HPV vaccine uptake and girls' age and ethnicity. It appeared consistently that low HPV vaccine uptake was associated with deprivation and childhood vaccination uptake respectively.

There was a gap in literature related to the influence of ethnicity on HPV vaccine uptake due to inconclusive evidence.

## **2.4. Summary**

Human papillomavirus is considered the commonest agent of STIs. It affects a high proportion (70%) of sexually active women and men during their lifetime, usually shortly after sexual debut. Almost all cervical cancer cases are linked with genital infection with HPV. Two HPV types (16 and 18) are thought to be responsible for 70% of cervical cancer cases worldwide. The period between infection with HPV and the development of cervical cancer varies from one year to one decade.

The European Medicines Agency has licensed two HPV vaccines: a quadrivalent vaccine and a bivalent vaccine which are safe, effective and cost-effective for prevention of cervical cancer for females aged 9 to 26. Only quadrivalent vaccine protects additionally against most genital warts in females and males and cancers of the vulva, vagina, and anus. Ideally, females should be vaccinated before the onset of sexual activity with three doses of vaccine. Currently it is known that the duration of vaccine-induced immunity is "at least" 5 - 6 years. Vaccinating girls is more cost effective than vaccinating boys.

In Europe, the vaccine was implemented at national level based on evidence related to burden of disease, safety, efficacy, effectiveness (anticipated impact on precancerous and cancerous lesions) and cost-effectiveness of vaccine, existence or lack of cervical cancer screening and vaccine acceptability by adolescents and their parents as well as by health professionals. European countries adopted HPV vaccination policies, which vary in relation to target population, vaccine delivery strategies and health services infrastructure. Two target populations were established for HPV vaccination, which was integrated in the national immunization programme: a routine and a catch-up group. The routine and catch-up HPV vaccination was provided in the public sector (i.e., in schools, health professionals' practices, public health clinics) and/or in the private sector, but only in some countries was it free of charge.

A literature review that addressed common determinants of the HPV vaccine uptake showed the HPV vaccine uptake a gap in relation to the influence of ethnicity and girls' age on HPV vaccine uptake due to inconclusive evidence.

In the next chapter, I discuss access to health services with emphasis on barriers faced by different ethnic groups mostly in the UK.

## **CHAPTER 3: PART 1 PRINCIPLES AND FRAMEWORK OF “RIGHT TO HEALTH”**

Chapter 3 is divided into two parts. Part one presents the conceptual framework of the “right to health” and part two presents the conceptual framework of evaluation of quality of care.

In the part one of this chapter, first I introduce the concept of right to health. Then I present and discuss the concept of access to health services. Because this concept is mostly related to the utilization of health services, I focused the discussion on barriers to access to health care faced by different ethnic groups mostly in the UK.

### **3(1). 1. Right to health**

The United Nations (UN) elaborated the General Comment No.14 - The Right to the highest attainable standard of health - in 2000 based on the Article 12 of the International Covenant on Economic, Social and Cultural Rights. The right to health requires available, accessible, acceptable and good quality health services. Available services are defined as those offered in sufficient quantity in the country (United Nations.Economic and Social Council, 2000) to meet people’s needs (Obrist et al., 2007). Accessibility was defined by WHO in terms of reaching the population with health services (Tamsma, 2009). Accessible services are characterized by the fact that everyone (without discrimination), especially the most vulnerable or marginalized sections of the population should benefit from health services in the country. Any discrimination in access to health care and underlying determinants of health “on the grounds of race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including

HIV/AIDS), sexual orientation and civil, political, social or other status” (United Nations.Economic and Social Council, 2000, p. 5) is prohibited. Accessibility includes physical accessibility so that services can be reached by all sections of the population such as ethnic minorities and indigenous populations. Accessibility also includes economic accessibility in order that everyone can afford payment (United Nations.Economic and Social Council, 2000) i.e., user’s fees and transportation cost (Gulliford et al., 2002).

In addition, accessibility includes information accessibility which refers to “the right to seek, receive and impart information and ideas concerning health issues” (United Nations.Economic and Social Council, 2000, p. 4). Access to information about medicines is a determinant of the right to health (Lemmens and Telfer, 2012). Medical information is created in a context dominated by conflicting interests between various stakeholders such as civil society groups, patient advocacy groups, researchers, government regulators and others. Transparent scientific debate and scrutiny of government regulatory decisions play an important role in promoting reliable information for the public (Lemmens and Telfer, 2012). Accurate and appropriate information about the safety and effectiveness of medical therapy must be accessible to patients and health professionals. Thus, an informed individual could make their own health and health care choices (Lemmens and Telfer, 2012).

The UN General Comment No.14 specifically addressed women, children and adolescents. Paragraph 21 states that “the realization of women’s right to health requires [among other interventions] information, including in the area of sexual and reproductive health” (United Nations.Economic and Social Council, 2000, p. 6). Paragraph 23 mentions that adolescents should benefit from a “supportive environment.., that ensures the opportunity to acquire appropriate information and to

participate in decisions affecting their health” (United Nations.Economic and Social Council, 2000, p.6).

To be acceptable, services should respect the culture of individuals and communities including minorities (United Nations.Economic and Social Council, 2000) and be adapted to meet user’s preferences (e.g. opening hours, walk-in, booking facilities (Gulliford et al., 2001)). Health services must also be scientifically and medically appropriate and of good quality (United Nations.Economic and Social Council, 2000). The assurance of good quality medicines and medical therapy necessitates government regulation (Lemmens and Telfer, 2012), “skilled medical personnel, scientific approval and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation” (United Nations.Economic and Social Council, 2000, p. 4).

Some EU member states have implemented legislation that recognizes and guarantees the right to health (Petrova and Clifford, 2009). In these countries, the right to health has been guaranteed through various mechanisms such as constitutional protections, social policy and the implementation of healthcare institutions which provide free public healthcare (e,g, the NHS in the UK) (Petrova and Clifford, 2009).

### **3(1).1.1. The National Health Service Constitution**

#### **The National Health Service**

The National Health Service (NHS) was launched in 1948. It is a publicly funded health service through taxation and is largely free at the point of delivery. It is efficient, egalitarian, based on need not the ability to pay, and comprehensive (including antenatal screening, treatments for long-term conditions, transplants, emergency treatment and end-of-life care). Although the majority of services are free, there is a patient co-payment for some prescriptions, optical and dental services.

NHS England is a commissioning organisation that has commissioned services at national level including primary care, specialised healthcare services, health services for serving personnel and families in the armed forces, health services for people who are in prison or other secure accommodation, and for victims of sexual assault (adults and children) (NHS England, 2014a).

In April 2013, the NHS in England was reformed (NHS Choices, 2013c) (NHS England, 2014a). PCTs and SHAs were abolished and from that time the new NHS has included in its structure new organizations such as clinical commissioning groups (NHS Choices, 2013c) made up of GP practices in the area which they cover. CCGs have commissioned various NHS services such as urgent and emergency care, elective hospital care, community health services, maternity and newborn, mental health and learning disabilities. CCGs manage a budget which is allocated on a 'weighted capitation' basis according to the size of the population, and adjusted for the age profile of the population; the health of the population; and the location of the population (NHS England, 2014a).

NHS services have been delivered by different providers represented by NHS foundation trusts (not directed by government) or NHS trusts (directed by government). There are several organizations monitoring these trusts and professionals. For example, Monitor is the financial regulator of foundation trusts to make sure that they provide quality care. The equivalent for the regulation of non-foundation trusts is the Trust Development Authority. The Care Quality Commission (CQC) is the independent regulator for quality in health and social care in hospitals, care homes, GP surgeries, dental practices and other healthcare services including private providers. The National Institute for Health and Care Excellence (NICE) has been responsible with the development of guidance and quality standards for social care. Public Health England (PHE) is a structure of the Department of Health that replaced the Health Protection

Agency and it has been responsible for health protection and health improvement addressing health inequalities, knowledge and information. Health and Wellbeing Boards (HWBs) are part of local government authorities (LGAs) and work in partnership with other health organizations and local government to improve the health and wellbeing of their local population. Each local authority in England has a Healthwatch organization which is responsible for patient involvement in healthcare. (NHS England, 2014a).

Each Government in the four nations of the UK has the responsibility of the NHS (NHS Choices, 2013c). There are some differences between the NHS in England and in the other countries in the way the health services are commissioned and delivered. Thus, in Northern Ireland there are separate organizations, some responsible for commissioning (Local Commissioning Groups) and others responsible for delivery of integrated health and social care (Health and Social Care Trusts). In Scotland and Wales there are boards that not only plan and commission but deliver NHS services for their area also (NHS England, 2014a).

The primary aims of the NHS Constitution is to set out rights and pledges applied to those who receive services NHS and work in NHS in England. A right is protected by law and is derived from obligations imposed on NHS healthcare providers. The pledge represents a commitment but is not obligatory and is supported by management and regulatory systems.

This is patients' right to receive NHS services free of charge in a GP's surgery, a hospital or a clinic, except some prescriptions, visits to the dentist, and when they are overseas visitors. People have the right to benefit from NHS services without discrimination on the grounds of their gender, race, religion or belief, sexual orientation,

disability (including learning disability or mental illness) or age. Since 2008, patients have had easy access to services within a maximum of 18 weeks from referral for non-urgent conditions. Since 2009, any member of the public has had access to GP services, regardless of which local GP practice that person has been registered with, from 8am to 8pm, seven days a week. People from the UK could access curative health services in other European Economic Area countries or Switzerland with NHS funding before the treatment or NHS reimbursement after the treatment.

Access to health care includes community needs assessment by the local NHS. The NHS has had to work in partnership with local authorities to provide effective, integrated and personalised services to meet the health and well-being needs of the local population. PCTs have been held responsible for involving their local populations in decisions about the local services that they commission.

### **Nationally approved programmes**

Everyone has the right to receive the vaccinations recommended by the Joint Committee on Vaccination and Immunisation (JCVI) and provided through a national immunisation programme (a new or existing one). The JCVI is an advisory body responsible for advising the Secretary of State for Health on issues regarding vaccination and immunisation. The Secretary of State has the responsibility to arrange the implementation of the national immunisation programme in England so that eligible people have access to the vaccine and receive it free of charge on the NHS. Also, the NHS has the duty to provide screening programmes as recommended by the UK National Screening Committee.

### **Quality of care**

There are pledges relating to quality of care. *High Quality Care for All* defined quality as having three dimensions: that care is safe, that it is effective, and that it provides patients with a positive experience. The NHS has had the responsibility to have arrangements in place to make continuous improvement in the quality of healthcare.

### **Respect, consent and confidentiality**

Everyone has the right to be treated with dignity and respect according to the European Convention on Human Rights. People need to be informed about the benefits and the risks of a health service before any physical examinations or treatment to be able to decide if they accept or refuse the treatment.

### **Informed choice**

Everyone has the right to make choices about NHS care. For example, everyone has the right to choose a GP practice, and to be accepted by that practice as well as to express a preference for using a particular doctor within that GP practice. A major priority for the NHS is to provide information to support people's choice. NHS Choices is a website that has been set out to provide information on services, treatments and lifestyles. It helps patients to understand what services are available and where these services can be accessed (Department of Health, 2009).

## **3(1).2. Access to health care**

Access to health care is a multi-faceted concept (Gulliford et al., 2001). Some studies on health services have used availability, affordability, accessibility, and acceptability dimensions all together to define the concept of access to health care (Obrist et al.,

2007). Maxwell considered access as one of the dimensions of quality of care (Gulliford et al., 2001).

Access to health care is a human right concept (Gulliford and Morgan, 2003) and has been defined from human rights perspective, health policy viewpoint, the organization and delivery of services standpoint (Raine et al., 2010). Access to health services presumes two steps, firstly, entering the health system and secondly, using the services (Raine et al., 2010). To have access to a service means that the service exists and that the service could be utilized if required. People could have access to services and choose not to utilize them because they do not accept them. To gain access means that the service has been utilized (Gulliford et al., 2001). Access to health care is “the actual use of ... health services and everything that facilitates or impedes the use of ... health services” (Sibley and Weiner, 2011, p. 21). The conceptual framework for this study is based on this definition.

Perhaps erroneously, access to health care is usually measured by utilization of health services as a proxy measure (Gulliford et al., 2002). Alternatively, access could be measured by indicators of service utilization (e.g. vaccination coverage) (Tamsma, 2009).

Utilization of health services reflects the perceived need for care (Norman, 2008) which is determined by severity of a condition (Sibley and Weiner, 2011; Sassi et al., 2001a). Utilization of health care results from the relation between people’s biological and psychosocial perceptions of needs and their previous experiences with health services (Gulliford et al., 2001). There are four types of need described in literature: (1) “normative need” established by a professional, (2) patients’ “felt need”, (3) patients’ “expressed need” as demand for care, and (4) “comparative need” based on a comparison of care use rates of different groups of people (Boeckxstaens et al., 2011).

### **3(1). 2. 1. Need**

Need has been defined as the capacity or ability to benefit or use a needed intervention to reduce disease or disability or to improve health. Need is different from demand or want. Need is the ability to benefit from an intervention recommended by a health professional to a person with a certain severity of a condition. If the person cannot benefit from the intervention according to professionally-defined need, then the person has an unmet need. Want is the belief held by a person that they have the capacity to benefit from an intervention. Demand represents a request for an intervention.

Utilization of health services could occur in the absence of need. When supplier induces demand, the rates of provided intervention exceed those expected, given levels of need. Supplier-induced demand could occur in the health systems with fee-for-service payments. Utilization of health services is influenced by population demography, need and supplier-induced demand, the availability and accessibility of services (Clarke et al., 2009).

### **3(1). 2. 2. Need assessment**

Need assessment is a systematic method of identifying need for health interventions and its distribution in a population. Need assessment is part of the process of planning health care, taking into consideration various aspects such as: effectiveness, affordability, allocative efficiency, equity and access. The aim of need assessment is to provide information on how “to maximize the appropriate delivery of effective health interventions and to minimize both the provision of ineffective health intervention and the existence of unmet need for health care in an evidence-based way; and to maximize equity” (Clarke et al., 2009, p.1558).

There are several models of needs assessment. An epidemiological needs assessment model of a problem (i.e., health condition) in the local population is developed

according to demographic information about the local population, welfare, public health issues, health status (i.e., incidence and prevalence of health condition and levels of severity), socioeconomic status, inequalities, demand for health care and underlying risk factors. Data about demography can be accessed easily, but information about the other enumerated aspects may be difficult to obtain. Gathering appropriate and sufficient data informs the process of identifying appropriate interventions (e.g. ranked according to evidence of effectiveness and cost-effectiveness) that will address the need in the local population. A comparative needs assessment model has the aim to identify organizational models and patterns of care for the identified need (health condition) in other areas (other systems and other populations). A corporate needs assessment model offers a clear understanding of current practice. It considers current service provision and compares it with expected service provision suggested by evidence on incidence and prevalence of the health condition in the local population. In addition, the model compares current service provision with the evidence of effectiveness of service provision. The model allows for identification of gaps in services, considering underserved groups in the local population as well as aspects of unmet needs, inequalities, equity and access to services. Gathering appropriate and sufficient data informs the process of planning a change (e.g. reorganization of services or change in patient care pathways within a service) (Clarke et al., 2009).

### **3(1). 2. 3. Utilization of health services**

The factors which could influence utilization of health services are availability, affordability, physical accessibility, and acceptability of services as well as information about health services (Gulliford et al., 2002; Gulliford et al., 2001). Travel time, costs and availability of transport could play a more important role than distance in the use of care (Gulliford et al., 2001). Access is highly dynamic (Department of Health, 2006).

The interaction of different factors such as socio-demographic (e.g. age, ethnicity, culture, religion, education) and health services related (e.g. quality, cost, location) causes variable use of health care (Say and Raine, 2007).

Most studies on access to health care have focused on the differential receipt of care or uptake of services (Szczepura, 2005). There is little evidence about the barriers to access to health care and factors influencing these (Szczepura, 2005). Disparities in access to health care for ethnic minority populations cannot be reduced to socioeconomic factors (Szczepura, 2005).

Health services research has identified several hurdles to access to health care due to financial and non-financial barriers. Some of these barriers manifest themselves at the demand side and others at the supply side (Table 9).

**Table 9. Barriers to access to health care**

| Demand side  | Supply side  |
|--|--|
| <ul style="list-style-type: none"> <li>• language (Szczepura et al., 2005; Crepaldi et al., 2009)</li> <li>• cultural preferences (Worz et al., 2006)</li> <li>• cultural differences (Crepaldi et al., 2009)</li> <li>• health beliefs (Tamsma, 2009; Say and Raine, 2007)</li> <li>• perceived quality of care (Say and Raine, 2007)</li> <li>• attitudes to health services (von Wagner et al., 2011)</li> <li>• religious practices (Say and Raine, 2007)</li> <li>• discrimination (Norman, 2008; Say and Raine, 2007)</li> <li>• income (Boeckxstaens et al., 2011)</li> <li>• socioeconomic status (Gulliford et al., 2001)</li> <li>• age (Boeckxstaens et al., 2011; Say and Raine, 2007)</li> <li>• gender (Gulliford et al., 2001)</li> <li>• health status (Boeckxstaens et al., 2011)</li> <li>• level of education (Say and Raine, 2007; Crepaldi et al., 2009)</li> <li>• information (Norman, 2008)</li> </ul> | <ul style="list-style-type: none"> <li>• providers' language (Szczepura et al., 2005)</li> <li>• providers' culture (Szczepura et al., 2005)</li> <li>• quality of health services (Say and Raine, 2007)</li> <li>• design and delivery of health care (Boeckxstaens et al., 2011)</li> <li>• geographical factors (distribution of providers) (Norman, 2008)</li> <li>• geographical factors (distance (Tamsma, 2009))</li> <li>• organizational factors (waiting lists) (Tamsma, 2009)</li> <li>• skills of the providers (Boeckxstaens et al., 2011)</li> <li>• lack of information (Tamsma, 2009)</li> </ul> |

( ) = reference

Barriers to utilization of services should be appraised considering that various groups of people have different health needs and culture (Gulliford et al., 2001). There is evidence

that vulnerable groups in the UK such as less wealthy people, BME (black and minority ethnic)<sup>8</sup> (Williams and Johnson, 2010) groups as well as elderly have faced difficulties in accessing health care (Department of Health, 2006). There are two categories of factors influencing access to health care by ethnic minority groups such as personal and organizational factors (Szczepura, 2005). Personal factors include cultural differences, language and literacy, and user ignorance (Szczepura, 2005). Examples of cultural differences include gender as an obstacle to service access for women, and family dynamics such as family support to attend or take up services (Szczepura, 2005). Linguistic competence could be an impediment in gaining information about what services are available due to poor knowledge or understanding of English (especially women and elderly from South Asian ethnic minorities) (Szczepura et al., 2005) (Department of Health, 2006). For example, the language barrier has been cited as a significant obstacle to accessing maternal and child health care, and for utilization of primary health care services among South Asians (Szczepura et al., 2005). User ignorance refers to poor access to health care for new populations as they first come into contact with different services such as antenatal care, obstetric care, and services for older people (Szczepura, 2005).

One of the organizational factors is related to staff's needs for cultural competency training (Szczepura, 2005). It seems that sometimes when linguistically appropriate services existed, they were rarely used because health professionals were not aware of patients' language proficiency in English (Szczepura et al., 2005). Health information from reliable sources may be processed differently by ethnic groups because of their beliefs and cultural practices (Szczepura et al., 2005). Access and use of services could

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<sup>8</sup> BME (black and minority ethnic) is a term used in the majority publications and government policy documents in the UK suggesting the minority status rather than the ethnicity because not all minority ethnic groups are Black.

be obstructed when care providers and people from ethnic minorities do not share the same language and culture (Szczepura et al., 2005).

The next section provides some evidence about access of minority ethnic groups to services for cancer screening and immunization.

### **3(1). 2. 4. Uptake of preventive health services in ethnic groups**

Inequalities in access to cancer screening for people from ethnic minority groups were reported in several studies conducted both in the UK and in the US (Szczepura et al., 2008). A cross-sectional analysis of colorectal cancer screening uptake in England indicated that the most ethnically diverse areas had lower uptake (38%) than other areas (52–58%) independent of socioeconomic status, age, gender and regional screening center (Department of Health, 2011; von Wagner et al., 2011). Another study conducted in England, in Coventry and Warwickshire, compared uptake patterns for breast and bowel cancer screening programmes among South Asian subgroups (Hindu – Gujarati; Other Hindu; Muslim; Sikh; other South Asian) and the majority population over a period of 15 years. The findings indicated significantly lower cancer screening uptakes for the South Asian population, which could not be attributed to socioeconomic, age and gender population differences. The major uptake differences between South Asian population and non-Asian group were related to ethnicity. Uptake rates for breast and bowel cancer screening were particularly lower for Muslim subgroup (51%-53%) between 1989 and 2004 in comparison with any other South Asian subgroup (60%-76%) in the same period. One of the barriers could be low literacy rates among Muslims and older South Asian women who could not read the written instructions to collect samples for bowel cancer screening (Szczepura et al., 2008). These findings were consistent with the results of other studies on cervical and breast cancer screening in the

UK. The main reasons for low uptake in both programmes were attributed to language barriers, a lack of knowledge about screening services (Szczepura, 2005; Thomas et al., 2005), individual's cultural values and beliefs, individual's misconceptions about perceived risk (Thomas et al., 2005), inaccurate screening registers (Szczepura, 2005), a lack of recommendations by health care professionals (Szczepura, 2005), poor attitudes of GPs (Thomas et al., 2005), and lack of local access to services (Thomas et al., 2005). Particularly, South Asian women in the UK had low uptake of breast and cervical screening (Gulliford et al., 2001). Nevertheless, a population-based cross-sectional study on uptake of cervical screening by ethnicity in Manchester indicated that uptake varied according to the relative size of the South Asian population. Thus, uptake of cervical screening was lower in areas with small South Asian populations (<5% of all women): 68.8% for South Asians versus 75.1% for other women. In areas where half or more of all women were South Asian, South Asians had higher uptake than other women (70.1% versus 51.6%). The same study showed also large variation in uptake ('screened in the last 5 years') by place-of-birth (Webb et al., 2004). Uptake for those born overseas was 57.4% compared to 75.6% for those born in Great Britain. Those born overseas who had uptake below 50% were from Greece/Turkey/Cyprus (47.3%), South East Asia (45%), and North Africa (43.8%) (Webb et al., 2004). A qualitative study of barriers to uptake of breast and cervical screening conducted among African Caribbean, African, Gujarati, Pakistani, Greek and Arabic groups in Brent and Harrow in the UK revealed various cultural attitudes to screening. For example, some cancers seemed to be taboo or important to be screened only for younger women (i.e., cervical cancer). If young women were Muslim or Greek orthodox, they tended to avoid cervical screening before marriage. Other women (i.e., African and Caribbean) turned to traditional medicines if they lacked confidence in screening and its outcome. Fear of

their own susceptibility to cancer was the greatest barrier to take up of screening (Thomas et al., 2005).

There is also evidence about inequalities in access to screening and immunization in the US. A National Health Interview Survey conducted by the CDC compared racial/ethnic disparities in adult cancer screening and immunization. The results indicated significantly lower colorectal and breast cancer screening rates for blacks and Hispanics (English- and Spanish-speaking) than for whites due to differences in personal and health characteristics as well as socioeconomic status (i.e., education and poverty). In contrast with disparities seen in cancer screening, the racial/ethnic (blacks and Hispanics versus whites) inequalities in influenza and pneumococcal vaccination uptake appeared to be independent of personal and health characteristics, socioeconomic factors, and measures of access to and utilization of care (i.e., number of visits to doctor and insurance status) (Lees et al., 2005).

### **3(1). 3. Summary**

The right to health requires available, accessible, acceptable and good quality health services. The right to access safe and effective health services and nationally approved programmes as well as to make informed choices about one's own health care has been recognized and guaranteed through legislation in addition to implementation of healthcare institutions in some EU member states. Access to health care, often measured by utilization of health services, reflects the need for care and is determined by the interaction of different factors such as socio-demographic (e.g. age, ethnicity, culture, religion, education) and health services related (e.g. supplier-induced demand, availability and accessibility). There is little evidence about the barriers to access to health care and factors influencing these. Health services research has identified several

hurdles to access to health care due to financial and non-financial barriers. There is evidence that vulnerable groups in the UK such as less wealthy people, black and ethnic minorities as well as elderly have faced difficulties in accessing health care due to personal (e.g. cultural differences, language and literacy, and user ignorance) and organizational (e.g. health professionals' cultural competency) factors.

In the next chapter, I discuss equity, health inequality, equity in health service delivery and equity in access to health care.

# **CHAPTER 3 PART 2: CONCEPTUAL FRAMEWORK OF EVALUATION OF QUALITY OF CARE**

Part two of this chapter presents a conceptual framework of evaluation of quality care. Firstly, I discuss the equity concept and then I provide full details about the relationship between equity and access. Secondly, I introduce the concept of health inequality and then I focus the discussion on the explanations of health inequalities and ethnic inequalities in health. In the next two sections, I present equity in health service delivery and equity in access to health care with a particular example of equity in access to vaccination.

## **3(2). 1. Approach to evaluation - quality of care**

Generally, evaluation is a way to judge the importance of something (e.g. a health intervention) (Ovretveit, 1998; Milstein et al., 1999). Ovretveit defines evaluation as “a comparative assessment of the value of the intervention, using systematically collected and analyzed data, in order to decide how to act” (Ovretveit, 1998, p. 274).

Quality was defined by Ovretveit as “meeting the health needs of those most in need at the lowest cost, and within regulations” (Ovretveit, 1998, p. 275). The concept of quality is multidimensional. There are different viewpoints from which frameworks for assessment of quality were constructed such as the population perspective, the external auditor or evaluator’s perspective, the practitioner’s perspective, and the payer’s perspective (Clarke and Rao, 2004). The assessment of quality is not only technical, but it includes the consumer’s opinion also (Maxwell, 1984). The views of patients have been that issues related to humanity, acceptability, equity and the holistic nature of

health care should be included in the quality assessment. It has been suggested that more consideration should be given to effectiveness of care rather than to these issues because it does not bring any benefit to offer ineffective care more equitably or more humanly (Clarke and Rao, 2004).

A comprehensive definition of service quality was developed by Maxwell on the basis of six dimensions (Maxwell, 1992; Ovretveit, 1998) which need to be distinguished (Maxwell, 1984) because each one provides a partial picture of quality (Campbell et al., 2000). Maxwell’s definition of each dimension (Maxwell, 1992) is presented in Table 10.

**Table 10. Dimensional definition of quality of care**

| <b>Dimension</b>     | <b>Definition</b>  |
|----------------------|--|
| <b>Access</b>        | “Can people get this treatment/service when they need it? Are there any identifiable barriers to service – for example, distance, inability to pay, waiting list and waiting times – or straightforward breakdowns in supply?”   |
| <b>Acceptability</b> | “How humanely and considerately is this treatment/service delivered? What does the patient think of it? What would an observant third party think of it? What is the setting like? Are privacy and confidentiality safeguarded?” |
| <b>Effectiveness</b> | “Is the treatment given the best available in a technical sense, according to those best equipped to judge? What is their evidence? What is the overall result of the treatment?”  |
| <b>Efficiency</b>    | “Is the output maximised for a given input or (conversely) is the input minimised for a given level of output? How does the unit cost compare with the unit cost elsewhere for the same treatment/service?”                      |
| <b>Equity</b>        | “Is this group of patients fairly treated relative to others? Are some people dealt with less favorably or less appropriately in their own eyes than others?”  |
| <b>Relevance</b>     | “Is the overall pattern and balance of services the best that could be achieved, taking account of the needs and wants of the population as a whole?”  |

Source : Maxwell, 1992, p. 171

Maxwell’s framework does not include key aspects of health care described by Donabedian (i.e., structure, process, outcome). Also, it omits the aspect of anticipatory

health care which relates to supply of care for expressed demand and unmet needs (Clarke and Rao, 2004).

Some of Maxwell’s dimensions and other components have been used by other researchers to develop frameworks for quality of care (Campbell et al., 2000). These frameworks do not overlap entirely as shown in Table 11.

**Table 11. Dimensions of quality of care**

| Maxwell 1992  | HSRG 1992           | Donabedian 1990 | O’Leary&O’Leary 1992 | JCAHO           |
|---------------|---------------------|-----------------|----------------------|-----------------|
| Access        | Access              |                 | Access               | Access          |
| Acceptability |                     | Acceptability   |                      |                 |
| Effectiveness | Effectiveness       | Effectiveness   | Effectiveness        | Effectiveness   |
| Efficiency    | Efficiency          | Efficiency      | Efficiency           | Efficiency      |
| Equity        |                     | Equity          |                      |                 |
| Relevance     | Continuity          |                 | Continuity           | Continuity      |
|               | Comprehensiveness   | Efficacy        | Efficacy             | Efficacy        |
|               | Patient-centredness | Legitimacy      | Patient perspective  | Appropriateness |

Source: (Ovretveit, 1998); (Campbell et al., 2000)

HSRG = Health Services Research Group; JCAHO = Joint Commission for Accreditation of Healthcare Organizations<sup>9</sup> (The Joint Commission, 2014)

Campbell et. al defined the concept of quality of care through two dimensions: access and effectiveness (Campbell et al., 2000). They suggested that these aspects are very important for provision of health care to individual patients. The patients want to access effective health care, according to their need (Campbell et al., 2000). The effectiveness includes the effectiveness of clinical care and the effectiveness of inter-personal care (Campbell et al., 2000). The effectiveness of clinical care depends on evidence-based medicine and professional standards of care (Campbell et al., 2000). Campbell et. al used other two dimensions to define the concept of quality of care: equity and efficiency (Campbell et al., 2000). They suggested that these aspects are very important for provision of health care to populations (Campbell et al., 2000). Quality of care for

<sup>9</sup> Joint Commission for Accreditation of Healthcare Services is an independent, not-for-profit organization in the US, which evaluates and certifies more than 20,500 health care organizations and programs in the US based on measurement of certain performance standards and quality of health care.

populations represents “the ability to access effective care on an efficient and equitable basis for the optimization of health benefit for the whole population” (Campbell et al., 2000, p. 1622). In the framework developed by Campbell et. al, equity is viewed as a sub-component of access (Campbell et al., 2000) and thus access to health care could be evaluated through equity (Sibley and Weiner, 2011).

### **3(2). 2. Equity – definition**

There is no standard definition for equity (Tamsma, 2009; McIntyre and Mooney, 2007). Equity is an ethical concept related to the principles of human right and distributive justice (Braveman and Gruskin, 2003). Equity is defined as a fair distribution of good things within a society (Mulholland et al., 2008). A few theoretical definitions were used for equity. Thus, the utilitarian theory promoted the idea that greatest good to be offered to the greatest number of people. Egalitarianism put emphasis on equal health for everybody, which could be attained through improvement of the access to health care for those who are ill. According to the theory of social justice the poorest people’s health should be improved through action on the determinants of health such as their income and wealth (Sassi et al., 2001a).

The equity concept has been used in literature in various forms related to equity in health, equity in health service delivery and equity in access to health care.

### **3(2). 3. Health equity**

Health equity is defined as “the absence of systematic differences in health and its determinants, between and within countries that are avoidable by reasonable action” (Ostlin et al., 2011, p. 1; Zere et al., 2007, p. 80). Thus, eliminating health disparities

between groups associated with “socially unfair and unjust factors” (e.g. poverty, ethnicity, religion, education, occupation, gender, deprived and rural neighborhoods, age, disability) result in equity in health (Braveman and Gruskin, 2003, p. 254; Zere et al., 2007, p. 80).

People could choose not to use a health service because of their religious belief or for ethical reasons. Under this circumstance excess in disease which might happen in that group is not considered unfair (Whitehead, 1992). From a human rights perspective, equity in health should be created giving all people without discrimination equal opportunities to be healthy (Whitehead, 1992; Braveman and Gruskin, 2003). Evaluation of health equity presumes comparative judgment of health status and its determinants between groups placed at different levels in the socioeconomic hierarchy (Braveman and Gruskin, 2003) as well as quantification of the degree of health inequality (Zere et al., 2007).

### **3(2). 4. Health inequity versus health inequality**

The distinction between inequity and inequality has been very much debated (Kawachi et al., 2002). Health inequity refers to those inequalities in health that are considered to be unfair or stemming from some form of injustice (Kawachi et al., 2002). Thus, identifying health inequities involves normative judgment based on theories of justice, theories of society or reasoning underlying the origins of health inequalities (Kawachi et al., 2002). This makes the distinction between equity and equality (Kawachi et al., 2002).

Health inequalities refer to differences, variations, and disparities in the health achievements of individuals and groups (Kawachi et al., 2002). It does not imply moral judgment (Kawachi et al., 2002). The reason is that some health inequalities are attributable to free choice (i.e., voluntarily assumed risk) while others to biological

variations (e.g. a random genetic mutation) (World Health Organization, 2012a; Kawachi et al., 2002). Health inequalities due to unavoidable factors (e.g. biologic or genetic) do not result in inequities in health (Zere et al., 2007). Other health inequalities are attributable to the external environment (e.g. political, cultural, institutional) and conditions over which individuals have less control (World Health Organization, 2012a) (e.g. less healthy lifestyle, unsafe and overcrowded housing, dangerous and dirty work, unemployment) (Whitehead, 1992).

### **3(2). 5. Explanations of health inequality**

Marmot claimed that socioeconomic inequalities are influenced by the interaction of the determinants of health such as material circumstances, the social environment, psychosocial factors, behaviors and biological factors (Marmot, 2010). The socioeconomic circumstances of persons (e.g. ethnicity, national identity, religious affiliation, shared history, kinship system, etc.) and the places where they live and work (e.g. social cohesion, social capital) influence their health (Macintyre et al., 2002; Centers for Disease Control and Prevention, 2011) and their healthy choices (Macintyre et al., 2002). The socioeconomic gradient in health refers to the worse health of those who are at a lower level of socioeconomic position measured by income, occupation, or education (Kawachi et al., 2002; Marmot, 2010; Cooper, 2002).

#### **3(2). 5. 1. Area socioeconomic status**

Area-based socioeconomic measures could be applied equally to all persons, regardless of age, gender, and employment status (Krieger et al., 2003). These measures are not affected by problems associated with occupation-based measures (e.g. people not employed) and education-based measures (i.e., those who have not completed their

education) (Krieger et al., 2003). Geographical variations in health have been explained considering compositional, and contextual factors. Compositional factors relate to the characteristics of individuals living in particular places. Contextual factors relate to features of the local physical environment (material infrastructure) and to socio-cultural features of communities (shared norms, traditions, values, and interests). Macintyre et al. pointed out that socio-cultural characteristics mostly used to explain the area differences in health comprised psychosocial constructs (i.e., social cohesion, social capital). They stressed that other features of non-material culture should be considered to reveal the area differences in health (e.g. ethnicity, national identity, religious affiliation, shared history, kinship system, etc.). The socio-cultural characteristics of a community should not be restricted to residential neighborhoods. For example, “the norms, values and shared economic interests of the descendents of immigrants might be more similar to those of current residents in the area of origin than to those of their neighbors in the current area of residence” (Macintyre et al., 2002, p. 131). Context might influence health, health-related behaviors or health risks, controlling for the characteristics of individuals (e.g. age, education, ethnicity, social class) or area (i.e., geographical classification) (Macintyre et al., 2002).

Individual and area deprivation are independently associated with poor health. It has been claimed that area characteristics (i.e., neighbourhood socioeconomic status) have relatively small effects on health and individual socioeconomic position have larger effects on health (Stafford and Marmot, 2003). A multilevel analysis of health differences between areas within Amsterdam in the Netherlands reported that the impact of area deprivation on the size of the differences in health does not depend on the geographical classification (area size). But, the geographical classification affects the degree of clustering of poor health by area. Thus, the independent area effect on the clustering of poor health is the largest in very small areas and smallest in bigger areas

(postcode sectors and boroughs). These area effects could be explained by individual health differences that are associated with individual socioeconomic status (Reijneveld et al., 2000). Small areas are relatively homogeneous with respect to population characteristics, economic status, and living conditions (Krieger et al., 2003). In such homogeneous areas the contextual factors have a greater impact on health (Reijneveld et al., 2000).

People in a higher employment grade are more likely to live in less-deprived areas. Having better health in non-deprived areas could be the effect of the availability of collective resources (e.g. services, job opportunities, and social supports) in these areas in comparison with deprived areas. Also, health could be affected by the local social inequality due to the discrepancy between individual and neighborhood socioeconomic position (Stafford and Marmot, 2003).

Some studies using multilevel models have considered the interaction between individual (e.g. gender, race, social class) and neighborhood deprivation to show how this interaction could influence health (e.g. morbidity, body mass index, serum cholesterol) and health-related behavior (Stafford and Marmot, 2003; Macintyre et al., 2002). It has been argued that health differences between individuals with higher and lower socioeconomic position are larger in more affluent areas. In contrast, other findings suggested that such disparities are larger in more deprived areas (Stafford and Marmot, 2003). Conflicting evidence about the extent and magnitude of area effects on health may be due to numerous factors. Different conceptualizations and operationalisations of area effects were used (Macintyre et al., 2002). Some features of individuals (e.g. health related behaviors, physical and mental functioning) were used in multivariate analyses either as intervening variables or as confounders to explain the

relationship between place and health (Macintyre et al., 2002). This might have been the consequence of a lack of a theoretical framework for the influence of area of residence on health and health behaviors (Macintyre et al., 2002). The contradictory findings may also be the result of the different geographical coverage as well as the different size of areas analyzed (i.e., small areas such as enumeration district in the UK, census tract in the US or large areas such as electoral wards in the UK, zip codes in the US and Australia) (Stafford and Marmot, 2003; Reijneveld et al., 2000). Administrative and postal delivery areas may not be appropriate scales to use in studies related to different types of human needs and activities (e.g. the provision of grocery stores) (Macintyre et al., 2002). Various studies, which investigated different health outcomes (i.e., mortality, cancer incidence, low birth weight, self-rated health, mental and physical symptoms, long term functional limitations, non-fatal weapons-related injuries) (Krieger et al., 2003; Reijneveld et al., 2000), used different measures of both individual and area deprivation (i.e., Townsend and Carstairs deprivation indices, income taxation data) (Stafford and Marmot, 2003; Reijneveld et al., 2000). Most studies of area effects on health had a cross-sectional design. The drawback of using this study design is that it does not consider the appropriate time interval between environmental exposures (e.g. food, tobacco, air pollution) and the effects on health, and results in an ecological fallacy, inferring individual level relationships from relationships observed at aggregate level (Macintyre et al., 2002).

There are four main types of explanations of the pathways and mechanisms underlying the social gradient: behavioral/cultural, material, psychosocial and life course.

### **3(2). 5. 2. Individual socioeconomic position**

Educational attainment and household income are two indicators used commonly to assess the influence of individual socioeconomic circumstances on health (Centers for Disease Control and Prevention, 2011). Poverty, wealth and crowding have also been used to define individual socioeconomic position (Krieger et al., 2003). Educational level is based on the highest educational qualification (Cooper, 2002; Reijneveld et al., 2000). Education is a strong determinant of future employment and income (Centers for Disease Control and Prevention, 2011). It forms the cognitive skills that are important for maintaining good health (Cooper, 2002). It reflects both the long-term influence of early life circumstances and the influence of adult circumstances on adult health (Centers for Disease Control and Prevention, 2011). Education has been considered a more inclusive measure of socioeconomic circumstances than occupation because education can represent adults who have never had a paid job. On this ground education has been considered more appropriate to investigate the ethnic inequality in health (Cooper, 2002). Occupational social class is based on the present occupation of people (Reijneveld et al., 2000). This measure was the commonest used in the UK health research to assess the extent and magnitude of socioeconomic inequality in health. Occupational social class is not inclusive of those who have never had a job. Employment (full-time and part-time) is another variable suggested for analyses of health given the variation in employment status between gender and ethnic groups (Cooper, 2002). Income is the indicator that most directly measures material resources (Centers for Disease Control and Prevention, 2011). Income is associated with personal (e.g. car access) and household circumstances (i.e., housing tenure). These two aspects were used in the UK census 2001 to measure individual deprivation. Given that individual deprivation is related to income, it was argued in the literature that area-based measures of deprivation could not be proxies of individual deprivation (Macintyre et al.,

2002). Income can influence health by its direct effect on living standards (e.g., access to better quality food and housing, leisure-time activities and health-care services) (Centers for Disease Control and Prevention, 2011)

### **3(2). 5. 3. Behavioral/cultural explanation**

The behavioral/cultural explanation refers to health inequalities which are the result of social variations in health-related behaviors, such as smoking, diet and lack of exercise (Bartley, 2004; Bradby, 2008). Health inequalities are assumed to be the result of individual choice. Explanations of health inequalities in terms of individual behaviors have been criticized for ignoring the context (Bradby, 2008). Most environmental exposures (e.g. targeting of tobacco advertising to low income children (Kawachi et al., 2002), lack of parks and sport centers in deprived areas (Bradby, 2008)) or the cultural background (e.g. ethnic, religious, linguistic) could influence how people make choices (e.g. the decision to start smoking or take exercise). Culture defined by education plays a role in social differences in risky behavior (Bartley, 2004). Any relationship between a damaging behavior (e.g. smoking) and social position does not depend only on attitudes but on habits developed over time (Bartley, 2004).

### **3(2). 5. 4. Health-related behaviors**

Health-related behaviors cannot account for all the current patterns of health inequalities (Bartley, 2004). The materialist explanation refers to health inequalities which are the result of social differences in material circumstances related to income, such as poorer housing, nutrition, and working environments (Bartley, 2004). Blane et al. defined materialist explanations as those which refer to experiences arising as a consequence of social structure and organization, over which the individual has no

control (Bartley, 2004). This could occur because psychological and social survival compete with biological needs (Bartley, 2004).

### **3(2). 5. 5. Psychosocial explanations**

Psychosocial explanations focus on the psychological effects of stressful conditions at work/home (Bartley, 2004) and the damaging effects of perceiving oneself to be poorer in an affluent society, which in turn harms health via the mechanism of stress hormones. A criticism of this explanation was that the problem lies in people's attitudes to their situation (Bradby, 2008).

### **3(2). 5. 6. Life course events**

Life course events such as the intensity and duration of exposure to unfavorable environments (stressful (Bradby, 2008)) as well as the exposure to different childhood conditions could result in health inequalities (Kawachi et al., 2002). The patterns of social, psychological and biological advantages and disadvantages combine over the life course and influence an individual's health (Bartley, 2004).

Before I discuss ethnic inequalities in health, I define two concepts, ethnicity and religion, in the next two sections.

### **3(2). 6. Ethnicity**

Ethnicity is a socially constructed concept (Ford and Harawa, 2010). Ethnic identity is subjective (Forsyth and Gardener, 2006). A person could self-identify (Bhopal, 2004) and self-report (Department of Health, 2011) belonging to a social group considering language, lifestyle, religion, food and origins (Szczepura et al., 2005). Also, others

could identify a person as belonging to a social group (Bhopal, 2004). However, the individual's view of his/her own identity is more important than other people's opinions (Department of Health, 2011; Agyemang et al., 2005). Ethnicity is a multidimensional (Agyemang et al., 2005) concept related to a social group (Bhopal, 2004) with "shared geographical and ancestral origins (Bhopal, 2004, p. 441) or social background;" and/or "a common language or religious traditions;" and/or "shared culture and traditions that are distinctive, maintained between generations and lead to a sense of identity and group" (Woolf et al., 2011, p. 2) within a larger community (Department of Health, 2011). Culture is made up of the beliefs, values and attitudes that underlie the behavior in a group of people (Szczepura et al., 2005). "Ethnicity differs from race, nationality, religion and migrant status..., but may include facets of these other concepts" (Bhopal, 2004, p. 442). Although race and ethnicity were used as synonyms, they are two distinct concepts (Agyemang et al., 2005). It has been agreed that race has social origins rather than genetic ones. This is because genetic studies showed that all humans have common genetic characteristics (Szczepura et al., 2005). Thus, the concept of race was used to indicate the differences between people based on their physical characteristics (e.g. facial features, hair, skin color (Szczepura et al., 2005)) and ancestral roots (Bhopal, 2004). There are four human races defined in anthropology as "Caucasian" ("white" or European), "Negroid" (Black or African), "Mongoloid" (Asian, Chinese, Indic), and "Australoid" ("Aboriginal" to Australia) (Szczepura et al., 2005).

It was difficult to use and to measure the concept of ethnicity in research because its dimensions could change over time (Agyemang et al., 2005). It is helpful to use precise and descriptive terms to address an ethnic group such as first, second or third generation as well as the country of birth (Agyemang et al., 2005). However, information based on country of birth could identify less than the real proportion of black and minority ethnic

(BME) people (Szczepura et al., 2005). For example, the 2001 Census showed that 79% of the Mixed group in Great Britain were born in the UK (Bradford, 2006).

In this research, ethnicity is used because it is a broader concept than race and it includes aspects of race (Szczepura et al., 2005; Department of Health, 2011) (Table 12). The terminology of ethnic group populations reflects the politics of the state (Aspinall, 2002). The chosen ethnic categories and definitions (Table 13) which are the most appropriate for the purpose and the context of this study are those for which there is a consensus in the UK (Bhopal, 2004; Agyemang et al., 2005). It is important to use precise ethnic categorization for culturally appropriate delivery of health care (Bhopal, 2004). There is a mix of ethnic and racial terms in the overarching terminology used in Britain which is different from that in the US and Canada (Aspinall, 2002).

**Table 12. Aspects that define ethnicity**

| <b>Epidemiology and public health literature</b> | <b>ONS* guidance on national standards</b> |
|--|--|
| Ancestral origin                                 | Descent from common ancestors              |
| Culture  | Common geographical origin                 |
| Language   | Shared history                             |
| Religion   | Common cultural tradition                  |
|  | Language                                   |
|  | Religion                                   |

\*ONS = Office for National Statistics

Ethnic groups cover people from all communities. According to the proportion of people in an ethnic group in relation to the population at national level, the group is called majority ethnic group (i.e., “White British” in England) or minority ethnic group. For example, “White Irish” people represent 1.3% of the population, so that they are a minority ethnic group at the national level (Department of Health, 2011).

**Table 13. Ethnic categories and definitions**

| <b>Ethnic group</b>                      | <b>Definition</b>  |
|--|--|
| <b>White-European</b>                    | Person with ancestral origins in Europe (Agyemang et al., 2005), who self-identifies, or is identified, as White (Bhopal, 2004). In the UK, it refers to “White British”, “White Irish”, and “Any other White background” (Department of Health, 2011).  |
| <b>Ethnic minority group</b>             | Minority populations of non-European origin (Bhopal, 2004) and characterized by their non-White status (Agyemang et al., 2005). In Britain, non-White is a collective descriptor for the minority ethnic group population that is not white (Aspinall, 2002)   |
| <b>Black</b>                             | Person with ancestral origins in Africa, who self-identifies, or is identified, as Black, African or Afro-Caribbean (Bhopal, 2004).  |
| <b>Black and minority ethnic</b>         | Collective term used in the UK for non-White (Aspinall, 2002)  |
| <b>African</b>                           | Person with ancestral origins who self-identifies, or is identified, as African, and excludes other ancestral origins (Europeans, South Asians, North Africans) (Agyemang et al., 2005; Bhopal, 2004).   |
| <b>African American</b>                  | Person with ancestral origins who self-identifies, or is identified, as African American. The term most applies to those with origins in sub-Saharan Africa. Most African Americans are descendants of slavery (Agyemang et al., 2005).  |
| <b>African Caribbean/ Afro-Caribbean</b> | Person with ancestral origins in Africa, with history of familial settlement in the Caribbean prior to emigrating who self-identifies, or is identified as Afro-Caribbean (Bhopal, 2004). Culture is different from other African populations in terms of language, diet, customs, beliefs, and migration history (Agyemang et al., 2005). |
| <b>Asian</b>                             | Person with ancestral origins in the Asian continent. In the UK, it usually refers to persons with ancestral origins in the Indian subcontinent (Bhopal, 2004).  |
| <b>South Asian</b>                       | Person with ancestry in countries of the Indian subcontinent, including India, Pakistani, Bangladesh, and Sri Lanka (Agyemang et al., 2005).   |
| <b>Bangladeshi</b>                       | Person with ancestral origins in the Indian subcontinent who self-identifies, or is identified, as Bangladeshi (Bhopal, 2004).   |
| <b>Indian</b>                            | Person with ancestral origins in the Indian subcontinent who self-identifies, or is identified, as Indian (Bhopal, 2004).  |
| <b>Pakistani</b>                         | Person with ancestral origins in the Indian subcontinent who self-identifies, or is identified, as Pakistani (Bhopal, 2004).   |
| <b>Chinese</b>                           | Person with ancestral origins in China, who self-identifies, or is identified, as Chinese (Bhopal, 2004).  |
| <b>Mixed ethnicity</b>                   | People whose ancestors are not of a single ethnicity (Agyemang et al., 2005). The groups are not well defined (Bradford, 2006). In the UK, mixed ethnicity refers to “White and Black Caribbean”, “White and Black African”, “White and Asian”, “Any other mixed background” (Department of Health, 2011).                                 |

One of the limitations of the Census is that it distinguishes people with Asian origins (Indian, Pakistani, Bangladeshi cultural background), but it cannot make a distinction between people speaking different languages within a specific ethnic group (e.g. Punjabi, Saraiki, Sindhi, Pashto, Urdu, Kashmiri, etc.) (Woolf et al., 2011). Black Africans encounter similar problems because they have origins in different countries in Africa and speak a variety of languages (Bradford, 2006).

## **3(2). 7. Religion**

### **3(2). 7. 1. Definition**

Religion, spirituality and religiousness are often used interchangeably in literature although they do not overlap entirely (Thoresen and Harris, 2002; Hill et al., 2000). Both religion and spirituality are multidimensional concepts and complex phenomena (Thoresen and Harris, 2002; Hill et al., 2000). There has been inconsistency among the various definitions for religion and spirituality in psychological and sociological research (Hill et al., 2000). Religion is considered a social phenomenon which involves social institutions attended by members who adhere to formal rules (e.g. church membership, church attendance), rituals (e.g. prayer), and covenants (e.g. commitment to belief system of a church or organized religion) (Thoresen and Harris, 2002; Hill et al., 2000). Religiousness refers to individual's personal experience as part of an organized religion (Thoresen and Harris, 2002). Thus, it includes both personal and institutional beliefs and practices (Hill et al., 2000). But religiousness is distinct from spirituality (Hill et al., 2000). Spirituality refers to individual's personal belief and experience (e.g. looking for meaning and purpose in life, peace, hopefulness, compassion) and is independent of any traditional organized religion (Thoresen and Harris, 2002; Hill et al., 2000).

Religion is difficult to measure because it includes different aspects such as religious background, belief and practice. It could vary from one religion to another and from one person to another. In 2001, ONS measured religion by religious identity rather than practice and produced eight categories of religious groups. Religion data from the Northern Ireland could not be combined with data from the other countries in the UK because of different questions and answer categories. ONS produced religion statistics for Great Britain, combining data for England, Wales and Scotland. In England and Wales, 83.1% of people self-identified as having a religion and 16.1% of people self-identified as having no religion. Among those who self-identified as having a religion, the majority were Christians (77.7%), Muslims (3.2%), and Hindus (1.2%). Others were Sikh (0.7%), Jewish (0.5%), Buddhist (0.3%) or had any other religion (0.3%). In Scotland 68.9% were Christian and 29.1% had no religion. Religious identity was subjective. It was stronger among people from non-Christian groups such as Muslims, Hindus and Sikhs.

An ethnic group in Great Britain includes people of different religions. For example, an Indian population included Hindus (45%), Sikhs (29%), Muslims (13%) and Christians (5%). Similarly, a religion in Great Britain included people from different ethnic groups. For instance, the majority of White British, Black Caribbean and Black African people were Christian and the majority of Pakistani and Bangladeshi were Muslim. The distribution of religious groups in Great Britain by country indicated that all religious groups other than Christian were more concentrated in England than in Scotland and Wales. The most numerous among these groups in England were Hindus (98%), Sikhs (97.4%) and Muslims (96%). Distribution of religious groups in England by the Government Office Region (GOR)<sup>10</sup> (Office for National Statistics, [2014]) indicated

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<sup>10</sup> Until April 2011, there were nine government office regions (GOR) which represented the primary statistical subdivisions of England. GORs reflected administrative areas made up of complete

that Christians were relatively evenly spread across the regions. Hindus were concentrated in London (52%), in the East Midlands (12%) and in the West Midlands (10%). Sikhs lived in London (31%) and in the West Midlands (31%). Muslims were the most widely spread religious population at regional level. They were concentrated in London (39%), in the West Midlands (14%), in the North West (13%) and in Yorkshire and the Humber (12%). More than half of Jews lived in London (56%), 11% lived in East of England and 10% in North West. In 2001, Hindus, Sikhs, Jews and Muslims tended to live in small areas<sup>11</sup> with higher religious diversity than Buddhists, Christians and people from other religions. Christians tended to live in small areas of relatively low religious diversity. The geographic distribution of the Indian population in England and Wales by religion showed that in the West Midlands there were 32.2% of all Indian Sikhs, 11.4% of all Indian Hindus, 9.3% of all Indian Christians and 8.2% of all Indian Muslims. The geographic distribution of the Muslim population in England and Wales by ethnic group showed that in the West Midlands there were 21.9% of all Pakistani Muslims, 11.2% of all Bangladeshi Muslims, and 8.2% of all Indian Muslims.

Households had ethnic homogeneity when all members of the household shared the same ethnicity or religion as the household reference person (i.e., head of the house). Households had ethnic diversity when members of the household had different ethnicity or religion than the household reference person. The majority of households (85%) in England and Wales were religiously homogeneous in 2001. Highly homogeneous households were Christian (90%), Sikh (85%), Hindu (84%) and Muslim (83%). Most of the households with religious diversity were Buddhist (22%) and Jewish (16%). Heterogeneity within households was the consequence of inter-ethnic marriages or ethnic differences between parents and children (Forsyth and Gardener, 2006).

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counties/unitary authorities, metropolitan counties and London boroughs. In each GOR there were Government Offices aiming to maximise prosperity and people's quality of life within that area.

<sup>11</sup> Middle-layer Super Output areas with an average of 7,200 people

### **3(2). 7. 2. Religion and immunization**

Religions are distinguished by beliefs and practices and modes of organization (Thoresen and Harris, 2002). Religious and spiritual beliefs and practices could influence a person's choices, attitudes, and values which could impact health (Thoresen and Harris, 2002). Religion and spirituality have been shown to be effective in coping with disability, illness, and negative life events (Hill et al., 2000). Religion could have a negative impact on health when medical services are refused on religious grounds (e.g. parents do not accept medical services for their children) (Thoresen and Harris, 2002). An ecological study was conducted in the Netherlands in a "Bible belt" area populated by orthodox protestant groups and other inhabitants. It aimed to determine the difference in coverage with Diphtheria Tetanus Pertussis Polio vaccine administered to two year old children between municipalities with and without orthodox protestant denominations. The findings indicated that low vaccination coverage in municipalities with orthodox protestant denominations was influenced by the presence of these religious groups (Ruijs et al., 2011). A qualitative study was conducted in Indiana, US, among congregation members to explore their attitudes to measles immunization after a measles outbreak. It was found that vaccine refusal by some church members was attributed to a combination of personal religious beliefs and concerns about vaccine safety (Kennedy and Gust, 2008).

When the HPV immunization programme was launched in 2008 some religious institutions such as the Catholic Church in the Netherlands and Muslim organizations in the UK opposed the provision of HPV vaccination for preadolescent girls. The Catholic Church opposed the vaccination policy on the grounds that young people would engage in sexual activity at an earlier age. Muslim organizations expressed reluctance on the grounds that administering the HPV vaccine would coincide with Ramadan (Petrova and Clifford, 2009).

### **3(2). 8. Ethnic inequalities in health**

Ethnic inequalities were explained by genetic/biological, cultural, migratory, social deprivation and racism factors (Kelly and Nazroo, 2008). There is a consensus that ethnic inequalities in health are largely a consequence of socioeconomic differentials (Cooper, 2002; Nazroo and Williams, 2006). Ethnic minorities are more likely to have lower socioeconomic status due to family income and education levels (United Nations Research Institute for Social Development, 2006). Health inequalities result from social inequalities (Marmot, 2010). The diversity in health experience across ethnic groups in the UK is influenced by differences in migration history, patterns of settlement in the UK and economic disparities (Nazroo and Williams, 2006). Socioeconomic inequalities faced by ethnic groups include more aspects than measures of socioeconomic position (i.e., class or education). It is important to assess socioeconomic inequalities over the life course (i.e., accumulation of risk across the life course and differences between first and second generation migrants) as well as other factors related to ethnicity (e.g. racism and geographical segregation) (Bradby, 2008; Nazroo and Williams, 2006) and the environments where people live (Bartley, 2004). There are explanations of health differences between first and second generation migrants. First, childhood experiences of first migrants may be very different from second generation. Second, experience of migration occurs alongside social and economic upheaval which might have a direct impact on health. Third, contemporary social and economic experiences might be different for the migrant and non-migrant generation. Fourth, generational differences are driven by particular political and historical events (Nazroo and Williams, 2006). Health Surveys for England (1999-2004) suggested consistent rates of poor health across generations, despite the health benefits resulting from upward social mobility (Smith et al., 2009).

In the UK, minority ethnic men are more likely to have low paid jobs and job insecurity (Cooper, 2002). Minority ethnic women tend to be more disadvantaged relative to men. For example, women of working age with higher rates of economic inactivity (“never worked” or “long term unemployment”) were from South Asian groups such as Bangladeshi (49%), Pakistani (44%), and Indian (13%) (Forsyth and Gardener, 2006). Gender inequality is much greater for Pakistanis and Bangladeshis than for other ethnic groups. This is because Pakistani and Bangladeshi women are much more involved in domestic and child-care activities (Cooper, 2002). In contrast, Black Caribbean women had a higher rate of economic activity than South Asian women and 54% of them worked in public administration, education and health (Forsyth and Gardener, 2006). It was shown that within any given occupational group, ethnic minorities are disproportionately represented in the less prestigious occupational grades, having poorer security and more stressful conditions (Bradby, 2008). Low status and low-paid occupations could be the effect of discriminatory treatment of minority groups (Cooper, 2002). Discrimination as well as perceptions of living in a discriminatory society contribute to ethnic inequalities in health (Nazroo and Williams, 2006). The Open Society Institute studied Muslims in 11 EU cities and the findings suggested that religious discrimination against Muslims represents a barrier to equal participation in society and that apart from discrimination many Muslims experience social and economic disadvantages, live in poorer housing and the poorer districts of large industrial cities, and face higher unemployment rates and higher poverty rates than the general population (Open Society Institute, 2010).

Social cohesion and social capital are socio-cultural characteristics mostly used to explain the area differences in health (Macintyre et al., 2002). Areas with high concentration of ethnic groups seem to have fewer services and a worse environment (Bartley, 2004). However, ethnic groups perceive the facilities (e.g. shops, schools,

place of worship) in these areas more positively than White people (Nazroo and Williams, 2006). The local area can confer psycho-social benefits which are important for groups who experience discrimination in the wider society (Nazroo and Williams, 2006; Graham, 2009). It was claimed that area characteristics (i.e., neighborhood socioeconomic status) have relatively small effects on health and that individual socioeconomic position has larger effects on health (Stafford and Marmot, 2003). The association between socioeconomic position and health persists over time and place because socioeconomic position determines the access to resources which promote health and the exposure to risk which damage it (Graham, 2009).

### **3(2). 9. Equity in health service delivery**

Equity has been a goal of health policy in many countries and international health organizations (WHO Task Force on Research Priorities for Equity in Health & the WHO Equity Team, 2005). Some definitions of equity are equal treatment for equal need (McIntyre and Mooney, 2007; Boeckxstaens et al., 2011), and equal treatment outcomes for people in equal need (Boeckxstaens et al., 2011). The concept of equal quality of care implies that every person should have an equal opportunity of being admitted for care through a fair procedure based on need rather than social influence (e.g. race, ethnicity) and of having the same standard of professional care as all sections of the population (Whitehead, 1992).

The equity–efficiency trade-off has been used as a framework for the consideration of equity in the allocation of healthcare resources (Sassi et al., 2001a). Efficiency represents the ratio between benefit and costs. Efficiency has two dimensions: allocative efficiency, which refers to use of those procedures that produce maximum benefit, and technical efficiency which refers to use of procedures in the most technically competent

manner. Achieving maximum benefit for all individuals in the population could not be affordable (Campbell et al., 2000). Equity concerns could occur when a particular technology is cost-effective for some subgroups of people but not for others (Culyer and Bombard, 2011). The health needs of individuals must be weighed against the possibility of optimising health outcomes for the population. Therefore, the resources should be distributed efficiently to particular subgroups in the population according to principles of need and equity (Campbell et al., 2000). There is a conflict between the goals of equity and efficiency. When improving efficiency, health inequalities increase (Sassi et al., 2001b). When increasing equity, more people would use the services including those who would benefit little, and this would lower the efficiency of services (Gulliford et al., 2001).

The literature describes the equity-effectiveness loop used as a framework to evaluate the impact of population health policies and programmes on health inequities to ensure that interventions benefit the disadvantaged. The WHO Collaborating Centre on Health Technology Assessment used this framework, which consists of five steps to develop and evaluate population health policies and programmes: burden of disease, community effectiveness, cost-effectiveness, knowledge translation into interventions and monitoring. The framework assesses the potential for health inequity at each step in order to determine if the intervention benefits the underprivileged. The framework assesses barriers and facilitators for improving health equity using four factors: diagnostic accuracy, coverage/access, provider compliance, and consumer adherence. All these factors could be lower in disadvantaged groups. All these factors as well as the efficacy of the intervention have impact on the community effectiveness, which is defined as the benefit obtained from an intervention implemented in the community. This framework assesses only the interventions supplied by a clinician provider. Also, it

measures the gap between the most advantaged and the most disadvantaged, but it does not measure the gradient in health across all levels of disadvantage (Welch et al., 2008).

Equitable delivery of health care is an essential aspect of the NHS in the UK (Department of Health, 2009). Health equity audit (HEA), developed and used in the NHS since 2003, has aimed at a fair distribution of services in relation to health need of different groups and areas in order to improve services and to reduce health inequalities between social classes (by area, gender, age, minority ethnic groups, vulnerable groups and the majority of population) (Department of Health, 2003).

### **3(2). 10. Equity in access to health care**

The commonest definitions of equity found in the literature are (1) equal access to available care for equal need (Obrist et al., 2007), and (2) equal utilization for equal need (Whitehead, 1992; Boeckxstaens et al., 2011; Sibley and Weiner, 2011; van Doorslaer and Masseria, 2004) irrespective of other characteristics, such as income, place of residence or ethnicity (Tamsma, 2009; van Doorslaer and Masseria, 2004). These definitions define the concept of horizontal equity used in economic evaluation (Sassi et al., 2001a). Also, health economists use the concept of vertical equity to define unequal access for unequal need, which indicates that those with less need have lower utilization rates (Sibley and Weiner, 2011).

Organization of health systems in the EU Member States and in OECD countries is based on the principles of equity and equitable distribution of health care (Tamsma, 2009) and adequate access to health care by all people according to their need (van Doorslaer and Masseria, 2004; Sassi et al., 2001a).

Equity in access to health care could be influenced by

- the availability of services (fair allocation of resources (Braveman and Gruskin, 2003) based on health care needs in each geographical area (Whitehead, 1992)),
- people's ability to make informed decisions about the therapies (Norman, 2008),
- the availability of information about language support services for ethnic minorities
- the availability of information about out-of-hours health services (Szczepura et al., 2005),
- equitable distribution of income among social groups (Norman, 2008) and
- externalities (benefit from others' consumption of health care) (Sassi et al., 2001a).

Equity in access to health care could be measured through availability and utilization as well as outcome of services (Gulliford et al., 2002; Gulliford et al., 2001). Deprived areas have the least available health services although they are most needed (the inverse care law) (Whitehead, 1992). But availability of services is not evidence of access to health care (Worz et al., 2006). In addition, equitable delivery does not guarantee equality of uptake (von Wagner et al., 2011). Evaluation of equitable access to care presumes a comparison between users and non-users of health services (Boeckxstaens et al., 2011) to distribute limited resources to those most in need of care (e.g. the poor) (Zere et al., 2007).

### **3(2). 10. 1. Equity in access to vaccination**

Universal coverage in immunization (Gilson et al., 2007)<sup>12</sup> and equity are principles of human and child rights. The rationale for reaching equity is to create herd immunity and to minimize as much as possible the likelihood of infection (Delamonica et al., 2005).

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<sup>12</sup> Universal coverage means that the whole population of a country has access to good quality of care, regardless of income, social status, or residency. 100% population coverage is achieved through equity in

Inequitable delivery of HPV vaccination has occurred in developing countries due to various barriers including cost and inadequate delivery infrastructure (Graham and Mishra, 2011). Other evidence has suggested that different types of immunization were delivered unequally to some groups (Mulholland et al., 2008) in developed countries. In England, the consequence of barriers in access to immunization was low uptake of the vaccines (e.g. DTP, polio, flu) especially among poorer families, living in deprived areas, among children with physical and learning difficulties and among ethnic groups (Department of Health, 2005). A social context with dominant family members (i.e., husbands, brothers, fathers) (Cain et al., 2009) in some ethnic groups was another reported barrier which limited women's access to information and their ability to make their own choices for their children for HPV immunization to prevent cervical cancer.

### **3(2). 11. Summary**

Quality of care is multidimensional, including aspects of access, acceptability, effectiveness, efficiency, equity and relevance. Access and effectiveness are important dimensions for provision of quality care to individual patients while equity and efficiency are essential for provision of quality care to populations. Equity is viewed as a sub-component of access and thus access to health care could be evaluated through equity. Equity has been a goal of health policy in many countries and international health organizations. Inequity refers to those inequalities in health that are considered to be unfair. Health inequalities refer to disparities in the health achievements of individuals and groups due to free choice, unavoidable factors (i.e., biologic or genetic) or external environment. There are four main types of explanations of the pathways and mechanisms underlying the social gradient in health: behavioral/cultural, material,

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payments, the rich paying more than the poor, financial protection of the poor not to become poorer as a result of using health care, and equity of access according to need rather than ability to pay

psychosocial and life course. There is a consensus that ethnic inequalities in health are largely a consequence of socioeconomic differentials (lower family income and education) and of living in deprived areas. Equity in access to health care could be measured through availability, utilization as well as outcome of services. Deprived areas have the least available health services although they are most needed (inverse care law). Equitable delivery of health services does not guarantee equality of uptake.

## Overarching conceptual framework

The “right to health” framework helped to identify the potential factors that influence access to HPV vaccine. The framework that focused on quality of care helped to identify equity as an important concept in the evaluation of access to health care. I developed an overarching framework, which I used to understand the context of factors that influenced access to HPV vaccine. The approach was through two studies. The first study was a quantitative research related to access<sup>13</sup> to information about HPV vaccine of all secondary schools in the UK by geographic and school factors. The second study was a mixed methods research including a quantitative component that investigated access<sup>14</sup> to HPV vaccine of girls in the secondary schools in a city of study by area deprivation, ethnicity and religion as well as a qualitative component that explored the mechanisms, strategies and practices that influenced delivery and uptake of HPV vaccine. This second study was an exploratory parallel study in terms of mixed method design (Creswell and Plano Clark, 2011), which will be discussed in Chapter 5.

In the next chapter, I present health promotion and models, a scoping literature review related to awareness and knowledge about HPV vaccine and a national study based on a mass campaign distributing teaching materials about HPV vaccine in the UK.

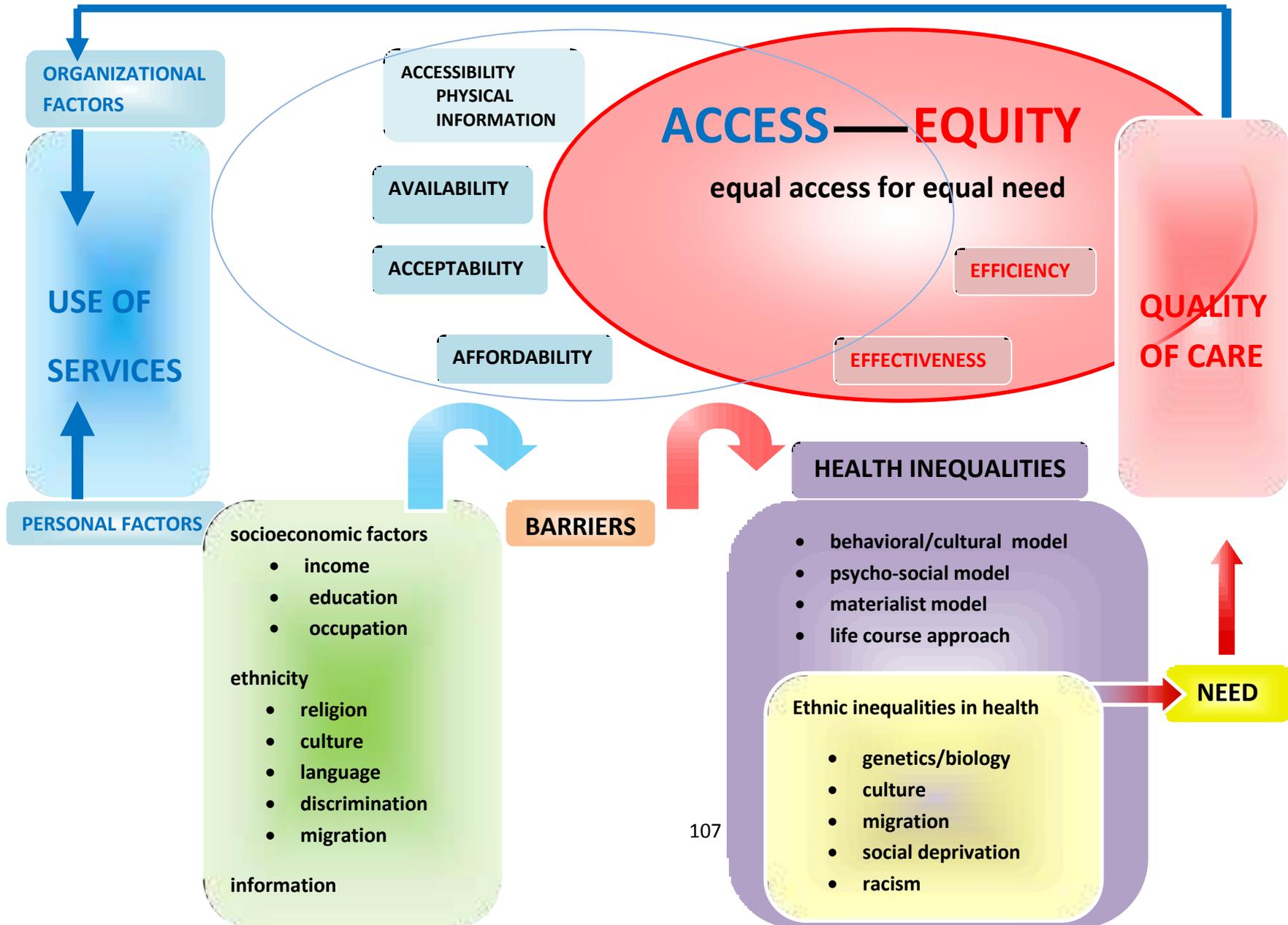
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<sup>13</sup> Measured by uptake of informative materials

<sup>14</sup> Measured by uptake of HPV vaccine

# DIAGRAM - OVERARCHING CONCEPTUAL FRAMEWORK

“Right to health” framework (access to health care) and framework of evaluation of quality of care



# **CHAPTER 4: NATIONAL STUDY – UPTAKE OF INFORMATIVE MATERIALS ON HPV VACCINE IN SECONDARY SCHOOLS IN THE UK**

This chapter presents three sections, including health promotion theories and models, a scoping literature review related to awareness and knowledge about HPV vaccine and a national study based on a mass campaign distributing teaching materials about HPV vaccine to secondary schools in the UK.

## **4. 1. Health promotion theories and models**

This section introduces the concept of health promotion, approaches to health promotion and three categories of models related to individual, interpersonal and community health behavior.

### **Definition of health promotion**

The Ottawa Charter defined the key concepts of health promotion in 1986 (Donev et al., 2007). Health promotion represent actions taken (Morton et al., 2012) at individual and community level (Sharma and Romas, 2012) to enable people to increase control over health and its determinants to improve their health and to prevent diseases (Davies and Macdowall, 2006). The increase in health or wellbeing could be measured for example by improvement in life expectancy, reduction in years of life lost or quality of life (Rootman et al., 2001). Health promotion involves a broad range of stakeholders such as governments, health and other social and economic sectors, nongovernmental and voluntary organizations, local authorities, industry and the media. Key actions to

promote health and to attain equity in health include efforts to influence the broader social context of health behavior (Glanz et al., 2008). The actions are directed towards building healthy public policy for safer and healthier goods and public services and cleaner environments, generating safe and enjoyable living and working conditions, strengthening community actions, developing personal skills and reorienting health services. Health promotion strategies also aim to empower communities increasing people's access to information, providing learning opportunities and education for health in different educational, professional and voluntary institutions as well as funding support to control their own health (Donev et al., 2007). Empowerment is facilitated through client-centred approaches (e.g. advocacy, counselling) aimed at increasing people's control over their health (Naidoo and Wills, 2000) and through community-based interventions that create supportive environments for people to make healthy choices about their behaviors (Baum, 2003). A healthy choice requires change in cost, availability and accessibility (Naidoo and Wills, 2000). There is evidence that behaviour change programmes aimed to persuade individuals in disadvantaged communities were not successful (Baum, 2003). Health promotion strategies and programmes should be adapted to the community needs according to socio economic context. Advocacy is one of the key strategies for the achievement of health promotion and aims to make political, economic, social, cultural, environmental, behavioral and biological factors favorable for health.

The second international conference on health promotion held in Adelaide in 1988 focused on building healthy public policy (Donev et al., 2007). The third international conference was in Sundsvall in 1991 and stressed the importance of sustainable development of communities to create supportive environments for health (Donev et al., 2007). The fourth international conference, which took place in Jakarta in 1997, put emphasis on promoting social responsibility for health, increasing community capacity

and empowering the individual, expanding and consolidating partnerships for health, increasing investment for health development, and securing an infrastructure for health promotion (Donev et al., 2007).

### **Approaches to health promotion**

I looked at three main approaches to health promotion. One is medical approach that focuses on medical interventions derived from epidemiological evidence for prevention of disease and premature death, such as immunization and screening (Naidoo and Wills, 2000). Another one is the behavioral change approach that addresses behavioral risk factors (e.g. smoking, alcohol abuse, poor diet, lack of physical exercises) at individual and group level (Baum, 2003) through provision of information to encourage individuals to adopt healthy behaviors (Naidoo and Wills, 2000). The third is the socio-environmental approach that puts emphasis on communities at risk of poverty, living and working in unsafe and stressful conditions and who lack social support to decrease inequities between population groups (Baum, 2003).

Health promotion interventions developed on the basis of theoretical models appear to be more effective than those which do not use a theory-based approach (Davies and Macdowall, 2006; Glanz et al., 2008; Whitehead, 2001; Agency, 2004). The reason is that theoretical models offer the guidelines for planning and delivery of a health promotion intervention. Health promotion theories or models which target individual and wider environment are more effective (Davies and Macdowall, 2006). Behavior both influences and is influenced by the socio-economic environment (Glanz et al., 2008). Environment includes social norms, policy, economic factors, programmes, practices, social influences (Morton et al., 2012). Health promotion strategies are based on social psychology theories (Naidoo and Wills, 2000; Baum, 2003). Health promotion

theories or models are individually oriented and do not include in their design socio-economic factors (Davies and Macdowall, 2006). The theories and models identify the determinants of behavior change. The purpose of the majority of models is to establish the relationships between people's knowledge, attitudes, beliefs, values and their behavior (Whitehead, 2001) to understand how people make decisions about their health (Naidoo and Wills, 2000).

There are three categories of models of health behavior mentioned in the literature: models of individual health behavior, models of interpersonal health behavior and community and group models of health behavior change (Glanz et al., 2008). Some examples of models in each of these categories are given below.

#### **4. 1. 1. Models of individual health behavior**

##### **4. 1. 1. 1. Health belief model**

The health belief model (HBM) is a theoretical model that stresses the role of beliefs in decision making. It has been used to predict uptake of preventive services such as immunization (Davies and Macdowall, 2006; Naidoo and Wills, 2000) and screening, as well as compliance with medical advice (Naidoo and Wills, 2000) and HIV-protective behaviors (Glanz et al., 2008). It is a behavior change model. An individual changes the behavior taking into consideration the benefits and the barriers of a recommended health action. The constructs of the model include the individual's assessment of the susceptibility to, the severity of and the threat of disease, as well as the barrier to undertaking recommended behavior (Glanz et al., 2008), the efficacy and the benefits of action (likelihood to be protected from disease) and self-efficacy (individual's ability to carry out the intended behavior) (Naidoo and Wills, 2000; Davies and Macdowall,

2006). The individual's assessment of the risk of disease is the main component of the model. Some factors influence people's perception and their assessment of risk such as demography (age, gender, and ethnicity), socio-psychological characteristics (personality, social class, and peer pressure) and cues to action (Naidoo and Wills, 2000; Glanz et al., 2008). The relation between individual's perception and decision is mediated by cues to action including mass media campaigns, advice from others, reminder from health professionals, personal experiences of illness, information provided in newspapers or magazines (Naidoo and Wills, 2000).

The advantage of the HBM is that it supports the development of messages delivered by mass media to improve knowledge (Davies and Macdowall, 2006), to change perceptions and reduce barriers (e.g. to screening and immunization) (Davies and Macdowall, 2006; Glanz et al., 2008). It also guided interventions delivered through printed materials and telephone calls to reduce perceived barriers and to enhance perceived benefits (e.g. mammography screening) (Glanz et al., 2008). The HBM has several limitations. It does not specify how constructs of the model interact with one another (Glanz et al., 2008) and it does not account for other factors that influence health behaviors (Janz and Becker, 1984). Cues to action are often difficult to assess (Glanz et al., 2008). Environmental factors outside one's control may prevent an individual changing their behaviors (Janz and Becker, 1984).

#### **4. 1. 1. 2. Theory of reasoned action**

The theory of reasoned action, developed by Azjen and Fishbein, predicts a person's behavior by own intentions. Intention depends on own attitudes (perceived consequences) and subjective norms (perception of the attitudes of others towards that behavior). A person's behavior is influenced by three factors: the strength of a belief about the consequences of the behavior as well as by personal motivation to comply

with social norms according to family's or peer group's expectations (peer pressure) and ability (behavioral control). People's perceptions of the attitudes of others towards their behavior make the theory of reasoned action differ from the health belief model (Naidoo and Wills, 2000) which will be described later. Two factors have a direct effect on behavior: the person's intention and their perception of control over behavior. Intention is not enough for behavioral performance because a person needs knowledge and skill to carry out that behavior. Depending on the context, in one population behavior could be determined by people's own attitudes while in another population it could be influenced more by the expectations of significant others (Glanz et al., 2008).

#### **4. 1. 1. 3. Stages of change (transtheoretical) model**

Prochaska and DiClemente developed the stages of change model on the premise that people change their behavior going through several stages including precontemplation (when there is low awareness of potential risky behavior), contemplation (when there is need for information to help decision making), preparing to change (when there is some extra support), making the change and maintenance of that change or behavior. This model differs from the other models through the fact that it shows how people change their behavior (Naidoo and Wills, 2000). One of the limitations of the model is that it does not apply very well to children and young people who have not used tobacco, alcohol or drugs (i.e. it is more about reducing existing unhealthy behaviours than choosing not to undertake them in the first place) (Glanz et al., 2008).

#### **4. 1. 2. Models of interpersonal health behavior**

##### **4. 1. 2. 1. Social cognitive theory**

Social cognitive theory is a self-regulatory model proposed by Bandura and is operationalized as self-efficacy (a person's belief in their own ability to successfully

perform a behavior) (Glanz et al., 2008), (Davies and Macdowall, 2006). The model examines the predictors of health-related behavior and an individual's cognitive process which results in taking or not taking actions when there is a risk of disease (Whitehead, 2001). Self-efficacy is proposed as the most important determinant for behavior change (Davies and Macdowall, 2006). For example, getting a flu vaccine or not getting it because of barriers are experiences which are interpreted differently according to an individual's character and cognition (Morton et al., 2012).

According to the theory, there is an interaction between an individual, their environment (Davies and Macdowall, 2006; Donev et al., 2007) and their behavior (Davies and Macdowall, 2006). The model is based on observational learning, which means that people learn from observing the behaviors of others to develop their knowledge and to model their behaviors, especially when the others are similar to them. For example, they could enact those behaviors when they anticipate positive outcomes or avoid them if they expect negative results (Glanz et al., 2008). Learning may be from direct observation or through mass media (Rogers, 2003) (e.g. celebrities used as role models) (Naidoo and Wills, 2000; Davies and Macdowall, 2006) and interpersonal channels (Rogers, 2003).

### **4. 1. 3. Community and group models of health behavior change**

#### **4. 1. 3. 1. Caplan and Holland's model**

Caplan and Holland's model refers to four paradigms of health promotion. Two of them are medical and behavior change approaches that were described earlier. The other two components of the model are the educational approach, based on the provision of knowledge to change individuals' attitudes to choose a healthy lifestyle, and

empowerment to increase people's control over their own lives (Naidoo and Wills, 2000).

#### **4. 1. 3. 2. Health action model**

Tones developed a health action model based on healthy public policy and health education (Naidoo and Wills, 2000). Health promotion is different from health education that represents learning experiences to improve knowledge and skills aimed at enhancing health in individuals and communities (Sharma and Romas, 2012). Health education ignores the role of social and economic factors on behavior. It does not modify the environment but empowers the community to create public pressure for a healthy public policy. Empowerment is the main aim of this model. Policy creates a healthy social and physical environment that enables individuals and communities to take control over their personal lives. The health action model differs from the health belief model and the theory of reasoned action through emphasis on self-esteem. There is an assumption that self-esteem (i.e., social and life skills and personal efficacy) is part of an individual's motivation system that influences health behavior (Naidoo and Wills, 2000).

#### **4. 1. 3. 3. French and Adams model**

French and Adams developed a model with a hierarchical structure, having at the bottom a behavior change model, in the middle a self-empowerment model and on top of it a collective action model. The emphasis put on health promotion as a collective action makes this model different from the other models. Changing environmental and social factors is the most important part of the model because health is seen as a social issue (Naidoo and Wills, 2000).

#### **4. 1. 3. 4. Diffusions of innovations theory**

Diffusion represents a type of communication using certain channels to transmit an innovation within a social structure. “An innovation is an idea, practice, or object that is perceived as new by an individual” (Rogers, 2003, p.12). Diffusions of innovations theory is related to the adoption of innovation in communities (Davies and Macdowall, 2006). The decision to adopt or to reject an innovation involves a process of information seeking and understanding of advantages and disadvantages of that particular thing. The process occurs over time in five steps: getting knowledge about an innovation, developing favorable or unfavorable attitudes towards an innovation (is or is not persuaded), making the decision either to adopt or to reject an innovation, uptake of an innovation and confirmation of decision to uptake or to reject an innovation when there are conflicting messages about it. At the persuasion and decision stages, an individual seeks the opinion of peers to strengthen their own attitude towards an innovation. A discrepancy could exist between the attitude in the persuasion stage and the behavior (adoption of an innovation). This discrepancy could be diminished by a cue-to-action (Rogers, 2003) which could be a model or a change agency (Davies and Macdowall, 2006).

People adopt new ideas at different times. This is because people need time from getting knowledge of an innovation until they adopt it. According to this criterion, people were categorized in five groups: innovators, early adopters, early majority, later majority and laggards. How early some people adopt new ideas in comparison with others could be explained by people’s socio-economic status, personality, values and communication behavior. Diffusion research showed that early adopters have more years of education and a higher social status than late adopters (Rogers, 2003) and have personal skills, as well as social and financial resources to uptake the innovation (Davies and Macdowall, 2006; Rogers, 2003). It could also be the consequence of the fact that those who

promote innovations usually target the segment of population with high socio-economic status (Rogers, 2003). The late adopters are those who initially are resistant to the innovation even if it is provided at no cost but who take it up later when are convinced of its benefits (Davies and Macdowall, 2006).

The rate of adoption represents the speed with which people adopt an innovation and is expressed as the number of people who adopt an innovation within a specified period of time (Rogers, 2003). The rate of adoption depends on the attributes of innovations, the communication channels, the nature of the social structure and the effort of health promoters to diffuse innovations. Innovation characteristics are represented by the relative advantage in comparison with existing practice, the compatibility with people's needs, the socio-economic and cultural values as well as the norms in the social structure, the simplicity to understand and use it, and observing successful results got by those who adopted it (Davies and Macdowall, 2006; Rogers, 2003). The relative advantage of an innovation is related to getting an immediate reward. The rate of adoption of preventive innovations is slower than for non-preventive innovations. The reason is on one hand that innovations are adopted now and the benefit occurs at some time in the future and on the other hand that people could have difficulty in understanding the event that could happen if they do not uptake those innovations. Diffusion of innovation theory and social learning theory have in common the idea that verbal and nonverbal interpersonal communication within networks could help the diffusion of innovation and behavior change. Interpersonal channels could slow the rate of adoption. The smaller the number of people involved in making a decision about innovation, the faster its uptake (Rogers, 2003).

#### **4. 1. 3. 5. Communication-behavior change model**

The communication-behavior change model developed by McGuire has a few components including a message coming from a source and transmitted through a channel to a target audience. The source influences the credibility of the message. The content and form of a message influence receiver's response. Diverse sources, messages and channels are necessary to reach different segments of the audience due to their social and cultural differences (Davies and Macdowall, 2006). People may respond to some health messages and may ignore other health messages according to their health-related values (Whitehead, 2001). The channel is chosen according to the complexity of the message. There are different channels such as mass media, interpersonal channels, and electronic communications. In general, mass media messages do not provide an individual with the specific information to help deal with uncertainty of innovation (Rogers, 2003). In contrast, interventions delivered by health professionals take longer time but are more effective in persuading an individual (Davies and Macdowall, 2006; Rogers, 2003). Mass media include television, radio and printed materials such as newspapers, pamphlets, posters. Other media include Internet and mobile phone messages (Davies and Macdowall, 2006). Mass media campaigns have generally aimed primarily to change awareness, knowledge and attitudes, with the purpose to change behavior. Mass media is appropriate to be used when wide exposure is desired and when it is intended to stimulate simple behavior changes such as immunisation or cholesterol testing (Agency, 2004). Mass media campaigns could reach a large proportion of people and could increase their awareness quickly and effectively (e.g "England's No Smoking Day" or "Don't fool yourself, speed kills" that targeted road safety in Australia) (Davies and Macdowall, 2006; Agency, 2004; Rogers, 2003; Baum, 2003).

#### **4. 1. 3. 6. Social marketing**

Social marketing applies techniques of marketing to social psychology theories to determine population-wide behavior change. One of the techniques is mass media campaign that promotes products and messages to a well-defined target audience in terms of demographics, behavior, psychology and media preferences. One of the limitations of social marketing is that it ignores the complexity of factors that affect health behavior as well as social structures that reduce people's ability to change their lifestyle. In addition, it could result in ethical problems because advertising could manipulate people's behavior by appealing to particular images (Baum, 2003).

#### **4. 1. 4. Critique of behavior-based health promotion**

There are some criticisms to all the above mentioned theories and models of behavior change because they focus on individual factors and may ignore the role of societal influences affecting someone's behavior (Baum, 2003). It has been argued that behavior is not the most important determinant of health (Naidoo and Wills, 2000). Different models of individual behavior change conceptualize behavior change as a rational choice. People choose their behavior according to what they believe is good for their health. The models assume that people will change behaviors if they are given information. Then individuals are made responsible for their own health disregarding the social and economic context where they live ("victim-blaming"). However, knowledge and understanding of health is different in the general population and among health professionals (Baum, 2003).

## **4. 2. Scoping literature review**

The scoping literature review aimed to identify the evidence available related to health promotion campaigns to prevent HPV infection through HPV vaccination. The literature search was carried out in OVID Medline and PubMed looking for articles (any type of evidence) about health information, awareness, knowledge, attitudes about HPV vaccine as well as health promotion of the HPV vaccine and factors influencing variation in outcomes of health promotion in general. I identified 58 articles published between 2006 and 2008 all over the world. Out of these, 21 articles were related to awareness, knowledge and attitudes about HPV, HPV vaccine and cervical cancer. Two studies were reviews and the others had different study designs. The study population included young women in different age groups (14-24 years old) (five studies), women attending gynecologic clinics (16-61 years old) (seven studies), parents of daughters 8-12 years old (four studies) and health professionals such as obstetrician/gynaecologists, family physicians and/or paediatricians (three studies). Studies were conducted in different European countries (the UK, Italy, Belgium, Finland, and Slovenia) as well as in Canada, Australia, Brazil and Kentucky counties.

Prior to the commencement of the vaccination campaign, the general public in the UK knew little about HPV (Marlow et al., 2007; Walsh et al., 2008). Adequate education was required, however, to support the take-up of the new vaccine, by helping young people and their parents to understand that cervical cancer is a genuine risk and that the vaccine is an effective preventive measure (Marlow et al., 2007). Most of the women who heard of HPV reported media as the main source (Pitts et al., 2007). Unfortunately, it was found that the available information from health agencies, pharmaceutical companies, and special interest groups, as well as through the news in media and on the internet, was conflicting, inaccurate, outdated, biased, incomplete, or written at inappropriately high literacy levels for general audiences (Friedman and Sheppard,

2007). In Western Europe and North America, the pharmaceutical industry provided a range of information related to HPV vaccine (particularly targeted at the upper- and middle-income markets) (Sherris et al., 2006), but people did not feel that they could trust it (Friedman and Sheppard, 2007). Given these circumstance of unreliable information from untrusted sources, there was a clear gap. Young people's knowledge of HPV was poor (Di Giuseppe et al., 2008; Donders et al., 2008; Moreira et al., 2006) and inadequate (Kollar and Kahn, 2008; McClelland and Liamputtong, 2006). This scoping review did not find evidence about health promotion of HPV vaccine in schools. A high percentage of parents did not hear of HPV and were not aware of the role of HPV in cervical cancer (Paul-Ebhohimhen et al., 2010; Noakes et al., 2006; Brabin et al., 2006) even among women with the history of cervical cancer (Stark et al., 2008). The WHO recommended that family planning clinics should provide health education to young people aged 10–13 years, especially to adolescents who did not attend school, as well as to women older than 26 years to prevent STIs including HPV infection and to understand the need for HPV immunization (World Health Organization, 2006). Some evidence suggested that knowledge about HPV infection and cervical cancer, as well as the need to vaccinate against oncogenic HPV infection, was lacking among physicians (Herzog et al., 2008; Esposito et al., 2007). One of the clinicians' concerns was that the adolescents might practice riskier sexual behaviors after vaccination and on this ground they were reluctant to recommend the vaccine to them and their parents (Kollar and Kahn, 2008). In this context, young people, parents and the health professionals who advise them needed accurate and appropriately targeted information about HPV and the HPV vaccine (Kollar and Kahn, 2008; Woodhall et al., 2007) through awareness campaigns (Walsh et al., 2008; Herzog et al., 2008; Vrscaj et al., 2008).

In addition, literature searching included identification of evidence about factors influencing variation in outcomes of health promotion. It was found an area level social gradient in the impact of health promotion efforts, whereby the impact of health promotion tends to be less in more deprived areas. For instance, people living in more deprived areas tend to have lower rates of smoking cessation (Giskes et al., 2006), lower rates of childhood vaccination (Middleton and Baker, 2003), and lower uptake rates of screening services (Middleton and Baker, 2003; Maheswaran et al., 2006). Explaining the relationship between area deprivation and the impact of health promotion activities has been the focus of far less research. Broadly, however, two kinds of explanation present themselves. The first kind of explanation relates to the receptiveness of people living in more deprived areas to health promotion messages. People in more deprived areas may “choose” to ignore the health promotion messages more than those in less deprived areas (Lynch et al., 1997). A second kind of explanation is that people living in more deprived areas are just as receptive to health promotion messages, but they are less likely to be exposed to health promotion messages than their counterparts in less deprived areas. It is this latter kind of explanation that is explored in the next section, where I present a national study based on an evaluation of a mass campaign using printed materials for use in formal education in the secondary schools.

### **4. 3. Quantitative research – National study**

In this section, I describe the methods and results for research question 1. First, I describe the HPV education programme, then I present the evaluation approach to this programme, followed by the methodology of the study including data sources and the techniques I used for data analysis. Second, I present the results of the study including descriptive and inferential statistics.

### **4. 3. 1. Methods**

#### **HPV education programme by RSPH**

At the beginning of 2007, the Royal Society for Public Health (RSPH)<sup>15</sup>, a major public health charity, and Sanofi Pasteur MSD, the manufacturer in the UK of the quadrivalent HPV vaccine, jointly identified the need for an information and education programme on HPV and cervical cancer. The programme targeted professionals (head teachers, teachers, the personal, social and health education (PSHE) leads, and healthy school coordinators) and healthcare professionals (school nurses, practice nurses, GPs with special interest, pharmacists, genitourinary medicine (GUM) staff, immunization coordinators, and directors of children services), to encourage a joined up approach in supporting the take-up of the HPV vaccination programme. The RSPH education programme was two-pronged. First, it aimed at providing teachers and school nurses with a means of supporting the messages about HPV and HPV vaccination within schools to help ensure timely take-up of the three doses of the vaccine. Second, it aimed to provide those health professionals outside schools who were likely to receive questions from parents about the HPV vaccine with appropriate information.

The first stage of the RSPH programme was an awareness raising campaign through the distribution and availability of an information leaflet. The second stage was a school-based campaign associated with the development of a curriculum linked to teaching and learning resources. The resources were designed to support teachers and school nurses in introducing and raising awareness and understanding of HPV and cervical cancer and the HPV vaccination programme.

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<sup>15</sup> At the time it was the Royal Society of Health (RSH), but it has since merged with the Royal Institute of Public Health (RIPH) to form the Royal Society for Public Health (RSPH). For simplicity, only the new name is used.

The RSPH programme was designed independently and in parallel with the work of the Department of Health (DH) (Salisbury, 2008) and NHS Health Scotland (Woods, 2007), and was intended to complement and support those awareness raising/information campaigns. From the discussion with the members of the Steering Group of the RSPH programme I found out that the DH aimed at raising awareness about the HPV vaccine focusing on cervical cancer through its communication and information programme (posters, stickers, leaflets, question and answer booklets, series of workshops/seminars and slides for health professionals, advertising programme, a new chapter of the “Green Book” (Department of Health, 2008c)). The RSPH sought to increase knowledge about the role of the HPV vaccine in the prevention of cervical cancer within an education programme through curriculum linked teaching materials, while supporting that effort with the distribution of information leaflets.

Phoenix Consultancy, an independent educational consultancy organization, designed the teaching and learning resources for the RSPH education programme. These resources consisted of three types of materials such as a lesson plan for students to take responsibility for their own health, another lesson plan related to benefits and risks of health and lifestyle choices, and a lesson plan about vaccination and immunisation.

The objectives of the lessons were to empower teenagers to make safe and appropriate decisions in relation to their physical, emotional and sexual health, to have an understanding of the importance of vaccination in the prevention of cervical cancer and to provide parents indirectly with an understanding of the need for vaccination and an awareness of the vaccination availability. The content of ‘Taking responsibility for your own health lesson plan’ aimed to enhance pupils’ understanding about taking responsibility for their own health and to increase their ability to take actions at their age of 12-14 years that will have an impact on their health in later life. Another learning objective was to increase pupils’ understanding of the importance of vaccination in the

prevention of cervical cancer and their knowledge that most cases of cervical cancer are preventable through a three-dose vaccination delivered to girls through schools. It also aimed to increase pupils' knowledge that cervical cancer is caused by HPV and that genital warts are caused by other types of this virus. This lesson intended to give them the opportunity to understand the concept of cause, detection and prevention of disease (Royal Society of Public Health, 2008a). The learning objectives of 'Benefits and risks of health and lifestyle choices lesson plan' aimed to establish how much the students knew about factors influencing their own health and to give them the opportunity to learn that cervical cancer is caused by some HPV types and that other types of this virus cause genital warts. It also aimed to increase students' knowledge that most cases of cervical cancer are preventable through a three-dose vaccination delivered to girls in their school or via a GP. Another objective of the lesson was to make the students aware that practicing safer sex is essential in the prevention of the spread of STIs (Royal Society of Public Health, 2008b). The content of 'Vaccination and immunisation lesson plan' included information about the impact of smallpox and the important role that vaccination and immunisation programmes have played in reducing the impact of diseases. It aimed to teach the pupils about the HPV vaccination and to make them understand why vaccination is still important nowadays. Another objective of the lesson was to teach them about the positive impact of vaccination and immunisation on public health (Royal Society of Public Health, 2008c).

Lesson plans were designed to be inclusive and to encourage engagement with both boys and girls. They were created for teachers and/or school nurses or other healthcare professionals, for PSHE educators and healthy schools coordinators to use them as a means of introducing the distribution and collection process for consent forms and as a follow up to vaccination sessions. The lessons were expected to be taught in the context of PSHE, Sex and Relationships Education, and Science Sessions in schools especially

in tutor groups. The lesson plans were linked specifically to each of the four UK country curricula. The teaching package included an evaluation form for student feedback and the Basics leaflet “the Royal Society of Health HPV and Cervical Cancer”.

### **Delivery of the HPV education programme**

In the first stage of the education programme the RSPH mailed out a letter and an information leaflet to UK schools, Primary Care Trusts, General Practices, Pharmacies, Genitourinary Medicine clinics, and City Councils. Recipients were invited to request additional leaflets and/or the teaching pack that had been developed. It was anticipated that all recipients might be interested in receiving additional leaflets, but only schools and off-site school nurses would be interested in receiving the teaching pack. Initial letters were sent out in March 2008, with the intention of delivering the additional resources in time to support the first round of school-based vaccination in September 2008. During the meetings of the Steering Group of the RSPH programme I found out that Phoenix Consultancy identified the schools which should be sent the letters (i.e., who should be targeted in the mail out) although it was not clear on what basis the schools were selected. There were 5,715 schools identified for the initial mail out in the UK. All the schools that were sent letters had children in the target age group for the HPV vaccine. However, although some of the schools (male, single sex schools) would not be a part of the government vaccination campaign. It was, nonetheless, felt by the RSPH that it was important for all schools to be included in the broader information campaign because HPV affects directly or indirectly both sexes, and as a sexually transmitted virus, is of public health relevance to both sexes.

An in-house mailing list was used as the basis for the mail out to the other organisations/professions.

At the same time that the leaflet and teaching pack were being prepared, an evaluation of the education programme was also planned. I designed and I did the evaluation based on the analysis of secondary data. I received these data, which included all schools that did and did not request teaching and learning resources, from Phoenix Consultancy.

### ***Research question 1***

What is the association between the uptake of educational materials about HPV vaccine by secondary schools and area level, social deprivation in England?

### **Aim**

The aim of this part of the evaluation was to assess the extent to which the HPV education resources developed by RSPH reached schools. By extension, the evaluation would also provide insight into the strengths and weaknesses of this kind of approach to health promotion, and inform future work. It was never the intention of the evaluation to assess the extent to which the RSPH education programme changed knowledge, attitude, or behaviour. This was excluded from the aims because of the inherent difficulty of disentangling the RSPH contribution to those changes from the DH contribution concurrently made through its own independent education programme.

## **4. 3. 2. Evaluation approach**

Programme implementation includes a combination of reach (who participated), dose (amount of intended units delivered), dose received (the extent to which participants use materials) (Baumana et al., 2006; Steckler and Linnan, 2002) and fidelity (quality of intervention delivered) (Steckler and Linnan, 2002; Brandt et al., 2005). Implementation assessment is a process evaluation (Baumana et al., 2006) (post-dissemination research and part of summative evaluation) (Flay, 1987). Process evaluation can be used to

assess the process of delivering a health promotion programme ( Rural and Regional Health and Aged Care Services Division, 2003). This type of evaluation focuses on what the programme does and for whom (Public Health Agency of Canada, 2007). Process evaluation measures the activities of the programme (Rural and Regional Health and Aged Care Services Division, 2003; Steckler and Linnan, 2002). By matching activities with associated objectives and indicators of success, it provides a useful blueprint or template for evaluation design (Baumana et al., 2006) (Rural and Regional Health and Aged Care Services Division, 2003). It addresses the question of how well the programme was implemented and who it reached (is the programme operating as planned?) (Corrigan, 2006). Process evaluation assures that planned interventions are carried out equally at all sites (Steckler and Linnan, 2002).

The evaluation applied to this study was what is known as an “objective-based” approach (Christie and Alkin, 2004). This approach has been particularly popular in educational evaluation and examines the match between the intended objectives of a programme and the actual achievement. Although the approach has been criticised for its simplicity, it is well suited to the current situation, where there is a clear operational objective in terms of maximising the “reach” or market penetration of the leaflets and teaching packs. “Reach” is one of five dimensions of RE-AIM (reach, efficacy, adoption, implementation and maintenance) framework used to evaluate the public health impact of health promotion interventions. The RE-AIM evaluation model can be used to evaluate studies with different designs. The evaluation based on the “reach” dimension refers to the proportion of the target population that receives or participates in an intervention. Calculation of participation rates is based on information about programme participants (the numerator) and the whole sample for a defined population (the denominator), such as all members in a given clinic, health maintenance

organization, or worksite. “Reach” requires information about the characteristics of participants and non-participants (Glasgow et al., 1999).

The focus of the evaluation was on the number of requests received for the teaching packs; and the analysis could be further disaggregated by the nature and type of school making the request, and its location. In this way, the extent to which responses were geographically localised or UK-wide could also be assessed.

The evaluation relied on information provided by Phoenix Consultancy about the schools targeted for the teaching packs, and records from RSPH of those schools which requested the additional resources.

The study took place at the Centre for Public Health Research at Brunel University between October 2007 and June 2009. Ethical approval was obtained from Brunel University.

### **Study design**

This empirical work was a cross-sectional study.

### **4. 3. 3. Data source**

A database was created of all schools that did and did not request additional information following the initial RSPH letter. There were 5,715 schools around the UK included in the initial mail-out in March. There were 36 schools in the database from the UK Isles, and these were excluded from the evaluation, leaving a school sample of 5,679 schools. The Isle of Man launched the HPV vaccination programme in 2010 (Isle of Man Government, 2014). Comparing responding and non-responding schools, it is possible to see if some types of school were more likely to request additional information than others, and the characteristics of those schools. The information provided by Phoenix

Consultancy included the size of the school, the type of school, and the age range of the students. Using the postcode of the school it was also possible to determine the location of the school and the level of deprivation of the area in which it was located (Department for Communities and Local Government, 2008).

#### 4.3.4. Results

The countries in which the schools were located is shown in Table 14. The majority of the schools are located in England (83.6%), fewer in Scotland (7.6%), Wales (4.5%), or Northern Ireland (4.2%).

**Table 14. Distribution of the schools across the UK**

| Country          | % of Total Schools | N    |
|------------------|--------------------|------|
| England          | 83.6               | 4750 |
| Scotland         | 7.6                | 434  |
| Wales            | 4.5                | 256  |
| Northern Ireland | 4.2                | 239  |
| Total            | 100                | 5679 |

Some of the descriptive statistics are not available in a disaggregated form for all countries. The number of leaflets and teaching packs distributed is described, as well as the proportion of schools requesting teaching packs. These data are further disaggregated by the location and type of school. Logistic regression, an analytic technique, was used to investigate the relationship between requests for additional information and region, level of area deprivation, school type, and school size.

All statistical analysis was performed using STATA/SE 10.0

## **Descriptive statistics**

Overall, around 30% of schools across the UK requested materials (28.9%), the majority of those requested teaching packs (i.e., n=1,632). A very small number of schools requested leaflets only (n=7). Most schools requesting a teaching pack only requested one. A total of 1,872 teaching packs were distributed across the 1,632 schools. It should also be noted that all teaching packs included at least one leaflet. Approximately 19,000 leaflets were distributed to schools specifically requesting leaflets. The median number of leaflets distributed to a requesting school was 250.

## **Geographic location**

The location of schools, and whether they requested teaching packs was mapped using map-resources from the US Centers for Disease Control and Prevention (CDC) site (Figure 2) (Centers for Disease Control and Prevention, 2009). The location of the schools was estimated on the basis of their postcodes (GeoConvert, 2009); unfortunately, location based on postcode could not be readily identified for Northern Ireland, so the map is for England, Scotland and Wales only.

**Figure 2. Distribution of schools in England, Wales and Scotland included in the mail-out**



(Orange points represent schools that requested teaching packs, green points represent schools not requesting teaching packs)

Figure 2 shows the logically anticipated preponderance of requests from urban areas. In England, the requests came mainly from schools in London, cities in the Midlands, and North West. In Wales, the requests came mainly from schools in the South between Cardiff and Swansea. In Scotland, the requests came mainly from schools in and around Glasgow and Edinburgh. From the map, it is difficult to get a sense of regional differences in the levels of requests, but what is provided is a sense of the general distribution of both requests and non-requests for teaching packs.

### Schools by Country

Of the schools in each country that were sent the initial letter, it was possible to calculate the proportion that requested the teaching packs, in each country (Table 15).

**Table 15. Distribution of the schools which requested and did not request teaching packs – variation by country**

| <b>Country</b> | <b>Request</b> |             | <b>No request</b> |             | <b>Total N</b> |
|----------------|----------------|-------------|-------------------|-------------|----------------|
|                | <b>%</b>       | <b>N</b>    | <b>%</b>          | <b>N</b>    |                |
| England        | 27.9           | 1327        | 72.1              | 3423        | 4750           |
| N. Ireland     | 20.1           | 48          | 79.9              | 191         | 239            |
| Scotland       | 38.5           | 167         | 61.5              | 267         | 434            |
| Wales          | 35.2           | 90          | 64.8              | 166         | 256            |
| <b>Total</b>   | <b>28.7</b>    | <b>1632</b> | <b>71.3</b>       | <b>4047</b> | <b>5679</b>    |

There was a substantial (>10%) disparity in the requests for teaching packs between the countries. A little over thirty eight percent (38.5%) of schools in Scotland requested teaching packs. A few percent less in Wales requested teaching packs (35.2%). In England, around 28% of school requested teaching packs (27.9%). Northern Ireland,

however, had a substantially lower take-up of teaching packs (20.1%), almost 20% less than Scotland.

### Schools in urban/rural areas

A similar analysis can be conducted with respect to the distribution teaching packs and the level of geographical isolation. England and Wales share a method for classifying regions as urban, town, village or hamlet in sparsely or less sparsely populated areas (according to 2001 Census data) (Bibby and Shephard). Scotland and Northern Ireland have each adopted different systems which are not entirely comparable with the England/Wales system – or indeed, each other. Given that, by a substantial margin, most of the schools and most of the requests for teaching packs came from England and Wales, the effect of geographic isolation was only examined in the context of those two countries. Four categories of school were created (Table 16):

- Schools in urban or town areas in less sparsely populated areas (Urban Less Sparse);
- Schools in urban or town areas in sparsely populated areas (Urban Sparse);
- Schools in villages and hamlets in less sparsely populated areas (Rural Less Sparse);
- Schools in villages and hamlets in sparsely populated areas (Rural Sparse).

**Table 16. The proportion of the schools in urban/rural areas in England and Wales requesting teaching packs**

| <b>Level of Isolation</b> | <b>Request</b> |             | <b>No request</b> |             | <b>Total N</b> |
|---------------------------|----------------|-------------|-------------------|-------------|----------------|
|                           | <b>%</b>       | <b>N</b>    | <b>%</b>          | <b>N</b>    |                |
| Urban Less Sparse         | 28.6           | 1255        | 71.4              | 3138        | 4393           |
| Urban Sparse              | 26.5           | 27          | 73.5              | 75          | 102            |
| Rural Less Sparse         | 27.3           | 124         | 72.7              | 331         | 455            |
| Rural Sparse              | 22.9           | 11          | 77.1              | 37          | 49             |
| <b>Total</b>              | <b>28.4</b>    | <b>1417</b> | <b>71.6</b>       | <b>3581</b> | <b>4998</b>    |

There is some variation in the take-up of the teaching pack with 23% of schools in villages and hamlets from sparsely populated areas requesting teaching packs. The number of schools, however, is few in all areas except the less sparsely urban areas, which includes the major cities, that no robust pattern could be discerned from the data. This is, however, returned to later.

### **Government Office Region**

The “Government Office Regions” (GOR) divide England into nine distinct local government administrative regions. Using the GOR for England and whole country for Wales and Scotland it is possible to obtain a clearer sense of regional variation in the take-up of the HPV teaching packs (Figure 3).

**Figure 3. Percentage of schools requesting teaching packs in Scotland, Wales, and the separate Government Office Regions of England**



London and the North East of England stand out as having the lowest take-up rates of teaching packs (20% and 21% respectively). The West Midlands and South East of England have both 27% take-up rates, which are almost the same as the take-up rates for England (28%). The remaining GORs in England have take-up rates varying between

30% (e.g, North West and Yorkshire and the Humber Side) and 34% (East of England). Wales (35%) and Scotland (38%), however, had the best take-up rates.

### **Deprivation of local area**

Having examined the take-up of the teaching packs by country, level of geographic isolation, and region, it would be appropriate to end the consideration of geography as a factor affecting take-up, by considering the relationship between local area deprivation and take-up of teaching packs.

The Index of Multiple Deprivation (IMD) 2007 combines 37 indicators related to a range of economic, social and housing issues, into a single deprivation score for each Local Super Output Area (LSOA) – small area in England with an average population of 1500 people (Department for Communities and Local Government, 2008). Accordingly, each LSOA is ranked relative to one another by their level of deprivation (Department for Communities and Local Government, 2008). The most-deprived areas have lowest ranks and highest scores. The IMD score of a postcode could be estimated on the basis of the LSOAs sharing the postcode.

Unfortunately, the deprivation scores derived for one country in the UK cannot be compared with those from the deprivation indexes of other UK countries and the IMD 2007 was available only for England. In England, the greatest percentages of LSOAs in the most deprived 20% were located in the north (North East, North West, Yorkshire & the Humber) and London (Department for Communities and Local Government, 2008), which may explain the regional variation in take-up of teaching packs.

The IMD scores were available for all but one of the schools in England (i.e., n=4,749). The score would reflect the level of deprivation of the local area in which the school was located. It would not necessarily reflect the level of deprivation of the areas in which the students attending the school lived. Nonetheless, for many students, the level of deprivation of the area in which the school was located would stand as a fair proxy of the level of deprivation associated with the areas in which they lived.

The IMD scores were divided into quintiles representing the schools located in the most deprived 20% of postcodes through to the schools located in the least deprived 20% of postcodes. Table 17 shows the relationship quintile of deprivation and take-up of teaching packs.

Table 17 shows a steady gradient of decreasing take-up of teaching packs with increasing levels of deprivation in schools in England. That is, schools located in more deprived areas appear to be less likely to take-up teaching packs than schools in less deprived areas. This theme is revisited.

**Table 17. Distribution of the schools which requested teaching packs by quintile of deprivation**

| <b>Quintiles of Deprivation</b> | <b>Requests</b> |          | <b>Total N</b> |
|---------------------------------|-----------------|----------|----------------|
|                                 | <b>%</b>        | <b>N</b> |                |
| <b>Least Deprived</b>           | 31.7            | 301      | 950            |
| <b>2<sup>nd</sup> Quintile</b>  | 30              | 284      | 948            |
| <b>3<sup>rd</sup> Quintile</b>  | 28.3            | 269      | 949            |
| <b>4<sup>th</sup> Quintile</b>  | 24.7            | 235      | 950            |
| <b>Most Deprived</b>            | 25.1            | 238      | 947            |

## School type

Eighteen distinct types of school were identified in the original mail-out database. Most of these types, however, could be reduced either to forms of independent school (i.e., schools that are not reliant on state funding) or to forms of maintained school (i.e., schools reliant on funding by the state at the level of local government, or higher). In the database, approximately 79% of the schools were maintained and 21% of the schools were independent across the UK.

Table 18 shows the breakdown of requests for teaching packs by independent and maintained schools.

**Table 18. Request for teaching packs by the type of school**

| <b>School Type</b> | <b>Request</b> |          | <b>No Request</b> |          | <b>Total</b> |
|--------------------|----------------|----------|-------------------|----------|--------------|
|                    | <b>%</b>       | <b>N</b> | <b>%</b>          | <b>N</b> | <b>N</b>     |
| <b>Independent</b> | 22.9           | 272      | 77.1              | 918      | 1190         |
| <b>Maintained</b>  | 30.3           | 1360     | 69.7              | 3129     | 4489         |

Independent schools requested less teaching packs than maintained schools. The explanation for this may lie in the particular religious or moral values maintained by independent schools, and this will be discussed later.

## School size

The relationship between requests for the teaching packs and the size of the student body in a school was investigated because it seemed possible that smaller schools would have less capacity to take-up new teaching materials than larger schools. Around 230 of the schools had a student body of fewer than 100 students. Schools were first divided

into quintiles according to the size of the student body. Table 19 shows the take-up of teaching materials across the schools of different sizes.

**Table 19. Distribution of the schools which requested teaching packs by quintile of the student body**

| <b>Quintiles of School Size</b> | <b>Requests</b> |          | <b>Total N</b> | <b>Average Size</b> |
|---------------------------------|-----------------|----------|----------------|---------------------|
|                                 | <b>%</b>        | <b>N</b> |                |                     |
| <b>Smallest</b>                 | 18.5            | 301      | 1146           | 227                 |
| <b>2<sup>nd</sup> Quintile</b>  | 28.8            | 284      | 1142           | 573                 |
| <b>3<sup>rd</sup> Quintile</b>  | 32.2            | 269      | 1160           | 842                 |
| <b>4<sup>th</sup> Quintile</b>  | 30.9            | 235      | 1169           | 1086                |
| <b>Largest</b>                  | 33.7            | 238      | 1062           | 1487                |

The results suggest that the smallest schools had the lowest take-up rate of teaching materials (18.5%). Once a school exceeds the smallest quintile of schools in size, however, it appears that further increases are not associated with further increases in the take-up rate.

### **Analytic statistics - logistic regression**

The descriptive analysis of the geographical data and the school specific data provides an appropriate entrée to a more complex analysis of the interrelationship between school and geographic factors and the take-up of the teaching packs. (An article specifically examining whether local area deprivation is an independent predictor of the take-up of teaching packs is appended.)

The analysis used logistic regression because of the binary nature of the outcome (request coded “0 = no” and “1= yes”). The aim of logistic regression was to examine the bivariate relationship between the geographic or school factors and whether a school did or did not request a teaching pack. A progressive modelling approach was used, in

which each geographic and school factor and its relationship to requests for teaching packs was examined in isolation. This provided crude odds ratios representing the strength of the association between the factors and the request for teaching packs. A multiple logistic regression model was then developed in which the statistically significant factors were simultaneously included in the logistic regression. Pooling the statistically significant school and geographic factors produced adjusted odds ratios. Adjusted odds ratios can be interpreted as the independent effect of one factor on schools' decisions to request teaching packs, after the effect of the other factors have been taken into account.

Table 19a shows the results of the series of bivariate logistic regression models. In the presentation of the results one category is the base category. For example, in the analysis of difference between the level of take-up by country, one country (England) is the base category, and the take-up level in the other countries are all compared to that one.

**Table 19a: The relationship between geographic factors and the take-up of teaching packs: unadjusted odds-ratios, 95% confidence intervals, and p-values**

| Factors                  | Unadjusted odds ratio | 95% CI      | p    | N     |
|--------------------------|-----------------------|-------------|------|-------|
| <b>Country</b>           |                       |             |      | 5,679 |
| England                  | (1)                   | –           | –    |       |
| Scotland                 | 1.61                  | 1.32 – 1.98 | .000 |       |
| Wales                    | 1.4                   | 1.07 – 1.82 | .013 |       |
| N. Ireland               | 0.65                  | 0.47 – 0.9  | .008 |       |
| <b>Area Deprivation</b>  |                       |             |      | 4,744 |
| Most Deprived            | (1)                   | –           | –    |       |
| 4 <sup>th</sup> Quintile | 0.98                  | 0.79 – 1.21 | .84  |       |
| 3 <sup>rd</sup> Quintile | 1.18                  | 0.96 – 1.44 | .114 |       |
| 2 <sup>nd</sup> Quintile | 1.27                  | 1.04 – 1.56 | .019 |       |
| Least Deprived           | 1.38                  | 1.13 – 1.69 | .002 |       |
| <b>GOR*</b>              |                       |             |      | 4,765 |
| London                   | (1)                   | –           | –    |       |
| South West               | 1.98                  | 1.52 – 2.59 | .000 |       |
| South East               | 1.52                  | 1.20 – 1.93 | .000 |       |
| West Midlands            | 1.47                  | 1.13 – 1.92 | .004 |       |
| East Midlands            | 1.97                  | 1.46 – 1.65 | .000 |       |
| East of England          | 2.05                  | 1.58 – 2.65 | .000 |       |
| North West               | 1.69                  | 1.32 – 2.17 | .000 |       |
| North East               | 1.06                  | 0.75 – 1.51 | .33  |       |
| Yorkshire-Humber         | 1.71                  | 1.30 – 2.25 | .000 |       |

\* England only

**Table 19b. The relationship between school factors and the take-up of teaching packs: unadjusted odds-ratios, 95% confidence intervals, and p-values**

| Factors                  | Unadjusted odds ratio | 95% CI      | p    | N     |
|--------------------------|-----------------------|-------------|------|-------|
| <b>School type</b>       |                       |             |      | 5,679 |
| Independent              | (1)                   | –           | –    |       |
| Maintained               | 1.47                  | 1.26 – 1.70 | .000 |       |
| <b>School size</b>       |                       |             |      | 5,679 |
| Smallest                 | (1)                   | –           | –    |       |
| 2 <sup>nd</sup> Quintile | 1.78                  | 1.46 – 2.17 | .000 |       |
| 3 <sup>rd</sup> Quintile | 2.09                  | 1.72 – 2.53 | .000 |       |
| 4 <sup>th</sup> Quintile | 1.97                  | 1.62 – 2.39 | .000 |       |
| Largest                  | 2.23                  | 1.83 – 2.71 | .000 |       |

Schools in Scotland and Wales were significantly more likely to request teaching packs than schools in England or Northern Ireland. One can see in Table 19a that the highest take-up rates were Scotland, with odds of requesting the teaching pack 1.6 times greater

than England. Northern Ireland, in contrast, was 0.65 times as likely to request a teaching pack as England. Schools in the least deprived areas had odds 1.38 times higher rate of requesting teaching packs than schools in the most deprived areas. There was, furthermore, a significant trend in the relationship between decreasing deprivation and increasing take-up of teaching packs ( $z=-3.99$ ,  $p<.001$ ). This trend was maintained even when the most deprived quintile of schools was removed from the analysis ( $z=-2.81$ ,  $p<.005$ ). Within England, schools in seven of the nine “Government Office Regions” were significantly more likely to take-up teaching packs than schools in London. The exception was the North East, where schools were not significantly more likely to take-up teaching packs than schools in London. Schools in the East and South West of England and in the East Midlands, were about twice as likely to take-up teaching packs as schools in London. Schools in the South East and in the West Midlands were about 1.5 times as likely to take-up teaching packs as schools in London.

Government maintained schools had odds about 1.5 times higher of requesting teaching packs than independent schools. School size was also significantly associated requests for teaching packs with smaller schools significantly less likely to take-up teaching packs than larger schools. The largest schools had odds of requesting teaching packs twice those of the smallest schools. There was, furthermore, a significant trend in the relationship between increasing school size and the take-up of teaching packs ( $z=7.59$ ,  $p<.001$ ). This trend was maintained even when the smallest quintile of schools was removed from the analysis ( $z=2.09$ ,  $p<.05$ ) (Table 19b).

Individually examining the relationships between each geographic or school factor and the take-up of teaching packs can mask dependencies in the data. For example, smaller schools were identified as less likely to request teaching pack, and some countries were

also identified as less likely to request teaching packs than others. If smaller schools, however, occur exclusively in those countries that are less likely to request teaching packs then it becomes impossible to disentangle a school size effect from a country effect. The relationships were further analysed using multivariate logistic regression. In this way, it is possible to identify the effect of a particular school or geographic factor after taking account of the effects of all the other school and geographic factors. Table 20a shows the multivariate analysis for all schools of the UK. The factors examined were country, school type (independent or maintained), and school size.

Independent of school size and country, there is no longer any association between the type of school and the take-up of teaching pack. After adjusting for school type and school size, however, there remained a significant association between the country and the take-up of teaching packs. Schools in Scotland remained significantly more likely to request teaching packs than those in England (OR=1.6,  $p<.001$ ) as were schools in Wales (OR=1.3,  $p<.05$ ). Schools in Northern Ireland remained significantly less likely to request teaching packs (OR=0.7,  $p<.05$ ). After adjusting for school type and country, there remained a significant association between the school size and the take-up of teaching packs, with larger schools associated with greater odds of requesting teaching packs than smaller schools. Indeed, schools larger than the smallest quintile of schools were roughly twice as likely to request teaching packs ( $p<.001$ ).

**Table 20a. The relationship between school and geographic factors in the United Kingdom and the take-up of teaching packs: adjusted odds ratios, 95% confidence intervals, and p-values**

| <b>Factors</b>           | <b>Adjusted odds ratio</b> | <b>95% CI</b> | <b>p</b> |
|--------------------------|----------------------------|---------------|----------|
| <b>School type</b>       |                            |               |          |
| Independent              | (1)                        | –             | –        |
| Maintained               | 1                          | 0.84 – 1.19   | .985     |
| <b>School size</b>       |                            |               |          |
| Smallest                 | (1)                        | –             | –        |
| 2 <sup>nd</sup> Quintile | 1.78                       | 1.44 – 2.2    | .000     |
| 3 <sup>rd</sup> Quintile | 2.05                       | 1.66 – 2.54   | .000     |
| 4 <sup>th</sup> Quintile | 1.94                       | 1.56 – 2.41   | .000     |
| Largest                  | 2.21                       | 1.77 – 2.76   | .000     |
| <b>Country</b>           |                            |               |          |
| England                  | (1)                        | –             | –        |
| Wales                    | 1.34                       | 1.02 – 1.74   | .033     |
| Scotland                 | 1.63                       | 1.32 – 2      | .000     |
| N. Ireland               | 0.7                        | 0.50 – 0.96   | .029     |

Table 20b shows the multivariate analysis for England only, which includes area deprivation and Government Office Region, but necessarily excludes country. An examination of the odds ratios for quintiles of area deprivation shows a steady increase in the take-up rate of teaching packs by schools as the level of deprivation decreases. This holds even after taking account of school size, school type, and the Government Office Region of England. Those schools located in the least deprived areas had odd 1.3 times greater of requesting teaching packs than schools in the most deprived quintiles (OR=1.31,  $p < .015$ ). The Government Office Region also showed an independent association with the request for teaching packs. Those associations identified in the univariate analysis largely held in the multivariate analysis.

**Table 20b. The relationship between school and geographic factors in England and the take-up of teaching packs: adjusted odds ratios, 95% confidence intervals, and p-values**

| Factors                  | Unadjusted odds ratio | 95% CI      | p    |
|--------------------------|-----------------------|-------------|------|
| <b>Area Deprivation</b>  |                       |             |      |
| Most Deprived            | (1)                   | –           | –    |
| 4 <sup>th</sup> Quintile | 0.94                  | 0.76 – 1.17 | .582 |
| 3 <sup>rd</sup> Quintile | 1.15                  | 0.94 – 1.42 | .180 |
| 2 <sup>nd</sup> Quintile | 1.24                  | 1.00 – 1.53 | .046 |
| Least Deprived           | 1.31                  | 1.05 – 2.53 | .015 |
| <b>GOR</b>               |                       |             |      |
| London                   | (1)                   | –           | –    |
| South West               | 1.91                  | 1.46 – 2.49 | .000 |
| South East               | 1.46                  | 1.14 – 1.86 | .002 |
| West Midlands            | 1.47                  | 1.12 – 1.92 | .005 |
| East Midlands            | 1.84                  | 1.37 – 2.49 | .000 |
| East of England          | 1.91                  | 1.46 – 2.49 | .000 |
| North West               | 1.56                  | 1.21 – 2.01 | .001 |
| North East               | 1.62                  | 1.23 – 2.13 | .001 |
| Yorkshire-Humber         | 1.03                  | 0.72 – 1.47 | .892 |
| <b>School type</b>       |                       |             |      |
| Independent              | (1)                   | –           | –    |
| Maintained               | 0.95                  | 0.78 – 1.16 | .602 |
| <b>School size</b>       |                       |             |      |
| Smallest                 | 1                     | –           | –    |
| 2 <sup>nd</sup> Quintile | 1.99                  | 1.56 – 2.53 | .000 |
| 3 <sup>rd</sup> Quintile | 2.23                  | 1.74 – 2.86 | .000 |
| 4 <sup>th</sup> Quintile | 2.17                  | 1.69 – 2.79 | .000 |
| Largest                  | 2.42                  | 1.87 – 3.12 | .000 |

Schools in the South West and the East of England were around 1.9 times more likely to request teaching packs than schools in London ( $p < .001$ ). The schools in the remaining regions, with the exception of schools in Yorkshire and the Humber were about 1.5 times more likely than schools in London to request teaching packs ( $p < .01$ ). There was no significant difference in the take-up rate of schools in London and schools in Yorkshire and the Humber. Although univariate analysis showed that the schools in the North East were not significantly more likely to take-up teaching packs than schools in London, the multivariate analysis indicated that the requests in the schools in the North East were significantly different to the requests in the schools in London. This is

because the multivariate analysis shows how well each independent variable predicts the dependent variable, controlling for each of the other independent variables. The p-value for each independent variable indicates if a particular independent variable is a significant predictor of the dependent variable, over the other independent variables. For example, an independent variable that is a significant predictor of a dependent variable in simple linear regression may not be significant in multiple regression. Apart from the individual influence of each independent variable on the dependent variable while controlling for the other independent variables, the multivariate analysis shows the combined influence of all independent variables on the dependent variable. In this respect, the multivariate analysis is more accurate than simple regressions for each independent variable (Tabachnick and Fidell, 1989).

After controlling for school size, area deprivation, and the Government Office Region, there was no significant association between the type of school (maintained or independent) and the take-up of teaching packs.

Size of school continued to show a significant association with the take-up rate of teaching packs, even after controlling for the other school and geographic factors. Schools in the second quintile of size were around twice (OR=1.99,  $p<.001$ ) as likely as the smallest schools to request teaching packs, and this rose to around 2.4 times in the fifth quintile of school size (OR=2.42,  $p<.001$ ).

## **4. 4. Summary**

Using a database of all schools in the UK, I investigated the relationship between requests for information materials and school and geographic factors. This chapter showed that around 30% of schools across the UK requested teaching packs. By country, the take-up of teaching packs ranged from 38.5% of schools in Scotland to

20.1% in Northern Ireland. In England, East of England had the best take-up rates (34%) and London (20%) had the fewest requests.

A multivariate logistic regression model showed that those schools located in the least deprived areas in England had higher odds of requesting teaching packs than schools in the most deprived quintiles when the other factors, the GOR, school type and school size, were held constant. After controlling for other school and geographic factors (school type, area deprivation, and the GOR), the largest schools had the highest odds of requesting teaching packs compared to the smallest schools. Independent of the effect of area deprivation, school type and school size, the schools in seven GORs, with the exception of schools in Yorkshire and the Humber, were more likely than schools in London to request teaching packs.

The findings of work relating to the national study suggested the lowest uptake of teaching packs in the most deprived areas. In addition, statistics related to cervical cancer age-standardized rates between 2005 and 2009 showed that the West Midlands was one of the regions with higher rates (9.6%) than the national average (8.7% in England). Therefore, it was a need for further research which constituted the case study in a city in the West Midlands which I will go on to describe and explain in more detail in the next chapters of this thesis.

In the next chapter, I describe the city of the study and the methodology of the study based on mixed methods research.

# CHAPTER 5: SETTING AND METHODS OF THE STUDY IN THE WEST MIDLANDS

This chapter includes two sections, one that describes the city of the study and another one that provides details about the methodology of the study.

The first section, which presents the health profile of the city of study, is structured in three parts. Part one contains statistical data about the population including aspects of demography, ethnicity and employment. Part two gives information about area deprivation and part three presents health programmes provided since 2008 with special emphasis on sexual health services.

## 5. 1. Setting – a city in the West Midlands

### 5. 1. 1. Population

#### 5. 1. 1. 1. Demography

According to the Office for National Statistics, the resident population in the city of study in June 2009 was 312,800 persons. Half of the population (53%) was of working age (20-59 years) in 2001 (Table 21).

**Table 21. Age structure in the city of study in 2001**

| <u>Age (years)</u> | <u>Percentage</u> |
|--------------------|-------------------|
| 0-9                | 12.87             |
| 10-19              | 14.33             |
| 20-29              | 15.01             |
| 30-44              | 21.34             |
| 45-59              | 16.58             |
| 60-74              | 12.45             |
| 75-89              | 6.89              |
| 90 and over        | 0.53              |

Source:(Office for National Statistics, 2004a)

### **5. 1. 1. 2. Ethnicity**

The estimates by ethnic group showed that 79.2% were White and the majority (74.1%) were White British. 12.3% were Asian. Out of these, 7.7% were Indian and 2.9% were Pakistani. 3.1% were Black, mainly Black African (1.6%) and Black Caribbean (1.3%). Chinese or other ethnic groups represented 3% (Office for National Statistics, 2011). Data on people's religion in the city of study from the 2001 Census showed that 76.9% of people had a religion. Out of these, 65.3% were Christians, 4.6% were Sikhs, 3.9% were Muslims and 2.6% were Hindus. The people with no religion represented 15.1% (Office for National Statistics, 2004b).

### **5. 1. 1. 3. Employment**

The ONS annual population survey in 2013 reported that in the city of study, the employment rate was 66.9% and the unemployment rate was 8.3%. By gender, the employment rate was 76.5% for men and 56.9% for women. The unemployment rate was higher for women than for men (8.3% vs. 7.2%). The employment by occupation groups (Office for National Statistics, 2000)<sup>16</sup> was high in professional (17.8%), associate professional and technical (12.9%), administrative and secretarial (11.1%) and elementary (14.9%) occupations (Office for National Statistics, 2014).

### **5. 1. 2. Deprivation**

The city of study was ranked 50<sup>th</sup> out of 265 Local Authorities (LAs) for average IMD 2010 scores<sup>17</sup>. This rank placed the city of study in the 16% most deprived LAs. It was more deprived in comparison to other parts of England. Almost a third of the total

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<sup>16</sup> Standard Occupation Classification 2000 is applicable to all paid jobs performed by economically active persons in the UK. Jobs are recognized by the associated job title. They are classified into groups according to the concept of “skill level” and “skill specialisation”

<sup>17</sup> The IMD score is allocated at Lower Super Output Area (LSOA)

population (31%) lived in “most deprived” neighborhoods, compared to 20% in England. Life expectancy was 11.5 years lower for men and 7.7 years lower for women in the most deprived areas than in the least deprived areas in the city (NHS Coventry and Coventry City Council, 2011).

### **5. 1. 3. Health programmes**

The Health Improvement Programme in the city of study commenced in 2009/10 and finished in 2011/12. The programme represented a partnership between the NHS and the City Council and it was designed to promote the health and well-being of the population in the city of study, using a combination of evidence-based programmes and innovative approaches in prevention and early intervention. Priorities included tackling smoking, obesity in children and sexual health of young people. The nine projects areas within Health Improvement Programme were alcohol, health at work, health checks, healthy weight, infant mortality, parenting, sexual health, smoking and well-being. The evaluation of the projects was outcome-based in relation to improving health and reducing health inequalities (NHS Coventry and Coventry City Council, 2011).

#### **5. 1. 3. 1. Sexual health services**

In 2008, the Board in the NHS in the city of study approved a Sexual Health Needs Assessment and adopted a sexual health and HIV Strategy. One of the objectives of the local policy was to reduce the rates of STIs, especially infections with Chlamydia, genital warts and gonorrhoea. Sexual health services (i.e., advice, health promotion, screening, contraception, hepatitis B immunization, STI testing) for those aged less than 25 years were provided in different settings such as Genito-Urinary Medicine clinics based at the hospital in the city of study and GP practices. Sexual health services were also provided in schools where nurses offered sexual health advice and made

recommendations for appropriate services. In addition, school nursing service supported the delivery of Relationship and Sex Education in schools. In contrast with local schools, the two universities in the city of study provided fewer sexual health services (NHS Coventry, 2009).

#### **5. 1. 3. 1. 1. Cervical screening**

The incidence of cervical cancer was higher in the city of study (17.1 per 100,000 women) than the incidence in the West Midlands overall (14.9 per 100,000 women). The NHS in the city of study has run a cervical screening programme, providing call and re-call services (i.e., text reminders, flagging patient records and personalized letters) to patients. An audit of access to cervical screening was carried out in 2009/10 and found a downward trend in cervical screening coverage, especially in the oldest (60-64) and youngest (25-29) age groups (Tennant, 2010). Cervical screening coverage was lower in the city of study (71.3%) compared to the West Midlands overall (73.9%) and England (74%) (NHS Coventry and Coventry City Council, 2011). The main conclusions of the audit were that deprivation was negatively correlated with coverage for cervical screening. Coverage was 81% for women in the least deprived areas of in the city of study compared to 71% among women in the most deprived areas. Coverage was particularly low in Muslim, non-Gujarati Hindu and Sikh women (significantly below the average for non-Asian women). There was no data about the use of cervical screening among non-Asian ethnic subgroups, nor among lesbian women. Some educational campaigns were made to advertise cervical screening in hair dressing salons and by radio, aiming at reaching young women, especially in deprived parts of the city (Tennant, 2010).

### **5. 1. 3. 1. 2. HPV immunization policy**

The DH and the Scottish Government began the implementation of a routine HPV immunization school based programme with the bivalent vaccine (Department of Health, 2008b, Salisbury, 2008; Kmietowicz, 2008; Woods, 2007) for girls aged 12-13 years in September 2008 (Department of Health, 2008a; Woods, 2007) along with a catch up campaign for girls aged up to 18 years (Woods, 2007; Sheridan and White, 2011). The national accelerated catch-up programme for HPV vaccine finished in August 2011 and since that time only year 8 girls have received the vaccine in line with the national programme (NHS Coventry and Coventry City Council, 2011). On advice from the Joint Committee on Vaccination and Immunisation (JCVI) it was decided that the vaccination programme was to be delivered through schools (Joint Committee on Vaccination and Immunisation, 2008a; NHS Coventry and Coventry City Council, 2011) as the majority of the target age group was in schools (Sheridan and White, 2011) and because school based programme might close racial, ethnic and socioeconomic gaps in immunization rates (Woods, 2007). In some instances the HPV immunisation programme was delivered by local general practitioners (GPs) for some of the girls in catch up cohorts (13 to 18 year old girls) (Sheridan and White, 2011).

The DH moved to a routine HPV immunization with the quadrivalent vaccine in September 2012 (Salisbury, 2011) in the context of NHS reform announced by the new Health and Social Care Bill (Department of Health, 2012).

### **5. 1. 4. Summary**

The population in the city was mainly White British. Asians (mostly Indian) were another ethnic group living in the city. 76.9% of all residents were religious such as Christians, Sikhs, Muslims or Hindus. Almost a third of the total population lived in “most deprived” neighborhoods, compared to England.

The incidence of cervical cancer was higher in the city than in the West Midlands overall. Cervical screening coverage was lower in the city compared to the West Midlands and England overall. Coverage was particularly low in Muslim, non-Gujarati Hindu and Sikh women.

An HPV vaccination programme has been delivered through schools since 2008. In the first two years, the programme covered routine and catch up cohorts and after 2010, it has targeted only year 8 girls.

## **5. 2. Methodology – Mixed methods research**

This section contains two parts. In part one, I present the research design and the justification for doing a case study, and I also mention the philosophical position of the researcher. In part two, I discuss the methodology based on mixed methods research, providing details about its rationale, purpose, design and mixing strategies.

### **5. 2. 1. Research design - case study**

#### **Case study design**

Yin defined a case study as an empirical inquiry that explores a contemporary social phenomenon thoroughly and within a real-life context (O'Cathain et al., 2007; Yin, 2009). A case study is chosen when the researcher has little control over events and when the boundaries between the phenomenon and the context are not clear. As any other research method, the purpose of a case study is descriptive, exploratory, or explanatory. A descriptive study depicts an intervention and the real-life context in which it occurred. An exploratory study aims at developing hypotheses for further inquiry. An explanatory study explains the presumed causal links in real-life interventions. The unit of analysis in a case study is selected in accordance with the

research question, and could be an individual or a group of people or organization(s). The case study's strength is its use of a full variety of evidence. This gives the opportunity to address a broader range of issues, to establish converging lines of inquiry and to enhance data credibility. Triangulation of data from multiple sources is the strategy to corroborate the same phenomenon viewed and explored from different perspectives (Yin, 2009). In this respect, a case study design is appropriate for mixed methods research because of its epistemological, ontological and methodological flexibility (Tashakkori and Teddlie, 2010). The disadvantage of a case study is that it is generalizable only to theoretical propositions and not to populations (Yin, 2009).

In this research, the case is a group of schools in a city in the West Midlands and it has an exploratory purpose to expand understanding about factors influencing uptake of the HPV vaccine delivered through a school-based programme. The proposition, which comes from the literature, states that different ethnic groups have faced various barriers to uptake of immunizations.

### **5. 2. 1. 1. The philosophical position of researcher**

Paradigms are perspectives of looking at reality (Hennink et al., 2011). A paradigm is defined as a model or framework that contains the philosophical issues of ontology, epistemology, methodology, and axiology. Ontology refers to assumptions and beliefs about the world (Tashakkori and Teddlie, 2010), how the world is viewed and what reality is thought to look like (Hennink et al., 2011). It is important what kind of ontological assumptions are brought to research because they determine the knowledge that is produced. Epistemology is the branch of philosophy that studies knowledge (Tashakkori and Teddlie, 2010). Methodology refers to the way in which knowledge about the world is generated (Tashakkori and Teddlie, 2010) and the way in which data collection is justified (Hennink et al., 2011). Axiology is the philosophical study of

value in social inquiry (Tashakkori and Teddlie, 2010). Values influence the choice of research, the observations in the field and the interpretation of observations (Johnson and Onwuegbuzie, 2004).

Different paradigms are described in the literature as examples of research models (Morgan, 2007). The positivist paradigm is the model for experimental approach and quantitative studies in social sciences, focusing on facts. The approach to quantitative research is based on deductive reasoning. The theoretical framework developed with information from existing literature guides data collection. The interpretative paradigm is the model for qualitative studies, seeking to understand the “meaning of social actions within the context where people live” (Hennink et al., 2011, p. 14). The approach to qualitative research is based on inductive reasoning. Concepts and theories emerge from information provided by participants (Hennink et al., 2011). Mixed methods research is considered the third research paradigm and is philosophically associated with pragmatism (Johnson and Onwuegbuzie, 2004).

### **5. 2. 1. 2. Pragmatism**

Pragmatism is a philosophical belief which was developed from the writings of Charles Sanders Peirce, William James and John Dewey. Pragmatism is viewed as a philosophical thinking focused on problem solving and outcomes. Pragmatism allows researchers to select any method based on its appropriateness (Tashakkori and Teddlie, 2010) and to mix the research approaches in ways (Johnson and Onwuegbuzie, 2004) that will best answer the research problem (Tashakkori and Teddlie, 2010). The strength of the pragmatic approach is given both by the epistemological interest in the nature of knowledge that is produced and by the technical interest in the methods used to produce that knowledge (Morgan, 2007). The pragmatic stance is the philosophical keystone for using mixed methods to generate information for answering research question

(Tashakkori and Teddlie, 2010). The pragmatic approach relies on abductive reasoning. It means to make a logical connection between theory and data and to “move back and forth between induction and deduction” (Feilzer, 2010, p. 10). Inductive results from a qualitative approach can serve as a basis for the deductive goals of a quantitative approach, and vice versa (Morgan, 2007).

Dewey’s pragmatism emphasizes the fact that there is a relationship between science (knowledge) and practice (action) and their results. In his view, knowledge is gained through the experience of actions in the world (Morgan, 2007) combined with reflection (Tashakkori and Teddlie, 2010). Knowledge is a human construction (Tashakkori and Teddlie, 2010) based on reality of the world people live in (Johnson and Onwuegbuzie, 2004). Dewey introduces the concept of intersubjectivity as a pragmatic emphasis on collaborative knowledge construction through social interactions (Morgan, 2007) and activity like observation, experience, and experiments (Johnson and Onwuegbuzie, 2004). Pragmatism allows researchers to use a value-oriented approach derived from cultural values (Johnson and Onwuegbuzie, 2004). The findings of research with a pragmatic stance are used to inform potential solutions to problems. In addition, the results of pragmatic inquiry are the basis for warranted evidence that can be used in other settings. This is known as the transferability of research results (Tashakkori and Teddlie, 2010). However, a major drawback of pragmatism is that it could not specify “for whom a pragmatic solution is useful” (Johnson and Onwuegbuzie, 2004, p. 19). Current philosophers criticize pragmatism because it has not proved to be a solution to many philosophical dualisms (Johnson and Onwuegbuzie, 2004).

## **5. 2. 2. Mixed method research**

### **5. 2. 2. 1. Rationale of mixed methods research**

The study employed a mixed method approach as the optimum way to address the research questions 2 and 3 (Tashakkori and Teddlie, 2010; Johnson and Onwuegbuzie, 2004).

Mixed methods research has frequently been used in health service research. The main justification for using a mixed methods approach has been comprehensiveness, and the need for a range of methodologies to understand the complexity of health care (O'Cathain et al., 2007). Several characteristics of mixed methods research justify its use in this study. First, it is valuable to combine quantitative and qualitative methods in one study without disregarding the philosophical principles of each one of them (Morgan, 2007). These different methods can be combined in such a way to complement their strengths and minimize their weaknesses. In order to mix research methods effectively, the strengths and weaknesses of quantitative and qualitative research should be considered (Johnson and Onwuegbuzie, 2004). Quantitative research has several strengths. It is useful to study a large number of people, to make predictions and to assess cause-and-effect relationships (Hennink et al., 2011; Johnson and Onwuegbuzie, 2004). The focus is on deduction, confirmation and theory/hypothesis testing. One of the disadvantages is that the knowledge produced cannot necessarily be applied directly to specific contexts or individuals (Johnson and Onwuegbuzie, 2004). The purpose of qualitative research is to understand and to explore how and why phenomena occur in local contexts. The focus is on induction, discovery, exploration and theory/hypothesis generation. The drawbacks are that the knowledge produced cannot necessarily be generalized to other people or settings and that data analysis is time-consuming (Johnson and Onwuegbuzie, 2004).

Second, mixed methods research with its methodological pluralism (Johnson and Onwuegbuzie, 2004) can address a variety of explanatory and exploratory questions at the same time, in comparison to single approach designs which focus on one type of inquiry (Tashakkori and Teddlie, 2010; Johnson and Onwuegbuzie, 2004). The roles of different methods within a mixed method study have been to address the range of research questions, to design the study (i.e., to determine the sample, to design study instruments), to combine data for further understanding, to interpret the findings and to determine generalisability (O’Cathain et al., 2007).

Third, mixed methods research is useful to obtain rich information because of the emergent themes derived from qualitative data collection and analysis (Tashakkori and Teddlie, 2010). Some of the disadvantages of mixed research are that it is time-consuming and it is difficult to interpret conflicting results (Johnson and Onwuegbuzie, 2004).

#### **5. 2. 2. 2. Purpose of mixed methods research**

Greene, Caracelli and Graham (1989) identified five purposes of mixed methods studies: triangulation, complementarity, initiation, development, and expansion (Greene et al., 1989). Mixed methods research could have one or more purposes (Onwuegbuzie and Leech, 2006). Triangulation is a methodological approach that represents the use of different and multiple research methods (O’Cathain et al., 2010) that study the same phenomenon (Onwuegbuzie and Leech, 2006; Johnson and Onwuegbuzie, 2004) (e.g., interviews and focus group discussion), sources (e.g., professionals and lay), theories (e.g., stages of behavior change and health belief model) or researchers (Farmer et al., 2006) to conduct a study, to have a broader understanding of the research findings (O’Cathain et al., 2010). The rationale of triangulation is to provide a stronger evidence for a conclusion (Johnson and Onwuegbuzie, 2004), overcoming any biases of the

different methods used (Greene et al., 1989). Thus, methodological triangulation increases the validity of research results (Farmer et al., 2006). Also, triangulation provides credibility to the process of integration of results (O’Cathain et al., 2010). However, there are some concerns in using this method with the purpose of confirmation (O’Cathain et al., 2007) because the coverage and the nature of findings from two or more data sets may differ and it may be difficult to determine agreement on results (Farmer et al., 2006).

Complementarity is used when different methods are applied to address different facets of a phenomenon (Greene et al., 1989) or different aspects of the research question (O’Cathain et al., 2007). This aspect differentiates complementarity from triangulation (Greene et al., 1989). Complementarity is used to elaborate, exemplify and clarify the results from one method with the findings from the other method (Johnson and Onwuegbuzie, 2004). The rationale of complementarity is to increase the interpretability, importance, and the validity of inquiry findings (Greene et al., 1989). Complementarity counteracts any biases of the different methods used and takes advantage of the strengths of different methods (Greene et al., 1989).

Initiation is used to discover contradictions and paradoxes (Onwuegbuzie and Leech, 2006). Disagreements between findings from different methods have been described as “inter-method discrepancy” (O’Cathain et al., 2010). Exploration of this discrepancy could result in a better understanding and reformulation of the research question (O’Cathain et al., 2010; Johnson and Onwuegbuzie, 2004). The rationale of initiation is to increase the depth of inquiry findings, interpreting them from different perspectives of different methods used and multiple paradigms (Greene et al., 1989).

Development uses the results from one method to formulate the research question (Onwuegbuzie and Leech, 2006), or to select the sample, or to develop the instrument or

to inform the analysis of the other method (Greene et al., 1989). The rationale of development is to enhance the validity of inquiry findings, taking advantage of different methods strengths (Greene et al., 1989). Expansion is used to increase the variety of research by using the most appropriate methods for different inquiry aspects (Onwuegbuzie and Leech, 2006; Johnson and Onwuegbuzie, 2004).

### **5. 2. 2. 3. Mixed methods research design**

The researcher can create a mixed-method design that effectively answers his/her research question (Johnson and Onwuegbuzie, 2004). There are six major mixed-method designs: the convergent parallel design, the explanatory sequential design, the exploratory sequential design, the embedded design, the transformative design and the multiphase design (Creswell and Plano Clark, 2011). Two aspects should be taken into consideration to create a mixed-method design: paradigm status (priority) and timing (Johnson and Onwuegbuzie, 2004). Quantitative and qualitative components of a mixed study could have equal status or one method could be dominant in comparison to the other one. Quantitative and qualitative phases could occur sequentially or concurrently (Creswell et al., 2004).

- The convergent parallel design occurs when quantitative and qualitative data collection and analyses are used at the same time with equal priority and the results are mixed during interpretation.
- The explanatory sequential design starts with quantitative data collection and analysis and its results are used for subsequent qualitative data collection and analysis.
- The exploratory sequential design starts with qualitative data collection and analysis followed by quantitative research method that tests or generalizes the initial findings.

- The embedded design is used when supporting data collection (i.e., qualitative) is added before, during or after the major data collection procedure (i.e., quantitative).
- The transformative design occurs when the concurrent or sequential qualitative and quantitative data collection and analysis are outlined within a theoretical framework that guides the methodology of the whole study.
- The multiphase design occurs when the concurrent or sequential qualitative and quantitative data collection is combined over multiple phases of a programme of study (Creswell and Plano Clark, 2011).

Apart from concurrent, sequential, conversion and fully mixed design, parallel mixed design is mentioned in the literature. Although it is a debatable design, it is accepted as a mixed design and is different from the convergent parallel design. The parallel mixed design is similar to the concurrent design when the data are collected and analyzed separately. What distinguishes the parallel mixed design from the concurrent design is the matter of integration. While the results of both data sets are integrated in concurrent design, the findings from the separate quantitative and qualitative data are not integrated in parallel mixed designs (Onwuegbuzie and Johnson, 2006) .

#### **5. 2. 2. 4. Mixing strategies in mixed methods research**

Mixing could occur in the design level (programme objectives, theory), methods of data collection, data analysis and data interpretation (Johnson and Onwuegbuzie, 2004; Onwuegbuzie and Johnson, 2006; Creswell and Plano Clark, 2011). The more methods are integrated into each of these procedures, the stronger the mix of the methods (Yin, 2006). The purpose of doing so is to keep, to analyze and to interpret mixed methods as a single study (Yin, 2006). Instruments of methods used (i.e., for quantitative and qualitative data collection) should include similar variables or items with the intention

to overlap or complement each other. In other words, designing quantitative and qualitative studies that address the same concepts facilitates merging the data sets. Mixing could be done through (1) merging the results of the two data sets, (2) connecting from the results of one type of data to the collection of the other, (3) embedding the two types of data within a larger design, (4) within a theoretical framework, or (5) within a programme objective framework (Creswell and Plano Clark, 2011). O’Cathain described three techniques for integrating qualitative and quantitative data in mixed methods studies: triangulation protocol, following a thread and mixed methods matrix. While triangulation protocol takes place at the interpretation stage of the research process, the other two techniques occur at the analysis stage of a mixed methods study. There are some strategies for mixing the two data sets of results (from quantitative and qualitative analyses) using triangulation protocol at the interpretation stage. One strategy is to summarize the findings, identifying the key concepts/themes in each data set (Creswell and Plano Clark, 2011), to list them on the same page (O’Cathain et al., 2010) and after that to compare or synthesize them (Creswell and Plano Clark, 2011). Another strategy is to look for differences within a data set of results based on the concepts/themes within the other data set of results. A third strategy is to transform the results from one data set (i.e., themes in qualitative research) into results specific to the other data set (i.e., numeric data in quantitative research). The interpretation of the merged results represents a discussion of how the two data sets of results converge, diverge or relate to each other (Creswell and Plano Clark, 2011) and offer complementary information on the same issue. Triangulation could also include “silence” which means that a finding arises from one data set and not another (O’Cathain et al., 2010).

### **5. 3. Summary**

In this research, quantitative data was used to define the context of the study, to describe and to explain the variation in HPV vaccine uptake across secondary schools by area deprivation, ethnicity and religion. The qualitative data supplemented the statistical results from the quantitative methods, and the statistical interpretation of relationships (O'Cathain et al., 2007) by adding meaning and context to them. The qualitative data provided material on the participants' experiences and views concerning the facilitators and the barriers to HPV vaccination uptake.

Quantitative and qualitative researches occurred concurrently. An equal priority and emphasis was given to collection and analysis of quantitative and qualitative data that occurred almost simultaneously. The design of this mixed methods research was a parallel design, which had two purposes: triangulation and complementarity. I collected and analyzed data separately and I produced two sets of findings that I present separately in the next two chapters.

In the next chapter, I describe the methods and the results of quantitative component of the mixed methods research.

# **CHAPTER 6 QUANTITATIVE RESEARCH – REPEATED CROSS SECTIONAL STUDY**

In this chapter, I describe the methods and results for research question 2. First, I describe my methods including data sources and the techniques I used to prepare the data for analysis; second, I describe methods of analysis including descriptive and inferential statistics and lastly I present the results of the study.

## **Research question 2**

Is there an association between uptake of HPV vaccine in secondary schools in a city in the West Midlands and area deprivation, ethnicity or religion?

## **6.1. Methods**

### **Study Design**

In order to answer this question I undertook a repeated cross-sectional study including all secondary schools in the city.

### **Sampling frame**

The city under study had twenty-nine secondary schools catering for girls in the relevant age groups.

### **Sample size**

I describe calculations to estimate the required sample size for my study, comparing two groups of secondary schools that had a continuous outcome variable (Campbell et al., 1995). I stratified the secondary schools in the city of study into two groups based on

deprivation of SCA (higher and lower than the median 27.50 of IMD score for SCA). The advantage of stratified sampling is that a separate and independent sample is selected within each stratum. In addition, creating strata increases the probability that key subgroups have sufficient sample size (Frankel, 2010). Random or probability sampling allows each school in the population (of all secondary schools in the city of study) to have a known nonzero probability of being selected in the sample. In addition, it allows generalization of the results (Frankel, 2010).

Quantitative studies aim to test a hypothesis. It is important to avoid errors known as type I and type II errors, which may lead to incorrect generalizations of the results (Fox et al., 2007). If the null hypothesis (i.e., there is no difference in uptake by area deprivation) is rejected when it is in fact true, then this error is called a Type I error. The statistical significance of a statistical test (p-value) is known as alpha ( $\alpha$ ) and this is the probability of making a type I error (Fox et al., 2007).  $\alpha$  is usually set to = 0.05, i.e. there is only a 5% chance of making a type I error. If the null hypothesis (i.e., there is no difference in uptake by area deprivation) is accepted, when it is in fact false, then this error is called a Type II error which means that an association which exists is missed (Bonita et al., 2006). This may be because of having a sample size which is too small to allow detection of that association by a statistical test at the established level of significance (i.e., if the p-value  $\alpha$  is set to = 0.05). Beta ( $\beta$ ) is the probability of making a type II error, and is related to the statistical power of the study: power = 1-beta (Bonita et al., 2006).  $\beta$  is often set to 0.20 (i.e. a 20% chance of making a type II error) and then power of the study is 0.80 or 80%. A non-significant result could indicate inadequate power of the study to detect differences or associations at the established level of significance. Power is increased by increasing sample size. The sample size

calculation also takes into account the value set for  $\alpha$ , such that a larger sample size will reduce the likelihood of both type I and type II errors (Fox et al., 2007).

Sample size calculations can be carried out with computer software (e.g., STATA, Excel) or with standard formulae (Bonita et al., 2006, Fox et al., 2007). In addition to the values of  $\alpha$  (usually 0.05) and  $\beta$  (usually 0.20 for 80% power), the formulae require estimates of the minimum difference the study is trying to detect ( $d$ ) and an estimate of the variance of the measurement in the population (the standard deviation [SD]). Usually the values of variance for the study population to use in the formulae are not available. Therefore, the value calculated for the sample size combines estimates for variance from previous studies in other populations, the size of the difference to be detected, the required statistical significance ( $\alpha$ ) and the required power ( $1-\beta$ ) (Bonita et al., 2006).

To calculate a sample size of secondary schools I used a formula from literature (in Appendix 2), including level of significance, power, difference in mean uptake between the two groups and standard deviation of HPV vaccine uptake in the general population. Comparing the means I tested the null hypothesis that the samples come from populations with the same mean (Peacock and Kerry, 2007; Campbell et al., 1995; Bland, 2000). To calculate the number of schools required in each group, I used a two-sided significance level of 5% and a power of 80% to detect a difference (Bland, 2000; Peacock and Kerry, 2007) of 10% in the mean uptake between the two groups (schools in high and low deprived catchment areas). An estimate of the population standard deviation of uptake of two doses of HPV vaccine<sup>18</sup> of 8.3 was taken from the literature also (Kumar and Whynes, 2011). The sample size required per group was 11 and the

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<sup>18</sup> HPV vaccine uptake of two doses in routine groups in 152 PCTs in England

total sample size was 22 secondary schools. However, the sample size could be different if the standard deviation of uptake of HPV vaccine for three doses has a different value than for two doses.

As mentioned earlier, the city under study had twenty-nine secondary schools. Based on the above calculations, I included all the eligible schools in my study [20 schools<sup>19</sup> were eligible. Nine were excluded because were special (Coventry City Council, [2013])<sup>20</sup> secondary schools (covering a total of approximately 114 eligible girls)]. I excluded them because of the small numbers of girls vaccinated in each school and because of inconsistent recording of uptake in each year.

### **6. 1. 1. Data sources and data preparation**

In order to undertake this study I needed to obtain data for each school on HPV uptake, including both numerators and denominators of eligible populations. For each school I also needed measures of ethnicity, religious affiliation and deprivation.

#### **HPV uptake**

The community health Trust<sup>21</sup> provided data on year 8 girls aged 12-13 years eligible for HPV vaccine in all secondary schools between 2008 and 2012. These data were extracted from the McKesson<sup>22</sup> child health system (Child and Maternal Health Intelligence Network, 2013)<sup>23</sup> and included school roll, immunization dates for each

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<sup>19</sup> School characteristics are presented in Table 1 in Appendix 3

<sup>20</sup> Special schools are part of the UK school education focusing on students primarily with learning, behavioral and emotional difficulties and/or disability

<sup>21</sup> Former PCT in the city of study

<sup>22</sup> Brand name software company

<sup>23</sup> Child health system is a patient administration system that provides a clinical record for individual children to support individual children's health for all children in a given local population through different services such as immunisations and childhood screening as well as support for children with Special Educational Needs

dose of the HPV vaccine and number of girls vaccinated<sup>24</sup> with first, second and third doses in each academic year (2008/9, 2009/10, 2010/11 and 2011/12). The Department for Children, Schools and Families defined school roll as the number of pupils at the school including both the attendance and the admissions register ( Department for Children, Schools and Families, 2008). In this research, school roll represents the number of year 8 girls who were admitted and attended a school included in the study. Data obtained from the Trust were requested and released under the Freedom of Information Act 2000.

### **Measures of deprivation, ethnicity and religious affiliation**

The Index of Multiple Deprivation (IMD) 2010 is a relative measure of multiple deprivation at Lower layer Super Output Area (LSOA) level which can be used to identify local variation and heterogeneity in an area. Thus, the area can be characterised as deprived, relative to other areas, in a particular dimension of deprivation depending on the proportion of people in the area experiencing a type of deprivation. LSOAs are defined as homogenous small areas of about 1,500 people. The higher the IMD 2010 score, the more deprived the LSOA. The IMD allows a community to compare its area with similar, or nearby, areas on different measures (Department for Communities and Local Government, 2012).

The Index of Multiple Deprivation (IMD) 2010 combines 38 indicators which relate to seven domains and are an update of indicators in the IMD 2007. The IMD 2010 was constructed by combining seven transformed domain scores: income deprivation, employment deprivation, health deprivation and disability, education skills and training deprivation, barriers to housing and services, living environment deprivation, and crime

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<sup>24</sup> Year 8 Girls vaccinated in school and in mop-up clinic combined

(Department for Communities and Local Government, 2012). Ethnicity is not included in the definition of IMD 2010 score.

I determined deprivation of the schools at two levels. One was Index of Multiple Deprivation (IMD 2010) for the school address postcode (SAP) to reflect area level deprivation of the school location and the other was IMD for the school catchment area (SCA) to reflect deprivation in the areas where the children attending the school live. Using the full postcode of the schools taken from the local council website (Coventry City Council, [2013]) it was possible to determine the location of the school (LSOA) through GeoConvert (Support, 2013) and the level of deprivation of the area in which it was located based on IMD 2010.

These data were linked to each school's postcode, Lower Super Output Area (LSOA), and IMD 2010, as well as to the proportion of people from each ethnic group in each LSOA in the city under study. Data on the LSOA and IMD 2010 score were obtained from the Department for Communities and Local Government (Department for Communities and Local Government, 2012).

In order to obtain IMD for SCA, I obtained data on attendance at each school by LSOA. I then calculated the population weighted average of the combined scores for all the LSOA in each school's catchment area. (Each LSOA Index of Multiple Deprivation score was multiplied by the proportion of the catchment area's population (girls) which fell into that LSOA and these were summed to make the catchment area score) (Department for Communities and Local Government, 2012).

Data about ethnicity by LSOA in England were obtained from the 2011 Census through Census Customer Services from the Office for National Statistics. Data on ethnicity included the number of people from each ethnic group aggregated by age and gender. I

summed the number of people by ethnic group by LSOA in the city of my study and created 6 ethnic groups (level 1), each of them including sub-ethnic groups (level 2) according to the Office for National Statistics's classification (Office for National Statistics, [2013]). I determined the proportion of people from each sub-ethnic group by LSOA. In Table 1 in Appendix 4 I present five ethnic groups and their subgroups. One ethnic group representing "Other" was not included in the Table 1 in Appendix 4 because of low percentages in the population (0-2%). One subgroup ("Other mixed") was omitted in the ethnic group "Mixed" because the percentages of the population were under 1%. Two subgroups ["Black/African/Caribbean/Black British Caribbean" (under 1.8%) and "Other Black" (under 1.5%)] were not shown because of much lower percentages in comparison with Black/African/Caribbean/Black British African people. A comparison between the groups in Table 1 in Appendix 4 shows that the predominant populations in the city of study were White British, Indian, Pakistani, and Black African.

Using the proportion of ethnic groups by LSOA I determined the ethnicity profile for each SCA for the 18 secondary schools reporting catchment areas. (The two private secondary schools did not report information on their catchment areas.) Using the total number of girls in the catchment area of each secondary school and the total number of residents in each catchment area, I estimated the percentage of girls in each ethnic group in each SCA. The percentage of girls could be slightly underestimated because the DE suppressed pupil numbers in some LSOAs with small numbers of children in order to protect pupil confidentiality. I used the age composition of ethnic groups in the population under 15 in the 2011 Census to estimate the composition of the girls' ethnic background for the eligible population for each school in my study.

The Department for Education (DE) provided me with the number of girls attending each secondary school in the city by LSOA of pupil residence. These data were related to 18 secondary schools (two private secondary schools were not included) and were collected through the School Census in January 2012. Data obtained from the DE were released under the Freedom of Information Act 2000. I linked LSOA of pupil residence with IMD 2010. Using the number of girls attending each secondary school by LSOA of pupil residence and IMD score by LSOA of pupil residence I calculated the weighted average of LSOA scores for the catchment area of each secondary school.

Details about these calculations are presented below in the section Deprivation of local area. The results of these calculations are related to one academic year. The analysis related to uptake of HPV vaccine is related to four academic years.

Data cleaning was performed in Microsoft Excel, for example to examine individual variables to detect unexpected values. Data analysis was carried out using descriptive and inferential statistics.

## **6. 1. 2. Data Analysis**

### **Exploratory analysis**

Uptake is defined by coverage with all three doses. I used data for uptake of the third dose of HPV vaccine because the third dose is given only after the documented uptake of the first dose and the second dose. Uptake of the HPV vaccine (third dose) is a proportion which represents the number of year 8 girls who were vaccinated with the third dose out of the total number of year 8 girls eligible to be vaccinated with the HPV vaccine at a school. Appendix 5 Table 1 presents the percentages of uptake of HPV

vaccine by school and by each academic year as well as by all academic years combined. All years combined gave the whole picture of the HPV vaccination programme for the first four years of its implementation. I calculated the percentages of uptake of HPV vaccine for all academic years as follows. I obtained the numerator summing the number of year 8 girls vaccinated with the third dose at a school in all four academic years. I determined the denominator adding the number of year 8 girls eligible to be vaccinated at a school in all four academic years. Then, I divided the numerator by the denominator and I multiplied by 100.

The first stage of descriptive statistics was to examine individual variables and to establish the relationship between variables. I used descriptive statistics to provide information about the uptake of HPV vaccine by school and to describe level of deprivation of school location and catchment area, and religious affiliation and ethnicity in catchment areas. Continuous variables were expressed using medians. In the exploratory analysis box plots, bar charts of means with error bars added and dot plots were produced to assess distribution of continuous variables (uptake of HPV vaccine) by academic year and by categorical variables (Fox, 1997; Field, 2013).

I created a binary dummy variable for each of the independent variables according to values above and below the median. Dummy variables were produced for deprivation of SCA, deprivation of SAP, and ethnicity (which represents the proportion of White English/Welsh/Scottish/Northern Irish/British people in each SCA). Another categorical independent variable “religion” was created to reflect schools’ religious affiliation. Faith schools were coded “1 = yes” and all other schools were coded “0 = no”. In addition, a categorical independent variable “academic year” was created and was coded “1 = 2008/09, 2 = 2009/10, 3 = 2010/11 and 4 = 2011/12”.

Scatter plot matrices were created to assess the linear relationship between continuous dependent and independent variables as a preliminary step before doing simple and multivariate linear regressions.

### **Inferential statistics**

Mann Whitney test statistics were carried out to assess statistically significant difference in mean values of uptake of HPV vaccine within categorical variables (deprivation, ethnicity and religion). I used the Wilcoxon-Mann-Whitney test, which is a non-parametric analog to the independent samples t-test, where the dependent variable was not normally distributed. Also, I used it for normally distributed dependent variables because of small sample size.

The same binary dummy variables for deprivation, ethnicity and religion were used within the regression analysis. The association between uptake of HPV vaccine and continuous variables (deprivation of school location and catchment areas and ethnicity in catchment areas) were determined by Pearson's Product-moment Correlation coefficient and Spearman's correlation coefficient. Also, I established whether there were associations between independent variables.

Analytic statistics included simple and multivariate linear regressions for all years combined.

I performed linear regression because the dependent variable was continuous (Katz, 2006; Peacock and Kerry, 2007). A univariate linear regression analysis was undertaken to investigate the association between uptake of the third dose of HPV vaccine and each of the independent variables deprivation of SCA, deprivation of SAP, ethnicity, school type (religious affiliation) and year.

The classical regression assumption requires that the outcome (dependent) variable is normally distributed. There were deviations from this assumption because the dependent variable did not follow a Normal distribution as shown in histogram in Figures 1-5 in Appendix 6 I used “ladder of power” in Stata which showed normality tests for various transformations. I selected the transformation with the lowest chi2 statistic, which tested each distribution for normality. The lowest chi2 statistic indicated cubic transformation. Because of difficult interpretation of the coefficients of cubic transformation, I looked at the distribution of different transformations shown in histogram in Figures 12 below and 1-3 in Appendix 7 (Stata.com, 2013). None of the transformations normalized the total distribution of the dependent variable. However, I used it in linear regression analysis based on evidence of strong and statistically significant correlations with independent variables presented in section “Linear relationship between uptake and continuous variables”. I looked at the histogram by transformation and chose “identity”. I used an untransformed dependent variable in further analyses. Two methods could justify the use of a skewed variable in the analyses. One of the assumptions in linear regression is to normalize the distribution of the residuals (Torres-Reyna). I predicted the residuals and I looked at their distribution on a kernel plot (Torres-Reyna, Peacock and Kerry, 2007). The distribution was normal to some degree. Next, I did simple linear regression using Huber variances with `vce(robust)` in Stata to obtain robust standard errors for the parameter estimates to control for mild violation of underlying assumptions (UCLA, 2013c). The independent variables in all analyses are in their original metric.

First, I built simple linear models between the outcome (dependent) variables and each of the independent variables (interval or categorical). I chose as reference category the first group (for school type (religious affiliation) and year). The reference category was not entered into analysis and the other categories were compared to that reference

category (Katz, 2006). Following the findings from the univariate linear regression analysis, multiple ordinary least-squares regression was undertaken to explore the relationship between uptake of the vaccine and area level of deprivation adjusting for ethnicity, religious affiliation of the schools and year. Multicollinearity between independent variables was considered for the interpretation of the results since in multiple regression analysis one explanatory variable should not be correlated with one or more of the other explanatory variables (Kaye and Freedman, 2000).

Two multiple regression models were created because of multicollinearity between area level of deprivation in catchment areas and area level of deprivation of SAP. Model 1 included area level of deprivation in catchment areas, ethnicity (White British population),

religious affiliation of the schools and year. Model 2 included area level of deprivation of SAP, ethnicity religious affiliation of the schools and year.

All statistical analyses were performed using STATA/SE 11.1.

In the previous section, I described my methods of data analysis. In this section, I will present the main findings of the study in line with the study aim. The findings will include both descriptive and inferential results.

## **6.2. Results**

### **Exploratory Analysis**

#### **Descriptive statistics**

7276 girls were eligible for HPV vaccination in all years combined which included 1857 in 2008/09, 1857 in 2009/10, 1785 in 2010/11 and 1777 in 2011/12 (Table 1 in Appendix 5). Third dose uptake by school varied between 65% and 100% with overall

median uptake in each year of 90% in 2008/09, 75% in 2009/10, 86.50% in 2010/11, and 89.50% in 2011/12 and 86.5% in all years.

I checked uptake by school for normality (Peacock and Kerry, 2007; Kaye and Freedman, 2000) and identified uptake of the third dose in 2008/09, in 2009/10, in 2010/11, and in all years as having a non-Normal distribution) (Figures 1-3 and 5 in Appendix 6). Uptake for the third dose in 2011/12 had a normal distribution.

IMD scores for SAP ranged from 9.71 to 66.63 with a median of 27.90 and had a non-Normal distribution. Similar figures for IMD scores for SCA ranged from 8.65 to 42.62 with a median value of 27.50.

The median proportion of the population who fell into the 'White' group was 65.50% overall for schools with a range of 35% to 79%.

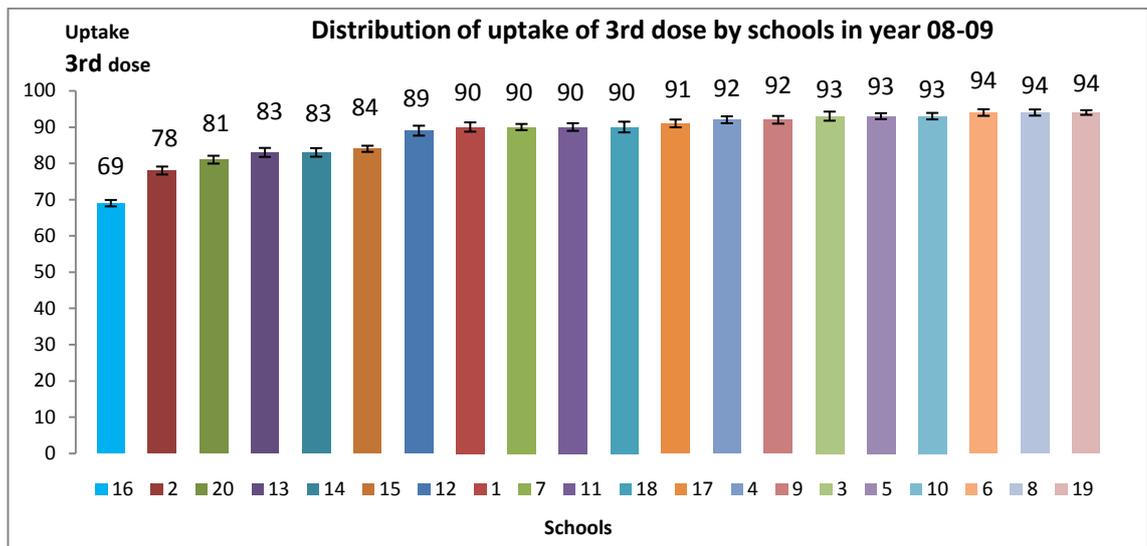
IMD scores for SCA were normally distributed whereas IMD scores for SAP and ethnicity were non normal distributed (Figures 1-3 in Appendix 8).

### **Pattern of uptake of the HPV vaccine**

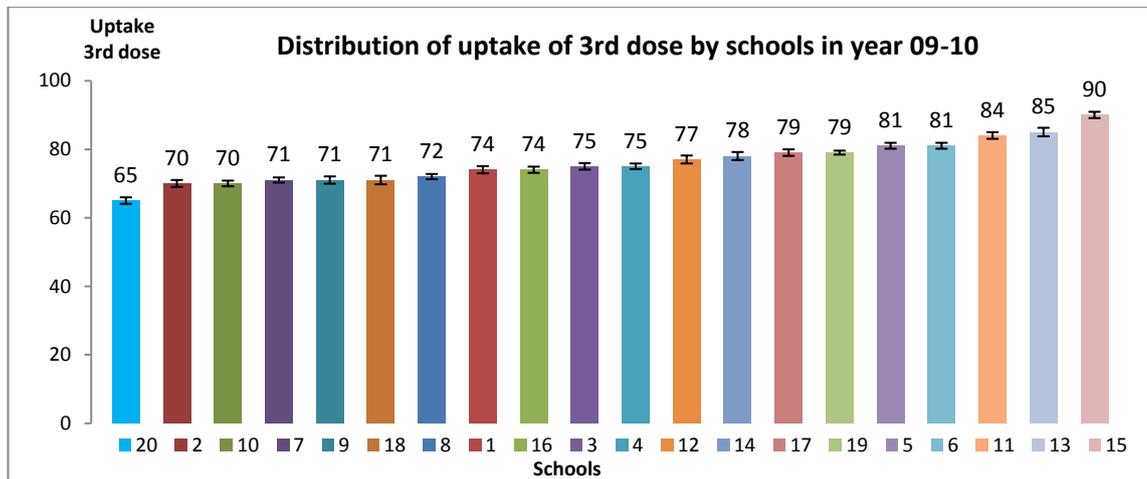
In this section uptake of the third dose of the HPV vaccine is described. Figure 4 shows that in 2008/09, overall uptake across the 20 schools ranged from 69% in school 16 to 94% in schools 6, 8 and 19. In 2009/10, uptake ranged between 65% in school 20 and 90% in school 15 (Figure 5). In 2010/11, uptake ranged between 72% in school 2 and 97% in school 8 (Figure 6). In 2011/12, the lowest uptake was 81% in school 16 and the highest level of uptake was 100% in school 14 (Figure 7). In all years combined, schools 16 had the lowest uptake (76%) while school 13 had the highest uptake (89%) (Figure 8). Overall, school 16 had the lowest uptake in two academic years (2008/09

and 2011/12) and in all years combined. There was also a pattern of low uptake in school 2 in three academic years from 2008/09 to 2010/11 as well as in all years combined. In conclusion, there are inconsistent coverage patterns across the years.

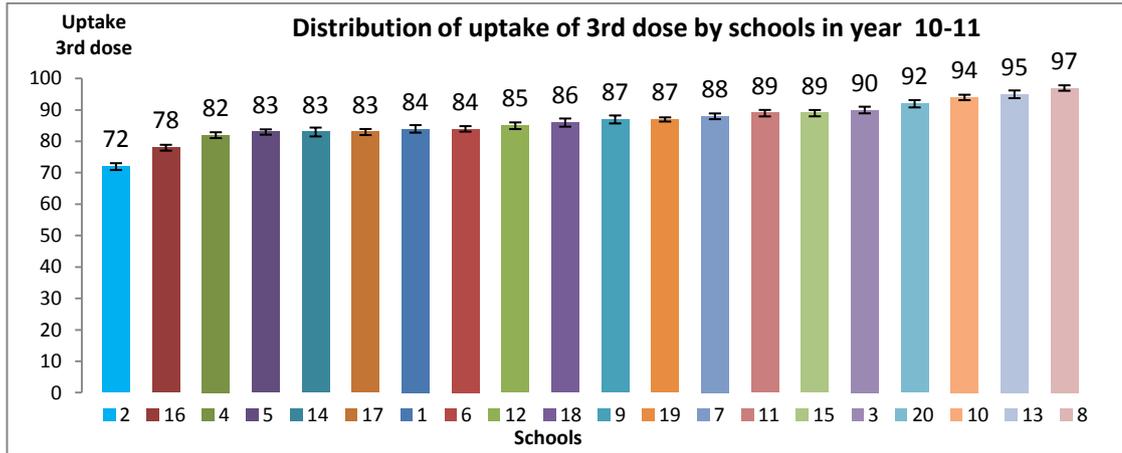
**Figure 4. Distribution of uptake of 3<sup>rd</sup> dose by schools in year 08-09**



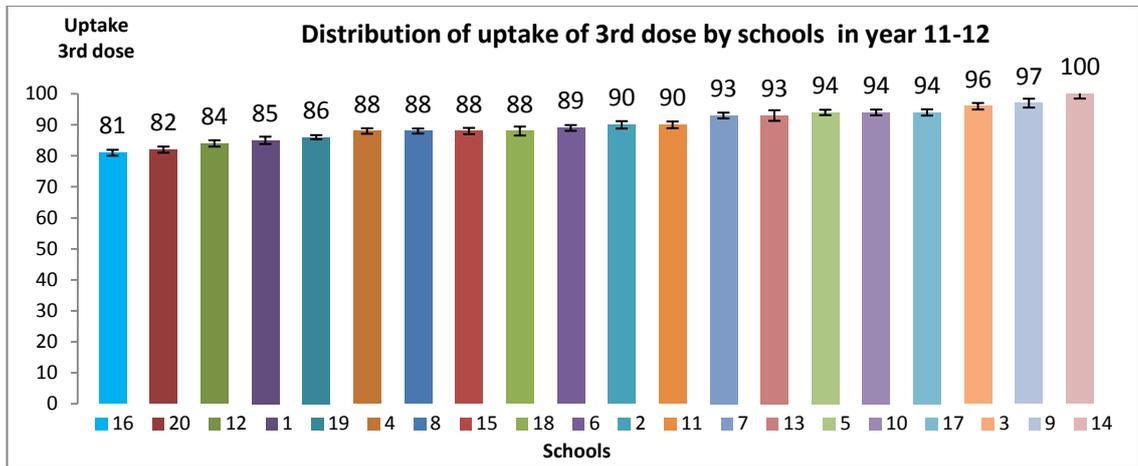
**Figure 5. Distribution of uptake of 3<sup>rd</sup> dose by schools in year 09-10**



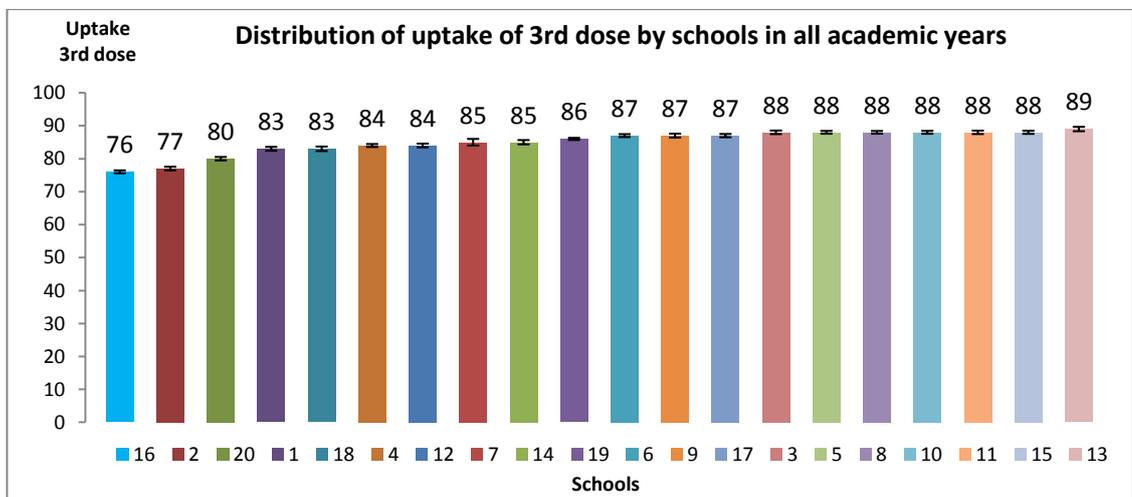
**Figure 6. Distribution of uptake of 3<sup>rd</sup> dose by schools in year 10-11**



**Figure 7. Distribution of uptake of 3<sup>rd</sup> dose by schools in year 11-12**

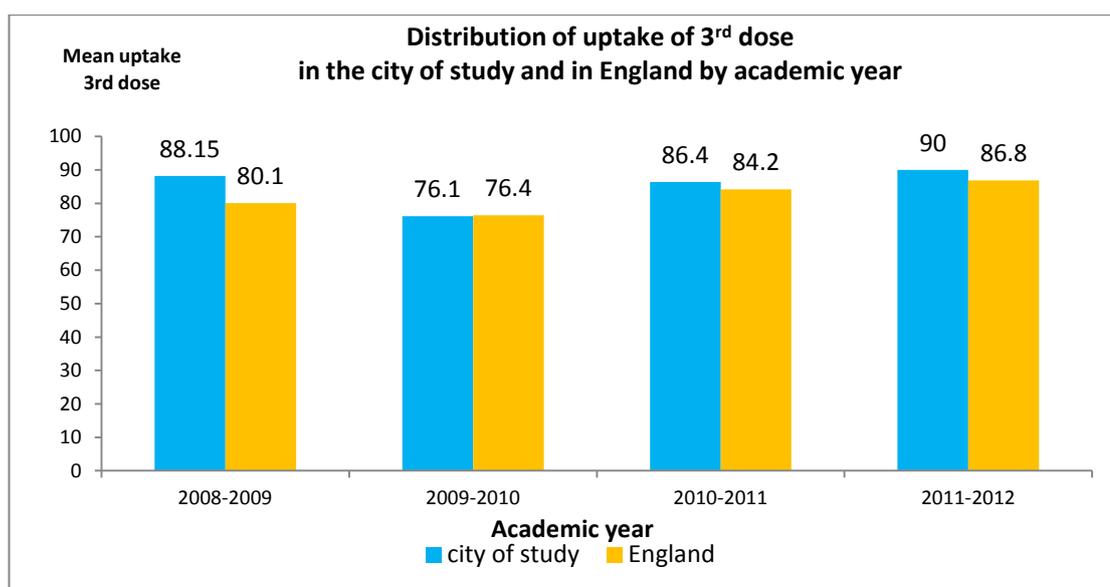


**Figure 8. Distribution of uptake of 3<sup>rd</sup> dose by schools in all academic years**



I compared the rates of coverage with the third dose of HPV vaccine between the city of study and England by academic year, which are represented graphically in Figure 9. There was a larger difference in vaccination rates in the city of study than at national level in 2008/9 (difference = 8% (Sheridan and White, 2011; Health Protection Agency, 2012) <sup>25</sup>), and a smaller difference in vaccination coverage in 2010/11 (difference = 2.2%) and in 2011/12 (difference = 3.2%). There was no difference in the mean of uptake in the second year of the programme (2009/10) which could suggest that the incident in October 2009 affected the schools in the whole country.<sup>26</sup>

**Figure 9. Distribution of uptake of 3<sup>rd</sup> dose in the city of study and in England by academic year**



Because the distribution of uptake of the HPV vaccine was skewed and the mean could have been affected by very large or very small values, I also used descriptive statistics [median (min and max)] which are robust to an outlying value (Thabane and Akhtar-

<sup>25</sup> Confidence intervals cannot be calculated because of limited access to data for England. Uptake in England by academic year was based on a sample of about 300000 girls in year 8 in total in 151 PCTs in each academic year and this data was obtained from the reports available on the website of the Department of Health

<sup>26</sup> An explanation is presented in Chapter - Results of qualitative data analysis - Theme 3

Danesh, 2008; Andersen and Skovgaard, 2010; Fox, 1997; Kaye and Freedman, 2000). Table 22 shows that there was a substantial disparity (>25%) in median uptake of the third dose between schools in the first three academic years 2008/09, 2009/10 and 2010/11. The difference in median vaccination rates between the schools reduced from 25% to 19% in the academic year 11-12. The figures for all academic years combined showed that there was inequality in the uptake of vaccine between schools (difference = 13%).

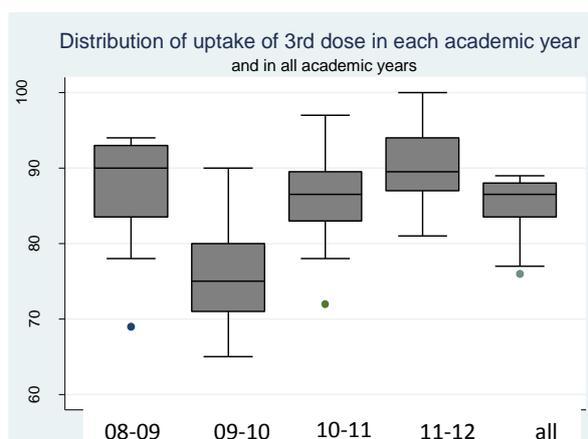
**Table 22. Summary statistics of uptake of HPV vaccine by academic year and in all years combined**

| Uptake    | N  | Quantiles |             |                |             |        |
|-----------|----|-----------|-------------|----------------|-------------|--------|
|           |    | Min       | .25<br>(Q1) | Median<br>(Q2) | .75<br>(Q3) | Max    |
| 2008/09   | 20 | 69.00     | 83.50       | 90.00          | 93.00       | 94.00  |
| 2009/10   | 20 | 65.00     | 71.00       | 75.00          | 80.00       | 90.00  |
| 2010/11   | 20 | 72.00     | 83.00       | 86.50          | 89.50       | 97.00  |
| 2011/12   | 20 | 81.00     | 87.00       | 89.50          | 94.00       | 100.00 |
| all years | 20 | 76.00     | 83.50       | 86.50          | 88.00       | 89.00  |

N = number of schools

Box plot in Figure 10 shows the characteristics of the distributions of uptake such as center (median), spread, skewness and outliers (Thabane and Akhtar-Danesh, 2008; Fox, 1997; Field, 2013). Asymmetrical distribution of uptake in 2008/09, 2009/10, 2010/11 and in all years confirmed that the uptake of the third dose was skewed. Also, it appeared that the middle 50% of observations in 2008/09 were more spread in comparison with the other academic years

**Figure 10. Distribution of uptake of the third dose in each academic year and in all academic years**



An outlier is defined as any observation greater than the upper quartile plus one and a half times the length of the interquartile range as well as any score smaller than the lower quartile plus one and a half times the length of the interquartile range (Field, 2013; Peacock and Kerry, 2007; Thabane and Akhtar-Danesh, 2008).

### **Delivery of the HPV immunization programme**

Three-dose completion rate of HPV vaccination programme and the intervals between administrations of the first dose and the second dose as well as between the first dose and the third dose are presented in Appendices 8, 9 and 10. The rationale to calculate these rates and these intervals was based on the results of qualitative data analysis in Chapter 7.

## **School Factors**

### **School type**

Four of the 20 schools were religious. Of these, three schools were Catholic and one was a Church of England faith school.

Table 23 shows uptake of the third dose of HPV vaccine by school type in all academic years. There was no statistically significant difference in mean uptake between the faith schools and those without a religious character.

**Table 23. Distribution of average uptake of HPV vaccine by schools' religious affiliation**

| <b>Uptake per year</b> | <b>N</b> | <b>Mean uptake non-religious schools</b> | <b>N</b> | <b>Mean uptake religious schools</b> | <b>Test Mann Whitney</b>            |
|------------------------|----------|--|----------|--------------------------------------|-------------------------------------|
| all years              | 16       | 84.81                                    | 4        | 86                                   | $z = -0.14, p \text{ value} = 0.88$ |

N = number of schools

A graph displaying the distribution of average uptake by religious affiliation in all academic years is presented in Figure 1 in Appendix 13.

## **Geographic Factors**

### **Deprivation of local area**

Table 24 presents summary statistics for the independent variable (deprivation of SCA) in terms of means and standard deviations. Because the distribution of the independent variable (deprivation of SAP) was skewed I used descriptive statistics median (min and max) (Thabane and Akhtar-Danesh, 2008). It appeared that the mean of deprivation of scores was slightly higher (greater deprivation) for the areas where the schools were located (postcode) than for SCAs. Deprivation values for SAP were spread over a larger range of values than deprivation of SCAs. Details about the distribution of the deprivation of catchment area as well as for SAP by school are shown in the Table 1 in Appendix 12.

**Table 24. Summary statistics of deprivation of school address postcode and deprivation of school catchment area**

| Deprivation           | N  | Mean  | S.D.  | Quantiles |             |                |             |       |
|-----------------------|----|-------|-------|-----------|-------------|----------------|-------------|-------|
|                       |    |       |       | Min       | .25<br>(Q1) | Median<br>(Q2) | .75<br>(Q3) | Max   |
| deprivation of<br>SAP | 20 | 28.59 | 15.68 | 9.71      | 15.87       | 27.90          | 33.73       | 66.63 |
| deprivation of<br>SCA | 18 | 25.58 | 9.44  | 8.65      | 15.75       | 27.50          | 33.02       | 42.62 |

### **Definition of deprivation levels**

IMD scores for all 197 LSOAs in the city of the study ranged from 3.72 to 78.43. Table 24 shows that the range of IMD scores for SAPs as well as the range of the average weighted IMD scores for SCAs were narrower. This was because only 20 out of 29 schools in the city were included in the study.

There is no cut-off for deprivation level mentioned in literature. I used median of IMD scores for SAPs (27.90) as cut-off point to define two deprivation levels of SAPs. Thus, my definition of a low level of deprivation of SAPs included IMD scores lower than and equal to 27.90 while my definition of a high level of deprivation of SAPs included IMD scores equal to and higher than 27.91. Similarly, I used median of IMD scores for SCAs (27.50) as the cut-off point to define two deprivation levels of SCAs. Low level of deprivation of SCAs was defined by IMD scores lower than and equal to 27.50 and high level of deprivation of SCAs was defined by IMD scores equal to and higher than 27.50.

### **Deprivation of school address postcode by academic years**

Table 25 shows differences in mean uptake between the two categories of deprivation of SAP in each academic year and in all years combined. The difference between the low and high level of deprivation of indicated that the mean uptake in more deprived areas was lower than in less deprived areas of school location (postcode). The figures for

these differences were 3.1% in 2008/09, 5.4% in 2009/10, 3.8% in 2010/2011, 4% in 2011/12 and 4.3% in all years combined. The difference between the mean uptake in high and low deprivation areas in the academic year 2009/10 and all years combined was statistically significant.

**Table 25. Distribution of average uptake by deprivation of school address postcode by academic year**

| <b>Uptake per year</b> | <b>N</b> | <b>Mean uptake in areas with low deprivation (<math>\leq 27.90</math>)</b> | <b>N</b> | <b>Mean uptake in areas with high deprivation (<math>\geq 27.91</math>)</b> | <b>Mann-Whitney Test</b>       |
|------------------------|----------|--|----------|---|--------------------------------|
| 2008/09                | 10       | 89.7   | 10       | 86.6  | $z = 1.14$ , $p$ value = 0.25  |
| 2009/10                | 10       | 78.8   | 10       | 73.4  | $z = 2.01$ , $p$ value = 0.04  |
| 2010/11                | 10       | 88.3   | 10       | 84.5  | $z = 1.06$ , $p$ value = 0.28  |
| 2011/12                | 10       | 92   | 10       | 88  | $z = 1.71$ , $p$ value = 0.08  |
| all years              | 10       | 87.2   | 10       | 82.9  | $z = 2.80$ , $p$ value = 0.005 |

N = number of schools

Graphs displaying deprivation of school address postcode in 2008/09, 2009/10, 2010/11, 2011/12 and all years are presented in Appendix 14.

### **Deprivation of school catchment area by academic year**

Table 26 shows distribution of average uptake by deprivation of SCA and by academic year. A consistent observation was that the schools in more deprived areas were more likely to have a lower mean uptake than the schools in less deprived areas of school catchment in each academic year and all years combined. The difference in average uptake between the areas with low and high level of deprivation of SCA varied across the years. The biggest difference was in 2008/09 (8.66%), and there was no difference in 2009/10. A statistically significant difference in the mean uptake was found in the academic year 2008/09 ( $p$  value = 0.001) but no overall difference was found between school with low and high levels of deprivation of SCA when all years were investigated.

**Table 26. Distribution of average uptake by deprivation of school catchment area and by academic year**

| Uptake per year | N | Mean uptake in                              | N | Mean uptake in                               | Mann-Whitney Test            |
|-----------------|---|---|---|--|------------------------------|
|                 |   | areas with low deprivation ( $\leq 27.50$ ) |   | areas with high deprivation ( $\geq 27.51$ ) |                              |
| 2008/09         | 9 | 92.66                                       | 9 | 84   | $z = 3.28$ , p value = 0.001 |
| 2009/10         | 9 | 75.88                                       | 9 | 75.55  | $z = 0.53$ , p value = 0.59  |
| 2010/11         | 9 | 87.33                                       | 9 | 84.77  | $z = 0.35$ , p value = 0.72  |
| 2011/12         | 9 | 90.77                                       | 9 | 89.44  | $z = 0.44$ , p value = 0.65  |
| all years       | 9 | 86.55                                       | 9 | 83.33  | $z = 1.53$ , p value = 0.12  |

N = number of schools

Graphs displaying deprivation of school catchment area in 2008/09, 2009/10, 2010/11, 2011/12 and all years are presented in Appendix 15.

### **Ethnicity in school catchment areas**

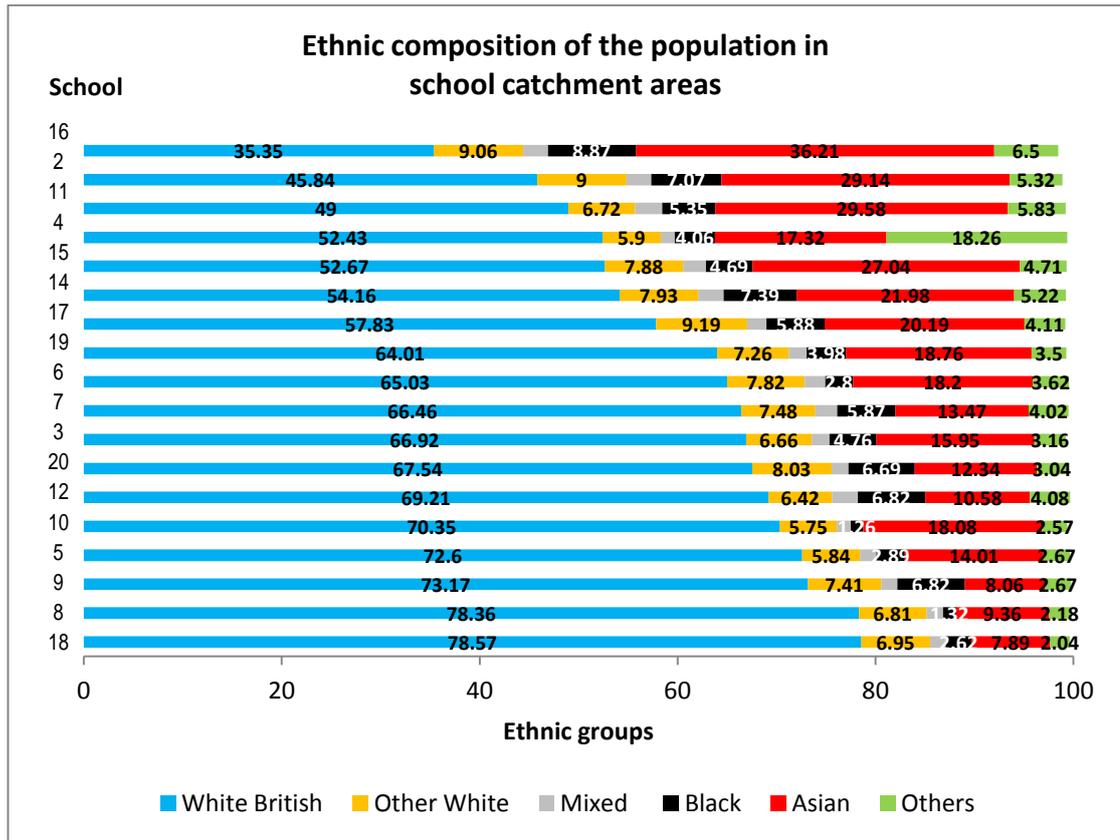
In Table 27 descriptive statistics median (min and max) are presented because the distribution of the independent variable was skewed (Thabane and Akhtar-Danesh, 2008). Table 27 shows that the variable “ethnicity” (the percentage of people in the white ethnic group) ranged from 35% to 79%.

**Table 27. Summary statistics for the independent variable ethnicity**

|           | N  | Quantiles |          |             |          |      |
|-----------|----|-----------|----------|-------------|----------|------|
|           |    | Min       | .25 (Q1) | Median (Q2) | .75 (Q3) | Max  |
| Ethnicity | 18 | 35.00     | 53.00    | 65.50       | 70.00    | 79.0 |

Ethnicity varied across schools. Figure 11 shows that White British was the commonest ethnic group in all schools except School 16.

**Figure 11. Percentage of population from different ethnic groups by schools**



These ethnic groups refer to total population including all age groups

Table 28 presents differences in mean uptake by ethnicity in each academic year and in all years combined. In general the areas with more white British girls had a higher mean uptake than the areas with a smaller proportion, although differences were small (1.4%) and non-significant when all years were put together.

However, in the academic year 2009/10, there was a large and significant difference between the areas (72.55% vs. 78.88%) (difference = 6.33%, p value = 0.03) showing that uptake was lower in areas with higher proportions of white British people compared to areas with a smaller proportion of white residents. This pattern was reversed in the following year when there was a large and significant difference in uptake between the two groups. Thus, in 2010/11, schools with a higher proportion of white residents in

SCA had an increased uptake (difference = 6.11%, p value = 0.02) compared to schools with a lower proportion of white British people in SCA.

**Table 28. Distribution of average uptake by ethnicity in school catchment area by academic year**

| Uptake per year | N | Mean uptake in areas with low % of white pop. in school catchment area ( $\leq 65.50$ ) | N | Mean uptake areas with high % of white pop. in school catchment area ( $\geq 65.51$ ) | Difference in mean uptake between areas with high % and low % of white population | Mann-Whitney Test               |
|-----------------|---|---|---|---|---|---------------------------------|
| 2008/09         | 9 | 86.11   | 9 | 90.55   | 4.44  | $z = -0.88$ ,<br>p value = 0.37 |
| 2009/10         | 9 | 78.88   | 9 | 72.55   | -6.33   | $z = 2.12$ ,<br>p value = 0.03  |
| 2010/11         | 9 | 83  | 9 | 89.11   | 6.11  | $z = -2.21$ ,<br>p value = 0.02 |
| 2011/12         | 9 | 89.55   | 9 | 90.66   | 1.11  | $z = -0.48$ ,<br>p value = 0.62 |
| all years       | 9 | 84.22   | 9 | 85.66   | 1.44  | $z = -0.67$ ,<br>p value = 0.49 |

N = number of schools

Graphs displaying average uptake by ethnicity in school catchment area in 2008/09, 2009/10, 2010/11, 2011/12 and all years are presented in Appendix 16.

I used the median of ethnicity (the percentage of people in the white ethnic group) in SCA (65.50%) as cut-off point to define two ethnic groups: white and non-white. Thus, in the “non-white” group the percentage of people in the white ethnic group was lower than or equal to 65.50%. The “white group” included a percentage of people in the white ethnic group equal to or higher than 65.50%.

The majority of the total population (all age groups) in the SCAs was White British (Figure 11). I calculated the number of the under 15s out of the total population in each ethnic group based on the age composition of ethnic groups in 2011 Census in Figure 1 in Appendix 17. Then I calculated the percentage of the under 15s by ethnic group out

of the total population of the under 15s which I presented in Table 1 in Appendix 17. Table 1 in Appendix 17 shows that in the teenage population at national level (England) there is as high a percentage of teenagers who are White British (74.45%). Based on these data I derived from the Census the children in the schools in the city of my study, who are not White British, came from a variety of backgrounds including Pakistani, African and Indian groups.

### **Linear relationship between uptake of HPV vaccine and continuous variables**

The strength of relationship between uptake of the third dose, deprivation of SCA, deprivation of SAP, and ethnicity were determined by the Pearson's Product-moment Correlation coefficient or the Spearman correlation coefficient ( $\rho$ ) (Peacock and Kerry, 2007). The Pearson's Product-moment correlation coefficient was carried out to estimate the linear association between continuous variables in which at least one of the variable followed a Normal distribution (Field, 2013). The correlation coefficient can be distorted by outliers (Kaye and Freedman, 2000). The Spearman correlation coefficient is a non-parametric statistic which was carried out when none of the variables were Normally distributed (Peacock and Kerry, 2007) and because the sample size was small (Field, 2013). A weak correlation is defined as the value between 0.1-0.3, a moderate correlation between 0.4-0.6 and a stronger correlation between 0.7-1 (Peacock and Kerry, 2007). I calculated the coefficient of determination  $R^2$  as squared Pearson's correlation coefficient to show the amount of variation in the outcome variable (uptake of the third dose) that was explained by the independent variable (Fox, 1997; Field, 2013). I calculated  $R_s^2$  as squared Spearman's correlation coefficient representing the proportion of variance in the ranks that two variables share (Field, 2013). Correlation coefficients between uptake and continuous variables, p values and CI 95% for each academic year and all years are shown in Table 29.

Table 29 shows that in 2008/09, there was a strong, negative and statistically significant correlation between uptake of the third dose and deprivation of SCA, and a moderate, positive and statistically significant correlation between uptake of the third dose and ethnicity. The Spearman's correlation coefficient between uptake of the third dose and deprivation of SAP showed a weak, negative and not statistically significant correlation.

In contrast in 2009/10, there was no significant relationship between uptake of the third dose and deprivation of SCA, deprivation of SAP and ethnicity. All coefficients indicated weak, negative and not statistically significant correlations.

In 2010/11 uptake of the third dose was significantly related to deprivation of SAP and ethnicity. The relationship observed between uptake of the third dose and deprivation of SAP was moderate and negative while the correlation between uptake of the third dose and ethnicity was moderate and positive. There was no significant relationship between uptake of the third dose and deprivation of SCA.

In 2011/12, uptake of the third dose was not significantly related to deprivation of SCA, deprivation of SAP and ethnicity.

In all years combined, there was a moderate, negative and statistically significant correlation with deprivation of SCA and a negative and statistically significant correlation with deprivation of SAP. Ethnicity was not significantly related to uptake of the third dose.

**Table 29. Correlations between dependent and independent variables by academic year**

| <b>Independent variables</b>                | <b>Uptake 3<sup>rd</sup> dose 2008/09</b> | <b>95% CI</b>    | <b>R<sup>2</sup>/R<sub>s</sub><sup>2</sup>**</b> |
|---|---|------------------|--|
| Deprivation of SCA                          | r= -0.7202 (0.0007)*                      | -0.888 to -0.382 | 0.5186   |
| Deprivation of SAP                          | rho = -0.3244 (0.1629)*                   | -0.671 to 0.138  | 0.1052   |
| Ethnicity                                   | rho = 0.4797 (0.0439)*                    | 0.017 to 0.773   | 0.2301   |
| <b>Uptake 3<sup>rd</sup> dose 2009/10</b>   |   |                  |  |
| Deprivation of SCA                          | r= -0.0610 (0.8100)*                      | -0.513 to 0.418  | 0.0037   |
| Deprivation of SAP                          | rho = -0.3834 (0.0952)*                   | -0.706 to 0.071  | 0.1469   |
| Ethnicity                                   | rho= -0.3053 (0.2179)*                    | -0.676 to 0.188  | 0.0932   |
| <b>Uptake 3<sup>rd</sup> dose 2010/11</b>   |   |                  |  |
| Deprivation of SCA                          | r= -0.3928 (0.1069)*                      | -0.726 to 0.091  | 0.1542   |
| Deprivation of SAP                          | rho = -0.5226 (0.0181) *                  | -0.784 to -0.104 | 0.2731   |
| Ethnicity                                   | rho = 0.4946 (0.0369)*                    | 0.036 to 0.781   | 0.2446   |
| <b>Uptake 3<sup>rd</sup> dose 2011/12</b>   |   |                  |  |
| Deprivation of SCA                          | r= -0.1683 (0.5045)*                      | -0.589 to 0.324  | 0.0283   |
| Deprivation of SAP                          | r = -0.3438 (0.1377)*                     | -0.683 to 0.116  | 0.1181   |
| Ethnicity                                   | r = 0.2031 (0.4188)*                      | -0.291 to 0.612  | 0.0412   |
| <b>Uptake 3<sup>rd</sup> dose all years</b> |   |                  |  |
| Deprivation of SCA                          | r= -0.5545 (0.0169) *                     | -0.811 to -0.118 | 0.3074   |
| Deprivation of SAP                          | rho = -0.7383 (0.0002) *                  | -0.890 to -0.439 | 0.5450   |
| Ethnicity                                   | rho = 0.2865 (0.2491)*                    | -0.208 to 0.664  | 0.0820   |

r= Pearson's product-moment correlation coefficient

rho = Spearman's correlation coefficient

\*p value p <0.05

\*\*coefficient of determination

N = 18 (deprivation of SCA), N = 20 (deprivation of SAP)

Tables 30 and 31 show correlations between independent variables. There was a statistically positive, moderate and statistically significant correlation observed between deprivation of SCA and deprivation of SAP as well as a moderate, negative and statistically significant correlation observed between deprivation of SCA and ethnicity.

**Table 30. Correlations between independent variables**

| <b>Independent variables</b> | <b>Deprivation of SAP</b> | <b>Ethnicity</b>     |
|------------------------------|---------------------------|----------------------|
| <b>Deprivation of SCA</b>    | r = 0.6021 (0.0082) *     | r= -0.4902 (0.0389)* |

r= Pearson's product-moment correlation coefficient

\*p value <0.05

N = 18 (deprivation of SCA), N = 20 (deprivation of SAP)

**Table 31. Correlations between independent variables**

| <b>Independent variables</b> | <b>Ethnicity</b>       |
|------------------------------|------------------------|
| <b>Deprivation of SAP</b>    | rho= -0.4060 (0.0946)* |

rho = Spearman's correlation coefficient

\*p value <0.05

N = 18 (deprivation of SCA), N = 20 (deprivation of SAP)

**Assessment of correlations between dependent and independent continuous variables and between independent continuous variables**

Figures 1-5 in Appendix 18 show scatter plot matrices to reveal the relationships between all combinations of raw variable pairs such as the dependent variable (uptake of the third dose) and any of the independent variables (deprivation of SCA, deprivation of SAP and ethnicity) in each academic year and all years. Figure 3 shows that the relationship between uptake of HPV vaccine and ethnicity (White British population) was linear in 2010/11. There was some degree of nonlinearity [i.e., a curved band or a big wave-shaped curve (Field, 2013; UCLA, 2013a; UCLA, 2013b)] for the relationships between the dependent variable and all independent variables in 2008/09, 2009/10, 2011/12 and in all years combined.

Dot plots in Figure 1 in Appendix 19 show the relationship between continuous variable (uptake of the third dose) and categorical variable (school type) for each academic year and all academic years. The spread and the values of the dots indicate the level of uptake. A consistent observation was that the spread of the dots representing religious schools was little in comparison to the schools without religious affiliation. This could suggest a similar pattern of uptake in faith schools.

**Analytic Statistics**

Simple and multiple linear regression analyses for each academic year are in Appendix 7.

## Simple and multiple linear regression analysis in all academic years

Table 32 presents the results of simple and multiple linear regression models with coefficients, standard errors, p-values in all years. The size of the coefficient for each independent variable gives the size of the effect that variable has on the dependent variable, and the sign of the coefficient (positive or negative) gives the direction of the effect (increase or decrease of the dependent variable).

Figure 12 shows that the distribution of the dependent variable (uptake of the third dose) by transformation remained skewed. Therefore, the outcome variable was entered in the models untransformed.

**Figure 12. Transformations of the dependent variable in all academic years**

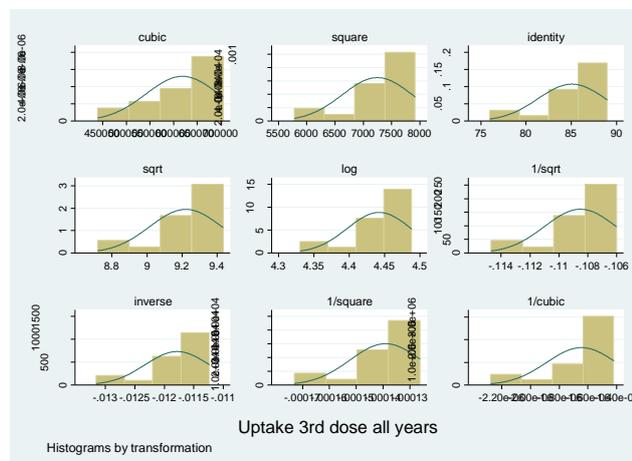


Table 32 shows the unadjusted and adjusted results of the association between uptake and the study area characteristics. The unadjusted results indicate that there was a negative statistically significant association between deprivation of SCA and uptake, as well as the deprivation of SAP and the academic year 2009/10. For a one-unit increase in deprivation of SCA, there was 0.22% decrease in uptake which was statistically significant (p value = 0.04). For a one-unit increase in deprivation of SAP, there was 0.15% reduction of uptake which was statistically significant (p value = 0.009). For a

one-unit increase in percentage of White British population, there was 0.16% increase in uptake but this was not statistically significant.

Differences in mean uptake were observed in the categories of two independent variables. There was small difference in mean uptake between faith schools and the schools with no religious affiliation (difference = 1.43%) which was not statistically significant. The difference in mean uptake between academic years 2008/09 and 2009/10 indicated that the mean uptake in the second year of the programme was 12.05% lower than in the first year of the programme which was statistically significant. There was a small difference (not statistically significant) in mean uptake between 2008/09 and 2010/11 as well as between 2008/09 and 2011/12.

Multiple regression model 1 including deprivation in SCA, ethnicity, school type (religious affiliation) and year did not show any statistically significant effect of deprivation in SCA on uptake after taking account of the effects of all the other independent variables. There was a large and significant reduction in mean uptake adjusted in year 2009/10 compared with 2008/09 (12.05%) after controlling for the other school and geographic factors (p value = 0.00). Also, adjusting for deprivation in SCA, school type (religious affiliation) and year, there was no statistically significant association between uptake and ethnicity. There was a small and not statistically significant increase in mean uptake adjusted in religious schools compared with schools without religious affiliation when the other variables were held constant.

When deprivation of SAP, ethnicity, school type (religious affiliation) and year were modeled together in multiple regression model 2, there remained a small but significant association between uptake and deprivation of SAP after controlling for the other variables. There was a large and significant reduction in mean uptake adjusted in year 2009/10 compared with 2008/09 (12.61%) after controlling for deprivation of SAP,

ethnicity and school type (p value = 0.00). Adjusting for school and geographic factors, there was no statistically significant association between uptake and ethnicity. In addition, there was no statistically significant increase in mean uptake adjusted in religious schools compared with schools without religious affiliation when the other variables were held constant.

The independent variables included in the regression analysis model 1 explained 56% of the variation in uptake and those modeled together in the regression analysis model 2 explained 58% of the variation in uptake.

**Table 32. The relationship between uptake and variables related to geographic factors and school factors in all years**

| Uptake              | Unadjusted |      |         | Adjusted |      |         |         |      |         |
|---------------------|------------|------|---------|----------|------|---------|---------|------|---------|
|                     | Coeff      | SE   | p value | MODEL 1  |      |         | MODEL 2 |      |         |
|                     |            |      |         | Coeff    | SE   | p value | Coeff   | SE   | p value |
| deprivation SCA*    | -0.22      | 0.10 | 0.04    | -0.15    | 0.07 | 0.054   |         |      |         |
| deprivation SAP**   | -0.15      | 0.05 | 0.009   |          |      |         | -0.13   | 0.05 | 0.008   |
| ethnicity**         | 0.16       | 0.08 | 0.053   | 0.10     | 0.07 | 0.15    | 0.07    | 0.06 | 0.28    |
| school type**       |            |      |         |          |      |         |         |      |         |
| No (reference)      | 0          |      |         | 0        |      |         | 0       |      |         |
| Yes                 | 1.43       | 2.11 | 0.5     | 0.68     | 1.2  | 0.57    | 2.21    | 1.18 | 0.06    |
| 2008/09 (reference) | 0          |      |         | 0        |      |         | 0       |      |         |
| 2009/10             | -12.05     | 2.00 | <0.001  | -12.61   | 2.02 | <0.001  | -12.61  | 1.96 | <0.001  |
| 2010/11             | -1.75      | 1.96 | 0.37    | -2.27    | 1.68 | 0.18    | -2.27   | 1.67 | 0.17    |
| 2011/12             | 1.85       | 1.85 | 0.32    | 1.77     | 1.73 | 0.30    | 1.77    | 1.70 | 0.30    |

\*N = 18 observations

\*\* N = 20 observations

School type = religious

## 6. 3. Summary

The quantitative study of the mixed methods research showed that the third dose uptake by school varied between 65% and 100% with an overall median uptake in each year of 90% in 2008/09, 75% in 2009/10, 86.5% in 2010/11, 89.5% in 2011/12 and 86.5% in all years. Every year median uptake rates were higher than the goal set by the WHO (70%) (World Health Organization, 2008). 19 schools out of 20 in the first two years and all 20 schools in the last two years of the HPV vaccination programme had uptake rates of 70% or above. Thus, I concluded that the programme was successfully implemented across the years. In this context, I looked at variation in uptake between schools located in high and low deprived areas (of SAP and SCA). I found that uptake rates were consistently over 80% in both high and low deprived areas (of SAP and SCA) across years, except the second academic year when uptake was over 70% meaning that even in the context of a dramatic event following the HPV vaccination, the goals of the programme were met.

While the lowest uptake was found in school 16 and school 2 repeatedly, the highest uptake was achieved by different schools across the years and in all years combined. It was noted that the percentage of non-white residents in SCA of school 16 was 65%, which was the highest among all the secondary schools included in the study. A similar high percentage (54%) of non-white residents was found in the SCA of school 2.

The unadjusted results indicate that there was a negative statistically significant association between deprivation of SCA and uptake, as well as the deprivation of SAP and the academic year 2009/10 (the last was possibly associated with the negative event in 2009/10 described in detail in Theme 3 of Chapter 7). In the two multiple regression models (i.e. after multiple adjustments for other factors), deprivation of SAP remained statistically significantly associated with uptake after controlling for ethnicity, school

type and academic year. Similarly, the academic year 2009/10 remained statistically significantly associated with uptake after adjusting for geographic and school factors. Deprivation of SCA was no longer statistically significant associated with uptake when the other variables were held constant and the same was true for the association between ethnicity (proportion of white residents) and uptake.

In conclusion, I found that uptake was only significantly associated with deprivation of SAP and no association was found between uptake and other geographic factors (deprivation of SCA and ethnicity) or school factors (religious affiliation).

In the next chapter, I present fieldwork approach, data collection, the methods and the techniques of thematic analysis and the results of the qualitative study.

# **CHAPTER 7: QUALITATIVE RESEARCH STUDY**

In this chapter, I describe how I obtained ethical approval for the qualitative component of the mixed methods research in schools which addressed research question 3. Then, I describe my methods of data collection: individual face-to-face interviews and non-participant observation. Next, I present how I collected data, including the recruitment of the participants, the conduct of the interviews, the transcription of the interviews, reflexivity and the procedures to minimize possible researcher effect and researcher bias and thematic analysis and in the end, I present the results.

## **7. 1. Ethics**

Permission to conduct this research was sought from the NHS Research Ethics Committee (NHS REC) Black Country. I received ethical approval from the NHS REC and a research passport at the University of Warwick in October 2012. A Disclosure from the Criminal Records Bureau was obtained April 2012. The West Midlands (South) Comprehensive Local Research Network granted NHS permission to conduct my study at an NHS site and the R&D approval allowed me to interview nurses and to observe them during vaccination sessions. I obtained secondary data from NHS through the Freedom of Information Act 2000.

I gained access to conduct interviews in the schools from the Head teachers although this was not straightforward and took some time. Gatekeepers increase barriers to children's participation in research to protect them from harm (Powell, 2011) although children's involvement in research is based on their right to express their views (Powell, 2011).

Principles of ethics in research include autonomy, beneficence and non-maleficence, and justice (Powell, 2011). Freely given informed consent is required when social research involves human subjects (Social Research Association, 2003; National Research Ethics Service, 2011). This is because before a subject decides whether or not to take part, it is important for him/her to understand (Powell, 2011) why the research is being done, and if there are benefits or risks for him/her in the study (Social Research Association, 2003). An acceptable risk for a child participating in research varies from study to study (National Research Ethics Service, 2011). Risk is minimal when research involves questioning or observing children (National Research Ethics Service, 2011).

The amount of information provided to participants to ensure that they are sufficiently informed about research (Powell, 2011) could be decided according to standard protocols (Social Research Association, 2003) or comments of service users or members of the public after they have read the information sheet (National Research Ethics Service, 2011). Evidence suggests that discussion between the researcher and the participants on different aspects of the written information sheet is a means to seek their “informed” consent (National Research Ethics Service, 2011). Consent is an ongoing process (National Research Ethics Service, 2011) so that the participants have the right to withdraw at any time without giving any reason (Powell, 2011; Social Research Association, 2003).

Participant information sheets and consent forms were developed according to guidelines of the National Research Ethics Service (National Research Ethics Service, 2011) and of the Social Research Association (Social Research Association, 2003) and approved by the NHS NREC (See Appendix 21). Consent involves verbal or written agreement (Powell, 2011). Informed consent in writing was gained from all people who

were part of the qualitative study. Those who participated were ensured that privacy - anonymity and confidentiality of their information was protected at all times. There are three types of confidentiality: public confidentiality (anonymity), social network confidentiality (i.e., family members, friends) and third party breach of privacy (Powell, 2011). Privacy considerations include a private physical location to conduct the research (Powell, 2011). The individual interviews with the nurses, the teachers and the girls took place in meeting rooms in the schools to secure confidentiality of discussions during individual interviews.

Anonymisation can prevent breach of confidentiality (Social Research Association, 2003) to maintain participants' trust (National Research Ethics Service, 2011). I planned anonymisation at the time of transcribing the interviews before data analysis. Participants were told in the participant information sheet that all identifiable information (i.e., name, place, profession) collected during interviews and non-participant observations would be removed from the interview transcripts or quotations. A person's name and a school's name was replaced with a number (e.g. nurse 1, school 1). Participants were told that the research information would be analyzed and reported anonymously so that no individual could be identified from the documents. They were told also that anonymised results of the research study would be used to write my PhD thesis in Public Health at the University of Warwick and that I and my supervisors would write articles in scientific journals and present the anonymised results at conferences. In addition, I mentioned to them in the information sheet that the data will be stored in the University of Warwick and accessed by me and my supervisors in accordance with the Data Protection Act 1998. In order to respect social network privacy, participants were told that the information about them that was collected from the study will be put away and no-one but the research team will be able to see it.

Research with children and young people raises ethical concerns and research practice is guided by different types of rights of the child to protection, choice and participation (Powell, 2011). In order to protect girls against potentially harmful effects of participating (Social Research Association, 2003), I made sure that the school counsellor was on site before the individual interviews. Also, I informed the girl that if she was distressed she could contact her school counsellor, or if she preferred she could call ChildLine by phone or contact Get Connected by phone or use WebHelp.

The participant information sheets for girls as well as the letters of invitation, the participant information sheets and the consent forms for Head teachers set out the limits to confidentiality and stated that this may need to be breached if there is a risk of harm to the child or someone else (Powell, 2011, p. 26). Disclosure would have occurred after I had talked to the girl about the best thing to do. In the UK it is considered a good practice to report disclosed information (Powell, 2011). In case of need, information disclosed by the participant would have been discussed by me (the researcher) with my supervisors (Professor Clarke and Professor Hundt) at the University of Warwick and if necessary with the Head teacher or the safeguarding governor or the chair of governors in the school.

As all the girls were under 16 years, I wrote to parents/carers about the study with the information sheet. Participant information sheets had my contact details so that all participants were welcome to contact me, if they had any questions or concerns. If the girls wished to participate to the study, they were asked to sign the informed consent form. At the same time informed consent was sought from girls' parents even if the girls had the capacity to give consent for themselves. Consent depends on the capacity to provide it (National Research Ethics Service, 2011). In the UK, Gillick competence is

applied because there is no law to decide definitive ages when a child can give informed consent and when the researcher should seek consent from a parent (National Research Ethics Service, 2011). Gillick competence refers to the capability of children under 16 years old to give valid consent (Powell, 2011) if they understand information presented to them (National Research Ethics Service, 2011).

I asked the head teachers' permission for the parent/guardian information sheets and opt-out forms to be sent to parents by the school administration which enabled them to know that the school has given support for my study and for them to use the opt-out option if they wished to. There is evidence that the opt-in approach reduces numbers recruited (National Research Ethics Service, 2011). The use of the opt-out forms has been recommended in studies with low risk participants (National Research Ethics Service, 2011). I chose to use the opt-out forms because they were used in another study in the University of Warwick and it worked well.

Guidelines of the National Research Ethics Service state that participants need at least 24 hours to make a decision (National Research Ethics Service, 2011). The girls received the participant information sheet two weeks prior to the interviews and the Information sheet was made easy to read and understand by piloting it on two girls of the same age not included in the study.

When interviewing, I carried an authenticated badge to show to respondents. The girls who agreed to participate to individual interviews and who had their parent's consent to participate, received again a participant information sheet and I spent time going through it to explain to the girls the purpose of the study, what an interview involved, that an interview lasted 30-45 minutes, that participation was voluntary, that they had the right to withdraw at any time without giving any reason (National Research Ethics

Service, 2011), that there were no right or wrong answers to any of the questions (Punch, 2002), and I used age-appropriate and understandable language (National Research Ethics Service, 2011). Then, I invited them to ask any questions they might have had related to the research. The girls were asked to sign a consent form.

## **7. 2. Methods**

I started the fieldwork after I received ethical approval, CRB and research passport in October 2012. The initial plan was to design the mixed methods research as a sequential exploratory study and first to conduct quantitative analysis to inform the sampling of data collection for qualitative analysis. In the end, it was a parallel design owing to the delays in getting access to both the quantitative and qualitative data. Negotiation of getting a secondary dataset and waiting for the staff in the Trust in the city of my study to extract the requested data took around six months from November 2012 to April 2013 that was much more than the time frame of my research plan. I decided to start qualitative data collection because HPV vaccination was carried out in the schools at certain times throughout the academic year such as in September for the first dose, in November for the second dose and in March-April for the third dose. I carried out qualitative data collection until October 2013. In parallel, I conducted quantitative data collection and analysis over the period from December 2012 until December 2013.

### **7. 2. 1. Fieldwork approach**

During the fieldwork, I collected two main types of data:

- 1) Field notes from non-participant observation of vaccination sessions in the schools

## 2) Individual interviews with adults and children

I discuss the rationale for the choice of these methods.

### **7.2.1.1. Interviews**

I conducted individual interviews with adults (nurses and teachers) and with preteenage girls. I interviewed 9 nurses and 4 teachers and 34 girls. The main advantage of doing an individual interview is that in-depth information is gained and sensitive issues can be discussed. It has some disadvantages. For example, it provides individual perceptions so that multiple interviews are needed to identify a range of issues. Also, sampling of participants depends on the achievement of data saturation (Hennink et al., 2011).

Interviews are classified as structured, semi-structured or unstructured. I used semi-structured individual interviews. I chose this technique because it was flexible so that the flow and sharing of views were more natural. It gives the opportunity to the researcher to probe to understand participants' perspectives and experiences. In addition, the respondent could influence the topic, so unexpected issues/topics emerge (Hardon et al., 2004). I developed a topic guide according to literature which I pilot-tested and refined during data collection (Hennink et al., 2011). Because the research questions of the study aimed to capture the young people's perspectives and opinions about barriers and facilitators to HPV vaccine, all questions were flexible and open-ended.

### **7.2.1.2. Non-participant observation**

I carried out non-participant observation in schools from November 2012 to April 2013 and I did this on Mondays, Tuesdays and Wednesdays in 12 schools. The aim of the use of non-participant observation was to understand the context of the HPV vaccination provision in schools and to become more familiar with the study setting and population

(girls, teachers, and nurses). The advantage of non-participant observation is that it provides contextual information, identifying people's actual behavior (Hennink et al., 2011) and it informs about the influence of the physical environment on people and interactions (Mulhall, 2003). The disadvantage of non-participant observation is that interpretation of the researcher's observation is subjective (Hennink et al., 2011). The researcher could pay attention to some people or events more than to the others, either because they are different or because of researcher's background knowledge (Wolfinger, 2002). In order to overcome this disadvantage I developed a guide what to look for when doing observation.

During fieldwork, I observed vaccination sessions looking at the interactions between nurses, girls and teachers. I used a comprehensive strategy to record notes supplying enough detail about what happened in the field and documenting the events strictly chronologically (Wolfinger, 2002). I recorded the events in the fieldwork at the time when they happened, to capture detail. I wrote the field notes at the end of each day after the events were observed (Mulhall, 2003). I wrote subjective interpretation of some events in brackets in the field notes (Hennink et al., 2011) and I kept a field diary where I wrote down all my reflections based on the observations. This helped me to develop questions and to seek clarifications later during interviews.

## **7. 2. 2. Data collection**

### **7. 2. 2. 1. Individual interviews with nurses**

I liaised with the lead nurse of immunization in the Trust in October 2012. She liaised with the general manager of the Children's Services in the Trust to negotiate my access in the Trust. I was invited to give a presentation about my research in a meeting with the heads and the team leaders from Children's Services as well as members from

Corporate Services. The general manager granted the permission for my study in the Trust. Afterwards, I met with the lead nurse of immunization to explain to her my research in more detail. I was told that bank nurses carried out the vaccinations and they were not based in the offices in the Trust. Therefore, I could not meet personally with the nurses. I gave her a pack with the information sheets and consent forms to inform the bank nurses about my study that included observing vaccination sessions in the schools and individual interviews with them. The lead nurse selected the nurses. Sampling was purposive and the criterion was to include nurses with various nursing specialties and roles (as presented in Table 1 in Appendix 22) and presumably different views on the implementation of the HPV programme in the schools in the city.

The lead nurse and I discussed how to organize the interviews with the bank nurses given that their workload was quite high and that they were employed only for two hours per school. The interview had to fit within those two hours. It was not feasible to conduct interviews with the bank nurses after the vaccination sessions because there was no place available to do it in the school or in the Trust. Sometimes the vaccinations were carried out in two schools on a day. The break between the vaccinations in the schools was enough to move from one school to another one. In addition, there was no financial incentive for the nurses to stay after the session had ended.

I started qualitative data collection in November 2012 during the second round of HPV vaccination. The lead nurse of immunization gave me the dates of the vaccination sessions in each school and she suggested I go with the bank nurses into all 20 schools and that I take the opportunity to interview the nurses where it was possible to do that. The vaccinations were carried out four days per week from Monday to Thursday. In

some schools, I made only field observations and in other schools, I made observations and I organized interviews.

The lead nurse introduced me to the nurse team at the time of vaccination session in the first school. Each day, only five-seven bank nurses participated in immunization activities depending on the school roll. Some of the bank nurses came every day while others came occasionally. Thus, the team changed slightly from one day to another. When the lead nurse was not present, another senior nurse introduced me to the bank nurses.

Observation was a dynamic activity (Mulhall, 2003). During observations in some schools, I sat away from the tables where the nurses vaccinated the girls but could see what the nurses, the girls and the teachers were doing, how the girls interacted with the nurses, the teachers, and with each other. In other schools, I stayed at the table where a nurse gave the vaccination to capture what the people were talking about without interacting with anybody and without disrupting them in any way. Sometimes I moved around to see what the girls were doing, before they were invited to receive the injection and to hear the conversation between other nurses and girls.

I interviewed one nurse per vaccination session (Table 1 in Appendix 22) and only in those schools where the time and the context allowed this. This was possible on those days when only one school was scheduled and towards the end of the vaccination session. The consent form was signed on the day of the interview.

I interviewed four nurses in a sports hall away from the site of vaccinations to respect the confidentiality of the discussion and to avoid noise. In another three schools I

interviewed the nurses in a separate room because in those schools the vaccinations were carried out in classrooms or small meeting rooms. I organized the interviews with the lead nurse and the senior nurse in their office in the Trust during the lunch break. In total, I interviewed nine nurses until I obtained data saturation (Hennink et al., 2011).

## **7. 2. 2. 2. Individual interviews with girls and teachers**

### **7. 2. 2. 2. 1. Getting access to schools**

I got a list of the secondary schools from the lead immunization nurse. There were 29 secondary schools in the city of which: 19 were mixed schools, one was a girls' school and nine schools were special<sup>27</sup>.

The original research design had been to complete the quantitative data analysis of mixed methods research and then to select four schools according to two criteria to reflect variation in uptake: high and low HPV vaccine uptake and year 8 girls' ethnicity. The sampling could not be carried out this way because qualitative data collection preceded secondary data analysis in quantitative study. The initial access to schools was difficult and time-consuming and I adopted a mixture of strategies and pathways to find four schools. I contacted 17 mixed schools and one girls' schools and I approached them in four stages. The first stage was in November 2012 when I sent a whole pack with invitation letters, information sheets and consent forms to the head teachers in 11 schools by email and by Royal Mail Special Delivery. I received the confirmation that all 11 packs were delivered. My request to Head teachers was to observe Personal, Social, Health and Education (PSHE) classes to organize individual interview with PHSE teachers and individual interviews with years 8 girls from different ethnic groups.

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<sup>27</sup> Special schools are part of the UK school education focusing on students primarily with learning, behavioral and emotional difficulties and/or disability.

One week later, I contacted the schools by email and phone and found that some of the head teachers had not read the pack of documents. Assuming that the Head teachers had a busy agenda, at the beginning of January 2013 when the schools reopened, I decided to send out only a personalized invitation letter by email to each head teacher. Each school was called a week after the receipt of the letter. The Head teacher of one school agreed to participate in the study, three did not reply and seven out of eleven schools declined to participate by email. Some of the head teachers who replied unfavorably informed me that HPV the vaccination was not the subject of any PSHE lessons and no teachers were involved in discussing the issues with the students, or delivering any kind of formally taught subject material.

The third stage was in February 2013 when I sent out personalized invitation letters to the head teachers in the three schools, which did not reply, and to seven other secondary schools requesting permission to conduct only individual interviews with year 8 girls. Five schools declined participate and the other five schools did not reply.

The fourth stage was in March 2013 when my supervisor introduced me to a public health professional, who would work with me to find alternative ways to access the schools. First, we revised the invitation letter to introduce my study to the schools and to ask permission to interview face-to-face year 8 girls. Second, she put me in contact with the Head of Personal & Social Development in the Learning & Young People's Directorate in City Council. She supported me to get access to the schools sending all my documentation with invitation letters, information sheets and consent forms to teachers in all 20 secondary schools in the city. Unfortunately, none of the schools replied either to her or to me. Therefore, I tried another two strategies. I went to two schools with the nurse team for the third round of vaccinations in April 2013. Once I

was in the schools, I went to Reception where I introduced myself and I mentioned that I had sent a pack of documentation to the head teacher and that he/she had received it. Further, on that day I explained to the Reception staff that the purpose of my visit in their school was to meet with the head teachers. I was told that the head teachers were busy at that time and without a prior appointment, I could not see them. I realized that this strategy was not going to work. The other attempt to get access to the schools was through snowball recruitment method, which is described later in this Section.

In April 2013 I and the public health professional decided to send reminder emails only to those five schools which did not reply in February 2013 and to follow them up one week later. Three schools out of five accepted participation in the study. All four schools which accepted participation in the research were maintained schools. The characteristics of the schools in terms of HPV vaccine uptake and the level of deprivation of their location and their catchment area are presented in Table 1 in Appendix 23.

I describe below how I organized the fieldwork in each school.

The access to the religious school in January 2013 was gained through the Deputy Head teacher. To gain access it is important who the researcher contacts, but also how the project is explained to them (Crang and Cook, 2007). I met with the Deputy Head teacher at the end of January 2013 to discuss with her the research in more detail. I explained to her that I was interested in interviewing a mixed group of 10 year 8 girls in terms of ethnicity because I wanted to see both differences and similarities across the groups of students. I asked her to select year 8 girls from all ethnic groups and religions in that school including vaccinated and not vaccinated girls to reflect the demographic

profile of the school. I asked her if any teacher in the school had talked to the girls about HPV vaccine at the beginning of the academic year. I found out that this was pastors' responsibility and I obtained permission to interview one of them. I explained to her that before the interviews I needed to get parental consent because the girls were 12-13 years old. We discussed the options to send the information sheets and the consent forms to the parents and we concluded that the best choice was to send them through the school. The reason was that the young participants may not have passed the information on to parents and as such they could have been taking part in the study without their parents' knowledge. In addition, sending the forms via school was a way to reassure parents that the school had given support to my study. The information sheets contained my contact details so that the girls or the parents could contact me, if they had any questions or concerns. The Deputy Head teacher agreed to select the girls and to inform them as well as their parents about my research and she suggested I waited two weeks to collect the consent forms. The person who chased up the consent forms was the administrative assistant to the Deputy Head teacher. I contacted her once a week to ask about how many parents had consented for their daughters to take part in my study. At the end of February 2013, I found out that she had nine forms with parental consent. We agreed to arrange a schedule of interviews and to carry them out in March 2013.

After I conducted all the interviews with the girls and the pastor, I met with the Deputy Head teacher to enquire if she could recommend one of her contacts in other schools in the city who might give support to my study. She gave me the name and the email address of the Assistant Principal in the school with the most ethnic groups in the city. Despite my efforts to get in touch with that Assistant Principal by email in which I included the name of the Deputy Head teacher from the religious school, I did not get

any reply. Then, I contacted the lead nurse of immunizations to enquire about her contact in this same school and I found out that the contact was the same person - the Assistant Principal. The lead nurse offered to help me and to write to the Assistant Principal to inform her that I worked very closely with the nurses for the first part of my research. The lead nurse tried to get her permission to let me come to the school. A month later, after I and my supervisor's secretary had sent several reminder emails and made phone calls, the Assistant Principal contacted me and agreed to her school participating in my study. I met with her and advised her to give the information sheets and the consent forms to 25 girls and their parents as she could expect to get about half returned consent forms with parental permission, In May, she got 11 forms with parental consent and then she scheduled the interviews with the girls. She accepted to be interviewed as well because she was the teacher in charge of the organization of HPV vaccination in the school.

In mid-April another two schools gave a positive response to my invitation, one being the smallest secondary school in the city and the other one being a girls' school with the biggest cohort of year 8 girls. In the former school, I liaised with the Safeguarding & Social Inclusion Manager who put me in contact with the Office Manager of the School Reception. The Manager of Reception was the coordinator of HPV vaccination in that school. She supervised School Reception staff that distributed my documentation to the girls and chased up the consent forms. In addition, she welcomed the opportunity to take part in an interview for my research. Within a week, only three year 8 girls got parental consent to participate in my research study and the Manager of Reception arranged for me to conduct interviews with them.

In the other school, the Assistant Head teacher answered my invitation announcing that her school gave support to my research. She introduced me to the head of year 8 who

handed out my information to the students at the time of the third round of HPV vaccination. After a month, the Assistant Head teacher informed me that the girls were keen but the parents did not agree to my request. However, I was able to interview the head of year 8 in June 2013.

In total, I interviewed four school staff. This was because in each school one person was the coordinator of the organization of the HPV programme.

I contacted these two schools again in September 2013 hoping that the parents of a new cohort of year 8 girls would consent for their daughters to be interviewed. I told my contacts that by that time I had interviewed successfully around 10 girls/school in another two schools in the city (giving the name of the schools) to encourage them to recruit. Then, I was able to interview seven more girls in one school (the smallest one) and four girls in the other school (girls' school) in October 2013 after the first round of HPV vaccination.

My contacts collected all the consent forms and kept them in the schools until the time I organized the interviews.

As planned in the research design, these young girls came from a variety of different backgrounds. The girls were selected from different Houses in the school. The year 8 girls sampled in each school are presented in Table 1 in Appendix 24.

#### **7. 2. 2. 2. 2. Interviews with 34 girls in schools**

I conducted interviews at different hours during the day when the girls were taken from classes.

All interviews in this research project were carried out within the school in a quiet meeting room. It may be argued that because the interviews took place within a school setting I perhaps would have had different data had I conducted the interviews in an out-of-school setting. In a school, the researcher has to pay particular attention to the setting of the interview to establish a comfortable space where children feel that they are welcome (Punch, 2002; Freeman and Mathison, 2009). I welcomed each girl offering biscuits at the beginning of interview. I tried to make the interview context informal and conversational with open-ended questions (Watt, 2007). Open ended questions are better to be used before the topic of researcher's interest because the children become comfortable when they discuss what is familiar to them (Freeman and Mathison, 2009).

I established the rapport gradually making initial conversation on non-threatening issues (Winter, 2011) and introducing myself as a student at the University of Warwick. I tried to get them to talk to me by asking easy to answer questions, such as "What lesson are you missing? Do you like literature? What are you learning about Shakespeare? Why are you interested in social care? Do you like Indian movies?" Also, I picked up on their watch/bag/earrings or something else to talk about. Children were used to a range of adults being in their school (e.g. bank nurses). My interaction with the girls was helped by the completed non-participant observations in November 2012. During the initial conversation, I advised them how to keep the audio recorder in their hand to get a clear recording and to help me monitor it if it was working properly. Additional items were included during the interview process with the girls guided by emergent findings such as own decision related to HPV vaccine, knowledge about cervical cancer and others' influences in their own uptake of HPV vaccine.

I built successful rapport with all 34 girls listening to them with non-verbal responses (Winter, 2011) mostly a smile (Kyronlampi-Kylmanen and Maatta, 2011).

At the beginning of each interview, the project was carefully explained to the students and I made sure that they had understood what it was about. The girls who agreed to participate to individual interviews and who had their parent's consent to participate to individual interviews received a participant information sheet again on the day of interview when I went through it to explain to the girls the purpose of the study, what an interview involved, that their participation was voluntary, that they had the right to withdraw at any time, the principles of confidentiality and anonymity. I used age-appropriate and understandable language for girls aged 12-13 years. I invited them to ask me any questions they might have had related to the research.

Each interview lasted between 30 minutes – 1 hour. All girls were taken from lessons. An audio recorder was used to record all interviews with the nurses, the girls and the teachers. Before beginning the interview, the interviewees were furthermore asked whether they felt comfortable with me audio-recording the interview. All participants gave signed consent to the audiotaping.

### **7. 2. 3. Reflexivity**

Qualitative research includes reflection on researcher's subjectivity and positionality. Reflexivity is important in data analysis (Mauthner and Doucet, 2003) because it adds credibility to qualitative research (Dowling, 2006). This issue will be revisited in Chapter 8 in the section "Strengths of qualitative study". Reflexivity is a process of conscious self-reflection on the influence of researcher's role or title (positionality) and researcher's characteristics (subjectivity) on data collection. I reflected on several issues. One aspect is how my decisions influenced data collection (i.e., the choice and implementation of study methods in research with children (Powell, 2011)). Also, I reflected on the influence of the social setting of the research (school), on the wider

social and political context of data collection (Hennink et al., 2011) as well as on ethnic difference between the participants (children) and me.

As a novice qualitative researcher, I recognized that I was affected by being in the field (school environment) and that I could have had an effect on the subjects of study (Dowling, 2006). I am a public health specialist physician and I interviewed nurses, teachers and girls who may have reacted in a socially desirable way owing to my status as a doctor. Therefore, during interviews with nurses and teachers I took steps to primarily identify myself as a student and although a physician I emphasised that I was familiarising myself with the UK setting. During interviews with the girls, I introduced myself only as a student trying to give them the impression that I had a similar status as them with the only difference that I was a student at University. At the beginning of the interview, I explained to them that I wanted to learn from them about their experiences with HPV vaccination with the purpose to convince them that I was a student. If I had introduced myself as a doctor to the girls, it may be that they would have felt uncomfortable when we discussed medical issues like cervical cancer. I made clear to them the point that I was not a teacher and that our interview was not an exam to give them a mark for their answers. Although I was a visitor in the school and I could not arrange the place of interview, the discussions with the girls took place in meeting rooms available for use by staff, which were different from a classroom. I believe that the environment supported to some extent my message to the girls that the interview was not going to be an exam. There was an age difference between the girls whom I interviewed and me. Power is a major issue in undertaking research with children because it is considered that adults have more power than children (Powell, 2011). Reflexivity could redress power imbalances encouraging the researcher to consider personal assumptions and how these impact on the study and on participants (Powell,

2011). The researcher's role as non-authoritarian adult could facilitate children's participation in research (Powell, 2011). Therefore, I tried to make the interviews resemble an everyday conversation as much as possible (Kyronlampi-Kylmanen and Maatta, 2011). To make easier for the girls to engage in the discussion and to maintain their enjoyment throughout the interview I displayed each question from the topic guide on a separate laminated paper with famous cartoon characters. I was unknown to all the girls at the time of interviews. However, I developed a trustful relationship with each of them because the school staff (the coordinator of HPV vaccine programme in the school) introduced me to the girls on the day of each interview. In addition, being a female researcher could have made the girls feel more comfortable in contributing to the discussion (Hopkins, 2007).

My country of birth and ethnicity were different from those of all participants. Some researchers consider that this aspect could be beneficial to the information gained in the interview. For example, it is likely that the participants could have described the discussion issues to me in greater detail than to a similar moderator of British background (Hopkins, 2007). Being an interviewer with differing characteristics to participants gave me the opportunity to ask for clarifications or explanations.

#### **7. 2. 4. Procedures to minimize possible researcher effect and researcher bias**

Semi-structured individual interviews were used to minimize the influence of my own views on the quality of information obtained during an interview. During the interview, I used a topic guide with probes to obtain an adequate answer to understand participants' perspectives (See Appendix 21). It also helped me to give voice to the participants and not to talk much in the conversation. Recording the interviews helped

me to get feedback on my performance from my supervisor after the first interviews. In order to avoid bias from interviewer performance, I planned three pilot interviews before the fieldwork: two pilot interviews with year 8 girls and one interview with a nurse. In order to avoid bias from interviewer characteristics, I controlled behavior, mannerisms, my appearance and voice. I read literature on effective communication with children before the fieldwork (Winter, 2011, pp. 74-95). I used my interpersonal skills to enable children feel safe, without fear of rejection or judgement (Winter, 2011, pp. 25-36).

## **7. 2. 5. Thematic analysis**

### ***Research question 3***

What are the mechanisms, strategies and practices that influence uptake of HPV vaccine?

#### **7. 2. 5. 1. Data management**

I transcribed half of the interviews and the other half were transcribed by a professional transcriber since transcription takes a long time and English is not my mother tongue so that my transcriptions were incomplete. I used thematic analysis (Braun & Clarke thematic analysis model) because it is inductive allowing categories to emerge from data (Saldaña, 2009) and also for the reason that I was a novice researcher. The field notes and the interview transcripts were coded in relation to research question reading and re-reading the material and asking myself questions about the data (Coffey and Atkinson, 1996) to search for patterns of meaning through a semantic approach (Braun and Clarke, 2006). I started with very open codes doing line by line analysis which involved close examination of data phrase by phrase (Corbin and Strauss, 2008). I used an inductive approach by not engaging with literature at those early stages of the

analysis (Braun and Clarke, 2006). An individual extract of data (identifying a feature) was coded across the entire data set (Braun and Clarke, 2006). I attached only one code to a segment of data (Coffey and Atkinson, 1996). As a beginner qualitative researcher, I used descriptive coding summarizing in a word or short phrase the topic discussed in a segment of data. Also, I used in vivo coding referring to a term used by young interviewees (Corbin and Strauss, 2008) (Saldaña, 2009). The data was reorganized according to the ideas that were obtained throughout the process of coding. Further, all data extracts relevant to each code were then collated (Braun and Clarke, 2006). All interviews with nurses, teachers, and girls represented the whole dataset. I coded separately the interviews for each group of participants (nurses, teachers, and girls). The codes were entered into NVivo 10 as free nodes in three different folders. I got 79 codes from the interviews with nurses, teachers, and girls that I organized in 9 categories which I synthesized in three major themes (Saldaña, 2009) (Table 1 in Appendix 25). The number of the categories reflected the nuances in the data (Powell and Renner, 2003).

To make sense of the data, I analyzed the content of each code and I considered differences, similarities and patterns in what the participants said and did using the OSOP technique (one sheet of paper). This method involved reading each code and writing down on a single sheet of paper the key ideas expressed within a code along with the relevant respondent IDs. In this way I obtained a summary of all the issues for each code (Bussche et al., 2010; Ziebland and McPherson, 2006). All categories were emergent categories which I defined after I worked with the data (Powell and Renner, 2003). Then, I formed overarching themes which were based on ideas brought up by the people in the interviews and on concepts which I developed during data analysis (Saldaña, 2009). I discussed the identified themes with my supervisor.

I conducted an interpretative analysis for each theme (Braun and Clarke, 2006) based on these relationships (Coffey and Atkinson, 1996). To show which categories appeared more important within a theme I used a visual model (tree map) in NVivo. Overall, I did a rich thematic description of my entire data set (Braun and Clarke, 2006) (including field notes from observations as well as interviews) to explain the phenomenon under my study (Corbin and Strauss, 2008).

### **7. 3. Results**

This section presents the analysis of the qualitative data comprising nine interviews with health professionals, four interviews with school staff and 34 interviews with girls attending the secondary schools in year 8. The first section addresses the research question related to the mechanisms and strategies that influence uptake of HPV vaccine on the way in which the delivery of the vaccination was organized in the schools. The second section is an analysis of factors facilitating uptake of the vaccine and the third section is an analysis of the barriers to uptake. These last two sections address the research question related to factors and practices affecting the uptake of HPV vaccine.

#### **7. 3. 1. Theme 1 - Analysis of delivery of HPV immunization in the schools to girls**

This first section of the findings chapter is an analysis of the school context for the implementation of the HPV vaccine programme in secondary schools in the city of study. It starts with an analysis of how the programme ran in the city of study according to the understandings of the health professionals involved, followed by an analysis of the reflections of secondary school staff who organized and delivered the HPV vaccine supplemented by fieldwork observations. Subsequently, the analysis focuses on the organization of delivery of HPV vaccination programme in the schools before and on

the day of vaccination. Also, it describes the way in which the HPV vaccine has been promoted in schools.

### **A school-based HPV vaccination programme**

The HPV immunisation programme in the UK is part of the national adolescent vaccination schedule and it is mainly a school-based programme. In the city of study, a highly skilled and well trained team of bank nurses has provided HPV vaccinations to pre-adolescent and adolescent girls in secondary schools since 2008. When I asked the nurses if GPs have been involved in the HPV immunizations, an immunization nurse stated that the GP involvement was related to the fact that HPV immunization is a three-dose vaccination schedule and that

*“When they [GPs] need to do it privately they send them [the girls] to us. They [GPs] need to really because is a three part immunization. They don’t know what the child already had.”* [Nurse 8]

According to the interviewees, the delivery of the HPV vaccination programme through a team of nurses was adopted for several reasons. One of the reasons was the issue of local data management. A few nurses said that the information from the consent forms is entered manually into the child health information system and then *“that information is passed on to the GP”* [Nurse 4]. However, it was felt that the information system is set up in such a way that the communication between the child health services and the GPs was difficult as described by one of the nurses in the following quote:

*“...the paper work going between practice and child health isn’t very robust...it takes long time, it takes a year. So they [GPs] will have that information to the end of August of all the girls who have been immunized. In the future when their information system links up that would be great because they will get the information automatically. So it’s*

*not going to be a problem. But until that happens, it's an issue. So you can end up with kids that are over immunized and things. It needs to be controlled by one area really."*

[Nurse 8]

Another reason given by the same nurse was related to cost effectiveness of employing bank nurses by the hour.

*"It's just a way the team was set up initially because that was going to be, like a couple of hours here and there and everywhere. It is more cost-effective just to employ nurses specifically, to target them at the time when you need them. That's why it was set up that way."* [Nurse 8]

It was thought that a mobile clinic strategy could increase the uptake of the HPV vaccine based on experiences with the provision of flu vaccine in hospitals:

*"Going into school and going to the girls is much better way of doing it. If you have a programme where people actually make the effort and go themselves...lots of them won't do it...whereas if you take it to them, the uptake is going to be a lot...I mean, I found this with doing flu vaccines in the hospital ...normally that's what they do...well, is here...you come and get it if you want it and some people do, but a lot don't...in the year with swine flu we went to them...That uptake was a loads more just because you actually took it to them and is amazing what a difference it makes."* [Nurse 2]

### **7. 3. 1. 1. School policy and HPV vaccine**

I asked the nurses about school policy in relation to HPV vaccination as a school-based programme. The nurses felt that most of the schools have supported and helped the delivery of the HPV vaccine programme.

*“The majority are really good....are very welcoming, very accommodating and friendly...The majority are really, really helpful and really want to try and do their utmost to help us because, you know, we realise as well that this is an extra added role for them, although obviously for us it’s our priority.” [Nurse 9]*

The staff involved in facilitating and organizing the HPV vaccination in their schools showed that acceptance of this programme was high and they *“took it on board straightaway.”* [School staff 36, School 9]

For example, an administrative staff member in one school said that both the Head teacher and the staff supported the delivery of the HPV vaccination:

*“the Head would make that decision... The Head [thought that] they [the girls] have just got to have their injection, that's important. It doesn't disrupt for long, it's something that happens, it goes on, the children are fine, and just get on with it. As a staff, we all agree that it is a good thing for the girls to have, if it will prevent people dying of something like that.”* [Support staff 20, School<sup>28</sup> 14]

The faith based schools also delivered the HPV vaccination programme. A teacher in a Catholic school described the involvement of staff and governors in decision-making process about the HPV vaccine programme in the school since 2008.

*“Our policy is that we do we support it and we offer the vaccination here in school. As long as we're doing it in accordance with the Catholic Church, then we carry on and we do it. Our Church leaders support it and they back the idea. Being a Catholic school we had to be very careful and very sensitive the very first time. Everybody had questions about it, not just the girls themselves; you know...the staff, the governors..... Once*

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<sup>28</sup> The number of the school in qualitative analysis is different than the number in quantitative analysis. The correspondence of the schools in the two studies is presented in Appendix 26

*everybody understood what it was, then we hadn't any problem at all. There were a lot of misconceptions at the very beginning. Once we found out these were misconceptions then it was fine.*" [Teacher 19, School 6]

I would seem that each school organizes the delivery separately as a support staff said: *"We don't talk to anybody else about how they do it. Everybody has got their own way of doing it."* [Support staff 20, School 14]

The goal of school policy is *"to have all the girls vaccinated. We try to drag as many people through it as possible."* [Teacher 33, School 7]. In order to achieve that goal, the schools encourage the parents and the girls to make a decision about the HPV vaccine but only the girls with parental consent are vaccinated as exemplified by the following quotation:

*"It is not in our policy that they have to have it done, that is up to their parents to decide. We just encourage it and support it really".* [School staff 36, School 9]

*"We can say that it's part of Government policy, now it's National Health Service policy and that we, as a school, are the vehicle really. We don't decide who has it, we don't decide what it is, it's offered to year 8 girls, we don't pay for it, we don't do any of that. It's the Health Service administering in school as it is merely the easiest, most practical way of administering it to the girls of that age."* [Teacher 33, School 7]

This quote clearly shows that the schools do not decide whether the girls receive the HPV vaccine. The schools represent a location where HPV vaccine programme is

delivered to the girls, but administratively handled by the NHS staff and the Local Authority.

Although the majority of schools have been in favor of the HPV immunization, the attitude has varied across the schools with some being more helpful than others. *“I feel that we go in there and this is a bit of a nuisance really and they’ve got to find staff to help on that session and they’ve got to find us a location. So there are a couple of schools that I do feel that we’re classed as a bit of a nuisance really.”* [Nurse 9]

One of the nurses felt also that:

*“Some of them are really keen and really helpful and some of them you can tell they are not really. They think it is all a bit of a pain. They don’t really want to do it but because is Local Authority they do it, they have to.”* [Nurse 2]

Another nurse suggested that factors that affect the approach within a school may be the time needed to organize the delivery of the HPV vaccination programme in an already crowded school curriculum.

*“I think generally they are quite good, but I think for the schools is very difficult because of their short of time and education is their priority so it can be quite difficult...for them to make time for us to come in because they have to fit it with what’s going on within their curriculum as well and sometimes I do feel that perhaps ...we are educating the children as long as we are looking for their health but I think sometimes they think...it is a separate thing and we shouldn’t always necessarily be coming into schools to give the vaccinations...but most of the time we’ve been able to do it.”* [Nurse 3]

The view of the teacher below clearly shows that in her school the vaccination programme is seen as a medical service and that the confidentiality of girls' immunization status is respected:

*“We don't keep a record of who has and who hasn't been vaccinated, because it's a medical issue which is really private in terms of vaccination, it's not anything that is likely to impact upon them in school.”* [Teacher 33, School 7]

In the city of study, there are five faith schools: three Catholic, one Church of England and one Muslim. The nurses expressed the view that sometimes it has been more difficult to go to some of the faith schools in comparison to others because, in some cases, the schools with religious affiliation *“are a bit anxious to be vaccinating girls or not.”* [Nurse 5]

One of the nurses gave an example, saying that liaising with one of the Catholic schools has been difficult. This school has not provided them with the girls' names and addresses for the reason that it *“is not covered on the Data Protection.”* [Nurse 8] The nurse said that this has affected their communication with the parents when they needed to send them a letter to offer a clinic appointment in case their daughters missed the vaccination in the school. The following quote illustrates her point:

*“That's their [schools'] decision not to give out that information that's fine, but then we need them [teachers] to be the ones to make the contact for us [nurses] then to the parents. If it is a case that the child hasn't taken the form home, how are these parents ever going to know that this child should have had their vaccination and their form and*

*everything? And I don't think our percentage at that school is particularly good. No, it's sort of, that school has got a 5% to 10% lower uptake than generally the others."*

[Nurse 9]

All nurses explained to me that only a small private Muslim school has entirely rejected the HPV vaccination and has not allowed them to enter that school since 2008. One of the nurses made clear that the school's refusal could be due to the link between HPV vaccine and the prevention of a sexually transmitted disease:

*"From the discussion with our manager there is one school that's the Muslim school and they [staff] are not happy for us to go in and as far as I am aware this is the only secondary school in the city where we hadn't had access to those girls which I think is terrible personally to deny them choice. It's not right. I am sure is sex thing. It's because we're protecting them against what essentially is a sexually transmitted infection."* [Nurse 5]

Another nurse thought that the parental refusal for HPV vaccination influenced that school's decision to restrict the nurses' access to the school. *"There it wasn't the [Muslim] school, it was the parents. We have since been in this school giving leaver boosters so it's not particularly vaccination that they are against, it's this particular vaccine"* [Nurse 4] *"because the subject [HPV vaccine] is quite controversial."* [Nurse 3] Another nurse mentioned that, *"They [school staff] always say 'We've asked and nobody wanted the vaccination.'"* [Nurse 8]

The nurses have not known for sure if the Muslim school informed the parents about the HPV vaccine.

*“We don’t really know. We just get their word that they sent out the forms. You can’t be really sure but you would imagine they did do. It’s a very small school with a small number of girls so you can only take it on trust that the forms did go out, but you haven’t a real proof.”* [Nurse 4]

### **7. 3. 1. 2. Organization of delivery of HPV vaccination programme**

#### **7. 3. 1. 2. 1. Liaising with the school**

There were variations in the delivery of the HPV vaccination programme across the schools. The nurses agreed that the HPV vaccination increased schools’ workload. Therefore, it appeared that *“some [schools] are better in organization than others.”* [Nurse 7]

Before the beginning of an academic year, the nurse immunization coordinators liaised with the school sending a letter to the Head Teacher. Further, the nurse coordinators worked with a contact in each school who was organising the administration of the HPV vaccine in addition as part of their job in the school.

This contact person *“varies from school to school. With some schools, it’s administration [school name] for example and some schools [name], it’s teachers. A lot of schools usually allocate the year 8 manager, the year 8 head as the contact person because obviously, they know that whole year group hopefully, so yes, it varies. It’s based on whoever has been allocated to do it really.”* [Nurse 9]

The nurse coordinators liaised with the contacts in the schools before the commencement of the new school year to discuss the programme for the coming year, to arrange three dates for vaccination sessions and to ask for a suitable room to ensure the programme was accommodated within the school calendar year. This communication is illustrated by the following two quotes:

*“They [nurses] usually contact me early in the autumn term..... The nurses contact me and they say ‘we’d like to do your vaccinations between these dates’ ...They’ll give me a choice of dates...and then, we’ll agree the three dates for the year.” [Teacher 33, School 7]*

*“When we first make contact we get three dates off them so that we can facilitate the rooms on one day, sort it out on the first day, so that those rooms are then free for future.” [School staff 36, School 9]*

A nurse described the process of communication with the contact person in each school to get information about the number of eligible girls so they can prepare an appropriate number of information packs per school to be given to the girls and their parents. The following quote highlights the importance of the return of consent forms to the schools whether the parents accept or refuse the vaccination.

*“Before the end of the academic year we’ll ask schools for their estimated coming roll for the next year.... then we’ll send that appropriate number of packs out to the school and that’s got a consent form in it, an information letter, which has been devised by us as a team and public health and an information leaflet. So then, I drop them to the school and I ask that every girl in year 8 receives that pack to take home for the parents to read all the information, make a decision, fill out the consent form and return it to the school. Whether their decision is a ‘yes’ or a ‘no’, a signed consent form is expected back for every girl in the school.” [Nurse 9]*

The information packs including NHS standardised materials (a leaflet and a consent form) are given to schools at the beginning of the academic year in September two or three weeks before the first HPV vaccination sessions. The nurse coordinators rely on

schools to distribute them to girls and their parents. The schools have used two ways to send the packs to the parents either via girls or by post. One of the nurses pointed to the disadvantages of one way compared to the other:

*“The senior members of our team decide that...they go on how it worked out previously, what the uptakes were liked ...they do communicate with each other and with the school to work out the best way really...I’ve seen actually both ways...sometimes if you give it to the pupils it does not always get home ...sometimes if you send it directly to the home address ...some families may have moved or it’s not always the right address.”* [Nurse 3]

Most of the schools preferred to distribute the packs via girls because posting them cost money. The administrative staff stated that her school chose to “*send them out by post*” and she explained the reason why:

*“I mean I could give them to the girls but I always think they are not going to get there, you know, a lot of the girls won't give them to their parents if I give them it by hand.”* [Support staff 20, School 14]

The coordinators of HPV vaccination in the schools plan the time and the place of the sessions in such a way so as not to disrupt teachers’ classes, using previous experience with the organization of other vaccinations done in the school. “*We used to do the TB ones before, so you sort of know what to do and you know what to expect...I will check the calendar and I will speak to staff or I will perhaps email. Science, maths and English don't like us to interrupt their classes because they are core subjects so I will try and avoid those classes - do it before break ...or before lunch...I just put a general email out to everybody ‘if you've got any objections let me know’*”. [Support staff 20, School 14]

In another school, a teacher explained how she decided on suitable vaccination dates, avoiding holidays and other days when important activities take place in the school: *“We have to make sure it’s not a training day, that they’re [girls are] all going to be in school. For example, it’s not in a holiday obviously, there’s nothing major going on that day which is likely to prevent them from having the vaccination. We wouldn’t do a vaccination programme on a day when we’ve got something else of significance going on really, which is going to involve our use of space. We need to make sure that that a [room is] free at that time...”* [Teacher 33, School 7]

A nurse pointed out, as the teacher above, that one of the logistical challenges for the HPV vaccination administration in schools is to allocate a suitable room for sessions. Another teacher mentioned that, *“getting the forms out is not a problem, it is trying to get a room. Obviously we have not got nursing rooms, we have to use classrooms. So it is making sure that timetables are sorted so that we have got rooms free.”* [School staff 36, School 9]

My observations showed that schools used different spaces such as a canteen, the staff room, a meeting room, a classroom, the gym hall, the kitchen, the prayer room.

The organization of the HPV vaccination required teamwork. A teacher stated that *“It is an effort...It is not just me, I oversee it and I make the process happen, but other people are involved in it...”* [Teacher 33, School 7]

One of the coordinator’s tasks is to allocate staff to provide the girls and the parents with the information packs as well as to chase up consent forms that are not returned by a specified date. The tutors predominantly assumed the responsibility of disseminating the packs to the girls.

As one coordinating teacher said, *“The timing of when you actually send the forms home is really important, because if you send it home too early, it will just be lost. If you send it home quite late on, you don’t give yourself enough time to chase up. They [parents] don’t, they will take their time and they’ll wait to be nagged...It’s a bit like paying on the red reminder, isn’t it? You always wait until the last minute, they [school staff] do a lot of chasing, a lot of talking to parents...It is my job to make sure that they have a timeline and so forth which enables them to do that...”* [Teacher 33, School 7]

In one school, the teachers chased the parents for the forms and *“asked to have them back at least a good two [weeks]”* before the vaccination date to be able to *“...chase any that are missing.”* [School staff 36, School 9] Chasing up the forms meant sometimes calling the parents. One of the teachers described how resource intensive and time consuming this process was in her school. If *“nurses will say ‘yes, we’ll accept verbal consent from the parent’... [then] the parents are phoned....We’ll keep doing it until, as I say, even on the day of the vaccination.”* [Teacher 33, School 7]

These quotes show that there were repeated attempts in different ways to obtain the signed consent forms and that different staff members took on this responsibility. The forms were sent out to the parents with an information pack, and then until the day of vaccination the parents were phoned by the teachers to remind them to sign. After that, on the day of the vaccination they were phoned again by the teachers or other school staff to obtain a verbal consent. The nurse coordinators explained that chasing up the forms is an essential strategy for a high HPV vaccine uptake. Their opinion is illustrated in the two quotes below.

*“...You do find some schools...allocate more help than other...ones that don’t allocate help or don’t want specific person responsible to help with the programme have a lower*

*uptake...that's because they don't have people that will chase the forms and make sure that they come back in."* [Nurse 8]

*"but by and large, the majority of schools are really good and really help, like chasing the forms and you can tell the schools are really very proactive and are very encouraging with the vaccine because that's when our uptake is really good, because they will chase the girls to get the forms back in. "* [Nurse 9]

The *"consent is obtained once for all three doses."* [Nurse 1] The organizers of the programme in the schools collect all the consent forms and they give them to the nurse coordinator at the first vaccination sessions. From that time on, the nurse coordinator administers the forms during and between the subsequent vaccination sessions to follow up the girls who did not return the forms and to identify those who are absent on the day.

*"We ask for a roll from the school; a list of all the girls on that roll, so when we then arrive at the school for the first HPV session the forms will have been collected back in the school. We ask them to be put back into the folder in an alphabetical order, which we've always done and then from there, then we'll mark off on the roll that we've been given."* [Nurse 9]

The organizers of HPV vaccination showed that the schools have adopted different approaches related to the announcement of the date when the HPV vaccination takes place. One teacher said that in her school the staff members do not make known the day of the vaccination to the students to avoid their absenteeism.

*"We never tell the girls when the vaccination is going to be. Some of them might make an excuse and not come to school, they'll 'say 'I'm not going to school, I don't feel very*

*well today mum'. But also we don't want parents keeping them off either, for whatever reason."* [Teacher 33, School 7]

Another school had a contrasting approach to this issue. The school staff member stated that it was good *"to tell them the day before so that they are not asking questions or they are not trying to skip school, to miss it."* [School staff 36, School 9]

Before the vaccination day, the teachers need to overcome the challenges of providing explanations to motivate the girls to get the vaccine and to reassure them *"that they had injections [before] ... and [these three jabs are] no different."* [School staff 36, School 9]

The school staff plays an important role in making the girls understand the potential benefits of HPV vaccine. In one school, the teacher explained that the tutors initiated conversations with the girls to support them in understanding the HPV vaccine and to persuade them to return the consent forms. She said:

*"The tutor will give the forms out to the girls and will tell them that that's what it is. And then when they're asking for the forms to come back, if the girls bring them back automatically, fine, thank you very much. If they're finding that girls aren't bringing them back, then they would speak to them individually...about it [HPV vaccine] and answer questions that they might have or any concerns they might have...Those that they have to chase up to return the forms are the ones who tend to get most of the conversations...it's reactive rather than proactive in terms of them having a conversation with them....So they might say, call them over and say 'I need your form', 'why haven't you returned the form?' And they might say 'I don't know whether I want*

*it or not*. *'Why don't you want it? Do you understand what it is? Yes?'*." [Teacher 33, School 7]

The same teacher described how the school staff made the girls aware of the importance of the vaccine if they have not brought back a signed form:

*"We'll talk to the girl: 'you've not got a form, you know this is a really important vaccination, it's important for your health. It doesn't mean that you're going to be sexually promiscuous, it doesn't mean anything like that, it's not a protection against pregnancy, it's nothing like that, but it will protect you ...Do you want it?'"* [Teacher 33, School 7]

These two quotes cited above clearly indicate that, apart from making the girls understand the benefits of the vaccination, the teachers tried to get the cooperation of the girls not telling them what day it will be on as well as persuading them to accept it. Persuasion in social science is defined as a type of influence with the purpose to create a positive result without threat or willingness to harm. It is a psychological process based on the transmission of a message that, according to these quotes, was verbal (Powers, 2007). Persuasive conversations between a teacher and each individual girl who did not return the form might have increased the likelihood of persuasion because of face to face communication and the credibility and the trustworthiness (Powers, 2007) of school staff as illustrated in the following quote:

One teacher explained that the girls in her school are *"...able to trust the people that are around them"* because the teachers *"...have a lot of contact with the students before they join [school name]."* [Teacher 19, School 6]

The staff expressed the view that the schools have good communication with the parents. A teacher affirmed, *“We stay with them [girls] from year seven right through to year eleven so we get to know the parents quite well or most of them.”* [School staff 36, School 9] Another teacher explained, *“We’re a school which does communicate a lot with parents and I think parents generally feel quite comfortable about approaching us as a school.”* [Teacher 33, School 7]

The teachers may exert influence in helping the parents to decide about the vaccination of their daughter.

*“It’s about talking to the mum, getting the mum on your side and then getting the mum to reassure the child...we are not saying ‘you have to, your daughter doesn’t have to have it’, we are just saying ‘it’s a good idea’” and usually they will say ‘Oh yes, go on, they [girls] will have it’.* [Support staff 20, School 14]

When parents are unwilling for their daughters to have the vaccination, school staff seemed to respect this, but had additional strategies and suggestions which showed their commitment to obtaining consent from parents.

Although *“we have to respect their decision obviously”* [Teacher 33, School 7],

*“We encourage them even after they said ‘no’...at least to speak to their nurses at their own surgeries to see if there is any way [to have it].”* [Teacher 19, School 6]

*“If they are still adamant then I will have passed it back to the vaccination team.”*  
[School staff 36, School 9]

The school staff contacts the parents, especially the mothers, and take different approaches getting across how important it is for them to agree to their child having the

injection in the school or at the community clinic. The following excerpt from an interview is an example of the way in which a teacher gives explanations to parents about the vaccination when they phone them up if they have not agreed on the consent.

*“I would say that many girls all over the country have it, it is considered to be very important, it is a protection, it is free of charge if you have it done at this age. If you want it later on in life, it’s going to cost money. You can have it at the clinic if not in school, but it’s much better if your daughter has it when everybody else is having it in school. So I’d talk more about the practicalities of it.*

*We just say that anybody can contract cancer of the cervix and it’s not to do with promiscuity, it is something which is particularly prevalent in younger women and if it is not treated and identified very early on, then it can be fatal and it usually is fatal if it is not treated very early on. Like any cancer treatment, the treatment is not pleasant and it has its side effects and prevention is better than cure. So if you can prevent it in the first place, then it’s much better to prevent it for the sake of a vaccination which is proven to have no side effects really. That’s the line we take with them. We certainly, as a school, would encourage it as part of normal health care and healthy living. And I say, one of my daughter’s has had it and I wish the other one had as well.*

*Sometimes they [the parents] don’t appreciate how important it is and sometimes by talking to them the teacher can encourage them to have it, and sometimes they will say ‘oh yes I didn’t realise, oh yes’, .... and then the form appears.*

*I would not start talking about it actually preventing a sexually transmitted disease, sexually transmitted diseases do come in to the picture here. Cervical cancer can be considered to be a sexually transmitted disease, but I wouldn’t go there because I don’t then want to be questioned further and further about it as something which I don’t know enough about. I would not do that, because I’m not a scientist and I’m not a doctor and*

*I wouldn't go on to say of course this vaccine does this and this vaccine does that and it has this effect on this and it has this effect on that. I just wouldn't go there. And also I'm not going to get involved in conversations which make any judgement at all on sexual activity. When it comes to cultural issues, I obviously have my own thoughts and my own feelings personally, but professionally it is not my place to pass judgement on people's religion.*" [Teacher 33, School 7]

The quotations above suggest that on the ground of moral considerations the teachers used a persuasive strategy making persistent phone calls, as discussed earlier, and transmitting the message about the need of vaccination to parents to obtain their consent.

### **7.3.1.2.2. The tasks on the day of the vaccination**

The organization of the vaccination on the day of the sessions involves effort, resources, and partnership working between the nurses and the school staff. The nurse coordinator said, "*It's hard for all of us covering shifts...as long as we get a good number of bank staff we can usually fill that gap.*" [Nurse 8]

My observations showed that the vaccination team worked with a number of nurses which varied from six to ten influenced mostly by the size of the cohort of the eligible girls in a school as well as by the number of school staff allocated to support the delivery of the programme on the vaccination day. I noticed that the number of girls varied between 44 and 175 and that in general, two or three school staff helped the nurses.

The HPV vaccination sessions increase the school's workload on the day as well as the effort to manage them effectively. One teacher explained the workload: "...you've got

*to make sure that all the staff...their lessons aren't being to be affected because of girls going out of the room to have the vaccination. But the effort put in is so important. It's never ever seen as 'Oh I don't want to do this...it's just annoying'. It's important, it's done and it's done well. It's a big effort and everybody is supportive of it. So for example, if one of my colleagues was free, she would happily take my lessons while I am supporting the girls. So everyone gets on board ...we need staff there to support it. ”*

[Teacher 19, School 6]

The senior nurse felt that allocation of different school staff every year can result in more work. She mentioned: *“Once the staff know how the session works, it does go a lot more smoothly I find. But when you get different staff every time we go in to do a session and they don't really know what they're doing and they don't know us and we don't know them, that makes it a bit harder.”*[Nurse 9]

The school staff's main responsibility on the day is to arrange the room and support the vaccination team as well as the girls. A teacher explained: *“We make little private cubicles, we use quite tall boards to separate out six mini cubicles so they [the girls] have got the privacy that they need and each nurse has their own station and their table with their equipment on it....a chair for the girl, a chair for the nurse...you know there is a place to sit down afterwards and is all very controlled and comfortable.”*

[Teacher19, School 6]

Another teacher added that it is required to *“...have crash mats out ready and benches [for girls] to put their legs up on.”* She also said, *“We have got eight nurses...they are great on the day they come in...We get the tables ready for them, they set everything up.”* [School staff 36, School 6]

The allocated staff on the day is different in each school and it could be Assistant Head Teachers, House Heads, Heads of year 8, support staff, and tutors. One teacher stated, *“there is always [name] assistant head teacher, is always her secretary, is always one of us [House Heads] as well. There is probably three teachers, but then you also have about four support staff, our teaching assistants as well.”* [Teacher 19, School 6]

At one school, only the support staff was involved in the process of coordination. *“We are just there conveniently for the nurses to give the injections. We are there to support them, that's why we are called support staff and not administrative staff. We don't get involved, we are just doing as we are told basically. It won't be teachers, it is support staff so it will probably be three of us so maybe one in there and then there might be one that might need to make phone calls...there will be perhaps two [staff] monitoring the girls because they get louder.”* [Support staff 20, School 14] Contacting the parents on the day of vaccination suggests staff's persistent attempts to obtain verbal consent that could have limited parents' right to freedom of vaccination choice.

The school with the biggest cohort of year 8 girls allocated almost double number of staff. *“We could have probably 16 different teachers in one day. If they are free... will come down and reassure them as well...because they know them, they see them every day. They are really good with them.”* [Teacher 36, School 9]

The schools accommodate the sessions in the morning during school hours. From my observations, it was clear that each session was planned to be two hours per school. One teacher explained how the time is managed: *“They are split into seven or eight different classes in the day. So, we try and do four classes during period one which is an hour and then the other three or four classes, period two. We give them [teachers] probably about 15 minutes to get the small group done and then they start bringing the other classes down. Eight girls are vaccinated at a time, so we get them done quite quickly so*

*then they go back to lessons. Sometimes it runs over so it does mean that I have to look at their timetables, work out which classes they are in, let their teachers know, get their teachers to bring them down and take them back.*" [School staff 36, School 9]

During the whole process, the coordinators of immunization have *"to get them through as quick as we can and calmly as we can. It helps the nurses, everybody gets done much quicker then...We encourage them to go straight back to their lesson...so that we don't have like girls wandering around or not going to their lessons."* (Support staff 20, School 14]

A nurse perceived that *"some of them [schools] are better than others in the organization...sometimes is very quiet...just a few girls come in at a time...but in other schools they seem to bring the whole year down and it's very noisy...and it's not easy to concentrate or to get the child that you're working with to concentrate because they are very interested in everybody watching them."* [Nurse 7] This quote indicates the importance to vaccinate in a quiet environment that facilitates the communication between the nurses and the girls.

A school staff member explained the way the process is coordinated: *"They [support staff] work in student reception so we get a list of the girls and they will organise the girls to come down in order so they might just choose class order or alphabetical order...The teachers know what is happening, they are all informed, so they are aware that the girls will be going out and coming back in. There is a student bulletin as well which we can put on messages for them and the staff will read that out in the morning. We are a small school, so there may only be 40/50 girls, we might get twenty down at a time and then they [nurses] usually do about five or six injections at a time. We just*

*have them queuing up waiting for their injection and it usually works quite well in the staff room because it is comfortable and it's quiet and it's cosy. There are sofas in there that they [girls] could rest on and we don't have so much panic in there. If they are really frightened we will try and get them in first so they haven't got so long to wait and worry.” [Support staff 20, School 14]*

The coordinators of the HPV vaccination in the school have a crucial role in “*organising the practicalities of the vaccination*” on the day. [Teacher 33, School 7] as well as managing the unexpected situations like “*Panics about having it done...[which] delays things a little bit...The ones that are going to say ‘I don’t feel well and I want to go home’...we try to keep them in school as much as we can.*” [School staff 36, School 9]

A school staff member said that “*it’s not the actual cancer that they are worried about, it’s just the injection...There will always be somebody that over reacts and even just messing about will freak the others.*” [Support staff 20, School 14]

Another teacher described how fearful girls are if they are vaccinated before the others. “*If they are really worried...we have got a certain amount of girls...we had about 15 girls that were really scared about having their injections, so we get them first, we pull them down first so it is very quiet it is a very small group, so they have not everybody around, they have not got a whole class there. And we just talk to them and just reassure them that it is in their best interests to have it done, that it is a little tiny needle it is not a great big needle,that it is over in a matter of seconds. So they are a lot better if we bring them down first.*” [School staff 36, School 9]

The analysis showed that the school staff used different strategies to create a supportive environment and to encourage the girls to receive the injections. A school staff member indicated the type of emotional support which she used: *“I will give them a cuddle, I will get them a drink of water if they are feeling sick, because I am first aid trained as well so I will keep an eye on the ones that are a little bit faint, so just again reassurance, being their mum for them.”* [School staff 36, School 9]

A nurse felt that the school staff adopted different ways to get the girls vaccinated. *“The teacher will come up and say, ‘Look...’ you know, either being the nicey-nicey teacher and say, ‘Look, you can hold my hand,’ or be the firm teacher saying, ‘Come on, pull yourself together.’”* [Nurse 9]

One of the nurse coordinators emphasized that some girls *“don’t want to have it in front of the friends because a lot of them might cry”* [Nurse 8] which would affect the other girls.

One of the nurses gave other two potential explanations for the barrier to vaccination in school. She said, *“Probably the environment within the school could possibly be a bit awkward for some of the children because if they have medical problems they will not want to have their friends around them or the parents sometimes prefer to go to another place to have it done.”* [Nurse 3]

A teacher added another reason and she said that the girls who do not have parental consent cannot be vaccinated on the day. If such a thing occurs, *“I won’t make that decision, the nurses have to make that decision obviously, because that’s a medical decision.”* [Teacher 33, School 7] This quote shows once again that the teachers do not involve in decision making for vaccination of girls.

If the girls cannot be vaccinated in the school as well as “*those who missed a scheduled immunization*” [Nurse 8], the health professionals offer them another opportunity to be vaccinated and invite them to clinic. One of the nurses indicated that “*we give them reminders...so we try and get a high consent...a high proportion of the forms back so we can vaccinate more pupils.*” [Nurse 3] Her statement emphasizes the idea that reminders are used as a strategy to increase HPV vaccine uptake.

Ethnicity may be a factor influencing uptake but this is speculation based on observations and nurses’ views. From observations and looking at the consent forms, I noticed that, apart from the girls with White ethnic background, Black and Indian girls were vaccinated also. I observed that there were girls with different religious beliefs such as Muslims, Sikh and Hindu who received the vaccine. For example, in one school almost half of the total vaccinated girls were Muslims (42 Muslim girls out of 97 girls). There could have been other girls with the same religions as those mentioned previously, whom I could not recognize because they were not dressed according to these traditions. There could have been girls with other religious beliefs (e.g. Jewish or Jehovah Witness) difficult to identify through observations. Similarly, there could have been girls with other ethnicities that remained unknown because they were not recorded in the consent forms. In addition, my data did not identify girls’ ethnic origin, except for a few of them whom I asked directly during interviews about their and their parents’ country of birth.

The literature review indicated that there are several ethnic groups in the UK. Apart from “White” residents there are people from other ethnic groups who could be British, immigrants or could have mixed heritage. This idea was emphasized by a teacher who stated that in her school: “*We are predominantly Catholic...we don’t tend to refuse*

*anyone on the religious basis... we have a lot of students from other countries, we have a lot of students from Poland, we do have some that come from India or from other countries, but we have some that are British and their parents were originally from those different countries.*" [Teacher 19, School 6] This quote shows that, in the school, there are students born in the UK or in their parents' countries. However, this poses the question if ethnicity influences uptake of the HPV vaccine as long as parents make the decision for vaccination as stated earlier in this section.

When I asked a nurse to make a comparison between the HPV vaccine uptake in different schools, she said that *"it changes to be honest...initially these schools [names] had the poorest uptake... [because] these have more vast ethnicity ranges."*[Nurse 8] This quotation indicates that uptake has changed over time across schools but ethnicity does not seem to explain this variation except for the first academic year.

Likewise, my data does not make it possible to make a statement about language as a barrier to the HPV vaccine uptake. Based on the minimal information which I obtained from the school staff it appeared that the schools have different mechanisms in place to provide interpreters when it is necessary. One teacher said that the teachers *"know their students and they know whether the parents can speak English or read English. They will say this child or this parent will not understand, then we'd arrange for them to make sure that they understood the information...We do have a Czech interpreter and we have a Romanian interpreter....if they would have language difficulties, then we get the interpreters obviously to contact the families directly...they do some home visits...they have built up quite strong relationships with the Roma families...Now we've got two of them working on a part time basis, where part of the time they are supporting in class and part of the time they are out working with parents and working with*

*students individually or small groups, but actually it's going to be a lot easier for them...If we've got some African parents or Somali parents, for example, then, to be fair, the Somali community is quite strong and if we want to speak to them, they will usually bring somebody with them who does speak English. If they know they don't speak English, they will often bring a relative or a friend or a neighbour, somebody from the community who does speak English. And sometimes we have used the child themselves sometimes. We've said, for example, if it's a situation where we haven't had a form back and the child has said to us that they would like the vaccination, then we say 'talk to your mum, talk to your dad on the phone, talk to them, tell them you'd like it' and we can get verbal consent if they'll give verbal consent. And usually they've got enough English to be able to give consent."* [Teacher 33, School 7] This quote shows that the school uses different interpreters to facilitate communication with the parents such as professional interpreters for Czech, Romanian and Roma families as well as relatives for African families and the girls for other families.

A teacher in another school mentioned that *"...There is a Sahil project that have a lot of Asian speaking staff, as there are different languages there. We do have some language teachers in school so they are French speaking or we have Japanese teachers, a teacher in school that speaks Urdu and we sometimes ask her to give parents a call and speak to them...."* [School staff 36, School 9]

This suggests that schools used other people as interpreters apart from trained interpreters: children, relatives, community members and teachers. This practice could perhaps affect the accuracy and completeness of interpretation because non-professionals could alter or omit something that is stated.

### **7. 3. 1. 3. Information about HPV vaccine in the schools**

#### **7. 3. 1. 3. 1. Information about the HPV vaccine in the curriculum**

I asked the coordinators of the HPV programme if the schools had talked to the girls about the HPV vaccine and sexually transmitted diseases in any of their classes. They said that they brought up issues related to barriers to the promotion of the HPV vaccine in the discussion about sex education in their school. Sex and Relationship Education (SRE) teaches about reproduction, sexuality and sexual health as well as relationships through compulsory science lessons and during PSHE lessons (Personal, Social and Health Education). SRE is a compulsory subject included in Key Stage 3 (Years 7 to 9) and Key Stage 4 (Years 10 and 11) of the National Curriculum. The parents cannot remove the child from statutory elements of SRE about reproduction taught in science (GOV.UK, 2013a).

The interviews showed that sex education is a very sensitive optional topic with little emphasis on vaccines and sexually transmitted diseases. The schools had materials about sex education in different subjects and science seemed to be one of the places where sexual health was taught.

*One teacher said “Sexual health will come partly under PSHE, science and partly under citizenship, sex and relationship education...it’s mandatory....In science it will be spoken about more from a scientific point of view, whereas it’s spoken about more in terms of relationships within the citizenship programme.*

*Health and social care would obviously talk about health. Pastoral programme talks about health and healthy eating and healthy lifestyles, but it doesn’t go in to detail about sexually transmitted diseases, because they are in vertical tutor groups. [The talk about sexually transmitted diseases] might come up to a certain extent in history when they’re talking about the history of medicine, which they do, the history of medicine is*

*one of their modules, so it might come up there, and obviously it could possibly be touched on in other areas of history, but I don't think it's, I wouldn't have thought it's gone in to anywhere else really...The sixth form programme [Year 12 and 13] may well deal more with that, but again, it's a profile of our sixth form, it's not an area that a lot of students are very comfortable with...I think culturally some of them find it difficult to talk about sexual activity full stop...we just have to handle these things quite sensitively.*" [Teacher 33, School 7] This extract of interview shows that teaching about sexually transmitted diseases is more difficult than about sexual health because of cultural barriers.

Another teacher in a different school stated, *"We talk about sex and relationships in religious education anyway and another one obviously science teaches a little bit biology at that point."* [Teacher 19, School 6]

Another teacher elaborated a bit on the way in which sex education is implemented in her school: *"They [the students] will have sex education in some form in science and in tutorials about protecting themselves still.... and they will use a lesson plan and materials then but not necessarily linked to having the vaccination...They [the girls] are informed that they are going to be doing sex education and parents have the right to write in to us and explain that they don't want to take part...But the year sevens will have a tutorial and they will have some form of sex education and then it gets more involved as they get older...STIs and pregnancy and teenage pregnancies and they do a lot of...that sort of starts in year nine. And then they have a talk from the nurse in year ten and eleven a bit more in depth about sexually transmitted diseases."* [School staff 36, School 9] This quotation indicates that sexually transmitted diseases are taught to older cohorts than those in year 8.

Time pressure is a constraint and the curriculum, especially the pastoral programme, is planned in advance before notification of the dates of the HPV vaccinations.

*“We probably haven’t done it [talk about HPV vaccine] ...because literally the time is so packed with so many other things...The science department is very..., they’ve got their syllabus to follow, every minute of every lesson is important, but this is health...The pastoral programme is so tightly prescribed and every session is written down point by point in terms of what has to be done. When that pastoral programme is written we don’t know the dates for the HPV vaccines, so it doesn’t get built in to the pastoral programme. It might be that if we knew dates early before the pastoral system were put together, we could perhaps plan at least a session where perhaps the girls were withdrawn from tutor groups just for one session, just to be spoken to, that might be a possibility.”* [Teacher 33, School 7]

Another issue is whether this information is specific to girls and if they could be spoken to separately from the boys in their classes.

*“I’m not sure whether the girls have ever been spoken to as a group, to be honest.”* On the other hand, the teacher added, *“they [the girls] are in mixed tutor groups and it’s not the kind of thing that we talk about in a mixed tutor group, particularly in this school, with our particular profile. Tutor groups are mixed ages, so you’ll have four year 7’s, four year 8’s, four year 9’s, four year 10’s and four year 11’s in one tutor group.”* [Teacher 33, School 7]

One school talked to the girls *“in tutorial ...because it is year eight they have the vaccine that is the only time that is discussed, the HPV.”* [School staff 36, School 9]

Nevertheless, in this school, a teacher thought that the tutors felt that they did not have the knowledge to counsel girls if asked to give them more information about the vaccine. *“Tutors struggle talking about sex in general...Some tutors are a little bit nervous about saying things as well because we have got a couple of teachers that are obviously from a religious background as well. So in those sort of cases we try to put a different tutor in so that they are quite open and they can have a frank discussion...”*. [School staff 36, School 9]

### **7. 3. 1. 3. 2. Talk about the HPV vaccine in assembly**

School nurses who work in the schools are generally not involved in giving information about HPV vaccine although some schools invite school nurses to give talks to the girls about it.

One nurse said that *“the school nurses [in the vaccination team] will do assemblies and things in [the school] and [the schools] let them discuss before we come in doing the jab...but that doesn't happen very often any more.”* [Nurse 8]

The interviews with three staff members showed that their schools organized an assembly and it was planned a month before the first HPV vaccination to allow the parents to get in contact with the school and to ask more information about it.

A teacher described how the assembly has been organized and what issues have been discussed with the students. *“The school nurse came and spoke to myself and...the Assistant of Head teacher....and explained all about it [HPV vaccine] and then the three of us took the assembly...between half an hour and 40 minutes. There is a Power Point...[which was] given to us initially when HPV vaccination first started...by the NHS... what the HPV vaccination is, why is so important for them to have it and...what*

*the [consent] forms mean...what the vaccine is fighting against...the risks of not having the vaccination and leaving it so late...the importance of what might happen if they don't fight against it now...In assembly will be very general practical questions.... 'will it hurt?' ...we don't go deeper than that..." [Teacher19, School 6]*

The interviews with the school staff suggested that the girls had the tendency to raise different questions when they were informed about the HPV vaccine and cervical cancer in their tutors groups or assemblies. One teacher reported on the types of discussion that occurs with tutors as illustrated in the following excerpt of interview.

*"...their tutors go through that form with them and answer any questions that they have got...They obviously have to explain that it is the three vaccinations, three injections. They are probably not aware of what is in the injection themselves, just that it covers them against cervical cancer in the future...I think it starts very quiet and then you will get one that is brave that will ask a question and then it will stem from there really. They [tutors] have been asked questions like 'what do you mean sex?', 'what is that?'....'when are they going to have it?', 'does it hurt?', 'how long is it going to hurt?' Other girls will then pipe up and the teacher will let the discussion happen and keep it under control... It is more those sort of questions than the sexual side of things, yes. Whether that is because they are still only twelve...I think they are probably a little bit more open because there are not boys there...There are a few that are shy and are totally oblivious to what is going on and what could happen, and they are the ones that you tend to have to speak to a little bit more. But no I think the girls on the whole are really good and I think they are probably a little bit more open because there are not boys there, they will talk quite openly....We obviously discuss that as they get older they are going to become more sexually active. So to do it now is an age that we think is appropriate for them where they shouldn't be having sexual intercourse but obviously*

*they are going to be starting, the sexual age I suppose is coming down and I think we need to explain that to them...and just that this is a good age to start getting that protection there...Some girls are quite worldly and will understand why they need it and how they could get the cancer. But then you have got a lot of the Asian population that haven't had that sort of discussion with parents and are totally unaware of what could happen and why they could get the cancer. So, they are the sort of people that you then have to explain to them, they are the ones that are probably a bit more inquisitive and 'why do we need it?'...it depends on what the tutor group is like and how much they want to know."* [School staff 36, School 9]

Another teacher indicated frequently asked questions about HPV vaccine during the assembly in her school: *"They [the girls] have questions concerning what cervical cancer actually is because they're still very young to be hearing about such adult diseases...We explain just by giving them the facts by trying to put it in as easy language as be possibly can for them...unprotected sex can lead to several different infections and left untreated they can lead onto more serious things...probably not during the assembly because they wouldn't feel comfortable...If they got more sensitive questions... like 'what does it actually mean?' ... 'how do you get that cancer?' ... 'what is cancer?' ...our school nurse did a drop in-service....so that everyone could go and speak to her...cos they might not want to tell me and they might not want to tell another teacher...One of the questions that comes after the first one [vaccination] is because the nurse has to say to them 'is there any chance that you might be pregnant?'...and our girls are quite horrified at that question...So a couple of questions come up then... 'Miss why do they ask me if I may be pregnant?' ... 'why do they think that I would be?'...you know...so...I try to explain to them that we are living in a society where girls are sexually active a lot younger than they used to be years ago and because of the nature*

*of the vaccination they have to be 100% sure that you are well enough for it.” [Teacher 19, School 6]*

This section showed that school based HPV vaccination programme was accepted by all the schools except for private Muslim school in the city of study and was delivered by a mobile clinic aiming to vaccinate all eligible girls. It described the organization of delivery of HPV vaccination programme before and on the day of vaccination through a partnership between the nurses and the school staff including setting up dates and places of vaccination as well as getting the informed consent. Gaining parental consent was the most important factor that affected uptake of the vaccine. The manner in which the school staff sought parents’ and girls’ written and verbal consent was often persuasive with repeated different approaches. Finally, there was limited discussion of the HPV vaccine in the school curriculum using a range of different lessons.

### **7.3.2. Theme 2 - Facilitators to uptake of HPV vaccine**

This section addresses the research question related to factors and practices affecting the uptake of HPV vaccine. It is an analysis of the facilitators to the vaccination. It starts with an analysis of the way the consent was obtained from the parents and from the girls, followed by an analysis of the role of girls’ social interaction within and outside the family on the decision for HPV vaccine uptake. The second part of this chapter explores the different influences related to girls’ personal characteristics as well as to their parents’ reported views.

The analysis in the previous chapter about the delivery of HPV immunization in the schools to girls showed that the school setting facilitates dealing with large numbers of girls at a time in a routinized way within the school day, and that the process of informing them about the vaccine is done by the teachers and that the school seeks

informed consent from the parents/carers of the girls. Aside from the school setting there are other factors that facilitate the uptake of the vaccine. One of these factors is obtaining consent from the girls themselves by nurses.

### **7. 3. 2. 1. Consent for HPV vaccine**

Consent for the HPV vaccine from the parents is obtained generally before the day of the vaccination and has been discussed in the previous chapter. When the nurses come into the school informed consent is requested from the girls themselves. One of them said “...*We discuss it [HPV vaccine] with them [the girls] and make sure they understand the implications and then they sign the form*”. [Nurse 5] A teacher pointed out that the girls might not be informed about HPV vaccine and in her view they sign the form because they are easily influenced by others: “*There are [girls] that don’t read [the consent form or leaflet] and just sign because they think it’s just a part of this course ‘We have it done’ [and] mum says ‘We have it done’...*”. [Teacher 19, School 6]

One nurse thought that “*It’s usually mum that’s signed the form...mums are the ones I think with the deciding factors and I think a lot of the dads will go along and they probably do support each other and they do it as a family decision*”. [Nurse 9]

Which parent signed the form was considered to vary across ethnic groups. For example, a nurse affirmed that “*In (White) British groups is usually the mother that signs because...probably is easier to the mother to explain to a daughter what is all about, it may be embarrassing coming from the father...*” [Nurse 4] Another nurse mentioned that “*Often we find with the Muslims girls [that] the fathers give the consent or not because is usually the fathers who speak better English than mothers.*” [Nurse 7]

When “*...the child is not in contact with the parents or some children weren’t in schools, especially extended schools, or they’ve been excluded from schools, first the*

*parent or usually social services have ultimate responsibility for their health and well-being...so you have to go through layers before you get to the consent, but we usually do get it in the end.” [Nurse 4]*

Parental consent plays a crucial role in the process of HPV vaccination. Sometimes the nurses needed to contact the parent in order to make sure that the parent’s signature was real. For example, *“If something was standing out to us that...’oh the writing was the same like the child’s signature’ [then] obviously we raise alarm bells about that...but I suppose in a way we have to trust that the form is brought back and signed by the parents.” [Nurse 6]*

If there is no signed parental consent, then the nurses will try to contact the parents/carers on the day of the vaccination, *“keep contacting until we actually speak to the parents on telephone” [Nurse 7]* *“upon the day when we are actually in the school” [Nurse 8]* to get verbal consent. During the conversations, the nurses addressed different perceived parental misconceptions with reassurance and communicating effectively about HPV vaccine. One of the most prevalent misconceptions was related to the safety of HPV vaccine.

*“We will have a chat with them on the phone first of all...I think the key is communication really...is having the time to chase your non responders and your refusers...If they want to come to the clinic we will arrange for them to come to the clinic and make sure we have enough time to put aside to spend more time with them at the clinic...We just go through all the evidence with them...we go through all the side effects if that’s what they’re worried about...and tell them how long it [HPV vaccine] has actually been around because a lot of them had been around for a couple of*

*years...we direct them to the Department of Health website information...to see the reports on the safety side of it ...". [Nurse 8]*

Nurses felt that another perceived parental misconception would be premature sexual activity after the girls receive HPV vaccine. Nurses explained how they talked with parents about their daughters' need for this vaccine.

*"When we talk to people the language we use is important ... and also to ensure that they know that is for prevention for the future...It's not that we expect to begin now and having sex at earlier age...it's just that the vaccination can actually work and protect them for the future when no doubt they will be sexually active as adults...possibly teenagers...parents don't want to talk about that." [Nurse 6]*

Although the parents were from different ethnic backgrounds, the way in which the nurses talked to them was similar. *"It's fairly similar in all of the groups. It's just explaining a little bit more about the virus and how it's quite common. It's a more common virus than a lot of people think and trying to explain that it can be passed from person to person, not just via full sexual intercourse." [Nurse 9]*

One of the nurses expressed the view that sometimes there is a language barrier in the communication with the parents and one nurse said that a good strategy would be to talk with the parents in their own language. *"I feel that would be a very important thing if we can have people who actually go to speak to parents...we need somebody who has the medical knowledge but also can speak a language as well". [Nurse 7]*

The success of the discussion with the parents depends on their attitudes towards the vaccine as illustrated by the following quote:

*“Sometimes speaking to them, they will understand more than actually reading the information...sometimes they are grateful and quite pleased that you’ve done that...you can speak to some of them and persuade them and change their mind...sometimes they are clearly quite abrupt. If it is somebody who got a very strong feeling about it...you have to go with how it feels on the day I think.”* [Nurse 2]

The views of the participants below suggest that some parents did not sign the consent form if their daughters were scared of injection.

A Muslim girl pointed out that *“Maybe the parents weren’t educated a lot about that vaccination so they wouldn’t think that it is as important as it is and they just wanted to make their kids happy. They don’t want them to go through the pain of the vaccination”*. [African girl 26, School 7]

One of the nurses made a similar point when she stated that *“Their daughter says, ‘I’m not having it. It will hurt,’ and they’ll [parents] say, ‘OK, they don’t have to have it’. I’ve found that quite a lot...we explain to the parents, ‘Well, let’s talk to them, let us see how we get on, a lot of girls are scared of the vaccine, but you know, they’re worried about the injection, but just let her [the nurse] speak to them and then with the reassurance that they [the nurses] obviously won’t traumatise them [the girls] or anything’ and parents are quite happy for us to do that.”* [Nurse 9] The nurses felt that with parental permission they could try to convince the girls to get the HPV injection.

When the parent does not consent for the HPV vaccination, the nurses could choose to apply Gillick competence which a nurse defined as *“Through the interview you decide what you think they [the girls] know exactly what is for, what are they doing...it’s your impression that you get really [after that]...we put on the form that we assessed them [the girls] and in their opinion they are competent to consent for themselves.”* [Nurse 2]

Applying Gillick competence to assess children’s 12–13 year old capacity to consent to vaccination is a challenging task. The nurses acknowledged a child’s right to be vaccinated if the child was considered competent to self-consent. Vaccinating a child in these conditions would require no breach of a child’s right to confidentiality. However, one of the nurses mentioned that parents’ decisions should be respected on the grounds of their right to refuse the vaccination: *“If mum has said ‘no’, [but] we’ve deemed these girls competent to consent for themselves and we’ve vaccinated them, [but] parents have not been made aware of it at the time, because obviously we need to respect the child’s privacy when they’ve [girls have] made that decision that they want it, but we never really want to go against parents’ wishes.”* [Nurse 9]

Nurses said that they would hesitate to give vaccination based on this assessment to so young and most often immature girls because of legal implications: *“We don’t very often do with 12-13 year old girls because probably some of them are a bit young ... it could cause problems ... we could be up in court for assault.”* [Nurse 7]

*“Although we do get them [the girls] to consent, it is only a kind of paper copy and in the eyes of the law it will not stand necessary up in court.”* [Nurse 3]

One of the nurses said how she assessed girls’ maturity. For example, *“If you explain to them [the girls] and they still don’t seem to understand, then you will deem them not competent.”* [Nurse 4]

When the nurses concluded that the girls did not have the ability to consent for themselves, they were willing to contact the parents. *“If it is a child who has some learning difficulties or I am not happy that she understands and is not able to give consent and the parents haven’t given consent, I wouldn’t vaccinate...so we can phone the parents ... [and] invite them to the clinic.”* [Nurse 5]

Nurses’ actions like checking for the validity of parental signature and caution in applying the Gillick test, as previously mentioned, indicate that one of the main facilitators to HPV vaccination is parental consent which, if it is not obtained via the school, is actively sought by the nurses. The nurses facilitate the process of vaccination chasing up the parents and increasing the delivery of information to help them to decide on the day of vaccination and after. This was illustrated by one of the nurses’ following remark: *“...We [nurses] can only advice, we can’t force the family to have it. We can only give information to the family to make their own decision”*. [Nurse 3]

There would seem to be a range of practices concerning whether to apply the Gillick approach and override parental lack of consent. The high uptake of HPV vaccine is thus achieved partly through the school staff actively seeking parental consent and subsequently the nurses seeking consent from non-responders or refusers or overriding parental wishes.

### **7. 3. 2. 2. Parental involvement in decision-making on HPV vaccine**

Social interaction and discussion between the girls and their parents played a significant role in the process of making a decision about the vaccine as well as helping the students to understand why it was important to have it done.

The nurses and the teachers assumed that the parents talked to their daughters about the value of the vaccine at the time when they received the consent form and signed it as showed in the following two quotations:

*“You would hope that if you are signing a form like that for your child, that you would have some discussion with your child to say this is what it’s about and this is why I think you should have.”* [Support staff 20, School 14]

*”The consent form that we use the parents actually have to sign to say [that] ...the child got no severe allergies and has no major health problems...so they must at least discuss that because will tick those boxes and sign that form...so I assume that by doing that they actually sat down with the child and read the information and discussed it together”.* [Nurse 5]

The analysis indicated that some girls talked to various family members about the vaccine.

*“I’ve asked all of my family would they have it done.”* [White British girl 37, School 9]

For example, *“I told my mum, I told my aunty, I told my sister.”* [British Asian girl 39, School 9]

*“My mum and my dad said it’s a good idea, my two sisters had it. Therefore it is a good idea for me to have it because if nothing happened to them then nothing will happen to me.”* [Polish girl 12, School 6]

In girls’ views, the parents’ decision was based on trust in the vaccine and protecting their daughters from disease.

*“...They [the parents] might think that any chance they get to protect their children they might just take it and just trust it”* [White British girl 18, School 6] because they *“want the best for their kids...they care about them...so they won’t become ill.”* [Polish girl 15, School 6]

A number of interviews showed that some of the girls felt that they could not make the decision for themselves.

For example, a Muslim girl, said *“You’re still really young at this age...sometimes you don’t know what you’re saying... you’re not fully grown up, that you can take your own decisions.... You still live in your parents’ house and you still have to abide by their rules... It’s best to leave it up to the parents, because they’re older than you, they’re mature and they know what they’re doing.”* [Mixed British girl 28, School 7]

Similarly, another girl pointed out that *“I decided with my mum because I knew that obviously she needs to choose what is right for me.”* [Slovakian girl 40, School 9]

Another girl mentioned, *“If we think we shouldn’t have it and our mums think we should, then you have got to kind of realise that you might actually need it.”* [White British girl 21, School 14]

Several girls described the conversations with their mothers as well as with their fathers who tried to convince them to get the injection explaining to them the importance of the vaccine for their future life. A Muslim girl said her mother told her *“You should really take it [HPV vaccine] because it will help you later on in life if you do get it [cervical cancer], then it’ll probably lessen the chances of getting it. So they [the parents] said that...it will be good for you. That’s how they sort of influenced me, sort of talked me into it”.* [British Asian girl 27, School 7] Another girl gave a similar example when she stated that *“She [mum] was saying ‘Oh, you might not think that is important now but when you get older you could be just like...oh, I wish I had had it now’ .“* [White British girl 18, School 6] Also, a Hindu girl talked about her Dad who *” told me the benefits of getting this and what would it do to you and what cervical cancer is. She [mum] was just saying that how we’re really lucky to get this injection because in her days they*

*didn't get a chance to have this injection done, so not everyone gets a chance to have an injection like this to cure an infection.*" [British Asian girl 32, School 7]

Some girls felt that their parents did not put pressure on them to get the vaccine. They perceived the discussion with their parents as support in making their own choice about the vaccine or as joint decision-making.

*"My mum made the decision with me, but she wanted to know how I felt about it as well"* [White British girl 37, School 9]

*"...She [mother] said it's my choice if I want to get it. I'm glad that she said 'you don't need to do it but I think it would be good if you did but is really up to you' ".* [White British girl 16, School 6]

A Muslim girl said about her parents that *"They give you the basic information about it [HPV vaccine] and then they say 'it's your decision and you have to decide. You are old enough, you are in year eight and you should be able to decide what is good for you and what's not'"* [British Arab girl 35, School 7]

Some girls preferred to talk to their mothers about the vaccine. Two girls said that they trusted their mothers more than they trusted their friends.

A Muslim girl mentioned that *"If you've got girl problems we would tell, like, our mum or our sister or someone. I think it's better to share it with your family, because, your mum she's given birth to you and she knows you so well."* [British Asian girl 39, School 9]

Another girl explained her reason, saying *"My mum is a nurse so I can talk to her about it...I read the letter as well just saying that we were going to have an HPV jab...I just*

*wanted to be clear with my mum just what it is.....All my questions were pretty much 'is it going to hurt?' and the pain and size of needles". [White British girl 21, School 14]*

The data show that some girls considered and welcomed parental advice. Some of the girls saw family as an important source of socio-emotional support and confidence building. They pointed out to the way in which their parents prepared them psychologically before having the injection and supported them to overcome their fear of it. A Muslim girl stated that *"My parents also wanted that I don't get cancer in my life and my life doesn't get ruined, so that's how they supported me, to take the vaccination and be brave and face my fear"*. [Mixed British girl 28, School 7] Another girl said *"Sometimes you don't understand what half of the words say, so my mum explained it in a simpler way for me...you were going to have injections into your arm, and I got a bit worried at that point, I was like, 'hang on'. She was like, 'it's not like a blood test' that I've had done in the past. 'It's just a little pin prick, you won't feel it...."* [White British girl 37, School 9] Parents and especially mothers had a strong influence on their daughters' decisions, as demonstrated by the fact that some girls conformed to their families' views rather than their own after some discussion.

*"I said that 'I don't wanna take it' and she said 'You have to' and I said 'What if I am like allergic to something inside it' and she said 'You could be allergic to anything'...she just said 'Go outside, you cross the road and anything will kill you... just take it, what's the worst that could happen because it's for a good cause anyway'."*

(African girl 14, School 6)

Some mothers encouraged their daughters to get the vaccine because of family history of cancer especially breast cancer.

In a teacher's opinion "*...A lot of parents take it [decision] into their own hands to say that the girls are having it done...[because] 'cancer has been in our family'. So, it is protecting them, it is giving them the safeguarding.*" [School staff 36, School 9]

A girl made a similar point when she talked about her mother's argument in favor of vaccine "*...She [mother] explained to me about all the cancer part, about my grandma and she was really supportive... 'Don't make a mistake about this, because if you don't have this done then look at grandma'... breast cancer...it's to do with my grandma, my mum's side and obviously my dad doesn't know much about it because no one on his side ever had cancer.*" [White British girl 37, School 9]

Another girl added "*Her mum's mum had breast cancer, and my mum's just found out she might have breast cancer, so she said it might not stop it because it runs in her family...but it just prevents it being that bad in a short space of time.*" [White British girl 43, School 14]

The girls reported that some of their mothers tried to make them understand that cervical cancer is connected to sexual relations.

"*She was just like 'when you have sexual intercourse with a boy, they can give you something called cervical cancer, which can affect you massively. It can harm you in a way and the cervical cancer goes around the....'*" [White British girl 44, School 14]

"*She [mother] said 'if you have a sexual relationship with someone when you are older, the sperm and everything that goes inside you, it might like have a disease and the injection will stop you from getting it' [cervical cancer]*". [White British girl 30, School 7]

Other parents seemed to give limited information about HPV vaccination to their daughters and did not explain to them why they needed to have it done but the girls trusted their views.

A Muslim girl said *“I asked her [mother], why do people have it, then she said, ‘Well, I don’t really know that question, but, the question in my head can only be that to be protected from it’ .... I leave everything up to my mum to tell me. So, if my mum thought it was right for me to tell the whole information she would...She just told me just about the injection...that it’s more safer to have it.”* [British Asian girl 39, School 9]

Some mothers could not read the documents in English related to HPV vaccination, which they received from school. This was the experience of a girl who said that she *“...needed to tell what is this paragraph about, what is this paragraph about and what is this paragraph about. So I needed to be very formal and say what is it about so she understood the whole thing”*. [Slovakian girl 40, School 9]

Due to the barriers of language experienced by some of mothers, other actors within the family, particularly fathers, may be important in communication with the mother about the vaccination. A Hindu girl mentioned *“My dad speaks English very fluently, so me and my dad discussed it and then he had told my mum about what this is about and what it’s for, so that’s why she [mother], at first she was concerned she didn’t know anything about it, so after my dad told her about it she was positive about me getting it.”* [British Asian girl 32, School 7]

Other girls had family members who opposed the vaccination. Some girls felt confidence in their ability to decide: *“It should be our decision whether we want to have it or not.”* [White British girl 11, School 6] One of the girls made the following point *“you can have a look at why the parents didn’t want you to have it and why you want to*

*have it, and which argument is better, take that on.” [Mixed British girl 28, School 7]*

Another girl described how she negotiated with her mother. *“I would make her [mother] understand why I should get it and what are the pros and cons of getting this vaccination done...and I’d also prove my point by going onto the internet, telling her about it, showing her the leaflet and getting some more information from everyone else.” [British Asian girl 32, School 7]* Another girl was keen to listen to health professionals.

*“Take a person that’s qualified in this vaccination, as they know more about it. Like the nurses, they know more about the vaccinations, so if the parents don’t agree, then you should listen to them [nurses]. That would be a second choice in my opinion”.* [Mixed British girl 28, School 7]

This section showed that the family had a major role in decision-making providing the girls with emotional support to overcome any fears of the injection as well as discussing the information. The decision-making was often jointly done or by helping them to make their own choice in most cases.

### **7.3.2.3. Girls’ views about the HPV vaccine**

Girls are given some information about the HPV vaccine at school as set out in the previous chapters and they have a range of views about it. Clearly if they think positively about it then this facilitates high uptake.

One of the teachers who said *“My feeling is that most of them feel that it is actually important to have it, even if they don’t like needles, even if they don’t like injections, they appreciate that it’s important.” [Teacher 33, School 7]*

The girls who were interviewed expressed views about a number of different benefits to having it done. First, in some girls' opinion, getting vaccinated had a lot to do with saving their life due to the perceived severity of having cervical cancer as showed in the following quotes:

*"It is just good for us to have the vaccine so that we don't get cancer at our age because we don't really know much about cancer"*. [White British girl 21, School 14]

*"Cancer it's quite dangerous cos it can kill you maybe. So, I just thought that it would help my body and keep me alive just a bit longer"*. [White British girl 16, School 6]

*"I am young and I still want to live so it is good to have it and be safe but it is just that I don't want to die really, so that made it more important"*. [Slovakian girl 40, School 9]

*"I thought there were more advantages [to have HPV vaccine]. I wasn't really sure about the risks, I knew there was one risk of cervical cancer, I didn't know any other risks, so instead of getting cancer, which could kill me, I had to take the vaccination...I already have an experience of cancer before this vaccination. My mum had cancer I think it was...."* [Mixed British girl 28, School 7]

Second, the desire for protection was a stronger motive for having the vaccination. One of the girls said that

*"It is a good medicine cos it protects your body and makes your body stronger. It's better to be safe than sorry"*. [African girl 14, School 6] and *"it can buy you time in life"*. [White British girl 43, School 14]

Some of the girls thought that the benefits of the vaccine outweighed its side effects.

One of the students felt that *"it doesn't affect anything in your life and ...it's good for everything."* [Polish girl 12, School 6]

*“It might be a low chance that it can be a side effect in the future and side effects might not even kill you.”* [White British girl 18, School 6]

Third, the girls expressed the views about the advantage of receiving the vaccine at school.

*“It’s good that they do it in school because it’s given to everyone instead of having to do on your own... it’s good that they do it in groups”* [White British girl 10, School 6],

*“It’s in school time and you don’t need to go out of the school...The school pays for it cos otherwise would be quite expensive if you just have to get it done privately”.* [White British girl 18, School 6]

#### **7. 3. 2. 4. Communication with friends about HPV vaccine**

The analysis showed that the girls talked not only with their family before the vaccination but also to their peers. A teacher pointed out: *“I think they have older sisters. I think they see other year groups of girls having it and girls talk and read magazines, read the pamphlets and look at the media. They just know now that it is something out there that girls have. And I think the longer it has gone on just as everybody knows that you have MMR or you have DTP they just know it is one of those vaccinations which girls have.”* [Teacher 33, School 7]

Peers can be an important resource of information and social influence. *“...When all the girls are talking, they don’t know everything about the HPV jab...some understood it more than others, so the one that understood it more was explaining it to the ones that really didn’t.”* [White British girl 21, Student, School 14]

Having the vaccination as a group together facilitated the decision to have it. *“I was kind of interested if someone else is having it because I don’t want to be the only one*

*who is having it. So I wanted someone else to come with me and actually have it.”*

[Slovakian girl 40, School 9] “

*“I was encouraged by friends and I'm sure everybody else was because their friend was taking it and other friends were taking it and their friends already took it and then it just goes on...it's mostly the students, they motivated me, not the teachers really...They [students] were just saying that they are going to take it because their parents told them to take it and their teachers told them to take it, so they were going to take it and everybody else came to take it so I was going to take it.”* [British Arab girl 35, School 7]

The administration of the vaccine to the group clearly supported uptake positively.

The girls described how social support from peers was important to them. A Hindu girl said *“We just talked about how it's important to get this done...how it would affect you in a good way...they know that as they've got this injection they know that they're not going to catch it [cervical cancer], so that's why they feel it's important”*. [British Asian girl 32, School 7]

Another girl added *“One of my friends said, ‘Yes I am going to have it because it is really important’...two of my friends said, ‘Yes I am going to have it, I still feel more pushed onto the good side than onto the bad side’...One of my friends was saying, “I am going to have this because I saw that you can't have it at your doctor, so it is good that there is a chance for you to have it here [in school]’ .”* [Slovakian girl 40, School 9]

One of the most recurrent topics they reported discussing was whether the injection would be painful or not. A girl mentioned that *“We just talked about the pain really”*.

[White British girl 22, School 14] Similarly, a Muslim girl said “...*It was just there was a pain that I really had it in on my mind, but I don't think we talked about it other than that.*” [British Asian girl 25, School 7]

When looking at girls' accounts of social interactions with their peers there was a tendency to consult not only friends in the same year, but older girls who had had the vaccination. A Muslim girl emphasized the idea that she trusted her close friends. “*I trusted my friends because the people who said it hurt weren't really as close to me as my friends so I trusted my friends more*”. [African girl 26, School 7] A Muslim girl said “...*I have some friends that are above this year and asked them whether they did take the injection or not...we mostly just discussed whether it would hurt or not... they said that it wouldn't be as much painful as it sort of seemed to be... we were just debating whether we should take it or not.*” [British Asian girl 27, School 7] These quotes highlight the importance of peer group interaction and support on decision-making concerning the uptake of the vaccination. This peer group support was also relevant during the administration of the vaccine.

The girls described communicative factors as influencing their attitudes towards vaccination. One of the girls affirmed that “*I did explain to my friends, they explained to me, and we just, we kind of made it each of us feel a little bit better towards ourselves. We were all like in a group and we just explained it to each other and we felt a bit better when we all understood that we had the same feeling about it.*” [White British girl 37, School 9]

Girls explained that friends provided important emotional support on the day of vaccination to overcome the fear of injection. “*We just told each other that we'd be there for each other* [White British girl 42, School 14] “... *Go with your friend so you are not on your own*” [White British girl 18, School 6] “...*an injection can't kill you*”

[White British girl 42, School 14] “ *Just look at their [girls’] faces not the needle and just think if their face is not showing any fear then your face shouldn’t.*” [White British girl 21, School 14]

This section demonstrated that discussion with friends and peer group support constituted a major role in decision-making by the girls through information and emotional support and in dealing with the injection itself.

### **7.3.2.5. Communication with nurses**

The girls’ social interaction with the nurses was very short and it occurred mainly on the day of vaccination. There were a few occasions when the girls met with the nurses before the day of vaccination, particularly when the nurses came to the schools to talk to them about the vaccine during assemblies.

*“The nurses came in and told us about it, what it was going to be like. We’d seen like a PowerPoint thing...what it would benefit, when you have it and telling you like the pain and not to worry about it and all that...They just said you can get cancer and I think because we all kind of know what cancer is and it’s bad that, yeah, they didn’t really need to say that much.”* [White British girl 22, School 14]

Compared to how much the students talked about their parents and their social interaction with peers, relatively little attention was given to nurses. However, the girls’ accounts showed that the students had positive attitudes about nurses:

*“They [nurses] are just helping people get over their fear...”* [White British girl 21, School 14]. For example, *“the first time I was scared what are they going to do but the*

*second and the third time I really trusted them because they were really nice....*” [Asian girl 34, School 7]

The talks between the students and the nurses related mainly to whether the injection would be painful or not. One of the girls said *“I asked the question to the woman, I said, ‘Does it hurt?’ because I thought, because everyone else was saying it hurt, and I said, ‘Does it hurt?’ and she went, ‘Well let’s say this, I’m not going to lie, it will hurt a little bit, you’ll feel a little pin prick, but it won’t hurt as much as if you did get cancer’ ”*. [White British girl 37, School 9]

Building trust was an important thing for nurses in their relationship with the girls. One of the nurses said *“you should try and tell them that what will happen is normal and will go off because I don’t want to say something that’s not right because they will not trust you again....”* [Nurse 2] Another nurse gave an example of such a conversation with the girls: *“it’s going to be more painful if you hold yourself very tense, if you calm down and relax it’s much easier to get the vaccine and will be less painful’ ...we play like dolls when we get them to have their arm flippy floppy if you can get them to do that.”* [Nurse 7]

Another important component of nurse-girl communication that facilitated a positive relationship was listening to girls’ worries to know how to address their concerns. One of the nurses made the remark: *“We often say ‘come and have a chat with us and tell us why you are worried about it...the reasons why you don’t want it...and a lot of the time it’s just reassurance, that’s what they want”* [Nurse 3] *“A bit of encouragement and that is enough.”* [Nurse 2]

Sometimes, the nurses' attempts to convince the girls to be vaccinated in the school were not successful. Nevertheless, the nurses took a flexible approach and offered them the opportunity for vaccination at a later point in time: "...we're not going to force anybody to do anything ... you can only advise and reassure them and promote the vaccine...". "...There is provision made for them to have it a later day if they are not sure or want more time." [Nurse 6] "...If they are really anxious about it [injection] then we can say 'well, you can contact your parent if you want to, if it makes you feel better or your parent can bring you down to the clinic and you can come down with your mum', or 'we can always catch you when we come back and do the next vaccine', so that's another way around it, there are options we can take...at the end of the day it's their decision... ." [Nurse 3] A nurse expressed the idea that one of the most successful options was to offer a mop-up clinic: "we give them the option of clinic because some people would rather be with their mum when they have the vaccine because they're worried, they're scared and they don't want to be worried and scared in school, but if they're with their mum in clinic it's all right. That's a couple of the ways that we get over it." [Nurse 9] A few girls explained that in their opinion some girls wanted to be vaccinated in the clinic because "She [the girl] wanted her mum to be with her to comfort her" [White British girl 18, School 6] "to talk to [her], to get [her] mind off" [White British girl 41, School 14], "making [her] feel better about it [injection]." [White British girl 37, School 9] These views indicate that for some girls, not the majority, being with their mother was the preferred option.

This section indicated that the nurses played a significant role in girls' reassurance during the vaccination session as well as in catching up the girls at the clinic when they postponed the vaccination for whatever reason.

In summary, the analysis showed that the main facilitators to HPV vaccination were parental consent as Gillick competence was difficult to be applied for year 8 girls. The role of the families was reported as important by the girls in overcoming their fears of injections as well as the opportunity to discuss the information with them. Other important facilitators were their peer groups of friends which provided information and emotional support in dealing with the injection on the day of vaccination. Nurses also played a significant role reassuring the girls during the vaccination session in the school and catching up with other girls at the clinic.

### **7.3.3. Theme 3 - Barriers to HPV vaccination**

This section of the findings is an analysis of the barriers to uptake of the vaccine from the interviews with staff, health professionals and the girls.

#### **7.3.3.1. Fear of injections**

The girls had different experiences of uptake of vaccination. One of the themes that was common to many of the interviews with the girls was the expressed feelings of anxiety about needles. Two school staff expressed their opinions that *“It’s the needle that they are frightened of, not the fact that it is a HPV injection”* [Support staff 20, School 14] and *“...It’s a little bit of panic on their part that they are going to have this needle and they are going to have it in school and their mum is not going to be there to hold their hand.”* [Teacher 19, School 6]

One of the nurses said *“You get the ones that sit down and they can be a bit stroppy and a bit bolshie like, ‘I’m not having it, I’m not having it’, and you say, ‘Why are you not having it?’ and, nine times out of ten it will be, ‘Because it hurts’ .”*[Nurse 9]

A girl explained *“It is like the fear of you thinking about the pain will bring more pain to you ... [I] didn’t know how to react with it...”* [White British girl 21, School 14]

A Muslim girl said, *“I can’t have an injection because I’m afraid of blood coming out of me, I don’t like anything to do with taking out my blood, because I get really afraid.”*

[British Asian girl 39, School 9]

Another girl added, *“I just forgot all of the stuff really like the important things like you don’t want to die from it [cervical cancer]. I just forgot that and my mind went blank.*

*So I was like, ‘I don’t want to have this anymore’.”* [Slovakian girl 40, School 9]

The nurses were clear that they did not vaccinate girls against their wishes.

Therefore, *“even if the parents want to give it to them [the girls], kicking and screaming, they’re not going to have it, then we [the nurses] are not going to force them to have it.”* [Nurse 8]

One of the nurses described how these reactions could affect the process of vaccination. As she said and as I observed at the schools, the nurses had the tendency to become authoritative in some cases to overcome these obstacles.

*“Sometimes it takes ages before we get [the girls vaccinated] although they signed the form, the parents have consented and the very last minute just when you want to put the needle into their arm they move and they don’t want it which is quite dangerous to the nurse and to the person you inject if they move, so we have to coerce them by saying that ‘You signed the form, go back to the class then or come to clinic’ and then they will very often will say ‘All right do it’ ....”* [Nurse 4]

The fear of the needle of some young people affected not only the nurses’ work but the attitudes of the other girls waiting to be vaccinated also. A nurse said that *“...the only thing is it [girls’ fear] will very often set off the rest of the group.”* [Nurse 4] For example, the account of one of the girls illustrated a change of her feelings created by mass vaccination setting:

*“When I was standing there, I saw some of the girls screaming that made me feel much more scared about maybe something is going to really hurt and maybe I’ll start screaming and crying just like other girls sitting there.”* [Polish girl 12, School 6]

In addition, the rumours spread by peers made the girls feel scared as highlighted in the following quotes: *“They [the girls] hear rumours that it is going to really hurt and ‘your arm is going to fall off’ and silly things...and I think that’s what puts them off, so they get quite nervous.”* [Nurse 9] Social interactions with peers affected young people’s attitudes and decision-making about the vaccine. One of the students made the comment *“They [the girls] might ask people’s opinions and what if they give bad points about it [vaccination] and not good. So they might think ‘okay, that is not good so I am going to tell my mum and dad I am not going to take it’.”* [Asian girl 34, School 7]

The girls and nurses were clear that there was talk amongst themselves about the vaccination that sometimes scared them. *“Girls joke around a lot and you don’t really know when they are going to be kidding or telling the truth.”* [White British girl 21, School 14] *“People will tell them horrible stories about vaccinations especially the boys and probably older girls as well who were very frightened and pass on to the younger sisters.”* [Nurse 7]

*“Some people just try to worry people on purpose...because they want you to worry more than they worried about it [injection]. They want you to feel as scared as they did.”* [White British girl 38, School 9] There were also some concerns about the health professionals, which demonstrated a lack of trust. A Muslim girl stated that *“if the nurse puts the injection in, then if it goes in the wrong bit they’ll have to put it in again or it will come out. It was really scary when people say stuff like that. She [the girl] was asking, ‘Is it going to be qualified nurses?’ And the teacher was like, ‘No, we’re just going to go and pick someone from the street and say put the injection in.’ Then*

*everyone started laughing because some people think that the nurses won't be trained."*

[British Asian girl 39, School 9]

For instance, a Hindu girl expressed her view that *"They [the nurses] may have identity but...it's fake identity that they could have just made fake badges. If they were in fact fake nurses, they [the girls] don't know what's going into their body."* [British Asian girl 32, School 7]

Another issue was the possible side effects of the vaccine. A girl, who was not vaccinated, said *"My mum and my friends in the school told me about different after effects [that] you might get a little bit of a cold and you might get another kind of cancer from getting the vaccine."* [British African girl 17, School 6] The perception of a Muslim girl was that parents influenced their friends' beliefs *"...Maybe they've [the friends have] had this idea from their parents or they had it from other friends which they had from their parents."* [British Arab girl 35, School 7] Another girl confirmed the point mentioned above that her parents shaped her negative attitude *"...They heard something from other people like they had it [HPV vaccine] or someone from their family had it and something happened so they don't want [me] to have it. If you haven't read anything on the Internet you don't really know what the results might be cos some people became disabled after vaccination but a higher amount of people ended up dead".* [Poland girl 15, School 6]

This section demonstrated that peers and family influenced their feelings about having the injection and its possible consequences.

### **7. 3. 3. 2. Attitudes about the effectiveness of HPV vaccine**

In the interviews, several of the girls brought up issues related to the perceived ineffectiveness of vaccines.

A Hindu girl explained, *“That all vaccines can’t be positive, it doesn’t have much of a chance, there may be like, I don’t know, 10% of a chance that you still get cervical cancer even if you’re vaccinated.”* [British Asian girl 32, School 7]

A girl discussed the vaccine with her family and made the remark that she could not trust it *‘How do you know that it [HPV vaccine] stops cancer because I am not sure if they’ve tested it...cos say ‘someone has cancer and they give the vaccine, I am not sure the cancer is gonna go away, I don’t think that there is any way really to know how it actually works.’* [African girl 14, School 6]

Another girl expressed this view about unreliable information: *“Some companies might be fake. They just want to make the vaccine for the money [and] it won’t work...some companies [produce] the actual vaccine and it will work [but] probably they didn’t test it on children at all, they probably tested it on, I don’t know what, like hamsters, not actual girls... If the people that make the vaccines say a better one [HPV vaccine] is coming then I don’t think that’s much use of giving the present one to the daughters and if they say the present vaccine is good, then [they should] give us more information about it how it can help us.”* [African girl 17, Student, School 6]

In addition, there was an idea expressed that other countries have a different HPV vaccine or policies than that provided in the UK. For example, *“They [countries] have different health care, maybe they [providers] might put a different solution in the vaccine so it might not work as the one here although the one here might not work as well. They [countries] might have different sciences that make it, different people and they might have different views about it.”* [White British girl 18, School 6]

These excerpts from the interviews with the girls at the schools demonstrate that in addition to fearing injections, for some there was a lack of trust in the nurses and a lack of belief that the vaccine was effective or safe.

### **7.3.3.3. Girls' knowledge about HPV vaccine and cervical cancer**

The analysis showed the girls had several sources of information about HPV vaccine and cervical cancer such as the school, family and friends. The findings presented in the other two sections above, related to the delivery of HPV immunization in the schools as well as to facilitators to HPV vaccine uptake, indicated that the information from these sources differed. The girls in some schools found out during tutorials, which focused on the vaccine rather than cervical cancer.

*'It was just really about the injection, it wasn't really about where it [cancer] is. I think I would have liked to find out a bit more about that.'* [White British girl 37, School 9]

*"They don't really tell us much but they basically just made it basic for us. They said that you are going to have a jab for HPV, something to do with cervical cancer, and they said that it's, yes, that's all they said. It wasn't very in-depth. They didn't give us a lot of information."* [British Arab girl 35, School 7]

A few girls tried to explain the little information provided in the school. One girl made the remark that *"None of the teachers actually talked to us about it [vaccine] .....they might not know much about it."* [White British 18, School 6] *"...The doctors could be reliable because they know more about it."* [British Asian girl 27, School 7] Other girls' discussions highlighted that limited information in a mixed school was related to this vaccine being for girls only. One girl said *"She [the Head of House] was talking about it [HPV vaccine] in that lesson [assembly] because there are all girls...so it would be weird to hear about...going to the boys...because the boys don't have it done because it's just for the girls."* [White British girl 10, School 6]

*"... I think it would affect the boys because you know boys like to know what happened, how it happened, did it hurt and that."* [British Asian girl 25, School 7]

Another girl thought that learning about HPV vaccine in tutor groups was a barrier to asking questions. She said, “...because it isn't just like me and the tutor, she had to sort out the rest of the [class].” [White British girl 42, School 14] However, a tutor encouraged the students to find information themselves “If you want to look for more information, it [letter] would give you some websites to visit.” [British Asian girl 32, School 7] The girls reported there was limited time and limited information in the face-to-face sessions at the schools but more information in the letters. When I asked the girls if they had read the materials about HPV vaccine received from the school, many of them reported that they had not read the letter which was sent to parents.

“I didn't read all the letter...” [White British girl 16, School 6]

“...just the important parts...” [British Asian girl 32, School 7]

“...my mum read it...I didn't read”. [British African girl 17, School 6]

Some girls gave different reasons. A Muslim girl said that, in her case, the teachers influenced her “Because I thought it was for parents. They [tutors] said to give it [letter] to your parents.” [Asian girl 29, School 7] Another Muslim girl explained that she felt negatively towards the vaccine which affected her intake of information. “At the time when I got the leaflet, I was adamant that I didn't want to get it, that's why I briefly read through it, I didn't really read through it properly because I did not want to have the vaccination.” [British Asian girl 27, School 7]

The girls' knowledge about cervical cancer was limited. The girls' views on the location of cervical cancer: “I think it was breast cancer, I am not sure” [Polish girl 12, School 6], “It's like when we have a baby” [British Asian girl 13, School 6], “It is somewhere like your ovaries or something near there” [Asian girl 23, School 14] and “It's like

*something that you could pick up from someone else that you could get from sexual contact.” [African girl 14, School 6]*

When discussing why the HPV vaccine is given to girls aged 12-13 years old, the girls expressed contrasting views.

*“I’m not actually sure why we are vaccinated at this age, but I think because it might give us a bit more protection because we’re younger.” [White British 18, School 6]*

*“It [HPV vaccine] can just stay in your body and if anything happens when you start to change your body, when you get older, it can protect you.” [White British girl 16, School 6]*

*“...This is like a mature age when people are actually starting to grow up. Young people might just take it as a joke” [White British girl 21, School 14]*

*“...We’re like starting our periods at this age and that’s when you can get pregnant”.*  
[White British girl 22, School 14]

Despite having been vaccinated, the students were unaware of the relation between sexual behaviour and HPV. Some of them did not make the connection between the vaccination and relationships while others were very clear about this link. Some of the girls’ comments reflected that they thought it would not change their behaviour.

*“A vaccination wouldn’t have anything to do with a relationship. If you ought to be out somewhere, you wouldn’t really behave differently because of the vaccination.” [White British girl 16, School 6]*

*“Because it [HPV vaccine] wouldn’t disturb you and all it will do is just protect you and you will just lead your normal life.” [British Asian girl 32, School 7]*

*“People don’t tend to remember the past or what injections they had, so I don’t think it [HPV vaccine] will affect their relationships.” [Mixed British girl 28, School 7]*

In contrast, some other girls mentioned that despite of the fact that they felt safer after vaccination, they would “*think twice for doing anything.*” [African girl 14, School 6] For example, a girl said “*I think I would always be careful. Once I’ve had the injection, I’d probably be a bit more like, ‘Oh, it’s okay though,’ but I’d still be very cautious...like when you want sexual intercourse with them [boys], just be very aware of what could happen or what it could cause...they could have something and they could pass it on to you.*” [White British girl 44, School 14]

Another girl made a similar point “*In a relationship between boyfriend and girlfriend, like when they’re older, I think the girls might be a bit protective, because they’ve had jabs and they don’t want to ruin the chance of the jabs, so they might ask their boyfriend to get tested...sometimes it [HPV vaccine] might not work, then [if] he’s got something that she could catch, then she could...get really ill, and it’ll be his fault, sort of, but he wouldn’t even know that he’s got anything if he doesn’t get tested.*” [White British girl 38, School 9]

These expressed views showed that the majority of girls had a poor understanding of the role of HPV vaccine as well as of the link between the vaccine and sexual behaviour.

### **7. 3. 3. 4. Parental refusal of HPV vaccine**

#### **7. 3. 3. 4. 1. Parents’ understanding of HPV vaccine**

No parents were interviewed but teachers and students and nurses had views about parental attitudes based on their contact concerning consenting to the vaccine being given to their daughters. The data is therefore based on what was reported second hand. Teachers thought some parents’ decisions not to vaccinate their daughters were influenced by their views about the HPV vaccine. A teacher explained that “*They have been spoken to on the phone...parents, but usually they have made up their mind quite*

*categorically that they don't want them [girls] to have the vaccination...and that's it...and obviously we have to respect that decision".* [Teacher 33, School 7]

In the opinion of the participants, some parents did not want to justify their decisions to others and the teachers felt that sometimes cultural factors were relevant for some parents from ethnic minority groups. One of the teachers gave the following example:

*"The only barriers that we have occasionally, we have parents who refuse that the girls to have the vaccination. They don't feel that it's something that they want and they do not always tend to give you a reason, they don't feel that they have to justify their reasons to us... The very first year we did have a parent that refused the vaccination and he actually had twin daughters. I think that he very much felt there was the risk of the girls becoming sexually active sooner than they should. I mean the culture that they came from was very protective, very innocent ... I know that the language was Tamil, but I can't remember the country...the father just didn't want the girls to have it. From what I gathered, it was a cultural thing, but he didn't really give me anything specific."*

[Teacher 19, School 6] One of the nurses expressed the view that *"The ethnic groups do not tend to put the reasons for refusal... we do put a space saying 'why do you refuse?' but they don't comment...they just leave that part blank."* [Nurse 8] This quote could suggest that either the parents wanted to keep secret their reasons or that they had language difficulties in understanding the form.

Some girls felt that the reasons for refusal were private. *"Some people like to keep their reasons away from other people...and it's private."* [Mixed British girl 28, School 7]

For example, *"one of my friends said that her mum wouldn't let her have it. But, she didn't give the reason... She just said 'My mum wouldn't let me'. I think she knew why her mum wouldn't let her, but I think it was just personal and she just wanted to keep it*

*to herself. She wouldn't even tell her best friends and they're really close together."*

[White British girl 38, School 9]

However, the data from interviews indicated that participants had various opinions about the factors that might have affected parental decisions regarding HPV vaccination. One of the nurses mentioned that a potential factor was lack of understanding of the information about HPV vaccine that the parents received from the school. *"I think that there are people across all ethnicities that will say 'no' often for a reason, the fact that they really don't understand about it [HPV vaccine], maybe they don't take on board what the leaflet says"*. [Nurse 7] A Muslim girl said *"Parents would just think it's useless [vaccine] because...they [parents] don't know anyone who has died or got the disease or been affected by the disease"*. [African girl 26, School 7] Another Muslim girl gave a view about parents being influenced by experiences from their country of origin. *"Some of my friends' parents didn't let them have it [HPV vaccine] because they thought it was a waste of time to have it...my friends said that their parents said 'It doesn't normally work' and they never said why they said it. I think that they think that the other injections that people have got, but they have still got cancer. My friend is from Afghanistan. She said that some people from her mum's country had it [injection] and it never worked and their country has a lot more diseases than they should have and it got worse"*. [Asian girl 29, School 7]

In their discussions, several of the participants brought up issues related to some influences affecting parents' understanding. Two interviewees felt that the parents did not make time to read the information about HPV vaccine. A teacher said *"There are really some parents that we have got, that have no interest in whether their child has an injection or not...] 'it is another letter, another form, can't be bothered' ...it is maybe just that, not anything against the injection"*. [Support staff 20, School 14].

Similarly, a nurse explained “*A lot of parents don’t have time to read materials...because sometimes the questions they asked [us]... it’s obvious that they did not read it [letter] properly and they made a presumption ...We had some parents [who] believed that it is MMR that we are offering*”. [Nurse 8]

Parents’ lack of English was felt to be a factor affecting their understanding of the materials related to HPV vaccination: *The problem is that we don’t know what language the parents speak beforehand so they have just got something in English and unless somebody comes back to us and say if we have any information in a different language, which has never happened, we don’t know how much they understand...We haven’t the time or capacity to look at how big it [the problem] is...this is just something that I suspect from a lot of foreign names for the refusals*”. [Nurse 8] Another nurse confirmed that sources of help for these people with language barriers were limited “*A lot of the time it’s very unlikely as well [for them] to maybe try and source somebody who could help them out with that*”. [Nurse 9]

Based on the minimal information which I obtained from the school staff it appeared that “*in the last three years only...a handful [of parents] at the most*” [Teacher 33, School 7] needed interpreters.

A Hindu girl expressed her belief that the parents did not have enough knowledge about the HPV vaccine because of their limited access to information: “*A lot of people may not trust what’s in the vaccine and people’s parents might not consider to get this because they don’t know a lot about this vaccination and some people may not have a computer at home that they can do more research on so that’s where they would have second thoughts on getting this done*”. [British Asian girl 32, School 7]

A nurse mentioned parents’ level of education as another factor that could have influenced their understanding of the information about HPV vaccine: “*Level of*

*education comes with everything and people's understanding and their interpretation of what the programme is about must have a major effect on what they are going to agree or their child to have the vaccine". [Nurse 6]*

This section showed that parents' understanding of information about HPV vaccine played an important role in decision-making for uptake of the vaccine. The factors that influenced parental levels of understanding were their level of English reading, education, and experiences in other countries of origin. In addition, parental views were reported as diverse concerning the desirability of the vaccination. A nurse said that parents were more likely to have a negative perception of the vaccine if they found information that it was for the prevention of a sexually transmitted disease: *"You get the very intelligent persons...They'll have done their own research, they'll have heard something about the vaccine that they're not happy with...I think that has something to do with the fact that it's got this negative image, that it's for a sexually transmitted disease ...and instead of maybe actually talking to one of us, or phoning us up, because the information that they get given has got our number if they want to phone us and ask us any information, they don't do that. That doesn't happen. I don't get a parent phoning me up and saying, "I've read this, this and this. Can you tell me if that's true?" [Nurse 9]*

The participants' discussions about factors influencing negative perception of the vaccine in relation to sexually transmitted diseases centred around three issues. Some parents were reported to think that their daughters were not at risk of getting a sexually transmitted disease so this was a barrier to vaccination: *"They [parents] don't believe their child is at risk with HPV, so it's not necessary. It comes down to the importance I suppose, doesn't it? Do they see it as a vaccine that's needed, important? and they say 'no'."* [Nurse 9]

Some nurses thought that parents might feel that the vaccine would promote sexual activity. *“People think it is a sexual vaccine”* [Nurse 7]

*“The main barrier I think is people’s attitudes towards vaccinating young girls against a sexually transmitted infection which is essentially what HPV is...A lot of parents don’t want their child vaccinated because they think that’s leading children into having sex, sexualizing children, and people say ‘oh, sex! No! Can’t be vaccinated because is to do with sex, she might have sex if she has this vaccination because she thinks she is safe’...they didn’t want to promote them having sex until they are 16. ‘Why should they have it in year 8 at such a young age?’ because they didn’t feel that their child will need it.”* [Nurse 5] One teacher expressed her opinion about the possible impact of parental views on adolescent sexual behaviour in some cultures. She said,

*“I think some cultures as far as women are concerned they have to be very monogamous in terms of their sexual relationships and it all has to happen under certain conditions and at certain times. And any thought of any kind of promiscuity or even different sexual partners at all is just something which is not supported in any way. I think the idea of this vaccine with sexual activity is one of the reasons why people who have those strong feelings feel that it is not appropriate for their daughters...But that is only a hypothesis...From just a couple of conversations with girls, and that is all I can base it on, nothing else, I don’t have any hard evidence other than what the girls have said, is that their dads feel that it would encourage them to be sexually promiscuous or sexually active even...I just think from what they see, from what they hear, from what other people say to them, from what they just think and believe themselves, I think they consider it to be connected with sexual activity.”* [Teacher 33, School 7]

Some participants made a clearer distinction between culture and the religion. A student felt that religious faith was a reason for which the parents declined the vaccine:

*“Religions have rules they need to follow. And if it says, like for example the girls with the headscarf, ‘You are not allowed to take your headscarf off, only when you are asleep or something’, they would obviously follow that. And if it said something like ‘You can’t have this vaccine’ then they would obviously follow that”.* [Slovakian girl 40, School 9]

A teacher highlighted the importance of religion in refusal of the vaccine because of parental beliefs in their daughter’s sexual abstinence until marriage. In her view, the parents felt that their daughter did not need the vaccine because she was supposed to have only one partner in her life: *“they [parents] think they don’t need it because their religion is that they will have one partner and that you can’t get cancer through having the one partner....A lot more of the Asian families, religious families... didn’t want to have it [HPV vaccine] done...it is just this ‘my daughter is not going to have sex until she is married, so it is not going to affect her, she won’t get it’.* “ [School staff 36, School 9]

A Muslim girl affirmed that premarital sexual intercourse is against some societal norms *“...in Islam they say that you shouldn’t do that action that causes the cancer, like you are only supposed to do it after you are married, not before...then there’s no point in taking the injection because some religions don’t believe in doing that [action].”* [British Indian girl 27, School 7] A nurse mentioned that *“in my experience it seems to be the Muslims and particularly Pakistani families...I think is a cultural thing that the girls remain virgins until they marry...”* [Nurse 5] Another nurse noted that *“a lot of Catholic parents will put on the refusals for the consent form ‘we believe in monogamy and my daughter will only have sex with her husband’.”* [Nurse 8] These quotes illustrate the existence of socio-cultural differences in sexual attitudes and behaviour

and parental views of their daughters' low susceptibility to HPV infection because of future monogamous relationships.

In comparison with these views, other opinions expressed by the participants were related to young men. A nurse explained that the younger generation of men does not conform to religious rules and this increases their susceptibility to HPV infection.

*“If you can guarantee that your child, your daughter’s partner has never had any other partners then they don’t need, they aren’t susceptible to HPV, they won’t need the vaccine, but unless you can guarantee that, there’s still a risk’....and I think a lot of parents, regardless of quite a few, regardless of religion and culture will realise they can’t make that guarantee...in my belief and what I’ve heard from other people, there are plenty of male Muslims who do have lots of sexual partners before they marry. They’re not inclined to just have no one and like Catholics, you don’t have any sexual partners before marriage, it’s the one and only partner you should have and I think whereas a lot of Catholics are realistic in this day and age, that doesn’t happen .”*

*“if you just explain to the parents that you only need one partner and if that partner carries HPV, it only has to be one person to pass it to you for you to then carry it and it lay dormant in your body... I have had one parent and sort of on the grounds that she said, ‘Well my daughter is not going to sleep around, my daughter is not going to have sex before she’s married,’ and she was quite adamant she didn’t need it, but when I then explained a bit more about the virus and the vaccine and said a bit more, that condoms won’t necessarily protect you, she was quite shocked at that....”* [Nurse 9]

Several girls talked about people’s reliance on divine power of protection as an alternative to vaccination. *“They [parents] probably believe in just God helping”* [African girl 26, School 7] and *“God is protecting my child.”* [White British girl 38, School 9]

*“When they [parents] pray to God probably they think that everything is going to be fine, nothing is going to happen to us...they don’t believe in nurses and doctors.”*

[Asian girl 34, School 7]

A nurse expressed the view that some parents’ thought that the vaccine could have adverse effects on fertility: *“You won’t be able to have children if you have the vaccine, a myth...that I did hear from a young girl from an Asian family. I’m not sure what their religious background was, but it was an Asian background and she had been told by her elders, a member of her family, an aunty, that now she’s had the vaccine she won’t be able to have children. Now, if the rumours and myths like that go round in families then that’s going to put people off”*. [Nurse 9]

A nurse felt that people did not trust HPV vaccine because they did not trust the vaccines in general: *“A very, very few [parents] don’t believe in vaccination at all. They’ve never had their child vaccinated with any of the childhood vaccines. I don’t think you’ll ever convince that parent that it’s [HPV vaccine is] good to have.”* [Nurse 9]

This section showed that interviewees thought that the parental reasons for vaccine refusal were religious beliefs in risky sexual behavior after vaccination, beliefs in daughters not being sexually active before marriage and distrust of vaccines.

#### **7. 3. 3. 4. 2. Concerns about the safety of HPV vaccine in the aftermath of the death of a girl**

Another expressed view was that some parents thought vaccination is unsafe. The reason for refusing that their daughter to participate in the vaccination programme was fear of adverse events about which they found out in different media sources. A girl said *“I think that British parents might not trust it [HPV vaccine] because...maybe things that they’ve got on the news they might be worried about so they might not want to have*

*it done.” [White British girl 18, School 6] A girl who was not vaccinated described how information on Internet affected her parents attitudes towards the vaccine and their reasons to decline it: “They [parents] went on the Internet to read more about it [HPV vaccine] after they got the letter and then they found out everything about it and told me like it’s better for me not to have it because of what they read that high amount of children that actually got the vaccination and they actually died or became very very ill. My mum said to me that with the vaccination or not the results will be still the same like I might have it [cervical cancer] or I might not.” [Polish girl 15, School 6]*

Other girls talked about their parents’ opposition to HPV vaccine because of mistrust of a medical intervention provided in school environment. An unvaccinated girl mentioned that *“They [parents] might feel a bit anxious about their daughter getting it because...it’s happening in the school and not like in a professional hospital and people might not be sure about what they actually get ... My mum said ‘no’ because she doesn’t want her child to get sick...yeah, until she is fully grown”*. [African girl 17, School 6] All nurses talked about an incident in the city when a girl died that was a significant barrier that influenced parents’ decision concerning the uptake of the HPV vaccine. *“We’ve experienced one major barrier...a child fell ill on the day of vaccination and that was a massive barrier because everyone associated the girl’s illness with the vaccine which was proved not to be the case...So I think that was a big hurdle to get over because it did affect the uptake of the vaccine and people’s attitudes towards the vaccine...Some people said that they don’t want to have it and wanted to wait and some of them had it a year later when everything settled down.” [Nurse 6]*

Several nurses discussed the relation between the incident and uptake of the vaccine: *“Everything stopped I think all around the country, I would imagine, until they looked into what had been the cause....” [Nurse 2]*

*“I think the first year we had over 90% [uptake], we were the highest in the country for all three vaccinations and I think in the end it dropped down to 40-50% that year.”*

[Nurse 4]

*“Because obviously everyone, girls included, were very unsure of the [HPV] vaccine. That was still on a lot of the girls’ minds, especially in 2010, 2011 ...We lost a lot of confidence with it [HPV vaccine] then. There were lots of questions about the safety of the vaccine... a lot of girls would ask ‘What about that girl that died?’, so even though their mum had said, ‘Yes you can have it’, they still had that doubt in their mind.”*

[Nurse 9]

Intensive vaccine promotion through various channels followed after the incident to remove people’s doubts and to clarify that the incident was not a side effect of the vaccine: *“We had a member of the Health Protection Agency, a gentleman, a head of health protection in [name place] who went along with us to every single vaccination session sitting there waiting for the girls to ask for any questions, waiting for the parents to ask for any questions, staff to ask for any questions who were there...and that person helped and the media, the newspapers, the journalists, TV, everything helped us and particularly the family...”* [Nurse 4]

In summary, the barriers to uptake therefore were fear of injections, concerns about safety, the impact of the death of a girl several years ago.

## **7. 4. Summary**

The above analysis has identified a number of issues affecting the implementation of HPV programme in secondary schools. It has shown that the school based HPV

vaccination programme was accepted by all the schools but one<sup>29</sup> in the city of study. The schools were used as a setting for the delivery of the programme for group vaccination by a mobile clinic aiming to vaccinate all eligible girls. The analysis has indicated that the organization of a school-based HPV programme was resource intensive in terms of staff, time and space. It appeared that the school staff had a part in the successful delivery of the HPV vaccines in their schools. Although their role in distributing and collecting the consent forms to obtain informed consent from the parents of the girls was one of the most challenging activities in the HPV vaccination administration, it was essential for a high HPV vaccine uptake. Despite the fact that HPV vaccination programme is not compulsory in the UK, the school and nursing staff faced the challenges of routinizing the delivery of this programme within the schools. The manner in which the school staff sought parents' and girls' consent was often persuasive through repeated phone calls to reach the parents, keeping secret the date of vaccination from parents and girls and having individual discussions with the girls; but, they believed this was the most effective strategy for gaining parental and girls' cooperation. Also, the analysis pointed to the fact that the HPV vaccine was promoted in a limited way in school environment owing to time pressure in the curriculum for compulsory subjects.

The analysis has identified a number of important facilitators affecting uptake of the HPV vaccine. It has shown that parental decision was the most important facilitator for getting the girls vaccinated. This was because applying Gillick competence, overriding parental lack of consent, was a challenging task and nurses hesitated to put it in practice for year 8 girls. Health care providers played a crucial role in the delivery of persistent messages about HPV vaccine to parents across all ethnic groups to bridge their

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<sup>29</sup> a private Muslim school

information gaps, to help them in the decision making process and to obtain their consent. The analysis has shown that a number of different influences such as parents, friends and nurses affected girls' choices. The girls had different levels of social interaction with all these people. Family played the most important role for daughters' emotional support as well as the provision of information to help them understand and make their own decision about the vaccine. The interactions with friends and nurses were beneficial for students' confidence and feelings on the day of vaccination to get the injection. The girls' discussions about factors influencing their own choice centered around two main things: pain of injection and uptake of the vaccine by peers.

Also, the analysis has pointed to several barriers affecting uptake of the HPV vaccine. It showed that girls' fears of injection, caused by their fear of pain and also their limited knowledge, rumors spread by peers and parental negative attitudes about the HPV vaccine, were major obstacles to uptake before and on the day of vaccination. The students' discussions about HPV vaccine, cervical cancer and future relationships highlighted their gaps of knowledge about the link between HPV and sexual behavior. Parents represented a significant factor in declining the vaccine because of inadequate information obtained from other sources than health professionals, their concerns about the safety of the vaccine and their religious beliefs related to their daughter's future sexual activity.

In the next chapter, I present the main findings from each section of the thesis, the strengths and limitations, comparison with other studies and recommendations for policy, practice and future research.

## **CHAPTER 8: DISCUSSION**

In this chapter, I summarise the main findings from each section of the thesis in relation to the original research questions, highlight the strengths and limitations of the present study, discuss the relationship between the findings and the results of previous research, discuss the implications for policy, practice and future research, and end with a broad conclusion.

### **8. 1. Principal findings**

I have described my study area, including epidemiology of HPV infection, HPV vaccine, and implementation of HPV immunization programme in Europe (in Chapter 2), as well as access to health services measured by utilization of health services and equity as a sub-component of access and as one of the main dimensions of quality of care (in Chapter 3).

I have done two pieces of empirical work. The first piece was a cross sectional study related to a national health promotion intervention about HPV vaccine targeting secondary schools in the UK (in Chapter 4) and the second piece was a mixed methods research related to the delivery of HPV vaccination programme in secondary schools in a city in the West Midlands (in Chapter 6 and 7). I have discussed the methodological issues including the study design, data collection tools and data analysis for each study (in Chapter 4 for the national study and in Chapter 5 and 7 for the West Midlands study) which I chose following the review of literature and discussions with my supervisors and statisticians. I selected the variables in the quantitative studies (in Chapter 4 and 6) that were available and I considered most relevant to my research questions based on the published literature. The findings related to each study are summarized in the next three sections.

## **8. 1. 1. Results of the national study**

A scoping literature review showed that the available information from health agencies, pharmaceutical companies, and special interest groups, as well as through the news in media and on the internet was unreliable. No evidence was found about health promotion of HPV vaccine in schools. Young people, parents, and the health professionals who advise them needed accurate and appropriately targeted information about HPV and the HPV vaccine through awareness campaigns. The impact of health promotion tends to be less in more deprived areas. This was the rationale for study 1, which addressed the research question related to the association between uptake of educational materials about HPV vaccine by secondary schools and area level, social deprivation in England.

This study reported in Chapter 4 showed that around 30% of schools across the UK requested teaching packs. By country, the take-up of teaching packs ranged from 38.5% of schools in Scotland to 20.1% in Northern Ireland. In England, East of England had the best take-up rates (34%) and London (20%) and in the North East of England (21%) had the fewest requests.

Modelling showed that those schools located in the least deprived areas in England had higher odds of requesting teaching packs than schools in the most deprived quintiles when the other factors (the GOR, school type and school size) were held constant. After controlling for other school and geographic factors (school type, area deprivation, and the GOR), the largest schools had the highest odds of requesting teaching packs compared to the smallest schools.

The findings of this work showed that the West Midlands had poorer take-up rates compared to the national level. My data did not allow me to make a statement about the proportion of schools in each city in England requesting informative materials.

Therefore, it was a need for further research that led to the case study in a city in the West Midlands to understand if uptake or non-uptake of educational materials, among other factors, had any influence on subsequent uptake of the HPV vaccine. This aim was addressed in a mixed methods research including two studies, one quantitative and the other one qualitative. Quantitative data was used to define the context of the study, to describe and to explain the variation in HPV vaccine uptake across secondary schools in a city in the West Midlands. The qualitative data supplemented the statistical results from the quantitative methods, and the statistical interpretation of relationships by adding meaning and context to them.

## **8. 1. 2. Results of quantitative component of mixed methods research**

A literature review that addressed common determinants of the HPV vaccine uptake showed that there was a gap in relation to the influence of ethnicity and girls' age on HPV vaccine uptake due to inconclusive evidence. Also, it identified that ethnic inequalities in health are largely a consequence of socioeconomic differentials (lower income and education) and of living in deprived areas. Deprived areas have the least available health services although they are most needed. Even if the delivery of health services is equitable, it does not mean always equality of uptake. This was the rationale for the quantitative part of study 2, which addressed the research question related to the association between uptake of the HPV vaccine by secondary schools in a city in the West Midlands and area deprivation, ethnicity or religion.

The results showed that the third dose uptake by school varied between 65% and 100% with overall median uptake in each year of 90% in 2008/09, 75% in 2009/10, 86.50% in 2010/11, 89.50% in 2011/12 and 86.5% in all years. Every year median uptake rates

were higher than the goal set by the WHO (70%). 19 schools out of 20 in the first two years and all 20 schools in the last two years of the HPV vaccination programme had uptake rates 70% or above 70%. Thus, I concluded that the programme was successfully implemented across the years. In this context, I looked at variation in uptake between schools located in high and low deprived areas (of SAP and SCA). I found that uptake rates were consistently over 80% in both high and low deprived areas (of SAP and SCA) across years, except the second academic year when uptake was over 70%, meaning that even in the context with a dramatic event following the HPV vaccination, the goals of the programme were met.

While the lowest uptake was found in school 16 and school 2 repeatedly, the highest uptake was achieved by different schools across the years and in all years combined. It was noted that the percentage of non-white residents in SCA of school 16 was 65% that was the highest among all the other secondary schools included in the study. A similar high percentage of non-white residents was found in SCA of school 2 (54%).

The unadjusted results indicate that there was a negative statistically significant association between deprivation of SCA and uptake as well as the deprivation of SAP and the academic year 2009/10 (the last was possibly associated with the negative event in 2009/10 described in detail in Theme 3 of Chapter 7). In the two multiple regression models (i.e. after multiple adjustments of other factors), deprivation of SAP remained statistically significantly associated with uptake after controlling for ethnicity, school type and academic year. Similarly, the academic year 2009/10 remained statistically significantly associated with uptake after adjusting for geographic and school factors. Deprivation of SCA was no longer statistically significantly associated with uptake when the other variables were held constant and the same was true for the association between ethnicity (proportion of white residents) and uptake.

In conclusion, I found that uptake was only significantly associated with deprivation of SAP and no association was found between uptake and other geographic factors (deprivation of SCA and ethnicity) or school factors (religious affiliation).

### **8. 1. 3. Results of qualitative component of mixed methods research**

The exploratory nature of the interviews led to broad findings. Firstly, the analysis showed that school based HPV vaccination programme was accepted by all the schools but one<sup>30</sup> in the city of study and was delivered by a mobile clinic aiming to vaccinate all eligible girls. It appeared that the school staff had a part in the successful delivery of the HPV vaccines in their schools. Although their role in distributing and collecting the consent forms to obtain informed consent from the parents of the girls was one of the most challenging activities in the HPV vaccination administration, it is essential for a high HPV vaccine uptake. Despite the fact that the HPV vaccination programme is not compulsory in the UK, the school and nursing staff faced the challenges of routinizing the delivery of this programme within the schools. The manner in which the school staff sought parents' and girls' consent was often persuasive through repeated phone calls to reach the parents, keeping secret the date of vaccination from parents and girls and having individual discussions with the girls (especially tutors). It could be that the school staff relied on their credibility and the trustworthiness to increase the likelihood of persuasion. Similarly, health care providers played a crucial role in the delivery of persistent messages about HPV vaccine to parents across all ethnic groups to bridge their information gaps, to help them in the decision making process and to obtain their consent. Applying Gillick competence and overriding parental lack of consent was a challenging task and nurses hesitated to put it in practice for year 8 girls. Because of no

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<sup>30</sup> a private Muslim school

legal requirement for written consent (Department of Health, 2012), the school staff and the nurses believed that persistence for obtaining a verbal consent from parents was the most effective strategy to gain both the cooperation of girls and parents for a favorable decision for vaccination and thus leading to a high uptake of HPV vaccine rates. As chasing up the consent forms to have them returned was the main activity that occurred two-three weeks before the vaccination day, on the day and after the vaccination, it could be argued that the organization of a school-based HPV programme was resource intensive in terms of time and staff (health providers and school staff). It seemed that some parents had concerns about the HPV vaccination. School and nursing staff's persuasive discussions with the parents were sometimes successful. This raises the difficult issue of balancing the public health viewpoint of it being in the public interest to have high coverage of the population to promote the health of all, against the individual right to informed consent. Vaccination choice is about ethics, human rights and individual autonomy. The parents did not have unrestrained freedom of choice and ability to choose (Powers, 2007) because verbal consent was sought over the phone with time pressure. However, nurses did not vaccinate the girls against their wishes or their parents' decision.

Secondly, the analysis showed that there were several facilitators to uptake of the vaccine. The HPV vaccine was promoted in a limited way in school environment owing to time pressure in the curriculum for compulsory subjects. Some attempts were made to talk to the girls about the vaccine in assemblies and in tutor groups in some schools. However, a number of different influences such as parents, friends and nurses affected girls' choices. The girls had different levels of social interaction with all these people. Discussion with parents, particularly mothers or older sisters, were reported as important source of information to help them understand and make their own decision about the vaccine. Vaccination in year groups facilitated the interactions with nurses as

well as with friends in the same year and older that were beneficial for students' confidence and feelings on the day of vaccination.

Thirdly, the analysis showed a number of important barriers affecting uptake of the HPV vaccine. Girls' fears of injection were a major obstacle to uptake before and on the day of vaccination. It was caused partly by their fear of pain and also their limited knowledge about the HPV vaccine, cervical cancer and the link between HPV and sexual behaviour. Parents represented another significant factor in declining the vaccine because of lack of understanding of the information about HPV vaccine received from the school, inadequate information obtained from other sources than health professionals, their misconceptions about the safety of the vaccine especially after a vaccinated girl's death and their religious beliefs related to daughter's sexual activity in the future.

The conclusion for the results of the national study and mixed methods research is that both quantitative studies found low exposure to health promotion campaign about HPV and HPV vaccine followed by low uptake of HPV vaccine in high deprived areas of SAP. It is not known if the same schools had low exposure to health promotion campaign and low uptake of the vaccine. The qualitative study conducted in four schools, three located in mid deprived areas<sup>31</sup> and one situated in a very highly deprived area<sup>32</sup>, enhanced the understanding of some school factors that influenced uptake of the vaccine in a school-based programme. The programme was successfully implemented, reaching uptake rates above the goal of the WHO (70%) even in the context of little information about the role of the HPV vaccine in the prevention of cervical cancer

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<sup>31</sup> Both SAP and SCA

<sup>32</sup> Both SAP and SCA

among the year 8 girls and their parents. The findings of this research highlighted that the key school factor that contributed to the achievement of high uptake rates was the organization and the delivery of the HPV vaccination programme, especially getting the parental consent. Parental decision and consent was essential as applying Gillick competence was a challenging task in the context of vaccination of year 8 girls aged 12-13 years. The barriers found in this research, like girls' fear of injections and parents' misconceptions, suggest indirectly low exposure to professional information about the HPV vaccine.

Before making a comparison with other studies, I discuss the strengths and limitations of the two quantitative studies and the qualitative study in this research.

## **8. 2. Strengths and limitations**

### **8. 2. 1. Strengths of quantitative studies**

The results of the national study are based on a large sample including all secondary schools in England.

The quantitative component of the mixed methods research had two strengths. One of them was the approach to analysis year by year from the beginning of programme implementation and I was able to determine variation in uptake rates of HPV vaccine within one academic year as well as across the four academic years. Variation in uptake within an academic year permitted understanding of diversity in HPV vaccination programme implementation, providing some clues that the programme in some schools was more effective than in others. The programme started successfully in 2008/09 with a median uptake of 90%, which dropped significantly in 2009/10 because of a girl's death shortly after receiving an HPV vaccination at her school in October 2009,

followed by an increase of median uptakes in the subsequent two years. It appeared that implementation of the HPV vaccination programme across the years was a dynamic process to increase uptake after 2009/10 and to achieve the initial high rate in 2008/09. The other strength was the use of the population weighted average of the combined IMD scores corresponding to all LSOAs to estimate the deprivation of each SCA. To the best of my knowledge, other studies used IMD scores that reflect the area deprivation linked to a postcode or a LSOA. This theme will be revisited later in the discussion.

### **8. 2. 2. Strengths of the qualitative study**

The qualitative component of the West Midlands study gave strength to the mixed methods research because it complemented the quantitative element, offering a more complete picture of the issue under study and thus increased my level of understanding of the uptake of HPV vaccine. The interview findings pointed to school factors affecting uptake of the vaccine that were not analysed in the quantitative research.

To validate my study I used the framework of Creswell et. al combining two perspectives, the lens of the researcher and researcher's paradigm assumptions. *Validity* was defined by Creswell et. al as how accurately the story represents participants' social realities of the phenomena under study (Creswell and Miller, 2000). The lens, which I used, was based on my views conducting the study and on the views of people who read and reviewed it. The validity procedures used from the perspective of the lens of the researcher were triangulation and researcher reflexivity (Creswell and Miller, 2000). *Triangulation* of data sources (nurses, teachers, girls) as well as triangulation of methods (non-participant observation and individual interviews) increased the validity of conclusions because they provided more detailed and multi-layered information

(Meijer et al., 2002; Creswell and Plano Clark, 2011). The story is valid because I relied on three forms of evidence rather than a single incident or data point in the study (Creswell and Miller, 2000). I described early in the research process my double position in the study (as a doctor and student) creating a separate section in Chapter 7 called “*Reflexivity*” (Creswell and Miller, 2000). I used my position as a student during interviews with the girls because I wanted to see and to hear only from their viewpoint without the influence of my medical training. I used my position as a doctor during observations and interviews with nurses and school staff looking for practical implications of what I found out in the fieldwork.

I used two validity procedures from the perspective of lens of people external to the study: the lens of readers (thick, rich description) and peer review or debriefing (Creswell and Miller, 2000). *Thick, rich description* of the themes (Creswell and Miller, 2000; Johnson and Onwuegbuzie, 2004) provided as much detail as possible about the HPV immunizations in the schools, bringing alive the relationships between nurses, school staff and girls especially before and on the day of the vaccination sessions. This procedure enables readers to make decisions about the applicability of the findings to other settings or similar contexts. My *peer reviewer* was my supervisor with a background in social sciences who reviewed the data and research process, provided me with written feedback, challenging my assumptions as a public health professional, and asked me questions about my interpretations (Creswell and Miller, 2000).

The paradigm assumption was constructivist with its criteria of trustworthiness: (Creswell and Miller, 2000) credibility, dependability, transferability, and confirmability (Creswell and Miller, 2000; Ryan et al., 2007). The trustworthiness or rigour of a study shows the plausibility, credibility and integrity of the qualitative research process (Ryan et al., 2007). *Credibility*, one of the criteria used to appraise

qualitative studies for their trustworthiness, was given by the richness of the data (D'Auria, 2007) obtained from 47 interviews. The type of sampling (purposive sampling of girls in each school to cover their diversity in terms of ethnicity and religion) also ensured richness in the data. Credibility was also demonstrated by prolonged non-participant observations (each lasting two hours) in 12 schools during the delivery of the second and the third dose of the HPV vaccine (Ryan et al., 2007). To enhance the credibility of the research I kept a field journal with my personal thoughts about the research process in relation to the contact with the participants, especially with the girls, during interviews that helped me in data collection. For example, I used various probes and I encouraged the girls to elaborate on what they said rather than just to give me simple answers to my questions. This strategy helped me to develop interview skills to talk less and to let the interviewees to talk more to express their views (Krefting, 1991). I also added credibility to my study seeking my supervisor's feedback as a peer debriefer (Creswell and Miller, 2000).

I described each stage of the qualitative research process (data collection and analysis) in the sections Methods and Data management in Chapter 7 to show the *dependability* of my study. This provides the reader with evidence of the decisions and choices which I made regarding methodological issues throughout the study (Ryan et al., 2007; Krefting, 1991). Several documents related to data collection demonstrate dependability (Ryan et al., 2007): (1) invitation letters sent to the Head teachers (showing the initial plan for sampling girls and teachers), (2) the topic guide for interviews (showing that I questioned the same areas for all the participants (Graneheim and Lundman, 2004)), (3) the Table 1 in Appendix 24 with the characteristics of the girls (showing the decision to interview all the girls recruited by school even if their ethnicity was not as diverse as expected), (4) the Table 1 in Appendix 25 with thematic analysis (showing the decision of triangulation). During the analysis, I used a code-recode procedure on data to

increase the dependability of the study (Krefting, 1991). First I coded all interviews on printed transcripts and after that I coded them again in NVivo. Apart from the description of selection and characteristics of participants, data collection and process of analysis in Chapter 7, I used a rich presentation of the findings with quotations to enhance *transferability* (Graneheim and Lundman, 2004) to enable the reader to appraise whether the findings can be applied to similar contexts with routinization of immunization. *Confirmability* was based on previous criteria (credibility, transferability and dependability). *Goodness* was demonstrated by explanations related to the whole study including context, data collection and management and the interpretation (Ryan et al., 2007).

Another strength of qualitative study was the opportunity to interview those delivering and implementing the programme in schools such as school staff and nurses.

I was trained in qualitative research methods in the University of Warwick prior to the commencement of qualitative data collection. A professional transcriber was used for half of interviews and I checked the transcripts for accuracy. NVivo was used to facilitate the process of coding and the subsequent analysis.

### **8. 2. 3. Limitations of quantitative studies**

The deprivation scores derived for one country in the UK could not be compared with those from the deprivation indexes of other UK countries and because the IMD 2007 was available only for England the national study was limited to England.

The use of IMD postcode as a predictor of uptake of informative materials did not reflect an individual's exposure to the health promotion materials. It may be that schools that did not request the materials from the RSPH but obtained the materials through a secondary source (i.e., the DH). It is not known if the schools which requested the

materials integrated them into the curriculum which could be constrained by competition with other topics (Buston et al., 2002), school policy or local culture (Schaalma et al., 2004). A range of unmeasured (and unknown) possible confounders makes any inference about a causal relationship between request of informative materials and school and geographic factors impossible.

Different limitations in the quantitative component of mixed methods research warrant consideration. I did not find a statistically significant association between uptake and deprivation of SCA as well as between uptake and ethnicity in multiple regression models. Therefore, the results of multiple regression models should be interpreted with caution. It is important to critique the study methodologies to consider whether the lack of associations were the result of chance or small sample size. The analyses of the associations including the two independent variables (deprivation of SCA and ethnicity) were based on a sample size of 18 schools, which is lower than 22 schools based on theoretical calculations. I assume that theoretical sample size could have been different and even bigger than 22 schools if I had access to standard deviation in population for uptake of HPV vaccine three doses.

The school's religion was a proxy for pupils' religion assuming that the pupils attending a faith school would have that particular faith also. However, this may not be true for all religious schools in the city as the findings of qualitative analysis suggest presented in theme 1 of Chapter 7. It might have been possible to ask the schools for a breakdown of their pupils' religions to test this assumption although they might have been unwilling to give out this information from the point of view of confidentiality.

My original null hypothesis was that there was no association between uptake of the third dose of vaccine and ethnicity. I did not find an association between ethnicity and uptake. I found a moderate collinearity between independent variables (IMD for SCA

and ethnicity) which could suggest an interaction effect between area deprivation and ethnicity. Ethnicity is not routinely collected by the participating Trust in this study. Thus, it was not possible to determine uptake of the HPV vaccine in more detail by each ethnic group in SCA.

This study utilized routinely collected data in the Trust related to 5672 year 8 girls aged 12-13 years. An issue, common to all routinely collected data, is that there are data input errors and the dataset could not be used as it was intended. The limits to confidentiality did not make it possible to have access to the full postcode addresses of year 8 girls' households to analyse HPV vaccine uptake at individual level. Therefore, I used the aggregated data at school level with a small sample size. The best way to reduce sampling error is to increase the sample size to have sufficient statistical power to detect statistically significant results (Bonita et al., 2006) and to detect the anticipated difference between groups of comparison (Machin et al., 2009). Statistical power is a function of three variables: sample size, the chosen level of statistical significance (alpha) and effect size (Fox et al., 2007).

Because I did not have access to individual-level measures of socioeconomic status, I relied on area-based measures of deprivation which could have potential limitations. There are a number of deprivation indices including the Carstairs index, the Townsend index and the Index of Multiple Deprivation. Carstairs scores represent a combination of four 2001 Census variables: male unemployment, overcrowded households, car ownership and low social class (Social Class IV and V). The Townsend Index comprises four variables based on 2001 Census Data: unemployment as a percentage of those aged 16 and over who are economically active, household overcrowding, non-car ownership and non-home ownership (Burr et al., 1997). In this analysis, I used the IMD 2010 based on the results of my previous study (quantitative study at the national level) and on previous publications. The IMDs are not the same because in one study IMD

2007 was used while in the other study IMD 2010 was used. Although IMD 2007 and IMD 2010 are comparable in terms of geographical scale, domains, indicators and methodology, some changes in the level of deprivation between the IMD 2007 and IMD 2010 took place due to small changes to indicators and methodology for IMD 2010 (Department for Communities and Local Government, 2012). The overall IMD 2010 is based on rankings and not real measures of deprivation.

The reason for using IMD scores for SCA from one academic year to make estimates of the uptake of HPV vaccine in four academic years was based on the assumption that the population in catchment areas was relatively stable. A school's catchment area is a geographical boundary from within which children have historically attended a school. It is used as a criterion in case of oversubscription in the admissions process (i.e., children who live in the catchment area served by the school or children who live in the catchment area served by the school, who have a brother or sister attending that school the following year or children living closest to the school) (Coventry City Council, 2013). IMD for SAP would not necessarily reflect the level of deprivation of the areas in which the students attending the school lived. Also, the population of a school does not necessarily reflect its catchment area, because local pupils may choose to go elsewhere to school (e.g. religious school). The IMD score for the environs of the school does not provide much information about deprivation at school level. A more precise measure of deprivation (e.g. the proportion of pupils eligible for free school meals (FSM)<sup>33</sup>) might lead to different results. Low income is a central component of the definition of multiple deprivation for the IMD 2010. The lack of association between uptake and deprivation of SCA could be because deprivation of SCA was a proxy for the deprivation of the places where the girls live. It could be a good proxy socioeconomic measure for access to services and improvement of health but it might

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<sup>33</sup> A definition of free school meals is presented in Appendix 27

not be a good measure for uptake of HPV vaccine which was delivered free of charge. The results might reflect the fact that other socioeconomic factors such as education may contribute more to uptake of the HPV vaccine.

The schools in this study were located in urban areas. Other school-level characteristics arising from factors internal to the school (e.g. teachers' attitudes towards the HPV vaccine) could affect uptake of the HPV vaccine to a greater extent.

Uptake of the HPV vaccine in the city is overestimated because nine special schools, which were excluded, had poorer performances and lower uptake.

The cross-sectional design of the two quantitative studies, when exposures and outcome are assessed at a single point in time, does not allow for establishment of a cause and effect relationship among the variables because it is not known whether the exposure precedes or follows the effect (Bonita et al., 2006). For example, a longitudinal study would be required in the future to establish satisfactorily such a relationship between measures of variables of interest (geographic and school factors) and uptake of the vaccine.

The findings of both quantitative studies may be subject to ecological fallacy because the association observed between the outcome (HPV vaccine uptake) and independent variables at the group level does not necessarily represent the association that exists at an individual level (Bonita et al., 2006). A multilevel analysis would have been appropriate to investigate results at individual and group levels to avoid ecological fallacy. I intend to do a multilevel analysis in the future if more data becomes available. For example, to do an analysis at individual level I would need at least a denominator for the population of all year 8 girls in all secondary schools in the city of study (Table 1 in Appendix 20). Types of models, assumptions, sample size, variance, multilevel

regression model 1 - intra class correlation, multilevel regression model 2 with individual variables, multilevel regression model 3 with individual and cluster variables, multilevel regression model with individual variables and random slopes are detailed in Appendix 20.

#### **8. 2. 4. Limitations of qualitative study**

The main weakness of the interview method was the sampling of the girls. Despite using purposive sampling and continuing recruitment until saturation, I was not directly involved in the selection of the girls and because the teachers recruited the girls, it may be that the participant girls were volunteers. Mainly vaccinated girls were included in the study except two girls who were unvaccinated so that data from girls who refused the vaccination is scant. No information was collected about girls who did not participate in the study. It cannot be determined whether there was any difference between the girls who participated and those who refused to participate, that is, whether there might have been selection bias. It is likely that the girls who did not participate may have had particular views about their experience of HPV vaccination. Another related factor is that the girls described their past experience, but the majority of them were interviewed at five - seven months after the initial dose when they or they together with their parents had made a decision for HPV vaccine. Therefore, their accounts may be subject to recall bias.

The qualitative analysis was subjective in nature, meaning that researcher bias could have affected the interpretation (Johnson and Onwuegbuzie, 2004; Ryan et al., 2007). Another limitation of qualitative study is that generalisations cannot be made to a wider context than the one studied (Johnson and Onwuegbuzie, 2004) because of two reasons. One reason was that the selection of schools was based on convenience sampling and the recruitment of participants within the schools (girls and staff) was based on

purposive sampling but both of them are non-random samplings. Convenience sampling of the schools was the result of difficulty getting access to the schools reflected by the response of only four schools to the invitations to participate in my study. It could be also a response bias of schools. To maximize the response rate, I sent invitation letters to all secondary schools in the city followed by several reminders. A covering letter, attached to the invitation letter to explain the importance of the research, was postmarked from the University. Low response rate could be because of different factors: (1) high uptake rates of HPV vaccine in most of the schools, (2) need of school staff and time to chase consent forms sent to parents to get permission for their daughters' participation in my research, (3) Head teachers' lack of time to read the documentation related to my study including invitation letter, information sheets and consent forms, and (3) lack of talk about the HPV vaccine in PSHE class which I intended to observe. Purposive sampling of the girls was used in each school to cover the diversity of girls from all ethnic groups and religions to reflect the demographic profile of the school. Another reason for which the results cannot be generalized was that data represented people's views, which could be prone to misinterpretation. A way to reduce the risk of misinterpretation would have been member check (Creswell and Miller, 2000) to validate my interpretation of the data.

A limitation of the study could be small sample of school staff. I conducted interviews only with four school staff and it might be possible that I could not obtain data saturation despite purposive sampling and diverse responsibilities, which they had in their schools. This was because in each school one person was the coordinator of the organization of the HPV programme.

One limitation of the study design was that there were no interviews with parents of the girls. All the data on parental attitudes is reported data by the girls, teachers or the nurses. Therefore, I am aware of their possible misinterpretation biases. If I were to

conduct the study again in order to avoid this problem I would hold a presentation evening for the parents to present my findings, followed by a discussion session afterwards for people to come forward with their views which might be similar or different from those found in my interviews with the girls.

Because the qualitative data collection was delayed owing to difficulties in accessing the schools, the mixed methods research design was changed from sequential exploratory to parallel design.

The results are now discussed in relation to previous work in this area.

### **8. 3. Comparison with previous studies**

My research focused on the HPV vaccination programme being implemented in secondary schools. It included analysis of uptake of information materials about HPV vaccine by schools during a national education campaign launched by the RSPH and uptake of the third dose of HPV vaccine in a routine cohort (year 8 girls) in a city in the West Midlands.

My study showed that the school based programme was successfully implemented across four years (2008-2012), achieving uptake rates of 70% or above 70% in almost all schools in each year. Overall median uptake in all years combined was 86.5%. The school based HPV programme has been successful both in developed countries (Rondy et al., 2010) (e.g., Portugal, 81% and UK, 80% (Dorleans et al., 2010) and developing countries (e.g., Peru, Uganda, Vietnam and India (over 80%)). Some countries in Europe (e.g., the Netherlands, Italy, France, and Belgium), Australia and the United States had low uptake rates (around 50%) using settings other than schools to deliver the programme (Fregnani et al., 2013). School based HPV programmes have several advantages. They have resulted in faster uptake (Cooper Robbins et al., 2011), have had

better completion rates for three doses (Smith et al., 2012), have been offered during school hours (Ogilvie et al., 2010), have been sustained over time (Sinka et al., 2014) and have overcome several obstacles including the cost of and access to both the vaccine and a health care provider (Cooper Robbins et al., 2011). Because the vaccine is available in school, parents do not need to leave work or children miss classes to travel to the health provider (Cooper Robbins et al., 2011; Ogilvie et al., 2010). Some parents perceived the school as a more convenient place for vaccination than sexual health clinics (Brabin et al., 2007).

Although the school-based strategy has achieved high uptake rates in different settings, variations in uptake have occurred as a result of various factors. I found that uptake varied by school between 76% and 89% for all years combined in the city of my study. Uptake was significantly associated with deprivation of SAP. However, deprivation of SCA, which was a proxy measure of the socioeconomic area where the girls live, was not associated with uptake. Uptake rates were consistently over 80% in both high and low deprived areas (of SAP and SCA) across years, except the second academic year when uptake was over 70%, meaning that even in the context of a dramatic event following the HPV vaccination, the goals of the programme were met. High HPV vaccination uptake (80%) was also noticed in areas of high deprivation in Scotland and in Wales (Boyce and Holmes, 2012) but there has not been any clear analysis in the literature of this.

Different measures of deprivation were used in other studies at individual, school and area level. A national study in Scotland showed that there was a significant association between individual level deprivation of the pupil population and a lower uptake of the second and the third dose of the vaccine (in a routine cohort) adjusting for programme year and other organisational factors (school denomination and vaccination setting).

Also, deprivation at the school level measured through the percentage of pupils eligible for FSM showed a significantly lower uptake of three doses in the highest FSM quintile than those in the lowest FSM quintile in the routine programme (Sinka et al., 2014).

A study conducted in England including 151 PCTs assessed coverage for routine and catch-up cohorts from 2008 to 2011 by area deprivation, which represented the population weighted average of the combined IMD scores for all the small areas in the PCT. PCT-level coverage with three doses of HPV vaccine showed that for the routine cohorts there was no significant correlation between HPV immunization coverage and deprivation. Also, no significant correlation was found between HPV immunization and IMD at the area-level for the catch-up cohorts including the girls under 16s in compulsory full time education. A significant correlation was found between coverage with HPV vaccine at age over 16 (catch-up groups) with area deprivation (Hughes et al., 2013). A study of three PCTs in South West England indicated that there was no significant association of uptake of three doses in a routine cohort by deprivation based on IMD scores of LSOAs linked to postcodes from individual records. Similarly, multivariable analysis of HPV vaccination initiation showed that there was no evidence of an association of HPV vaccination initiation and deprivation (Fisher et al., 2013). Spencer et al. found that the most deprived quintile of area deprivation, based on IMD 2010 scores linked to LSOAs derived from the address postcode in the North West of England, was significantly associated with incompleteness of the programme with three doses of vaccine in the catch-up group. Deprivation was not associated with routine (12–13-year-olds) vaccination initiation. In this study, the researchers linked girls' HPV vaccination records by address to cervical screening records for their mothers and found that mother – daughter pair living in the most deprived areas did not take up either cervical screening or the HPV vaccine (Spencer et al., 2014). In Scotland, a widening gap was found between starting and completing a three dose series with HPV vaccine

by deprivation. The uptake of the first dose had a high and even level across deprivation quintiles and across years. Completion of the programme was increasingly lower in the most deprived compared with the least deprived areas by year between 2008 and 2011. Thus, the gap between starting and completing a course of HPV vaccination by deprivation became bigger over time (Sinka et al., 2014).

In a study on uptake of the first two doses, Kumar and Whynes used a measure of deprivation at an aggregate level (PCT) in the first year of the programme. They found a significant association between deprivation and catch-up girls who were mostly vaccinated in community clinics or general practice. There was no significant association for uptake in the routine cohort and deprivation. The limitations of this study were that the analysis was related to the first two doses and because it was done at aggregate level did not show the variation in uptake across schools in a PCT (Kumar and Whynes, 2011).

These studies indicate that lower uptake seemed to be associated with area deprivation in catch up groups who were more likely not to complete the programme. In my study, I found that uptake of three doses was related to deprivation of school postcode address and this is an original contribution to this debate. I conclude that it is likely that the schools in less deprived areas had a higher uptake than the schools in more deprived areas because of better organization and lower absenteeism rates. There were studies that reported a relationship between school attendance and completion of the programme (Brotherton et al., 2013).

Ethnicity is another important factor that may affect uptake, both because of the way it may operate through deprivation and because of the way it may influence religious and cultural attitudes to HPV vaccination. Ethnicity has been analysed in quantitative studies to assess the association with uptake. In my study, I did not find an association between ethnicity, representing the proportion of the population who are White

residents in SCA and uptake of the third dose. Similarly, Fisher et al. found weak evidence for variation in uptake of three doses in routine cohort by ethnic composition at PCT level. However, there was evidence for an overall association of HPV vaccination initiation by ethnicity. In that study, researchers found that Asian, Black, Chinese or other groups were less likely to initiate HPV vaccination (to receive the first dose) in comparison with White groups (Fisher et al., 2013). Findings related to HPV vaccination completion in Black and other ethnic (Chinese) groups in both routine and catch-up vaccination cohorts were reported in a study conducted by Spencer et al. There were no ethnic differences in completion rates in the routine group, but they were present in the catch-up group. This study found that mixed and other ethnic groups had reduced completion rates in the catch-up group (Spencer et al., 2014).

Other studies using correlation and multivariate analyses reported a significant association between ethnicity (measured by UK Census or country of birth) and low HPV vaccine uptake (1 or 2 doses) in routine and catch-up cohorts (Rondy et al., 2010; Roberts et al., 2011; Widgren et al., 2011; Kumar and Whynes, 2011). In the context of contradictory results and inconsistent classification of ethnicity across studies because of insufficient data (not recorded in health system (Spencer et al., 2014)) or different definitions across countries (Rondy et al., 2010; Roberts et al., 2011; Widgren et al., 2011) it is difficult to draw a conclusion for the effect of ethnicity on uptake. Certainly, in my study I found that ethnicity, based on UK Census classification, was not associated with uptake of three doses of the HPV vaccine. One explanation could be that the majority of schools (18 schools) had more than 50% White population in their catchment areas (as shown in Figure 11 in Chapter 6). Another explanation could be that if the girls were from other ethnic groups than White group they could be the first generation of migrants (e.g., UK born having at least one parent non UK born) or the second generation of migrants (e.g., UK born having both parents UK born) or

immigrants (e.g., non UK born having both parents non UK born) (Marlow et al., 2009). Marlow et al. used this classification of generational status that reflected acculturation in a UK study on ethnic differences in HPV vaccine acceptability and did not find any statistical significant association with acceptability in multivariate analyses. The authors concluded that acculturation might not be a mediator in the relationship between HPV vaccine acceptability and ethnicity (Marlow et al., 2009).

Other studies have attempted to explain variation in uptake in relation to organizational factors in schools. Although there is little research on the delivery of the HPV immunisation programme in the UK, one study conducted in Scotland (Boyce and Holmes, 2012) indicated the success of a school-based programme, which achieved uptake rates over 90% for all three doses of the vaccine in the first two years. The success was the consequence of a project management approach to the implementation of the programme with a focus on school-based delivery, logistics and tailored communications directed at adolescent girls (Potts et al., 2013).

The qualitative part of my research conducted in four schools explored in more detail the promotion and organization of the HPV programme and brought understanding how these contributed to high uptake rates in the city. It showed that a mobile clinic, comprised of a team of bank nurses, delivered the vaccinations in all the schools. Although a school nurse was part of the team, it seemed that she was not attached to a school, as she was accompanying the team in some schools in the city. I found that no school nurse attached to a school was involved either in the promotion or in the delivery of the programme.

There is no evidence about implementation of the programme at school level in other areas. Studies conducted in the UK showed that the programme was organized and delivered in different ways at PCT level (Brabin et al., 2011; Boyce and Holmes, 2012)

mainly in schools (Potts et al., 2013) involving school nurses (Boyce and Holmes, 2012) as they were the main deliverers of childhood and adolescent vaccinations (e.g., in Scotland (Boyce and Holmes, 2013)) and more interested in teaching sex education to pupils (McFadyen, 2004). In contrast, the team in my study was set up to include bank nurses because it was cheaper. They were employed by the NHS Trust in the city. School nurses were also employed by PCTs (in England) or Local Health Boards (in Scotland, Wales, and Northern Ireland) before NHS reform in April 2013. In Wales, each school has its own school nurse. In Northern Ireland and Scotland, a school nurse could cover more schools (Boyce and Holmes, 2012) but this could increase her workload. A study in Greater Manchester described the performance of two different nurse teams. A PCT used four teams of school nurses to vaccinate the eligible girls in all secondary schools. Another PCT set up a vaccine team, comprising three school nurses, to deliver the vaccination sessions asking the school nurse attached to a particular school to help the team on the day. It seemed that this team was more successful than the other one because of the relationship between the school and school nurse which was affected by the school nurse's workload, and school's help with consents (Brabin et al., 2011). This study interviewed only 15 school nurses. A rapid evidence assessment based on interviews with 80 health professionals from across the UK, including 36 school nurses and 26 coordinators showed that school nurses addressed health inequalities in the HPV immunization programme targeting girls who did not attend the school or missed doses. These girls were more likely to live in areas and communities of high deprivation or to belong to vulnerable groups (e.g., travellers, looked after children). The strategy, which they adopted to increase uptake in these groups, was to follow up the girls persistently (Boyce and Holmes, 2012). Similarly, high uptake at a school in an area in England with high deprivation, mixed ethnicity and

high teenage pregnancy was due to a nurse chasing up the forms (Boyce and Holmes, 2013).

In my study, the school staff chased up the forms persistently before and on the day and the nurses sometimes called the parents on the day and after the session if consent was missing. The health care providers played a crucial role in the delivery of persistent messages about HPV vaccine to parents across all ethnic groups to bridge their information gaps, to help them in the decision making process and to obtain their verbal consent. The school staff and the nurses believed that persistence for obtaining a verbal consent from parents was the most effective strategy to gain both the cooperation of girls and parents for a favorable decision for vaccination, leading to a high uptake of HPV vaccine rates.

Focusing on the parents' side it could be claimed that vaccination choice is about ethics, human rights and individual autonomy. Routinization of vaccination is a process through which people are expected to adhere to a social norm (Habakus and Holland, 2013) because of the benefit of herd immunity (Habakus and Holland, 2013; Caplan and Schwartz, 2013). Some parents did not adhere unreflectively to a social norm for uptake of HPV vaccination (Fairhead and Leach, 2012). They seemed to be convinced with difficulty to make a decision pro-vaccination for their child in the context of debates about the safety and value of vaccinations (Caplan and Schwartz, 2013) especially after conflicting information about MMR (Fairhead and Leach, 2012). Vaccines could protect some people but could harm others also. Therefore, individuals have the right to free and informed consent to make their own decisions (Habakus and Holland, 2013). I would argue that teachers' messages were persuasive because the school staff did not inform parents about the existence of exemptions from vaccination (Habakus and Holland, 2013) (e.g. religious, philosophical, medical). A powerful tool in persuading the parents could have been related to fear produced by their messages (Colgrove, 2004)

suggesting the parents to choose between the prevention through vaccination and available cancer treatment (Powers, 2007). Although the teachers presented to parents other vaccination choices, such as vaccination later in life, their persuasive discussions with the parents, which sometimes were successful, were perhaps not entirely ethically justified. It is not known whether all parents understood teachers' arguments. On the other hand, it might be that the parents did not have unrestrained freedom of choice and ability to choose (Powers, 2007) because informed verbal consent was sought over the phone with time pressure.

Based on the evidence in literature, I argue that teachers' actions were more persuasive than coercive. Coercion is also a type of influence but the distinction between a coercive and a persuasive action is not very clear in the literature. It has been said that a situation is evaluated as coercive or persuasive according to the context and on moral grounds. Usually coercion is exerted within a legal framework such as public health law requiring vaccination of children (Powers, 2007). This did not apply here because the HPV vaccination programme is not compulsory in the UK.

A study in Victoria (Australia) highlighted that difficulties in returning consent forms to schools with a high proportion of indigenous students resulted in significant lower vaccine uptake. The process of following-up non-returned consent forms could also be impeded by restrictions in the provision of student lists by schools (Brotherton et al., 2013).

The literature indicated that the consent form return rate could be increased through incentives, for example reminding and encouraging the girls to complete the course with three doses (Smith et al., 2012). It appeared that classroom peer incentives (Cooper Robbins et al., 2011) were more effective than individual incentives for immunization against Hepatitis B (Rose et al., 2011). In Western Australia, sending a second consent form was more effective than a letter, phone call or school incentives for improving

return rates (Brotherton et al., 2013). The school staff in an area of New Zealand, with previous experience in school-based immunization programmes, such as Hepatitis B and MMR vaccines, suggested sending multiple notices home to parents than to phone them or to send forms to parents by texting, use of e-mail and Web sites (Rose et al., 2011).

Another successful tactic used by the nurses in my study with girls who missed doses was to invite and vaccinate them at a mop-up clinic on Tuesday in the evening between 4pm and 6pm. This is in line with the findings of another study which showed the benefits of mop-up clinics at flexible times which were convenient to girls rather than the school nurses (e.g., late Saturday morning, evenings and weekends, Christmas holidays, and home visit). Apart from mop-up clinics, this study indicated the importance of obtaining informed consent by teachers and nurses, of reminding the girls to complete the HPV vaccination schedule, of persistently chasing consent forms and addressing parents' concerns. Persistence in chasing up those who missed vaccination occurred because there was no recommendation how many attempts should be made to follow them up (Boyce and Holmes, 2013).

Fisher et al. found that funding an additional member of staff to encourage young women to receive missed scheduled doses in community health clinics increased uptake at the PCT/local authority level (Fisher et al., 2013). A successful reminder method to attend a community catch-up clinic for school-based vaccinations as found to be telephone call in addition to a postal reminder letter compared to a reminder letter only (Cooper Robbins et al., 2011). An evaluation of the programme in New Zealand showed that opportunistic drop into schools was a successful tactic when the vaccinator was in the area (Smith et al., 2012). In British Columbia, children who are absent on the day could receive vaccines either in local public health units or in schools when the school

nurses returned for other vaccinations (Ogilvie et al., 2010). My study confirmed the findings in New Zealand and British Columbia and revealed that teachers and nurses increase uptake rates by being persistently persuasive. Whilst high take up is in the public interest, one could argue that there may be an issue here of protection of the rights of the individual versus the NHS/state's desire to increase vaccination rate.

Applying Gillick competence and overriding parental lack of consent was a challenging task and the nurses in my study hesitated to put it in practice for year 8 girls (aged 12-13) especially because of the legal implications. They used it for catch up groups in the first two years of the programme. It seemed that they did not follow a structured approach to assess girls' competency because the assessment was subjective based on their impression of girls' understanding of the HPV vaccine which they would gather in a very short time at the beginning of the sessions. However, the nurses and the school staff did not force any girl to be vaccinated against her parents' wishes. These findings were consistent with the results of a feasibility study conducted in 2007–2008 in the northwest of England. Even if the child was considered to be Gillick competent, the nurses, who knew how to assess this competency, would not have given HPV vaccination if the parents refused or they would have sought parents' permission when the consent form had not been returned. However, contacting the parents in these circumstances might be considered as raising the concern of breaching a child's confidentiality (Stretch et al., 2009). Similar practices were shown by school nurses in Wales. Likewise, school staff would not override parental refusal in order not to damage the relationship between the family and the school (Wood et al., 2011). A semi-qualitative study showed that parents' ethnicity was significantly associated with views on this type of consent. Both White and Black Caribbean parents agreed that a child could request vaccination at a sexual health clinic without parental consent if the child

had ability to understand and process information. The limitation of the study was that data was obtained from surveys and the response rate was relatively low (Brabin et al., 2007).

In order to understand information about HPV vaccine and to consent for it, the girls needed to have access to information, which was limited in the school environment in my study. Tutors attempted to talk to the girls about the vaccine in tutor groups but some were reluctant to talk about sensitive issues (e.g., that HPV was related to an STI). I found in my study that some tutors were teaching religion. One explanation for their reluctance could be that teachers do not have the knowledge to counsel parents or girls if asked and that they need to be given more information about the vaccine (Ling et al., 2012). My quantitative study did not find an association between uptake and a school's religious affiliation (the sample included affiliated church schools both Catholic and Church of England, and non-religious schools). Other researchers have noted similar findings. In Scotland, there was no influence on uptake by type of school (nondenominational/ denominational) (Sinka et al., 2014). However, my qualitative research showed that a private Muslim school had rejected the HPV programme since 2008. Another qualitative study based on interviews with school nurses indicated that smaller religious schools, such as Christian schools, a Church of Wales school and ultra-Orthodox Jewish schools rejected the HPV immunisation programme also (Boyce and Holmes, 2013). The ultra-orthodox Jewish community had a low uptake of other childhood vaccinations (Sekwalor, 2012). In contrast, schools with high percentages of Muslim or Catholic students had good uptake (Boyce and Holmes, 2013).

As the HPV vaccine prevents an STI it was expected that the girls would be taught in Sex and Relationship Education classes. However, none of the schools in my study were able to find a place for the HPV vaccine in the SRE curriculum.

It was reported that head teachers do not have a direct influence on the sex education programmes, but they have a broad influence on the timetabling of PSHE (Buston et al., 2001). School policy and cultural aspects could constrain sex education. Past sexual health promotion in schools in Scotland showed that despite apparently successful training, some teachers remained reluctant to deliver sex education (Schaalma et al., 2004).

Schools in other settings have been shown to be involved in the promotion of the HPV vaccine. For example, in British Columbia, the HPV vaccine programme was widely promoted through schools using different resources including a web site, information packages and DVDs targeted at parents and girls, pamphlets, brochures and information sessions held locally by public health nurses for parents and providers (Ogilvie et al., 2010). In Australian states and territories, the programme was also promoted in schools using methods used for other adolescent vaccines (Brotherton et al., 2013). In the Netherlands, the organization of meetings with pupils at schools in order to inform them about the vaccination was associated with higher uptake (Rondy et al., 2010). Similarly, the success of the HPV vaccination programme in Brazil was due to the integration between the public health and schools. The schools had a significant role in the dissemination of information, which increased vaccine uptake in children 10–16 years old exceeding 85% for each individual dose (Fregnani et al., 2013).

In contrast, the findings based on a systematic review indicated that an educational package for students delivered in classroom prior to vaccination did not increase uptake of Hepatitis B vaccine. Information increased students' knowledge, attitudes, and awareness of Hepatitis B vaccine and possibly supported them to make an informed consent and to reduce anxiety (Cooper Robbins et al., 2011). There is evidence that the most effective interventions for health promotion (e.g., to reduce smoking or increase physical activity and/or healthy eating) include provision of information combined with

professional advice because it could improve knowledge and recall. In addition, information could change behaviour only when it is combined with behavioural strategies such as teaching self-management techniques (Michie et al., 2009).

These studies show contradictory results about the influence of information on uptake of the vaccine. Based on this evidence it is difficult to assess the effectiveness of each resource. It might be that direct communication is more successful than printed materials, which could be read, or not. However, none of these studies indicated that information about the HPV vaccine was included in the curriculum to be taught in a formal class.

In the context of limited information provided by the schools in my study, the girls were dependent on information from other sources especially mothers or older sisters. In some cases, it was reported that parents lacked understanding of the information about the HPV vaccine received from the school or had inadequate information obtained from sources other than health professionals and for that reason, may have declined the vaccine. My data did not indicate parents' level of education. A study reported that parents with higher levels of education were less likely to consent to their daughters receiving HPV vaccination in a school-based vaccination programme (Cooper Robbins et al., 2011). Having more education was associated with a decreased likelihood of having a daughter receive the HPV vaccine presumably because of more access to the Internet and other forms of media compared with less-educated parents in British Columbia (Ogilvie et al., 2010). Thus, inaccurate information about the HPV vaccine could impair decision-making and could result in lower uptake.

The qualitative part of my study showed that some parents (especially Asians) did not talk to their daughters about the vaccine regarding the link between HPV and an STI. Therefore, school plays a major role in teenagers' education about sex and relationship and self worth. Schools provide students with knowledge and skills and opportunities

for personal and social development created by the school organization, curriculum and pedagogic practice. The students and their families have social norms and values related to their social class and culture. School's influence on students' lives was compared with influences of social class and the communities where the students live through a measure called school-level meaningfulness. Students attending low school-level meaningfulness are less likely to adopt valued school identities and as a result they could be negatively influenced by social peer pressures (e.g., adopting substance use) (Markham, 2014).

### **Original contribution**

My original contribution to knowledge is empirical, methodological and conceptual.

I made an empirical contribution including two pieces of research in this thesis. One piece of research was a national study about uptake of informative materials by all secondary schools in the UK and the other one was a mixed methods research about uptake of the HPV vaccine by secondary schools in the West Midlands. The aim was to understand to what extent the results of the first study about information related to the HPV vaccine informed the second study about uptake of the vaccine. The assumption was that increased knowledge would play a role in increasing uptake of the vaccine. My first study aimed to evaluate the process of distributing teaching materials to teachers in the secondary schools to assist in the teaching of year 8 girls about HPV, HPV vaccine and cervical cancer in a formal class in order to help them to make safe and appropriate decisions in relation to their physical, emotional and sexual health and to develop an understanding of the importance of vaccination in the prevention of cervical cancer. To my knowledge, awareness and knowledge about the vaccine and uptake of the vaccine have been addressed separately in other studies.

To my knowledge, there is no evidence about the implementation of the programme at school level in a Local Authority area/PCT. The qualitative section of my research investigated the organization of the programme in schools in city through interviews with teaching staff and nurses and observation of HPV delivery.

The original methodological component of this study was the use of the population weighted average of the combined IMD scores for all the LSOA in each school's catchment area to reflect deprivation in the areas where the children attending the school live. This was different to other studies which have used deprivation at individual, school and PCT level.

The purpose of analyzing uptake by deprivation in SCA was to distinguish factors related to girls' personal characteristics (ethnicity and living area) from school factors. Area deprivation is an indicator of socio economic circumstances of persons and the places where they live. Contextual factors in the catchment area could be interpreted in terms of socio-cultural characteristics and contextual factors of school location could be interpreted in terms of material infrastructure (Macintyre et al., 2002).

Another original conceptual contribution made by this thesis is related to the debate concerning vaccines and the ethics of informed consent. To my knowledge previous studies have focused on strategies of delivery of the programme and the return of consent forms to increase uptake of the vaccine. Routinization of vaccination is a process through which people are expected to adhere to a social norm (Habakus and Holland, 2013) because of benefit of herd immunity (Habakus and Holland, 2013; Caplan and Schwartz, 2013). Delivery of the programme is a public health issue but obtaining informed consent is an ethical issue. School and nursing staff's persuasive discussions with the parents were sometimes successful but this raises the difficult issue

of balancing the public health viewpoint ( being in the public interest to have high uptake and coverage of the population to promote the health of all), against the individual right to free and informed consent for individuals to make their own decisions (Habakus and Holland, 2013). Vaccination choice is about ethics, human rights and individual autonomy. The parents did not have unrestrained freedom of choice and ability to choose (Powers, 2007) because informed verbal consent was sought over the phone with time pressure.

## **8. 4. Implications for policy**

There were neither direct financial nor organizational barriers to the receipt of the HPV vaccine in this programme as it was offered for no cost to the participants. Eligible year 8 girls had two routes via which to access the vaccine in the city: at school or at the community clinic. Integration of school-based and primary care delivery was important to ensure high vaccine uptake, particularly as some girls missed doses or were delaying uptake for different reasons. Mop-up clinics were organized after each dose, targeting girls who missed the previous dose, either at the community clinic or in the school when the next vaccine was delivered. Also, there were vaccination opportunities in the next school-year for those who had missed doses (especially in the second year of the programme with the negative event) and this had an important effect on the equity of vaccine coverage.

School-based programmes have achieved the equity uptake goal to some extent because it has been delivered to year 8 girls from all ethnic groups without discrimination. However, my data does not allow me to make any statement about vaccination of year 8 girls in hard to reach and vulnerable groups. In addition, there is evidence that girls who are educated in non mainstream educational settings are less likely to initiate the HPV vaccination and even if they initiate it they are less likely to complete the course with

three doses (Fisher et al., 2013). The implication for policy would be to target also these groups to assure equitable delivery of the programme to all eligible girls.

School-based programmes have exceeded the desired uptake goal, which was 70% of the eligible population. However, the delivery of the programme varied across schools as reflected in the variation of vaccine uptake by 13% in all years combined. It means that the programme did not run equally across all schools in the city. This has an implication for policy to assure that HPV vaccination sessions are carried out equally at all schools. Lower uptake in areas with lower socioeconomic status needs attention since participation in cervical screening is also lower in these areas (Spencer et al., 2014). To reduce inequalities in affected schools with low uptake it is necessary to allocate more resources including school staff, vaccination nurses and schools nurses and to invest more time in meeting with parents directly.

As I have already mentioned the NHS Trust in the city of my study used a team of bank nurses for the reason of being cost-effective. Although the team had good relationships with all secondary schools, the nurses were health visitors in each school. Therefore, they relied on schools' efforts in the delivery of the HPV vaccination including distribution of consent forms, chasing them up, informing the girls and the parents about the HPV vaccine. The schools used teachers or administrative staff but not school nurses to organize and deliver the HPV vaccination. Variation in schools' allocation of school staff as well as in NHS allocation of bank nurses resulted in overall inequity in the allocation of resources involved in the delivery of the HPV vaccination. The equity–efficiency trade-off has been used as a framework for the consideration of equity in the allocation of healthcare resources (Sassi et al., 2001a). Theoretically, efficiency represents the ratio between benefit and costs. But the resources should be distributed efficiently to particular subgroups in the population according to principles of need and equity (Campbell et al., 2000).

The national immunisation team in the Health Protection Directorate of Public Health England has the responsibility for planning and implementation of national immunisation programmes. NHS England, through its area teams at local level, is responsible for the commissioning of all national immunisation and screening programmes (Public Health England, 2013). Immunisations are part of the Healthy Child Programme (5-19). School nursing services are a key component of the Healthy Child Programme (5-19) including development reviews, screening tests, immunisations, health promotion guidance. Since April 2013, Local Authorities have been responsible for commissioning public health services for school-aged children (5-19) which encompass the Healthy Child Programme (5-19). However, the Local Authorities need to work with area teams of NHS England and provider services (e.g. school nursing services or health visitors) to ensure high uptake (PHD-PHN/32420, 2014), to reduce health inequalities and to ensure that disadvantaged groups can access immunisation programmes (Public Health England, 2013).

School nursing services, commissioned by Local Authorities (Public Health England, 2013), have been delivered differently across England. It may be because school nursing services are funded from the public health grant (PHD-PHN/32420, 2014). Public health services have been and will continue to be funded by NHS England (NHS England, 2014b). On the other hand, the school nursing workforce is relatively small and cannot deliver the Healthy Child Programme alone. It has been proposed that they to work across a range of organisations including education services, general practice, secondary care and children's services. School nursing teams need to work with other partners including health and social care teams, teachers and youth workers to deliver public health interventions in schools (PHD-PHN/32420, 2014). For example, NICE guidance related to immunisation for children and young people is that school nurses should work with the director of public health and local public health services to advise young people

and their parents about the vaccinations recommended at secondary school age to reduce differences in the uptake of immunisations. NICE has made also recommendations on the extended school role referring to head teachers, school governors, managers of children's services and Sure Start children's centres and primary care immunisation coordinators that they should work with parents to support schools to become settings for vaccinating local children (National Institute for Health and Care Excellence, 2014).

Policies regarding the process to obtain parental informed consent to respect individual right should be implemented. Guidelines to assess Gillick competence within a school setting are needed. A standard framework to assess Gillick competence and to establish adolescents' consent to vaccination is necessary to be developed and used by all vaccinators irrespective of their nursing specialty. In addition, managerial and legal support structures should be in place in the event of parental complaints (Stretch et al., 2009) and head teachers would also need to be familiar with these guidelines to face parental objections (Wood et al., 2011).

## **8. 5. Implications for practice**

I conducted my study in a city in the West Midlands corresponding to a PCT where I discovered a model of delivery where none of the school nurses attached to a school was involved. The implication for future practice would be to compare different delivery strategies based on a bigger sample of schools from more PCTs/Local Authorities in the West Midlands to recommend the best practice aiming to achieve high uptake.

Some school nurses promoted the HPV vaccine in assemblies in schools in the first years of the programme but not in the following years. School nurses have the

responsibility to educate pupils about health. The implication for practice would be to reorganize school assemblies, which would provide an appropriate forum for dissemination of information about the vaccine including boys also, creating a “supportive environment... that ensures the opportunity to acquire appropriate information and to participate in decisions affecting their health” as stipulated in Paragraph 23 of the UN General Comment No.14 (United Nations.Economic and Social Council, 2000, p. 6). Assemblies could include talks about STIs, which currently are taught in older years (10 and 11).

Teaching materials, including lesson plans distributed by the RSPH, would be useful resources for PSHE, science or tutor classes because they were designed to be inclusive and to encourage engagement with both boys and girls. The advantage to provide information both to girls and boys would be that the inclusion of HPV vaccine for boys in vaccination programmes is currently debated (Eurosurveillance editorial team, 2012). It has been introduced in Australia (Brotherton et al., 2013) and it could be adopted in the UK also. If this occurs, the implication for practice would be a different way of delivery of the programme as well as of organizing the process to obtain consent.

All information materials including leaflet, letters and consent forms given by the nurses to the girls and their parents were in English. NHS Choices is a website that has been set out to help patients to understand what services are available and where these services can be accessed (Department of Health, 2009) including the HPV vaccine. It could be accessed in English as well as in other languages but it remained unknown in my study whether parents have accessed it or not. In maintaining equity of uptake, consideration is needed on how to effectively address the information needs of those

with language barriers. Schools and health providers need to be aware that some parents especially mothers might not speak English.

Parents from different ethnic groups might want to delay their daughter's vaccination until an older age. To obtain information related to this issue they have to actively seek nurses' advice. Nurses would direct them to their GP if the girl is under 18. My recommendation for practice would be to involve school staff and health professionals in the promotion of the HPV vaccine targeting both parents and the girls through direct communication in assemblies or other meetings held in schools. Also, GPs should be involved in the process of follow up of these girls until the age 18.

Without the school roll data to check consents, vaccinators cannot ascertain whether or not any eligible girls have missed out on the opportunity of the free vaccine (i.e. has a girl declined or simply lost their consent form?). The implication for practice would be to inform head teachers to cooperate in handing over the school roll to the nurses.

Practices regarding the process to obtain parental informed consent respecting individual rights should be implemented. The best reminder methods for follow up of consent forms should be chosen based on evidence to increase the return rates and clear guidelines and training given.

## **8. 6. Implications for research**

Further research could include a multilevel analysis of these data and could also include data about ethnicity and religion at individual level. A further analysis of the geographical location of professionals visiting the HPV vaccine web-pages on the

RSPH website (using the log of IP-addresses), could elucidate some of the reasons for schools' lack of requests.

There is a lack of research on the views of parents and if conducted this could extend understandings of barriers to consent for the HPV vaccine for their year 8 daughters.

Not all factors in the conceptual framework were used in the analyses of this research because of unavailable data but they could be a valuable topic for further research for optimal vaccine delivery strategies to routinely reach girls with 3 doses in ways which are acceptable, affordable, ethical and sustainable and which achieve high and equitable coverage in vaccination.

Further qualitative research could be conducted within the context of routine school-based programmes on the process of obtaining informed consent from the perspective of all participants.

If the HPV vaccination is extended to boys in the near future, further research on the implications for delivery could be done.

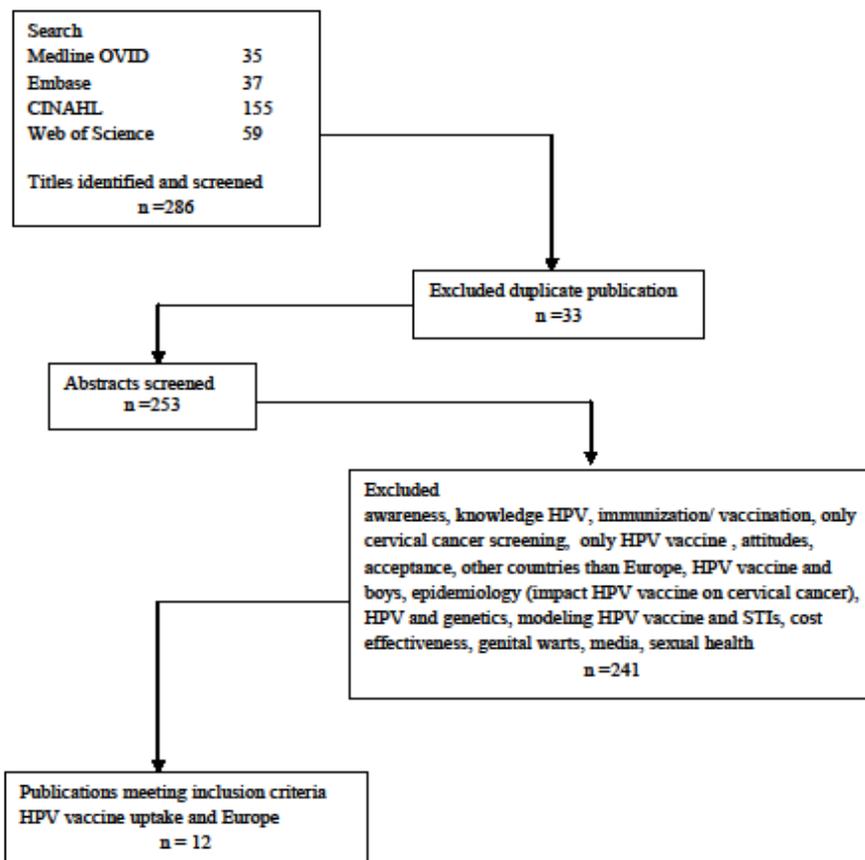
## **8.7. Conclusions**

The delivery of the HPV vaccine to teenagers is an important area of public health and the use of school setting with further mop up clinics for this seems to ensure high uptake. There is a need to balance in the future the public health interest and the individual rights to informed consent. Despite the differences, I found in uptake by deprivation and my concerns with ethics and truly informed consent, uptake of the HPV vaccine remains very high and well above target levels. I have found interesting areas for further research and I have made recommendations for changes in practice which might be beneficial in terms of uptake and informed consent and which could be implemented relatively rapidly.

# APPENDICES

## Appendix 1. The PRISMA<sup>34</sup> Flow Diagram – literature review related to HPV vaccine uptake

Flow chart of study selection process



<sup>34</sup> PRISMA = Preferred reporting items for systematic reviews and meta-analyses

## Appendix 1. Table 1 Searches in OVID MEDLINE

|                          | Search terms and combination of search terms                           | Results |
|--------------------------|--|---------|
| <input type="checkbox"/> | 1 papillomavirus vaccines.mp. or exp Papillomavirus Vaccines/          | 3221    |
| <input type="checkbox"/> | 2 human papilloma virus vaccines.mp.                                   | 15      |
| <input type="checkbox"/> | 3 human papilloma virus.mp.  | 2953    |
| <input type="checkbox"/> | 4 hpv.mp.  | 20856   |
| <input type="checkbox"/> | 5 exp Vaccination/ or exp Mass Vaccination/ or vaccination.mp.         | 101250  |
| <input type="checkbox"/> | 6 exp Immunization/ or immunisation.mp. or exp Immunization Programs/  | 133763  |
| <input type="checkbox"/> | 7 immunization.mp.   | 115738  |
| <input type="checkbox"/> | 8 vaccin*.mp.  | 235979  |
| <input type="checkbox"/> | 9 3 or 4   | 21883   |
| <input type="checkbox"/> | 10 5 or 6 or 7 or 8  | 309292  |
| <input type="checkbox"/> | 11 9 and 10  | 4309    |
| <input type="checkbox"/> | 12 1 or 2 or 11  | 5073    |
| <input type="checkbox"/> | 13 great britain.mp. or exp Great Britain/                             | 284294  |
| <input type="checkbox"/> | 14 exp Europe/ or europe.mp.   | 1058074 |
| <input type="checkbox"/> | 15 13 or 14  | 1061871 |
| <input type="checkbox"/> | 16 12 and 15   | 637     |
| <input type="checkbox"/> | 17 exp "Patient Acceptance of Health Care"/ or patient acceptance.mp.  | 149227  |
| <input type="checkbox"/> | 18 health attitude.mp. or exp Attitude to Health/                      | 264897  |
| <input type="checkbox"/> | 19 exp Health Knowledge, Attitudes, Practice/                          | 63467   |
| <input type="checkbox"/> | 20 consumer health information.mp. or exp Consumer Health Information/ | 2448    |
| <input type="checkbox"/> | 21 health promotion.mp. or exp Health Promotion/                       | 54482   |
| <input type="checkbox"/> | 22 uptake.mp.  | 242875  |
| <input type="checkbox"/> | 23 health inequalities.mp.   | 1679    |
| <input type="checkbox"/> | 24 17 or 18 or 19 or 20 or 21 or 22 or 23                              | 553902  |
| <input type="checkbox"/> | 25 16 and 24   | 138     |
| <input type="checkbox"/> | 26 limit 25 to yr="2007-Current" *                                     | 136     |
| <input type="checkbox"/> | 27 16 and 22 and 26  | 35      |

\* "Current" = 2012

## Appendix 1. Table 2 Searches in OVID EMBASE

|                          | Search terms and combination of search terms                           | Results |
|--------------------------|--|---------|
| <input type="checkbox"/> | 1 papillomavirus vaccines.mp. or exp Papillomavirus Vaccines/          | 5748    |
| <input type="checkbox"/> | 2 human papilloma virus vaccines.mp.                                   | 24      |
| <input type="checkbox"/> | 3 human papilloma virus.mp.  | 4508    |
| <input type="checkbox"/> | 4 hpv.mp.  | 28545   |
| <input type="checkbox"/> | 5 exp Vaccination/ or exp Mass Vaccination/ or vaccination.mp.         | 164722  |
| <input type="checkbox"/> | 6 exp Immunization/ or immunisation.mp. or exp Immunization Programs/  | 243685  |
| <input type="checkbox"/> | 7 immunization.mp.   | 152194  |
| <input type="checkbox"/> | 8 vaccin*.mp.  | 364365  |
| <input type="checkbox"/> | 9 3 or 4   | 30007   |
| <input type="checkbox"/> | 10 5 or 6 or 7 or 8  | 461607  |
| <input type="checkbox"/> | 11 9 and 10  | 6678    |
| <input type="checkbox"/> | 12 1 or 2 or 11  | 8995    |
| <input type="checkbox"/> | 13 great britain.mp. or exp Great Britain/                             | 321781  |
| <input type="checkbox"/> | 14 exp Europe/ or europe.mp.   | 1223389 |
| <input type="checkbox"/> | 15 13 or 14  | 1231278 |
| <input type="checkbox"/> | 16 12 and 15   | 1060    |
| <input type="checkbox"/> | 17 exp "Patient Acceptance of Health Care"/ or patient acceptance.mp.  | 225842  |
| <input type="checkbox"/> | 18 health attitude.mp. or exp Attitude to Health/                      | 74227   |
| <input type="checkbox"/> | 19 exp Health Knowledge, Attitudes, Practice/                          | 74173   |
| <input type="checkbox"/> | 20 consumer health information.mp. or exp Consumer Health Information/ | 2011    |
| <input type="checkbox"/> | 21 health promotion.mp. or exp Health Promotion/                       | 70164   |
| <input type="checkbox"/> | 22 uptake.mp.  | 357609  |
| <input type="checkbox"/> | 23 health inequalities.mp.   | 2452    |
| <input type="checkbox"/> | 24 17 or 18 or 19 or 20 or 21 or 22 or 23                              | 711692  |
| <input type="checkbox"/> | 25 16 and 24   | 122     |
| <input type="checkbox"/> | 26 limit 25 to yr="2007-Current"                                       | 116     |
| <input type="checkbox"/> | 27 16 and 22 and 26  | 37      |

\* "Current" = 2012

### Appendix 1. Table 3 Searches in CINAHL

| Search ID# | Search Terms                            | Search Options   | Actions  |
|------------|---|--|--|
| S10        | S7 AND S8                               | <p><b>Limiters -</b><br/>Published Date<br/>from: 20070101-<br/>20121231</p> <p><b>Search modes -</b><br/>Find all my search<br/>terms</p> | <p><b>View Results</b>  (155)</p> <p><b>View Details</b></p> <p><b>Edit</b></p> |
| S9         | S7 AND S8                               | <p><b>Search modes -</b><br/>Find all my search<br/>terms</p>  | <p><b>Rerun</b> </p> <p><b>View Details</b></p> <p><b>Edit</b></p>               |
| S8         | accept* or uptake                       | <p><b>Search modes -</b><br/>Find all my search<br/>terms</p>  | <p><b>Rerun</b> </p> <p><b>View Details</b></p> <p><b>Edit</b></p>               |
| S7         | S3 AND S6                               | <p><b>Search modes -</b><br/>Find all my search<br/>terms</p>  | <p><b>Rerun</b> </p> <p><b>View Details</b></p> <p><b>Edit</b></p>             |
| S6         | S4 OR S5                                | <p><b>Search modes -</b><br/>Find all my search<br/>terms</p>  | <p><b>Rerun</b> </p> <p><b>View Details</b></p> <p><b>Edit</b></p>             |
| S5         | vaccin* or immuni*                      | <p><b>Search modes -</b><br/>Find all my search<br/>terms</p>  | <p><b>Rerun</b> </p> <p><b>View Details</b></p> <p><b>Edit</b></p>             |
| S4         | "vaccination" OR (MH<br>"Immunization") | <p><b>Search modes -</b><br/>Find all my search<br/>terms</p>  | <p><b>Rerun</b> </p> <p><b>View Details</b></p> <p><b>Edit</b></p>             |
| S3         | S1 OR S2                                | <p><b>Search modes -</b><br/>Find all my search<br/>terms</p>  | <p><b>Rerun</b> </p> <p><b>View Details</b></p> <p><b>Edit</b></p>             |
| S2         | hpv or hpv vaccine                      | <p><b>Search modes -</b><br/>Find all my search</p>  | <p><b>Rerun</b> </p> <p><b>View Details</b></p>                                |

|    |  | terms   | Edit  |
|----|--|---|---|
| S1 | (MH "Papillomaviruses") OR "Human papillomaviruses" OR (MH "Papillomavirus Vaccine") | <b>Search modes -</b><br>Find all my search terms | <b>Rerun</b> <br><b>View Details</b><br><b>Edit</b> |

## Appendix 1. Searches in WEB OF KNOWLEDGE/ WEB OF SCIENCE

**Topic** = ("papillomavirus vaccin\*" or "human papillomavirus" or hpv or "human papilloma virus\*")

**AND**

**Topic** = (vaccin\* or immunis\* or immuniz\*)

**AND**

**Topic** = (uptake)

**Refined by:** Countries/Territories = (England **OR** France **OR** Greece **OR** Switzerland **OR** Netherlands **OR** Hungary **OR** UK **OR** Ireland **OR** Italy **OR** Sweden **OR** Belgium **OR** Scotland **OR** Spain **OR** North Ireland **OR** Norway **OR** Germany **OR** Denmark **OR** Wales)\*

**Doc Type** = All document types;

**Language** = All languages;

**Time span** = 2007-2012

**Results:** 59 records

\*It was no option to select UK or Great Britain. I had to choose available individual European countries.

## Appendix 2. Sample size calculations - Comparing means from two groups

$$n = 2 k SD^2/d^2$$

n = number in each group

k = multiplier for conventional values (significance level and power). Assuming 5% significance level and 80% power k = 7.8 (tabulated)

SD = standard deviation

d = difference to be detected

Source: (Bland, 2000; Peacock and Kerry, 2007)

## Appendix 3. Table 1. School characteristics

| N/20 schools | School characteristics | N/20 schools | School characteristics |
|--------------|------------------------|--------------|------------------------|
| 2/20         | Private                | 18/20        | Public                 |
| 4/20         | Religious              | 16/20        | Non religious          |
| 11/20        | Academies              | 9/20         | Secondary              |

**Appendix 4. Table 1. Ethnic groups (including all age groups) in school catchment areas**

| Secondary school | % Girls year 8 * | % White: English/Welsh/Scottish/Northern Irish/British | % White : Irish | % White: Polish | % Other white | % Mixed/multiple ethnic group: White and Black Caribbean | % Mixed/multiple ethnic group: White and Asian | % Black/African /Caribbean/ Black British: African | % Asian/Asian British: Indian or British Indian | % Asian/Asian British: Pakistani or British Pakistani | % Asian/Asian British: Bangladeshi, British Bangladeshi | % Asian/Asian British: Chinese | % Other Asian | % Other ethnic group: Arab |
|------------------|------------------|--|-----------------|-----------------|---------------|--|--|--|---|---|---|--------------------------------|---------------|----------------------------|
| 2                | 0.12             | 45.84  | 2.3             | 2.81            | 3.89          | 1.45   | 1.07   | 7.07   | 12.12   | 9.91  | 2.43  | 0.78                           | 3.9           | 1.11                       |
| 3                | 0.13             | 66.92  | 2.17            | 1.47            | 3.02          | 1.04   | 0.74   | 4.76   | 8   | 2.67  | 1.99  | 1.2                            | 2.09          | 0.77                       |
| 4                | 0.12             | 52.43  | 1.95            | 1.55            | 2.4           | 0.82   | 0.58   | 4.06   | 10.19   | 2.78  | 0.99  | 0.82                           | 2.54          | 0.63                       |
| 5                | 0.33             | 72.6   | 2.29            | 1.51            | 2.04          | 0.97   | 0.68   | 2.89   | 9.4   | 1.23  | 0.33  | 0.49                           | 2.56          | 0.34                       |
| 6                | 0.14             | 65.03  | 3.01            | 2.2             | 2.61          | 1.28   | 0.79   | 2.8  | 9.53  | 4.48  | 0.53  | 0.63                           | 3.03          | 0.46                       |
| 7                | 0.13             | 66.46  | 2.33            | 2.35            | 2.8           | 1.52   | 0.69   | 5.87   | 8.18  | 1.86  | 0.5   | 0.41                           | 2.52          | 0.49                       |
| 8                | 0.26             | 78.36  | 3.55            | 1.39            | 1.87          | 1.04   | 0.64   | 1.32   | 5.33  | 2.04  | 0.14  | 0.38                           | 1.47          | 0.29                       |
| 9                | 0.19             | 73.17  | 2.18            | 2.48            | 2.75          | 1.06   | 0.59   | 6.82   | 5.72  | 0.43  | 0.24  | 0.29                           | 1.38          | 0.22                       |
| 10               | 0.28             | 70.35  | 1.95            | 0.73            | 3.07          | 0.62   | 0.77   | 1.26   | 11.37   | 1.59  | 0.72  | 2.01                           | 2.39          | 0.6                        |
| 11               | 0.3              | 49   | 1.71            | 2.29            | 2.72          | 1.98   | 0.75   | 5.35   | 12.59   | 10.97   | 1.31  | 0.32                           | 4.39          | 0.79                       |
| 12               | 0.25             | 69.21  | 2.27            | 2.11            | 2.04          | 2.02   | 0.56   | 6.82   | 6.36  | 1.27  | 0.34  | 0.32                           | 2.29          | 0.31                       |
| 14               | 0.08             | 54.16  | 2.08            | 2.78            | 3.07          | 1.76   | 0.8  | 7.39   | 10.75   | 5.89  | 1.76  | 0.34                           | 3.24          | 0.76                       |
| 15               | 0.19             | 52.67  | 2.15            | 2.8             | 2.93          | 1.41   | 0.92   | 4.69   | 12.9  | 8.5   | 1   | 0.45                           | 4.19          | 0.68                       |
| 16               | 0.19             | 35.35  | 1.61            | 3.05            | 4.4           | 1.36   | 1.14   | 8.87   | 14.62   | 11.99   | 4.09  | 0.82                           | 4.69          | 1.51                       |
| 17               | 0.17             | 57.83  | 2.32            | 2.98            | 3.89          | 1.13   | 0.85   | 5.88   | 11.63   | 3.12  | 1.93  | 0.78                           | 2.73          | 0.82                       |
| 18               | 0.12             | 78.57  | 2.7             | 1.14            | 3.11          | 0.88   | 0.71   | 2.62   | 3.12  | 1.36  | 0.18  | 2.01                           | 1.22          | 0.34                       |
| 19               | 0.2              | 64.01  | 2.36            | 1.96            | 2.94          | 1.02   | 0.76   | 3.98   | 8.52  | 4.93  | 1.5   | 1.03                           | 2.78          | 0.71                       |
| 20               | 0.21             | 67.54  | 2.25            | 2.38            | 3.4           | 1.08   | 0.64   | 6.69   | 7.88  | 1.08  | 0.5   | 1.06                           | 1.82          | 0.64                       |

\* out of all ethnic groups in secondary school in academic year 2011/12

**Appendix 5. Table 1. Distribution of HPV vaccine uptake (third dose) by school in each academic year and in all academic years**

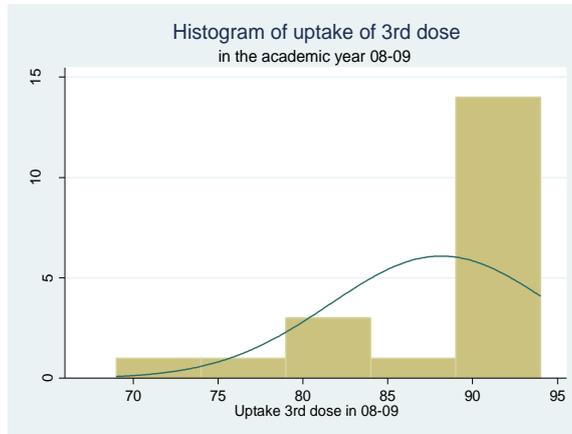
| School    | Uptake 3 <sup>rd</sup> dose<br>2008/09 |     |    | Uptake 3 <sup>rd</sup> dose<br>2009/10 |     |    | Uptake 3 <sup>rd</sup> dose<br>2010/11 |     |    | Uptake 3 <sup>rd</sup> dose<br>2011/12 |     |     | Uptake 3 <sup>rd</sup> dose<br>all years |     |    |
|-----------|--|-----|----|--|-----|----|--|-----|----|--|-----|-----|--|-----|----|
|           | n                                      | N   | %  | n                                      | N   | %  | n                                      | N   | %  | n                                      | N   | %   | n  | N   | %  |
| School 1  | 50                                     | 55  | 90 | 50                                     | 67  | 74 | 50                                     | 59  | 84 | 52                                     | 61  | 85  | 202                                      | 242 | 83 |
| School 2  | 51                                     | 65  | 78 | 48                                     | 68  | 70 | 44                                     | 61  | 72 | 57                                     | 63  | 90  | 200                                      | 257 | 77 |
| School 3  | 55                                     | 59  | 93 | 62                                     | 82  | 75 | 72                                     | 80  | 90 | 84                                     | 87  | 96  | 273                                      | 308 | 88 |
| School 4  | 92                                     | 100 | 92 | 84                                     | 111 | 75 | 78                                     | 95  | 82 | 105                                    | 118 | 88  | 359                                      | 424 | 84 |
| School 5  | 129                                    | 138 | 93 | 89                                     | 109 | 81 | 97                                     | 116 | 83 | 121                                    | 128 | 94  | 436                                      | 491 | 88 |
| School 6  | 108                                    | 114 | 94 | 89                                     | 109 | 81 | 93                                     | 110 | 84 | 94                                     | 105 | 89  | 384                                      | 438 | 87 |
| School 7  | 113                                    | 125 | 90 | 89                                     | 125 | 71 | 94                                     | 106 | 88 | 100                                    | 107 | 93  | 396                                      | 463 | 85 |
| School 8  | 124                                    | 131 | 94 | 88                                     | 122 | 72 | 125                                    | 128 | 97 | 121                                    | 136 | 88  | 458                                      | 517 | 88 |
| School 9  | 77                                     | 83  | 92 | 46                                     | 64  | 71 | 47                                     | 54  | 87 | 47                                     | 48  | 97  | 217                                      | 249 | 87 |
| School 10 | 108                                    | 116 | 93 | 72                                     | 102 | 70 | 119                                    | 126 | 94 | 103                                    | 109 | 94  | 402                                      | 453 | 88 |
| School 11 | 73                                     | 81  | 90 | 74                                     | 88  | 84 | 75                                     | 84  | 89 | 70                                     | 77  | 90  | 292                                      | 330 | 88 |
| School 12 | 43                                     | 48  | 89 | 44                                     | 57  | 77 | 65                                     | 76  | 85 | 69                                     | 82  | 84  | 221                                      | 263 | 84 |
| School 13 | 45                                     | 54  | 83 | 47                                     | 55  | 85 | 60                                     | 63  | 95 | 30                                     | 32  | 93  | 182                                      | 204 | 89 |
| School 14 | 50                                     | 60  | 83 | 45                                     | 57  | 78 | 35                                     | 42  | 83 | 43                                     | 43  | 100 | 173                                      | 202 | 85 |
| School 15 | 100                                    | 118 | 84 | 98                                     | 108 | 90 | 80                                     | 89  | 89 | 77                                     | 87  | 88  | 355                                      | 402 | 88 |
| School 16 | 62                                     | 89  | 69 | 68                                     | 91  | 74 | 71                                     | 90  | 78 | 73                                     | 90  | 81  | 274                                      | 360 | 76 |
| School 17 | 71                                     | 78  | 91 | 70                                     | 88  | 79 | 74                                     | 89  | 83 | 88                                     | 93  | 94  | 303                                      | 348 | 87 |
| School 18 | 37                                     | 41  | 90 | 33                                     | 46  | 71 | 44                                     | 51  | 86 | 38                                     | 43  | 88  | 152                                      | 181 | 83 |
| School 19 | 221                                    | 233 | 94 | 187                                    | 236 | 79 | 173                                    | 198 | 87 | 159                                    | 184 | 86  | 740                                      | 851 | 86 |
| School 20 | 56                                     | 69  | 81 | 47                                     | 72  | 65 | 63                                     | 68  | 92 | 69                                     | 84  | 82  | 235                                      | 293 | 80 |

n = number of girls vaccinated with the third dose

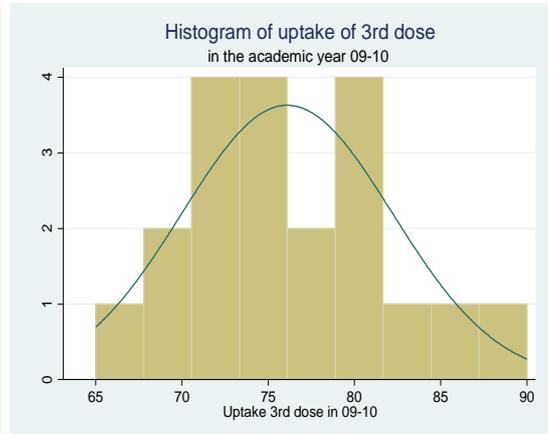
N = total number of year 8 girls eligible to be vaccinated

**Appendix 6. Histogram of the dependent variable in 2008/09, 2009/10, 2010/11, 2011/12 and all years**

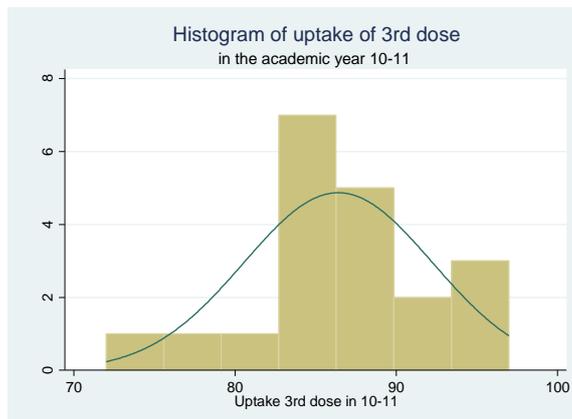
**Appendix 6. Figure 1.  
Uptake 3<sup>rd</sup> dose in 2008/09**



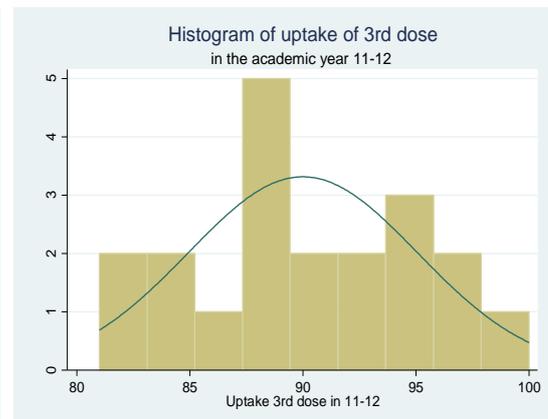
**Appendix 6. Figure 2.  
Uptake 3<sup>rd</sup> dose in 2009/10**



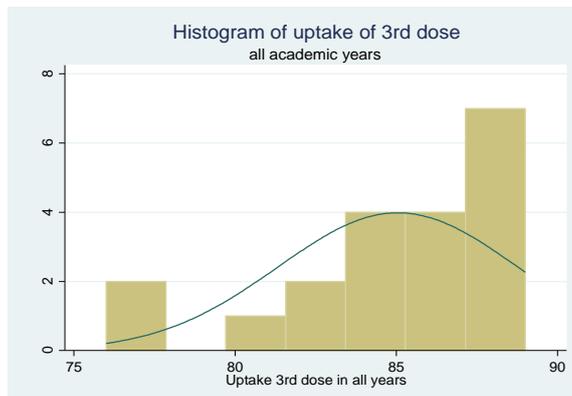
**Appendix 6. Figure 3.  
Uptake 3<sup>rd</sup> dose in 2010/11**



**Appendix 6. Figure 4.  
Uptake 3<sup>rd</sup> dose in 2011/12**



**Appendix 6. Figure 5. Uptake 3<sup>rd</sup> dose in all years**



## Appendix 7. Linear regression analyses in 2008/09, 2009/10, 2010/11 and 2011/12

### Linear regression analysis in the academic year 2008/09

Figure 1 shows that the distribution of the dependent variable (uptake of the third dose 2008/09) by transformation remained skewed. Therefore, the outcome variable was entered in the models untransformed.

### Appendix 7. Figure 1. Transformations of the dependent variable in the academic year 2008/09

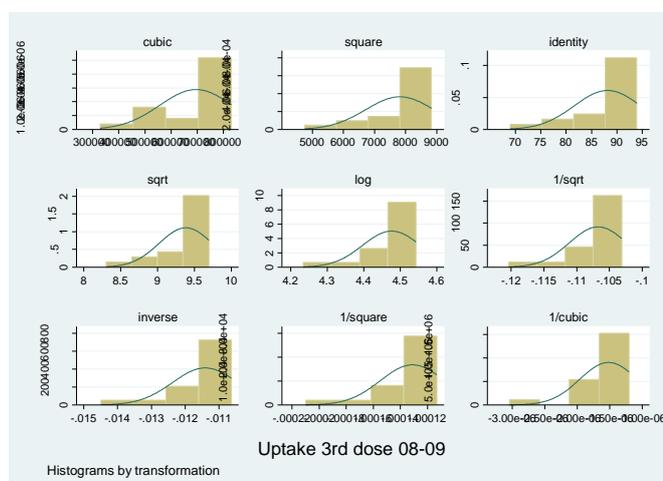


Table 1 shows the unadjusted and adjusted results of the association between uptake and the study area characteristics. The unadjusted results indicate that there was a negative statistically significant association between deprivation of SCA and uptake (i.e. a unit increase in deprivation was associated with a reduction of uptake). There was a positive statistically significant association between uptake and ethnicity as well as religious schools. In multiple regression model 1, deprivation of SCA remained statistically significantly associated with uptake after controlling for ethnicity and school type. In multiple regression model 2 (i.e. after multiple adjustments of other factors), deprivation of SAP became statistically significantly associated with uptake. In the two multiple regression models, ethnicity remained statistically significantly associated with uptake

when the other variables were held constant and the same was true for the association between religious schools and uptake.

**Appendix 7. Table 1. The relationship between uptake and variables related to geographic factors and school factors in 2008/09**

| Uptake            | Unadjusted |      |         | MODEL 1 |      |         | MODEL 2 |      |         |
|-------------------|------------|------|---------|---------|------|---------|---------|------|---------|
|                   | Coeff      | SE   | p value | Coeff   | SE   | p value | Coeff   | SE   | p value |
| deprivation SCA*  | -0.51      | 0.16 | 0.006   | -0.30   | 0.11 | 0.01    |         |      |         |
| deprivationSAP ** | -0.18      | 0.12 | 0.15    |         |      |         | -0.16   | 0.06 | 0.02    |
| ethnicity**       | 0.40       | 0.12 | 0.006   | 0.28    | 0.10 | 0.02    | 0.29    | 0.09 | 0.006   |
| school type **    |            |      |         |         |      |         |         |      |         |
| No (reference)    | 0          |      |         | 0       |      |         | 0       |      |         |
| Yes               | 5.12       | 1.93 | 0.01    | 3.11    | 1.17 | 0.01    | 5.65    | 2.07 | 0.01    |

\*N = 18 observations

\*\* N = 20 observations

School type = religious

The independent variables included in the regression analysis model 1 explained 71% of the variation in uptake and those modeled together in the regression analysis model 2 explained 68% of the variation in uptake.

In conclusion, I found that uptake was significantly associated with geographic factors (deprivation of SCA, deprivation of SAP and ethnicity) and school factors (religious affiliation).

### **Linear regression analysis in the academic year 2009/10**

Figure 2 shows that the distribution of the dependent variable (uptake of the third dose 2009/10) became Normal after 1/square root transformations. However, log transformation showed that the outcome variable had a distribution near to Normality. For an easy interpretation of the results of regression analyses, the dependent variable was entered in the models log transformed.

**Appendix 7. Figure 2. Transformations of the dependent variable in the academic year 2009/10**

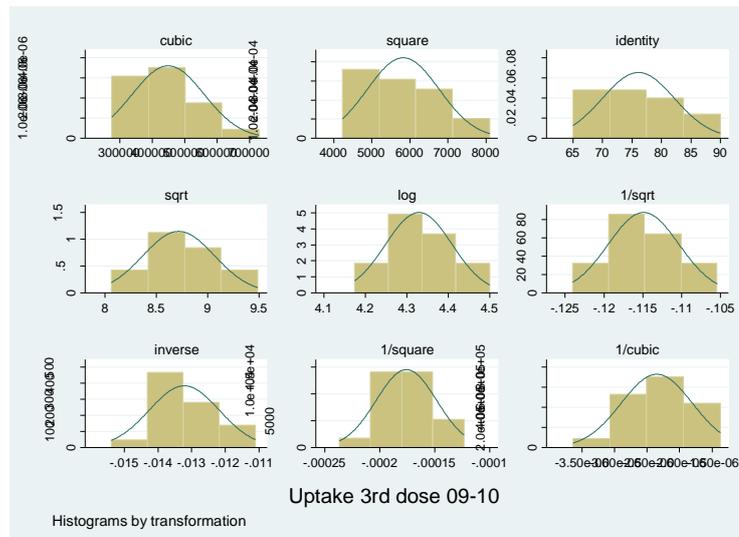


Table 2 shows the unadjusted and adjusted results of the association between uptake and the study area characteristics. The unadjusted results indicate that there was a negative statistically significant association between uptake and deprivation of SCA as well as deprivation of SAP (i.e. a unit increase in deprivation was associated with a reduction of uptake). There was a positive statistically significant association between uptake and ethnicity as well as religious schools. In multiple regression model 1, deprivation of SCA remained statistically significantly associated with uptake after controlling for ethnicity and school type. In multiple regression model 2 (i.e. after multiple adjustments of other factors), deprivation of SAP remained statistically significantly associated with uptake. In the two multiple regression models, ethnicity remained statistically significantly associated with uptake when the other variables were held constant.

**Appendix 7. Table 2. The relationship between uptake and variables related to geographic factors and school factors in 2009/10**

| Uptake            | Unadjusted |       |         | MODEL 1 |       |         | MODEL 2 |       |            |
|-------------------|------------|-------|---------|---------|-------|---------|---------|-------|------------|
|                   | Coef<br>f  | SE    | p value | Coeff   | SE    | p value | Coeff   | SE    | p<br>value |
| deprivation SCA*  | 1.16       | 0.01  | <0.001  | 1.05    | 0.01  | <0.001  |         |       |            |
| deprivationSAP**  | 1.12       | 0.01  | <0.001  |         |       |         | 1.03    | 0.007 | 0.001      |
| ethnicity**       | 1.06       | 0.002 | <0.001  | 1.04    | 0.004 | <0.001  | 1.05    | 0.003 | <0.001     |
| school type**     |            |       |         |         |       |         |         |       |            |
| No (reference)*** | 0          |       |         | 0       |       |         | 0       |       |            |
| Yes               | 75.4       | 1.81  | <0.001  | 1.42    | 0.49  | 0.32    | 0.93    | 0.34  | 0.85       |

\*N = 18 observations

\*\* N = 20 observations

\*\*\*geometric mean = 75.98

School type = religious

The independent variables included in the regression analysis model 1 explained 98% of the variation in uptake and those modeled together in the regression analysis model 2 explained 98% of the variation in uptake.

In conclusion, I found that uptake was significantly associated with geographic factors (deprivation of SAP, deprivation of SCA and ethnicity) and no association was found between uptake and school factors (religious affiliation).

### **Linear regression analysis in the academic year 2010/11**

Figure 3 shows that the distribution of the dependent variable (uptake of the third dose 2010/11) became Normal after cubic and square transformations. Without transformation, the outcome variable had a distribution near to Normality (shown by histogram corresponding to “Identity”). For an easy interpretation of the results of regression analyses, the dependent variable was entered in the models untransformed.

**Appendix 7. Figure 3. Transformations of the dependent variable in the academic year 2010/11**

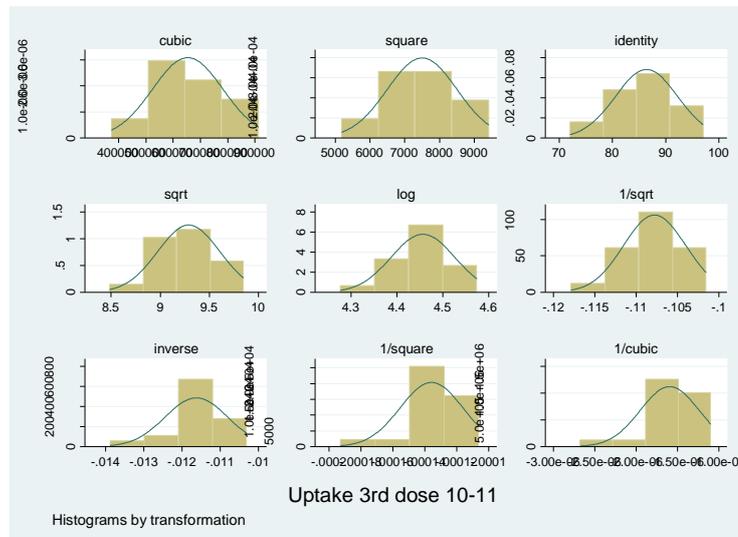


Table 3 shows the unadjusted and adjusted results of the association between uptake and the study area characteristics. The unadjusted results indicate that there was a negative statistically significant association between deprivation of SAP and uptake (i.e. a unit increase in deprivation was associated with a reduction of uptake). There was a positive statistically significant association between ethnicity and uptake (i.e. a unit increase in percentage of white residents was associated with an increase of uptake). In multiple regression model 1, ethnicity remained statistically significantly associated with uptake after controlling for deprivation of SCA and school type. In multiple regression model 2 (i.e. after multiple adjustments of other factors), no association was found between uptake and geographic factors (deprivation of SAP and ethnicity) or school factors (religious affiliation).

**Appendix 7. Table 3. The relationship between uptake and variables related to geographic factors and school factors in 2010/11**

| Uptake             | Unadjusted |      |         | MODEL 1 |      |         | MODEL 2 |      |         |
|--------------------|------------|------|---------|---------|------|---------|---------|------|---------|
|                    | Coeff      | SE   | p value | Coeff   | SE   | p value | Coeff   | SE   | p value |
| deprivation SCA*   | -0.24      | 0.13 | 0.10    | -0.08   | 0.11 | 0.48    |         |      |         |
| deprivation SAP ** | -0.19      | 0.07 | 0.01    |         |      |         | -0.08   | 0.06 | 0.22    |
| ethnicity**        | 0.30       | 0.10 | 0.01    | 0.26    | 0.11 | 0.03    | 0.24    | 0.12 | 0.07    |
| school type**      |            |      |         |         |      |         |         |      |         |
| No (reference)     | 0          |      |         | 0       |      |         |         |      |         |
| Yes                | -0.5       | 2.32 | 0.83    | -0.67   | 2.17 | 0.76    | 0.24    | 1.88 | 0.90    |

\*N = 18 observations

\*\* N = 20 observations

School type = religious

The independent variables included in the regression analysis model 1 explained 39% of the variation in uptake and those modeled together in the regression analysis model 2 explained 41% of the variation in uptake.

In conclusion, I found that uptake was only significantly associated with ethnicity and no association was found between uptake and other geographic factors (deprivation of SAP and deprivation of SCA) or school factors (religious affiliation).

### **Linear regression analysis in the academic year 2011/12**

The outcome variable uptake of the third dose 2011/12 was Normally distributed.

Table 4 shows the unadjusted and adjusted results of the association between uptake and the study area characteristics. The unadjusted results indicate that there was no statistically significant association between uptake and geographic factors (deprivation of SCA, deprivation of SAP and ethnicity) or school factors (religious affiliation). In the two multiple regression models (i.e. after multiple adjustments of other factors), no association was found between uptake and geographic factors (deprivation and ethnicity) or school factors (religious affiliation).

**Appendix 7. Table 4. The relationship between uptake and variables related to geographic factors and school factors in 2011/12**

| Uptake            | Unadjusted |      |         | MODEL 1 |      |         | MODEL 2 |      |         |
|-------------------|------------|------|---------|---------|------|---------|---------|------|---------|
|                   | Coeff      | SE   | p value | Coeff   | SE   | p value | Coeff   | SE   | p value |
| deprivation SCA*  | -0.09      | 0.14 | 0.54    | -0.02   | 0.16 | 0.88    |         |      |         |
| deprivation SAP** | -0.11      | 0.07 | 0.15    |         |      |         | -0.08   | 0.09 | 0.36    |
| ethnicity**       | 0.08       | 0.10 | 0.42    | 0.07    | 0.13 | 0.56    | 0.02    | 0.12 | 0.81    |
| school type **    |            |      |         |         |      |         |         |      |         |
| No (reference)    | 0          |      |         | 0       |      |         | 0       |      |         |
| Yes               | 1.87       | 2.17 | 0.40    | 1.60    | 2.07 | 0.45    | 2.19    | 2.35 | 0.36    |

\*N = 18 observations

\*\* N = 20 observations

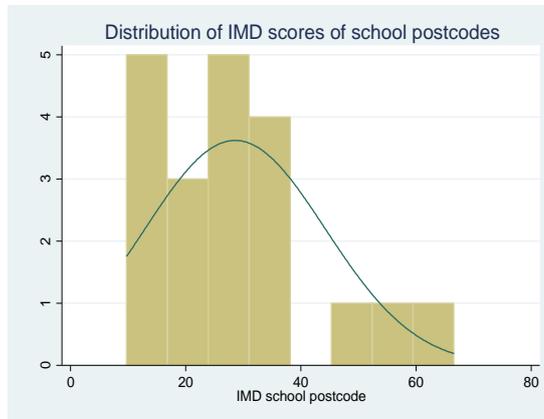
School type = religious

The independent variables included in the regression analysis model 1 explained 6% of the variation in uptake and those modeled together in the regression analysis model 2 explained 11% of the variation in uptake.

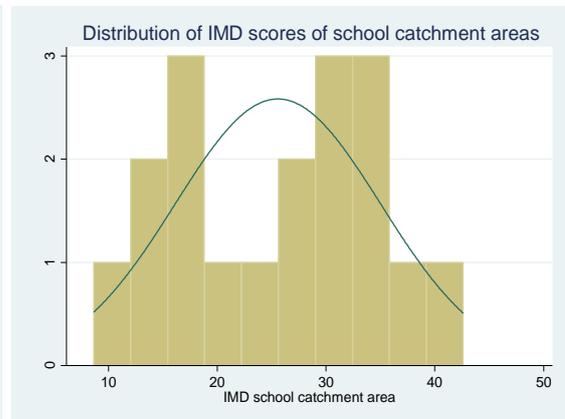
In conclusion, no association was found between uptake and geographic factors (deprivation and ethnicity) or school factors (religious affiliation).

**Appendix 8. Histogram of the independent variables: deprivation of school address postcode, deprivation of school catchment area and ethnicity**

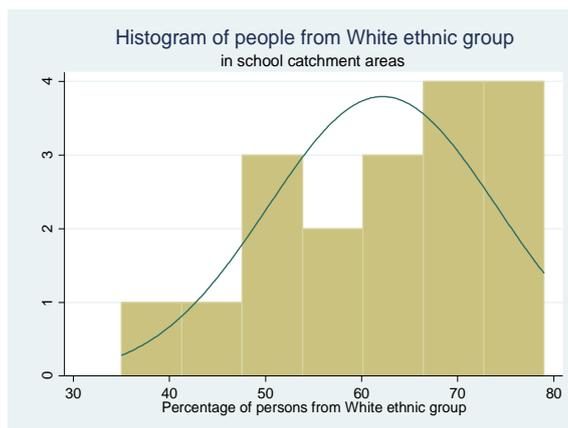
**Appendix 8. Figure 1. IMD of SAP**



**Appendix 8. Figure 2. IMD of SCA**



**Appendix 8. Figure 3. Ethnicity**



### Appendix 9. Three-dose completion rate of HPV vaccination programme

The statistics for the three-dose completion rate by academic year were calculated according to the following definition: the relative proportion of girls who completed vaccination to the total number of girls who only received the first dose. Table 1 gives details about the completion rates by school and by academic year. The number of schools which vaccinated all year 8 girls was one in 2008/09, nine in 2009/10, four in 2010/11 and six in 2011/12.

**Appendix 9. Table 1. Completion rate of HPV vaccination programme by school and by academic year**

| School | Completion Rate 2008/09 | Completion Rate 2009/10 | Completion Rate 2010/11 | Completion Rate 2011/12 |
|--------|-------------------------|-------------------------|-------------------------|-------------------------|
| 1      | 98                      | 100                     | 98                      | 98                      |
| 2      | 94                      | 91                      | 85                      | 98                      |
| 3      | 96                      | 100                     | 97                      | 99                      |
| 4      | 100                     | 85                      | 101                     | 100                     |
| 5      | 97                      | 103                     | 100                     | 98                      |
| 6      | 98                      | 101                     | 99                      | 98                      |
| 7      | 98                      | 96                      | 98                      | 100                     |
| 8      | 98                      | 100                     | 100                     | 97                      |
| 9      | 95                      | 82                      | 94                      | 98                      |
| 10     | 99                      | 94                      | 99                      | 99                      |
| 11     | 92                      | 109                     | 99                      | 99                      |
| 12     | 98                      | 88                      | 96                      | 93                      |
| 13     | 98                      | 102                     | 98                      | 100                     |
| 14     | 88                      | 90                      | 95                      | 100                     |
| 15     | 97                      | 101                     | 96                      | 97                      |
| 16     | 97                      | 97                      | 99                      | 100                     |
| 17     | 99                      | 97                      | 96                      | 97                      |
| 18     | 95                      | 106                     | 100                     | 100                     |
| 19     | 98                      | 97                      | 99                      | 96                      |
| 20     | 98                      | 92                      | 95                      | 95                      |

The percentage of year 8 girls who completed the programme in each academic year was very high - on average 97-98%. The completion rate of the programme varied more widely across the schools in 2009/10 (from 82% to 109%) in comparison with the other academic years when the rates ranged from 88% to 100% in 2008/09, from 85% to 101% in 2010/11 and from 93% to 100% in 2011/12. (It should be noted that the

percentages of year 8 girls vaccinated in the academic year 2009/10 and 2010/11 exceeded 100%). In all years combined, uptake of the first dose was 88% and uptake of the third dose was 85%. In all 97% of year 8 girls completed the programme from 2008/09 to 2011/12. Table 2 presents summary statistics (mean, standard deviation and median) for the completion rate of the programme by academic year.

**Appendix 9. Table 2. Summary statistics for the completion rate of HPV vaccination programme (percentage of girls receiving the first vaccine who received the second and final dose) by academic year**

| <b>Completion rate</b> | <b>N</b> | <b>Mean</b> | <b>Std. Dev.</b> | <b>Min</b> | <b>Max</b> |
|------------------------|----------|-------------|------------------|------------|------------|
| <b>2008/09</b>         | 20       | 96.72       | 2.78             | 87.71      | 100        |
| <b>2009/10</b>         | 20       | 96.56       | 7.00             | 82.14      | 108.82     |
| <b>2010/11</b>         | 20       | 97.22       | 3.56             | 84.61      | 101.29     |
| <b>2011/12</b>         | 20       | 98.03       | 1.91             | 93.24      | 100        |

N = number of schools

**Appendix 10. Delivery of the HPV immunization programme - Interval between administrations of doses<sup>35</sup>**

**Interval between administration of the first dose and the second dose**

According to the schedule of HPV immunization, the vaccine should be administered at 0, 1 month and 6 months. I calculated the interval between administration of the first and the second dose. Table 1 shows the interval (expressed in days) for each academic year. I considered one month being on average 30 days.

The second dose of the vaccine was administered 27-35 days after the first dose in the majority of schools in the academic year 2008/09 (18 schools) and in the academic year 2010/11 (14 schools). Similarly over half of the schools (12 schools) gave the second dose after 28-35 days in the following academic year 2011/12. In contrast, in 2009/10 the girls were vaccinated with the second dose after a longer interval (36-95 days) in more than half of the schools (12 schools).

Figures 1 and 2 present the variation of the interval between administration of the first two doses by bar charts with error bars by school in the academic years 2009/10, 2010/11 and 2011/12. Figure 1 shows that in the academic year 2009/10, four schools (3, 10, 15 and 18) administered HPV vaccine two three months later than the schedule.

<sup>35</sup> Based on the results of qualitative data analysis in Chapter – Theme 1 and theme 2

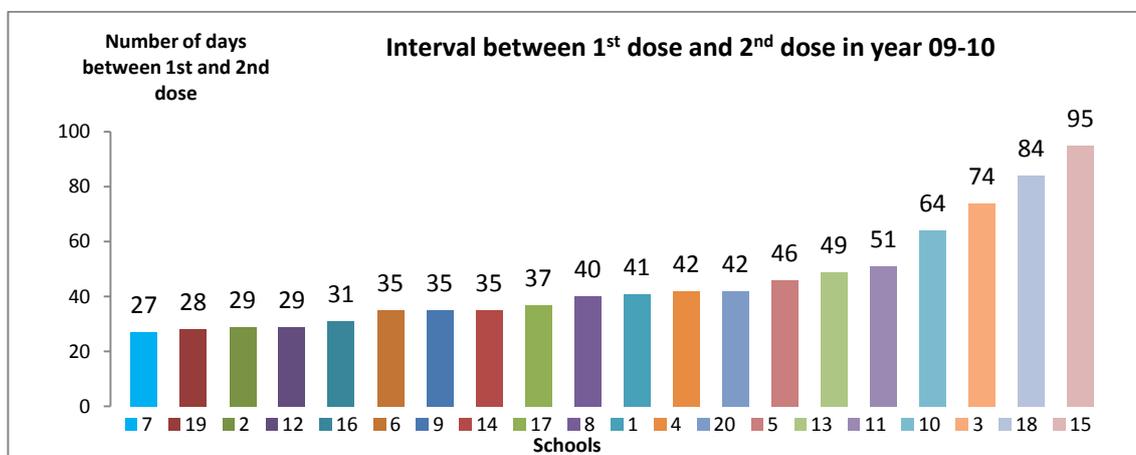
Figure 2 indicates that three schools (1, 6 and 9) vaccinated the girls with the second dose at one and a half months after the first dose in 2010/11 and Figure 3 shows that this occurred in five schools (2, 3, 4, 5 and 16) in 2011/12. This interval could reflect the way in which the HPV immunisation programme was offered by the vaccination team. Usually one-two schools were visited per day four days per week so that all the schools were covered in about two-three weeks.

**Appendix 10. Table 1. Interval between the administration of the first dose and the second dose by academic year**

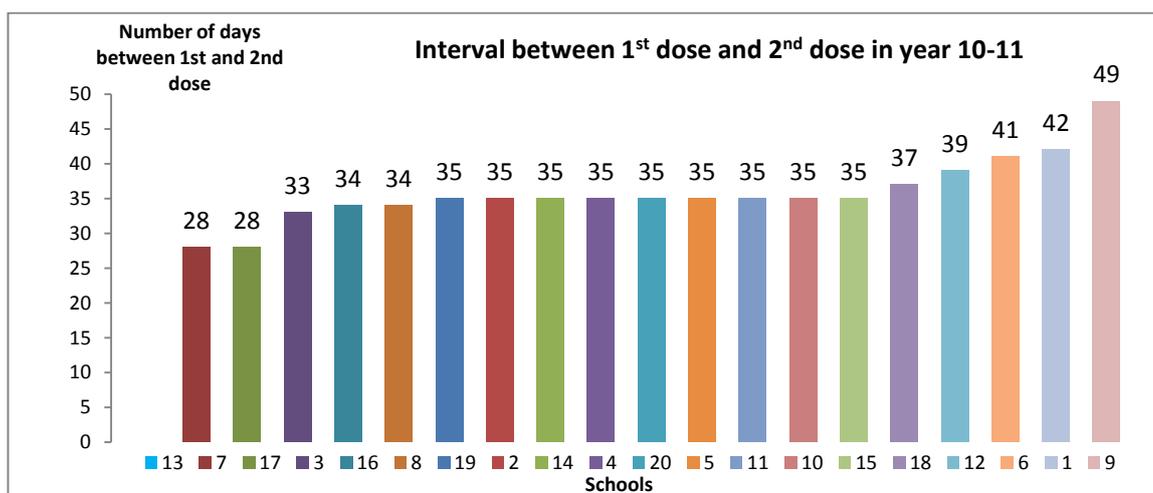
| Academic year | 2 <sup>nd</sup> dose given within 1 month after the 1 <sup>st</sup> dose |           | 2 <sup>nd</sup> dose given > 1 month after the 1 <sup>st</sup> dose |           |
|---------------|--|-----------|---|-----------|
|               | Interval 1 <sup>st</sup> – 2 <sup>nd</sup> dose *                        | N schools | Interval 1 <sup>st</sup> – 2 <sup>nd</sup> dose                     | N schools |
| 2008/09       | 35   | 18        | 38  | 2         |
| 2009/10       | 27-35  | 8         | 36-95   | 12        |
| 2010/11       | 28-35  | 14        | 36-49   | 5         |
| 2011/12       | 28-35  | 12        | 36-49   | 8         |

\*days

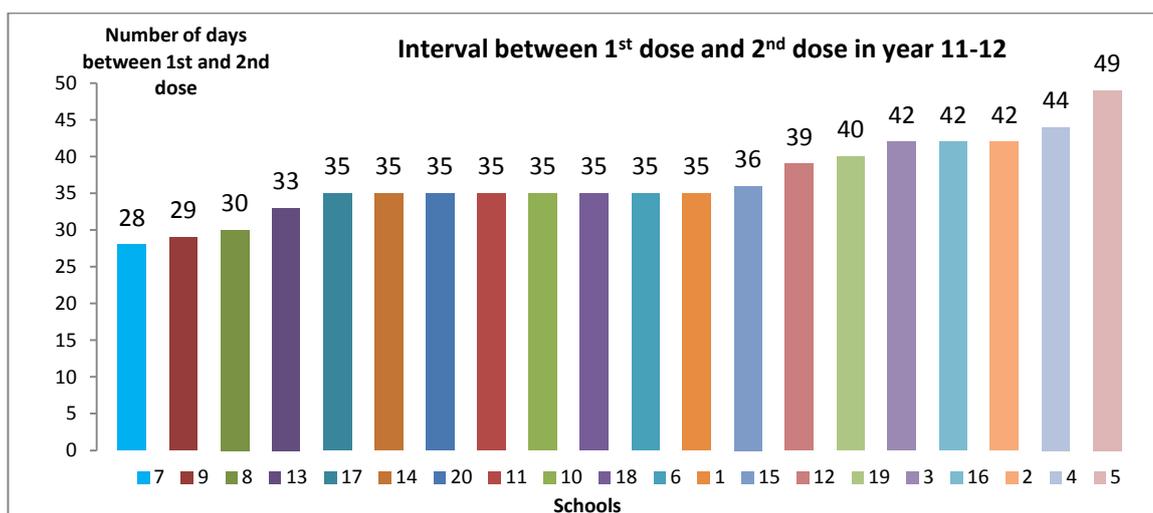
**Appendix 10. Figure 1. Interval between the first dose and the second dose in year 2009/10**



**Appendix 10. Figure 2. Interval between the first dose and the second dose in year 2010/11**



**Appendix 10. Figure 3. Interval between the first dose and the second dose in year 2011/12**



**Appendix 11. Interval between administration of the first dose and the third dose**

Using the date of immunization for the first dose and the third dose, I calculated the interval between administration of the first and the third dose for each academic year, which is presented in days. The schedule for the third dose is at six months after the first dose. I considered this interval to be equal to 180 days. Table 1 shows that from 2008 and 2012, the interval varied between 143 and 234 days. I divided this interval in three periods as follows. A period less than 180 days indicated that the vaccinations were given earlier than the schedule. The time corresponding to 180 -185 days suggested that the programme was delivered according to standard vaccination schedule (in five working days within a week). The interval, which exceeded 185 days, pointed to a delay

in delivery of HPV immunizations. Because the way the programme was delivered in practice as mentioned previously, a period corresponding to 186-200 days could still be considered to fall into the recommended vaccination schedule because of the extra time the vaccination team needed to cover all the schools with the third dose of HPV vaccine (additional ten working days within two weeks). Across the years, a few schools, between two and four schools, administered the third dose between 5 and 37 days (within one week – one month) earlier than the schedule. Almost half of the schools (8 schools) administered the third dose at six months after the first dose in the academic year 2008/09. More than half of the schools (12-13 schools) administered the third dose 36-48 days later than the schedule (equal to seven or more months from the date when the first dose was given) in three academic years (2009/10, 2010/11 and 2011/12).

**Appendix 11. Table 1. Interval between administration of the first and the third dose of HPV vaccine by academic years**

| Academic year | 3 <sup>rd</sup> dose given < 6 months after 1 <sup>st</sup> dose |           | 3 <sup>rd</sup> dose given at 6 months after 1 <sup>st</sup> dose (standard immunization schedule) |           | 3 <sup>rd</sup> dose given > 6 months after 1 <sup>st</sup> dose |           |
|---------------|--|-----------|--|-----------|--|-----------|
|               | Interval 1 <sup>st</sup> –3 <sup>rd</sup> dose *                 | N schools | Interval 1 <sup>st</sup> –3 <sup>rd</sup> dose*  | N schools | Interval 1 <sup>st</sup> –3 <sup>rd</sup> dose*                  | N schools |
| 2008/09       | 143-179  | 3         | 180-185  | 8         | 186-212  | 9         |
| 2009/10       | 148-179  | 4         | 180-185  | 3         | 186-234  | 13        |
| 2010/11       | 145-179  | 2         | 180-185  | 5         | 186-222  | 13        |
| 2011/12       | 175-179  | 2         | 180-185  | 6         | 186-231  | 12        |

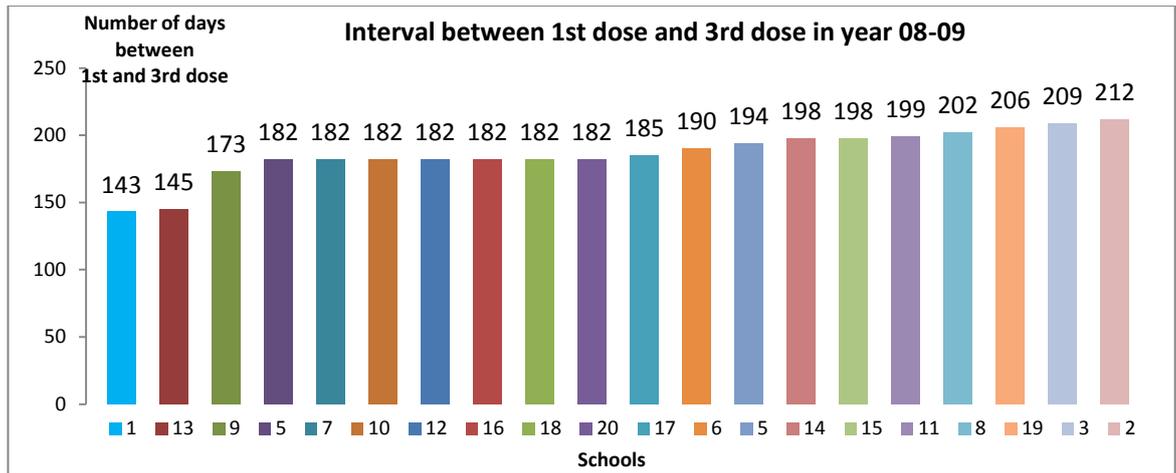
\*days

In Figures 1-4 the interval between administration of the first and the third dose are represented graphically by bar charts by schools in each academic year. I made a comparison across the years to understand the pattern of the third dose delivery. A consistent observation was that year after year the same six schools gave the third dose later than six months. School 14 administered the third dose at more than six months after the first dose in all four academic years. Three schools (schools 5, 6, 8) gave the third dose later than the schedule for three consecutive years in 2008/09, 2009/10 and 2010/11. Other two schools (schools 18, 20) administered the third dose beyond 180 days in 2009/10, 2010/11 and 2011/12. Two schools (11 and 19) vaccinated the girls with the third dose later than the schedule in the first and the last two years of the programme (2008/09, 2010/11 and 2011/12).

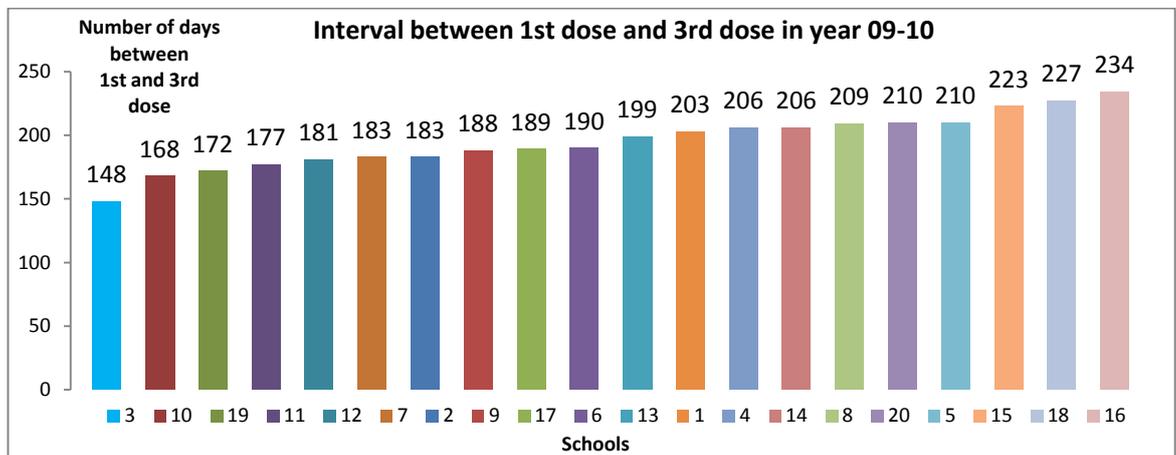
As mentioned before, the vaccination team gave the third dose at six – seven months (180-200 days) as recommended schedule. Figures 1-4 show that there were schools

which offered the third dose later than this schedule (delay by 2 and 34 days). Thus, in 2008/09 there were four schools (2, 3, 8, 19), in 2009/10 eight schools (1, 4, 5, 8, 14, 15, 16, 18), in 2010/11 ten schools (4, 5, 6, 8, 9, 11, 12, 14, 18, 20), and in 2011/12 eight schools (7, 14, 15, 16, 17, 18, 19, 20).

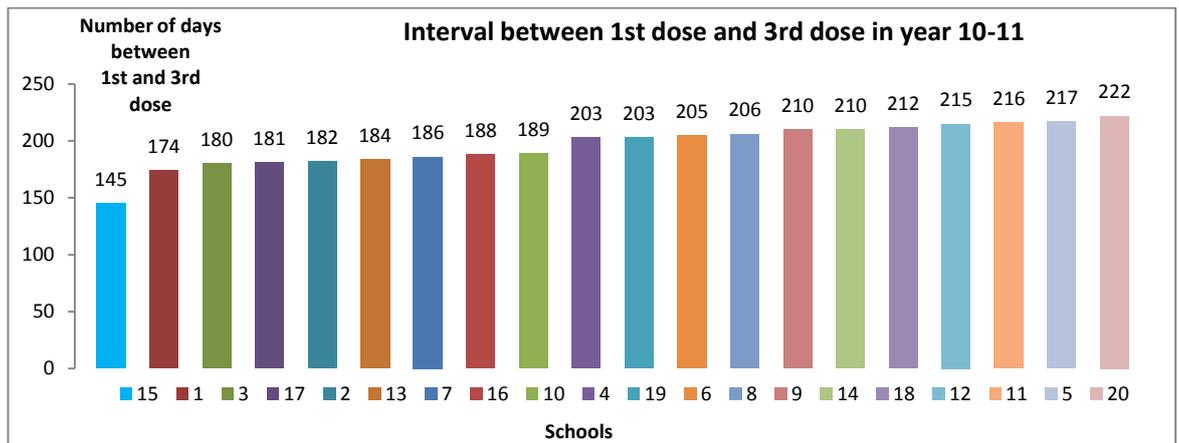
**Appendix 11. Figure 1. Interval between the first dose and the third dose in year 2008/09**



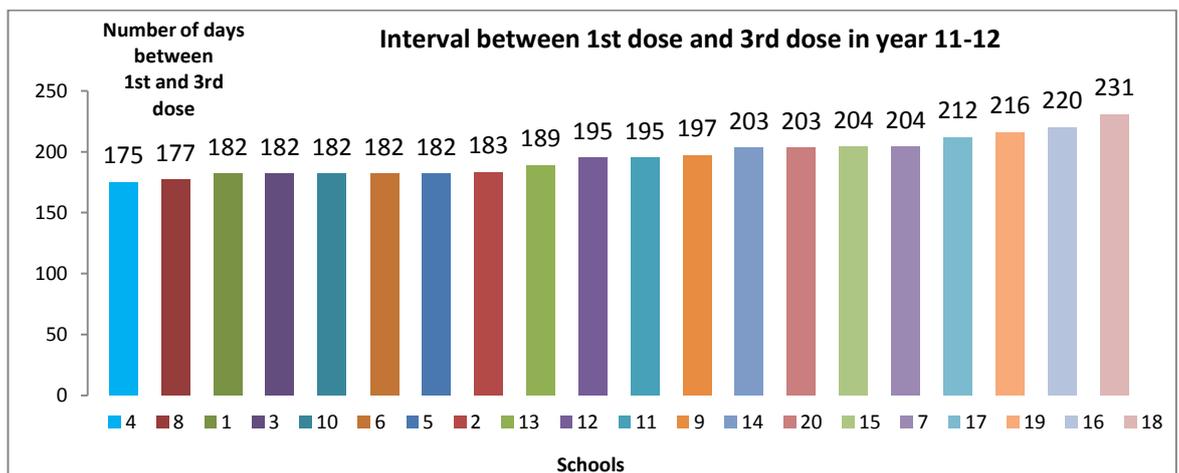
**Appendix 11. Figure 2. Interval between the first dose and the third dose in year 2009/10**



**Appendix 11. Figure 3. Interval between the first dose and the third dose in year 2010/11**



**Appendix 11. Figure 4. Interval between the first dose and the third dose in year 2011/12**



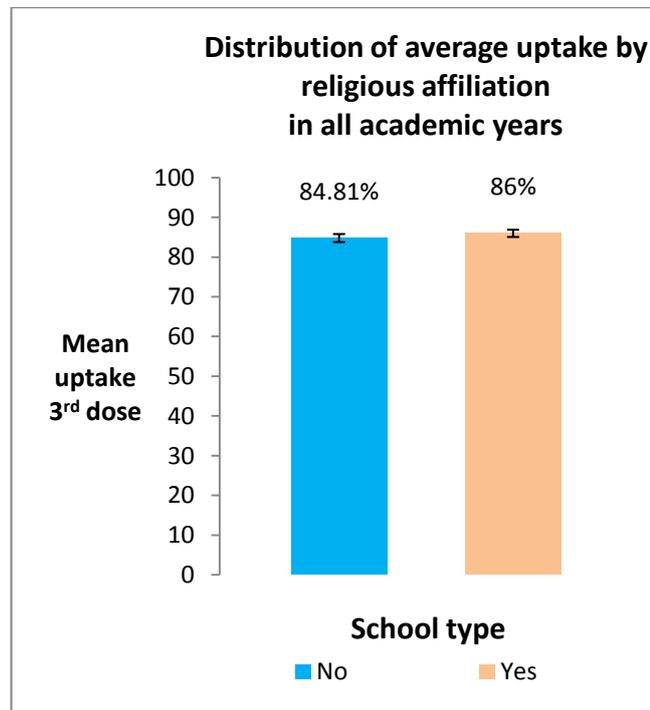
**Appendix 12. Table 1. Distribution of IMD score for school catchment area and school address postcode**

| <b>school</b> | <b>average IMD score SCA</b> | <b>IMD score SAP</b> |
|---------------|------------------------------|----------------------|
| 1             | NA                           | 48.93                |
| 2             | 32.21                        | 36.44                |
| 3             | 17.13                        | 9.71                 |
| 4             | 14.94                        | 33.21                |
| 5             | 14.92                        | 22.57                |
| 6             | 20.50                        | 26.27                |
| 7             | 31.48                        | 59.12                |
| 8             | 15.74                        | 11.66                |
| 9             | 36.93                        | 34.24                |
| 10            | 8.64                         | 9.71                 |
| 11            | 33.27                        | 28.29                |
| 12            | 30.55                        | 11.27                |
| 13            | NA                           | 11.08                |
| 14            | 33.50                        | 23.54                |
| 15            | 28.31                        | 20.08                |
| 16            | 42.61                        | 66.63                |
| 17            | 26.68                        | 27.51                |
| 18            | 24.15                        | 29.52                |
| 19            | 15.68                        | 30.07                |
| 20            | 33.01                        | 31.97                |

NA= not available

### Appendix 13. Religious affiliation of the schools

Appendix 13. Figure 1. Distribution of average uptake by religious affiliation in all academic years

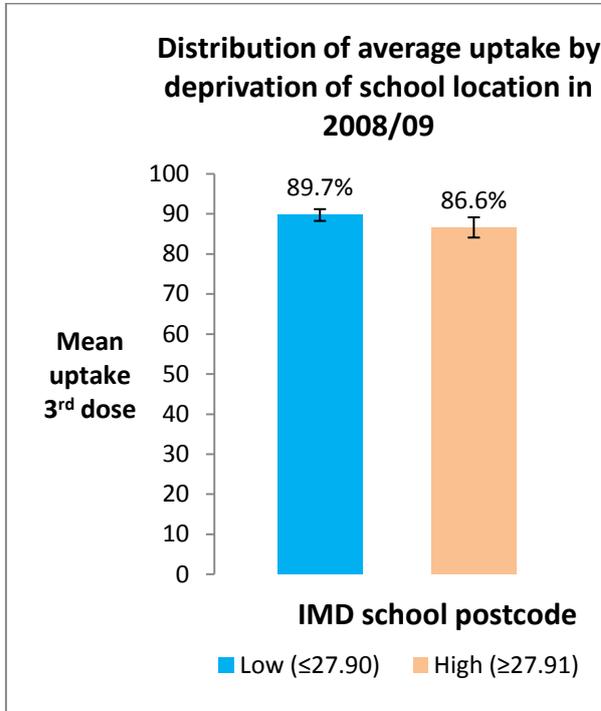


Mann-Whitney test ( $z = -0.14$ ,  $p$  value = 0.88)

**Appendix 14. Deprivation of school address postcode in 2008/09, 2009/10, 2010/11, 2011/12 and all years**

**Appendix 14. Figure 1.**

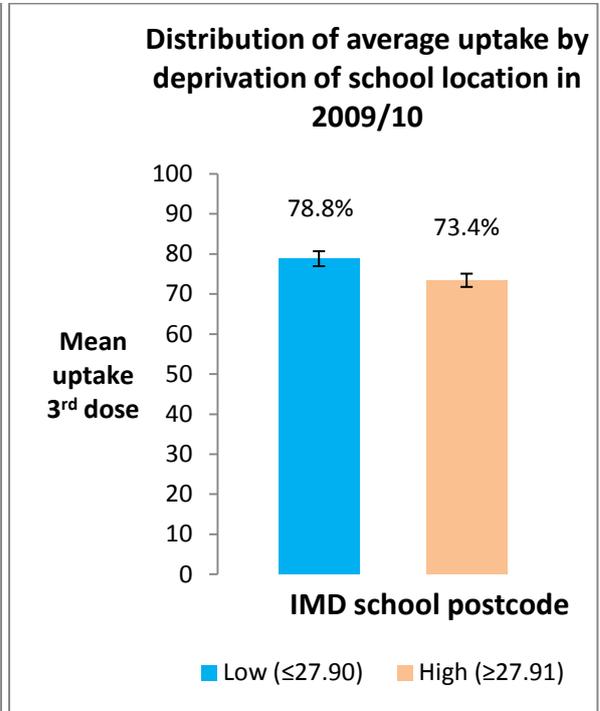
**Distribution of average uptake by deprivation of SAP in year 2008/09**



/Mann-Whitney test ( $z = 1.14$ ,  $p$  value = 0.25)

**Appendix 14. Figure 2.**

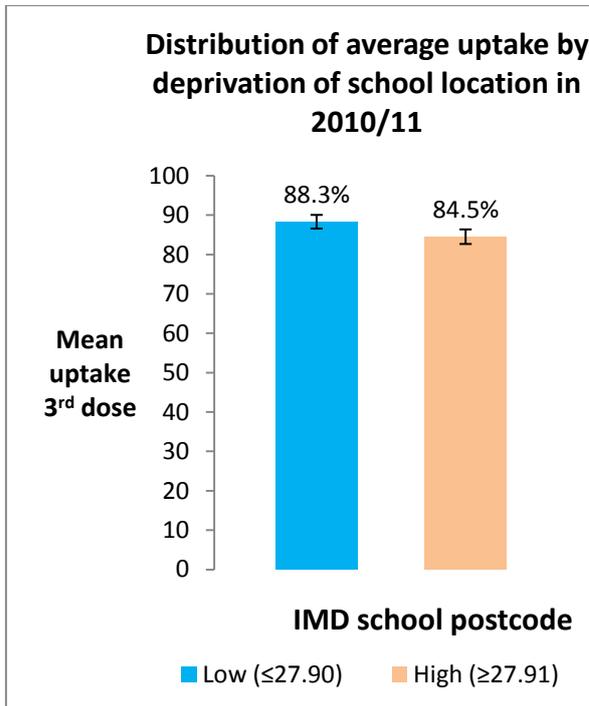
**Distribution of average uptake by deprivation of SAP in year 2009/10**



Mann-Whitney test ( $z = 2.01$ ,  $p$  value = 0.04)

**Appendix 14. Figure 3.**

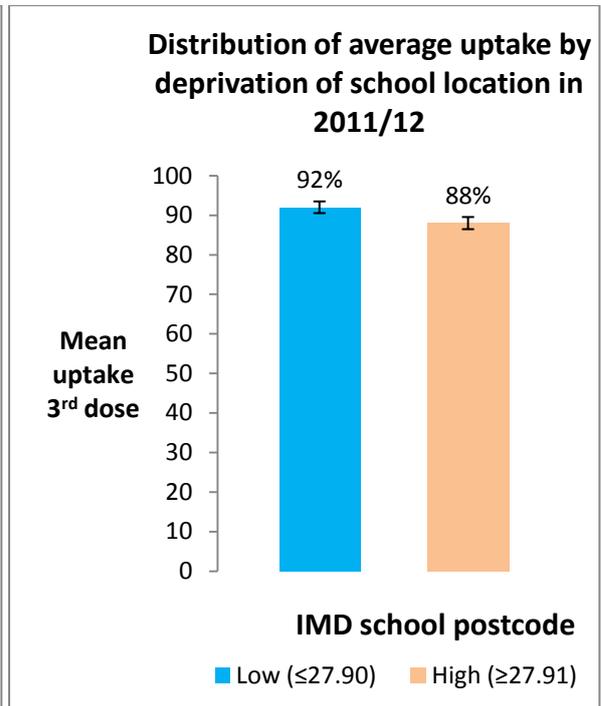
**Distribution of average uptake by deprivation of SAP in year 2010/11**



Mann-Whitney test ( $z = 1.06$ ,  $p$  value = 0.28)

**Appendix 14. Figure 4.**

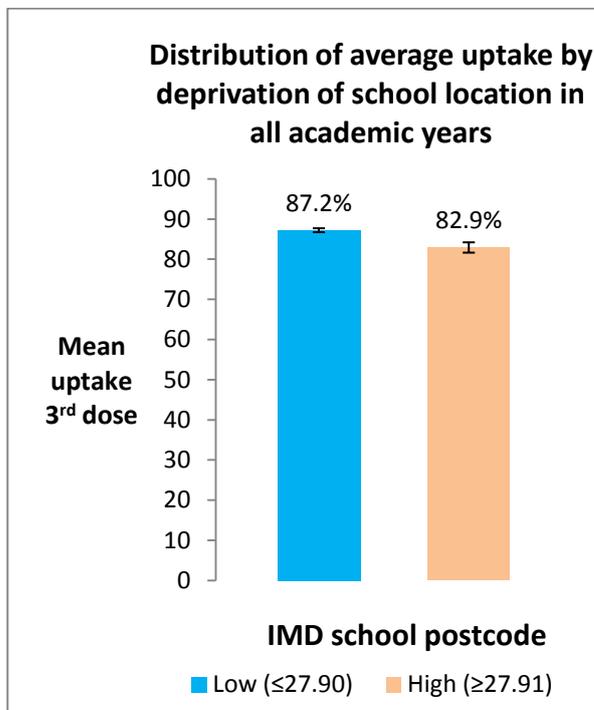
**Distribution of average uptake by deprivation of SAP in year 2011/12**



Mann-Whitney test ( $z = 1.71$ ,  $p$  value = 0.08)

**Appendix 14. Figure 5.**

**Distribution of average uptake by deprivation of SAP in all academic years**

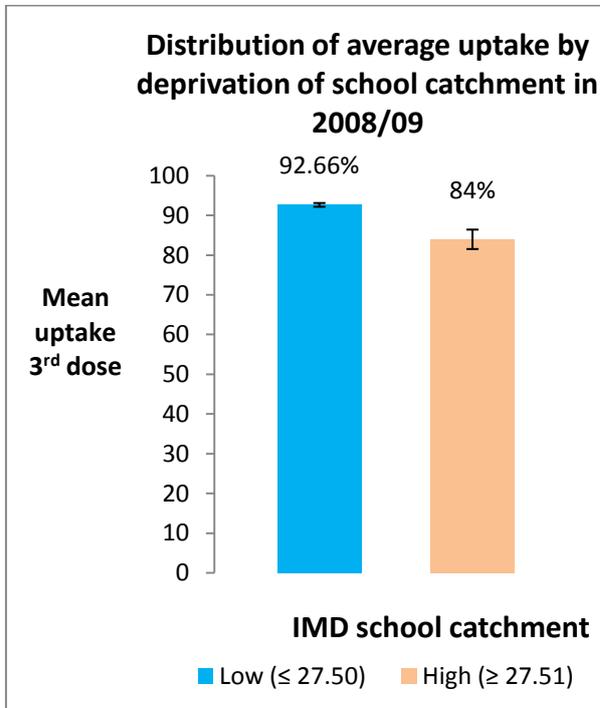


Mann-Whitney test ( $z = 2.80$ ,  $p$  value = 0.005)

**Appendix 15. Deprivation of school catchment area in 2008/09, 2009/10, 2010/11, 2011/12 and all years**

**Appendix 15. Figure 1.**

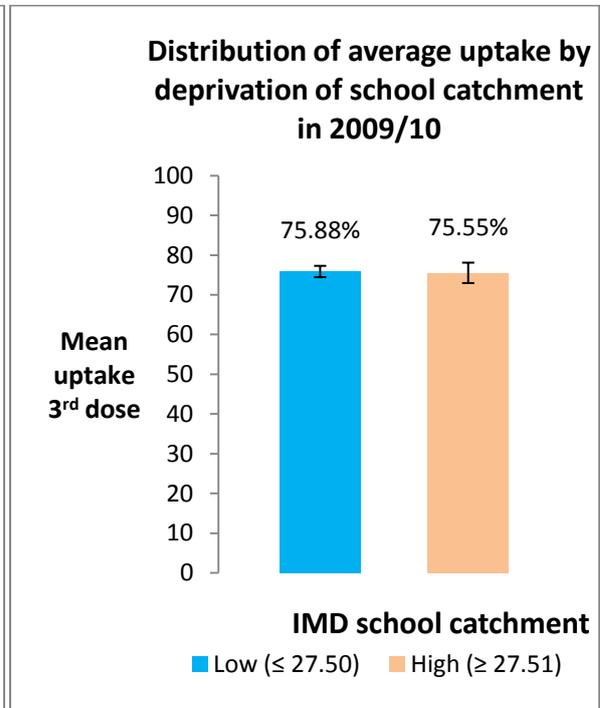
**Distribution of average uptake by deprivation of SCA in 2008/09**



Mann-Whitney test ( $z = 3.28$ ,  $p$  value = 0.001)

**Appendix 15. Figure 2.**

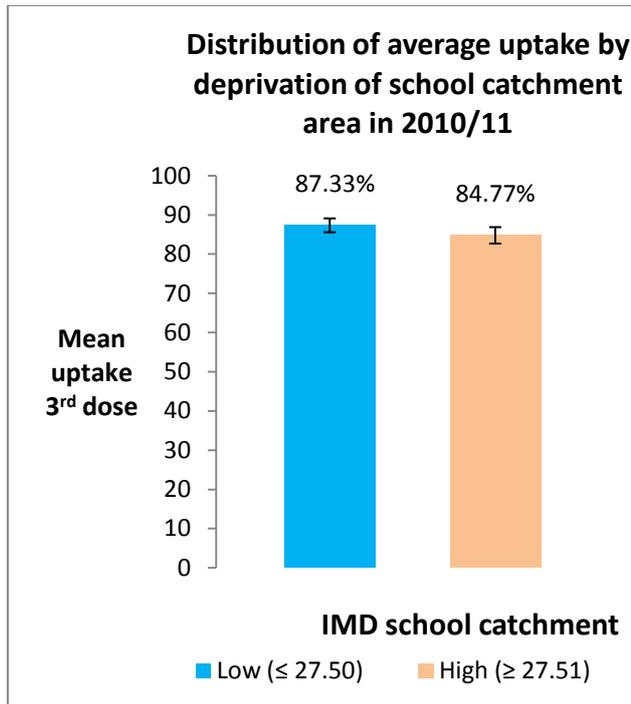
**Distribution of average uptake by deprivation of SCA in 2009/10**



Mann-Whitney test ( $z = 0.53$ ,  $p$  value = 0.59)

**Appendix 15. Figure 3.**

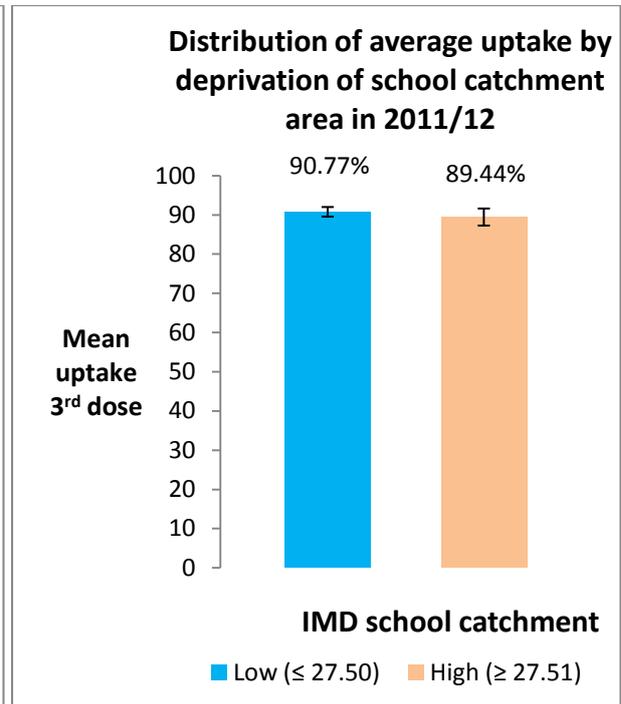
**Distribution of average uptake by deprivation of SCA in 2010/11**



Mann-Whitney test ( $z = 0.35$ ,  $p$  value = 0.72)

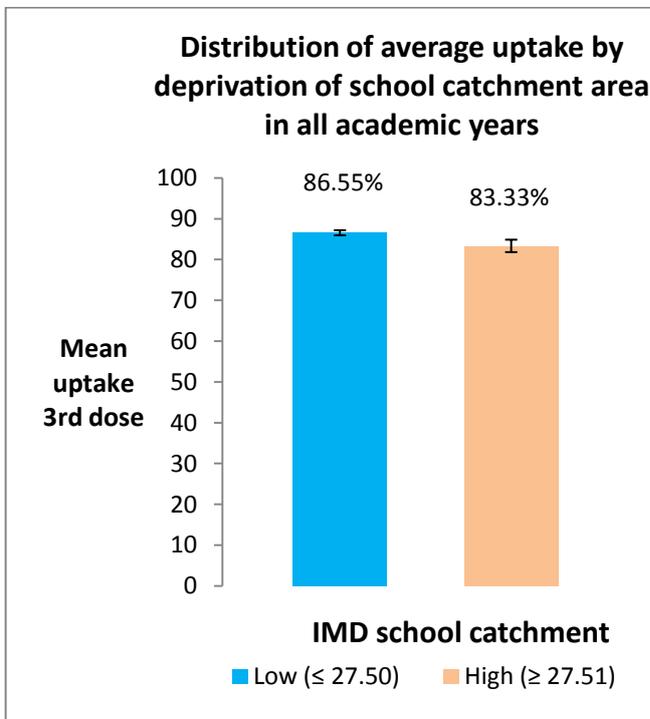
**Appendix 15. Figure 4.**

**Distribution of average uptake by deprivation of SCA in 2011/12**



Mann-Whitney test ( $z = 0.44$ ,  $p$  value = 0.65)

**Appendix 15. Figure 5. Distribution of average uptake by deprivation of SCA in all academic years**

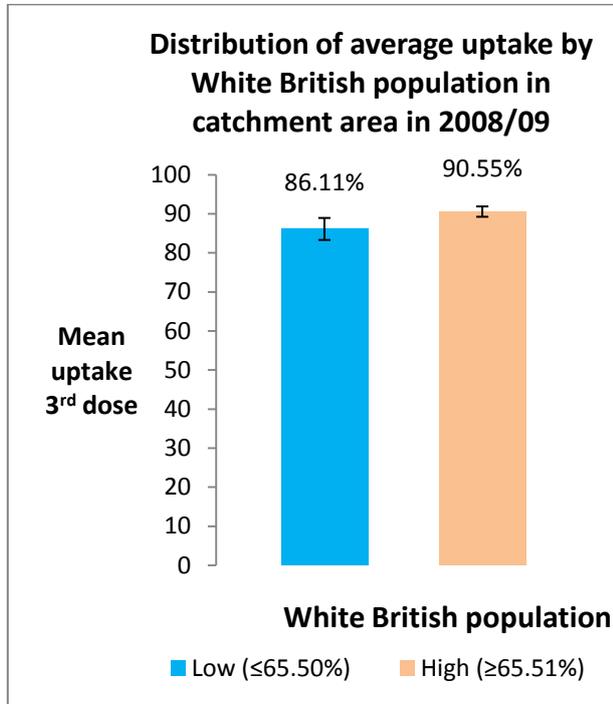


Mann-Whitney test ( $z = 1.53$ ,  $p$  value = 0.12)

**Appendix 16. Distribution of average uptake by ethnicity in school catchment area in 2008/09, 2009/10, 2010/11, 2011/12 and all years**

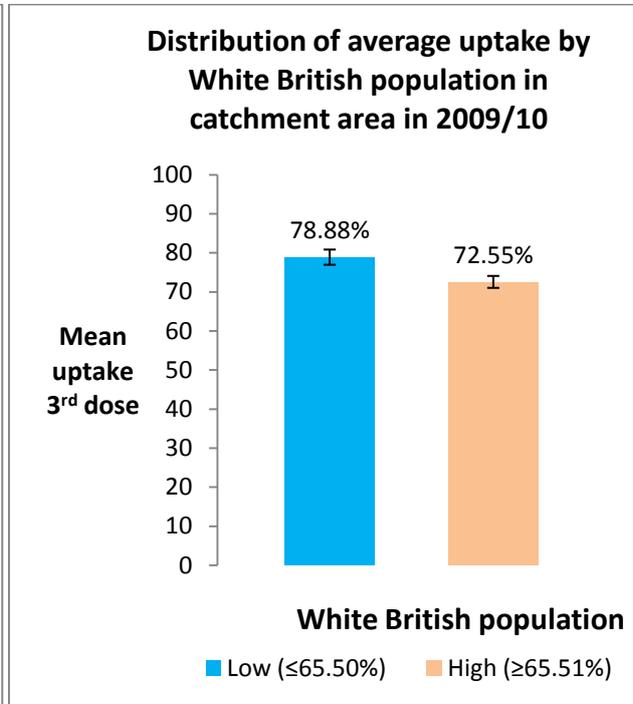
**Appendix 16. Figure 1.**

**Distribution of average uptake by ethnicity in SCA in 2008/09**



**Appendix 16. Figure 2.**

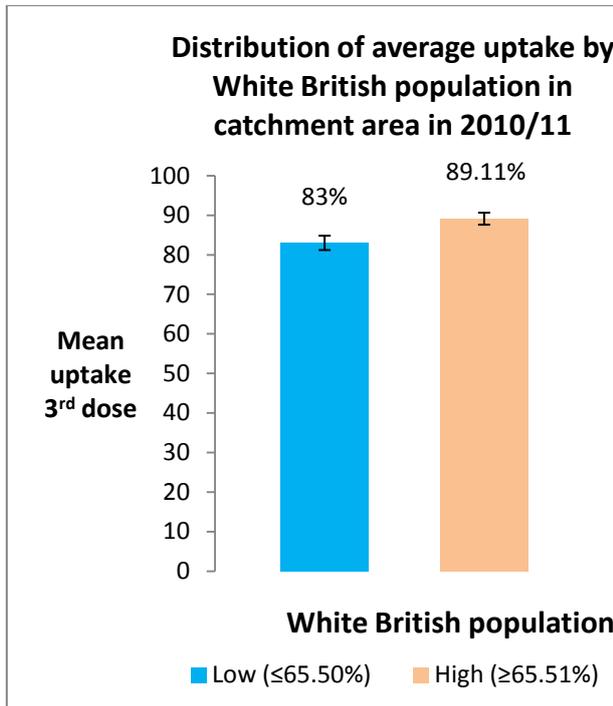
**Distribution of average uptake by ethnicity in SCA in 2009/10**



Mann-Whitney test ( $z = -0.88$ ,  $p$  value = 0.37)    Mann-Whitney test ( $z = 2.12$ ,  $p$  value = 0.03)

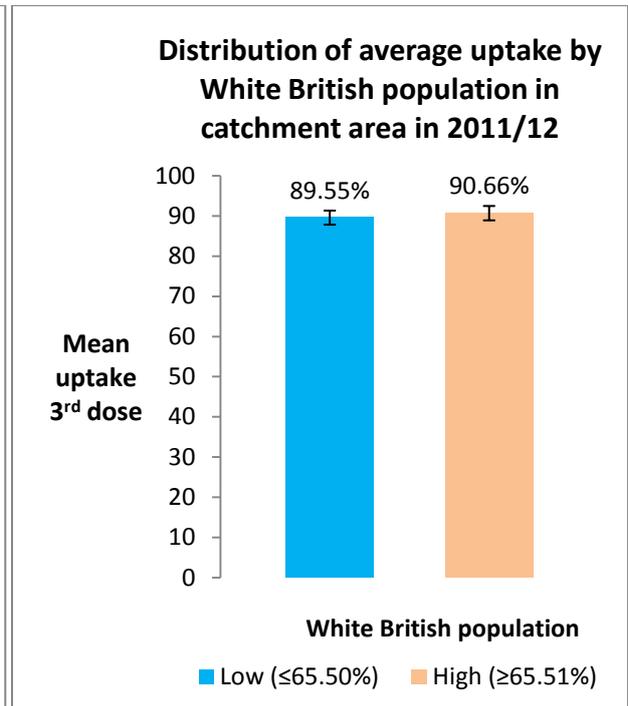
Appendix 16. Figure 3.

Distribution of average uptake by ethnicity in SCA in 2010/11



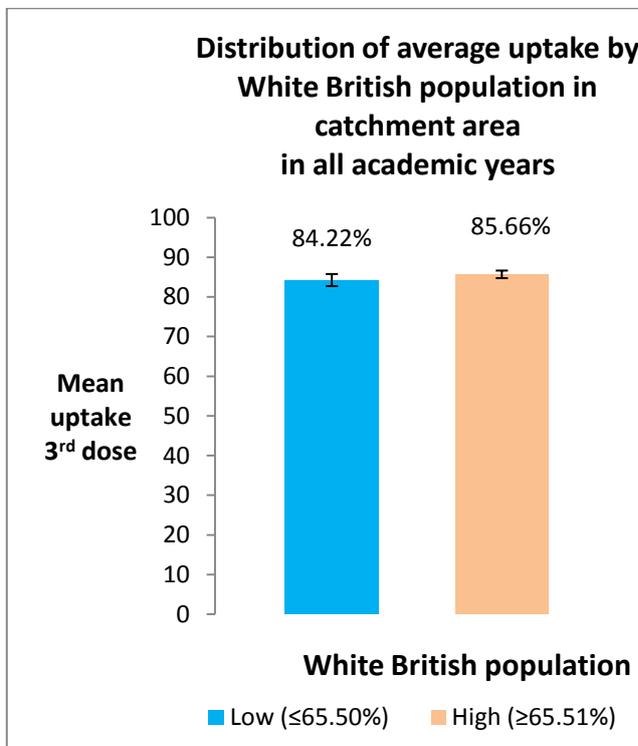
Appendix 16. Figure 4.

Distribution of average uptake by ethnicity in SCA in 2011/12



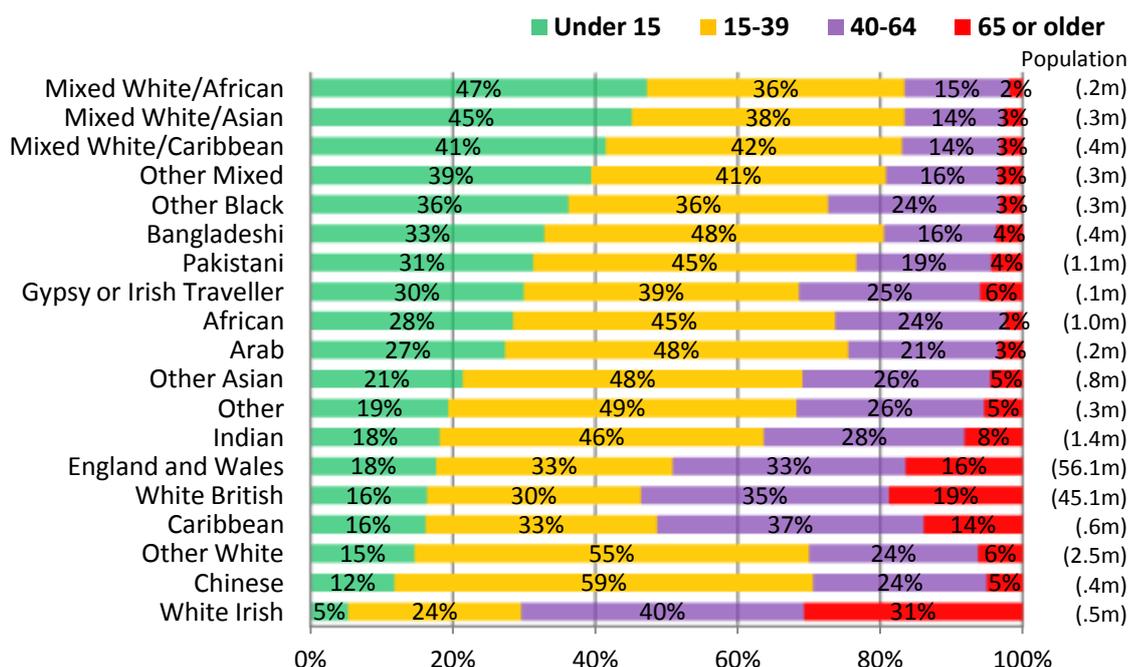
Mann-Whitney test ( $z = -2.21$ ,  $p$  value = 0.02)    Mann-Whitney test ( $z = -0.48$ ,  $p$  value = 0.62)

Appendix 16. Figure 5. Distribution of average uptake by ethnicity in SCA in all academic years



Mann-Whitney test ( $z = -0.67$ ,  $p$  value = 0.49)

**Appendix 17. Figure 1. Age composition of ethnic groups in the UK in 2011 Census**



Source: Centre on Dynamics of Ethnicity, 2013

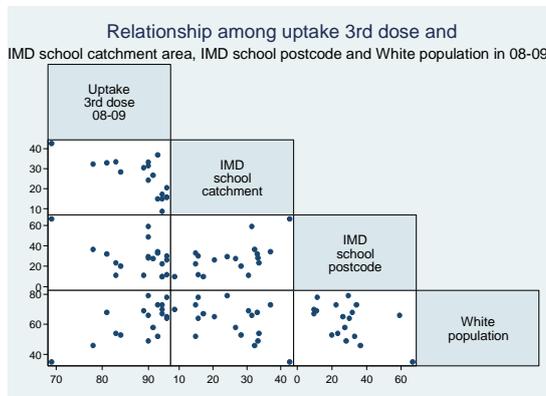
**Appendix 17. Table 1. Percentage of under 15s by ethnic group in 2011 Census**

| Ethnic group           | Number under 15s | Percentage under 15s |
|------------------------|------------------|----------------------|
| White Irish            | 25000            | 0.25                 |
| Gypsy                  | 30000            | 0.30                 |
| Chinese                | 48000            | 0.49                 |
| Arab                   | 54000            | 0.55                 |
| Other                  | 57000            | 0.58                 |
| Mixed White African    | 94000            | 0.96                 |
| Carribbean             | 96000            | 0.99                 |
| Other Black            | 108000           | 1.11                 |
| Other Mixed            | 117000           | 1.20                 |
| Bangladeshi            | 132000           | 1.36                 |
| Mixed White Asian      | 135000           | 1.39                 |
| Mixed White Carribbean | 164000           | 1.69                 |
| Other Asian            | 168000           | 1.73                 |
| Indian                 | 252000           | 2.60                 |
| African                | 280000           | 2.88                 |
| Pakistani              | 341000           | 3.51                 |
| Other White            | 375000           | 3.86                 |
| White British          | 7216000          | 74.45                |
| TOTAL                  | 9692000          | 100                  |

**Appendix 18. Assessment of correlations between dependent and independent continuous variables and between independent continuous variables**

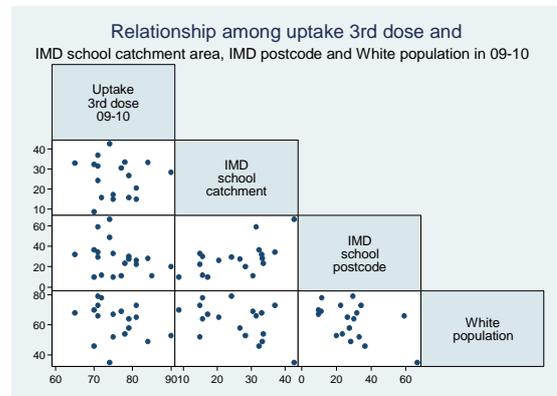
**Appendix 18. Figure 1.**

**Scatter plot matrix for 2008/09**



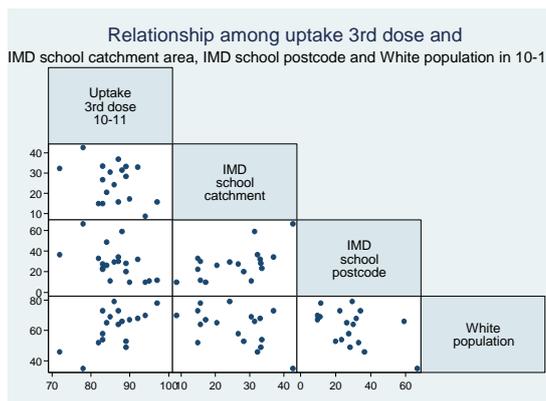
**Appendix 18. Figure 2.**

**Scatter plot matrix for 2009/10**



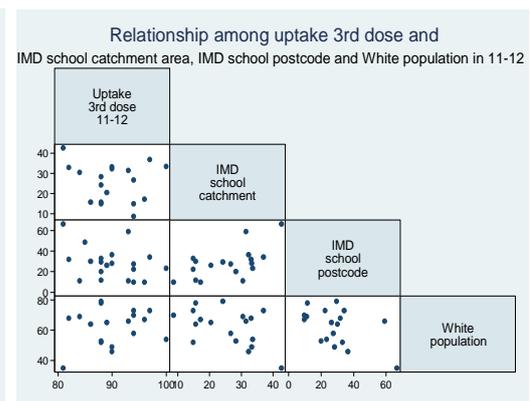
**Appendix 18. Figure 3.**

**Scatter plot matrix for 2010/11**

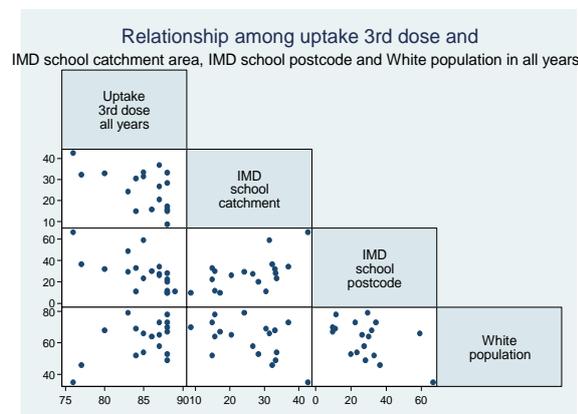


**Appendix 18. Figure 4.**

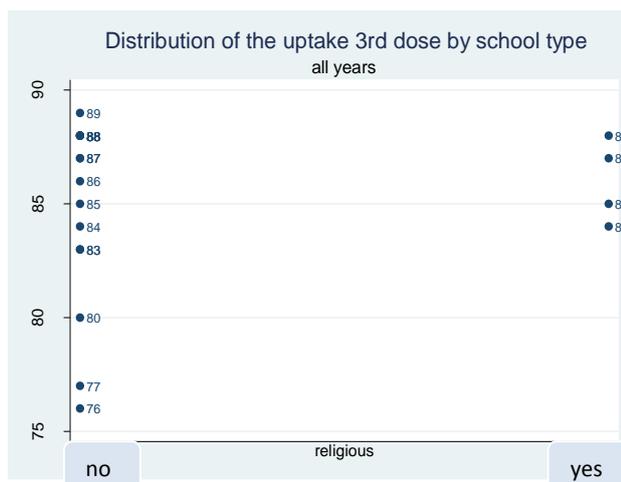
**Scatter plot matrix for 2011/12**



**Appendix 18. Figure 5. Scatter plot matrix for all years**



## Appendix 19. Dot plot for uptake of the third dose by school type



## Appendix 20. Multilevel regression analysis

Appendix 20. Table 1. Data required for multilevel regression analysis

| Girl vaccinated 3 <sup>rd</sup> dose | Girl not vaccinated 3 <sup>rd</sup> dose* | Year | Ethnicity* | Postcode individual*** | LSOA1 | IMD score1 | School | Postcode school | LSOA2 | IMD score2 |
|--------------------------------------|---|------|------------|------------------------|-------|------------|--------|-----------------|-------|------------|
| n = 5676                             | N = ?                                     |      |            |                        |       |            |        |                 |       |            |

\*currently data is not available

\*\* currently data is not available

\*\*\*currently 3 digits of postcodes are available

currently incorrect match individual postcode to LSOA1

LSOAs in the city of study = 194

### Multilevel regression analysis

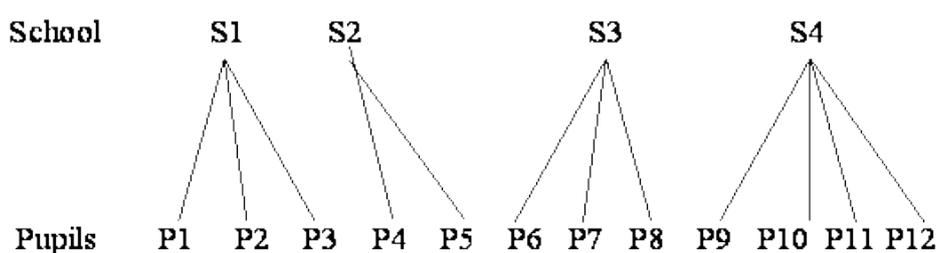
Multilevel analysis has different terms such as hierarchical modeling, random effects models, variance heterogeneity to name a few. It is used when data can be clustered or organized in a hierarchical structure. For example, individuals could be nested within geographical areas or institutions such as schools (University of Bristol, 2011a).

### Types of models

Ideally, data, which I received from the community Trust and I presented in the Table 1 above, could have been used to create different hierarchical structures such as two level

nested models, three level nested models and non-nested models proposed by the Centre for Multilevel Modelling in the University of Bristol which are shown in Figures 1-4 below. The simplest and commonest model used is two level nested models. Examples of two level nested models are pupils within schools as well as pupils within areas. I could have created these two types of models and for areas I could have used SCAs. More complex models such as a three level nested model would have the following structure: pupils within cohorts within schools (University of Bristol, 2011a) with repeated measures of outcome made on the schools over time (University of Bristol, 2011d). My data included four cohorts of pupils in each school from four academic years. Another possible three level nested model is pupils within schools within areas. The structure of a non-nested model is pupils nested within school and pupils nested within areas<sup>36</sup>. This model is appropriate when pupils who attend the same school come from different areas (University of Bristol, 2011a).

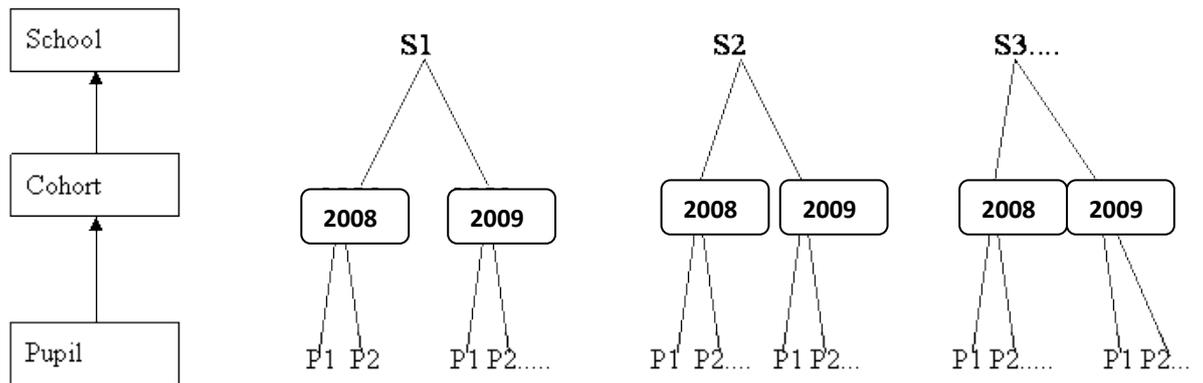
**Appendix 20. Figure 1. Two level nested model - pupils within schools**



Source: (University of Bristol, 2011a)

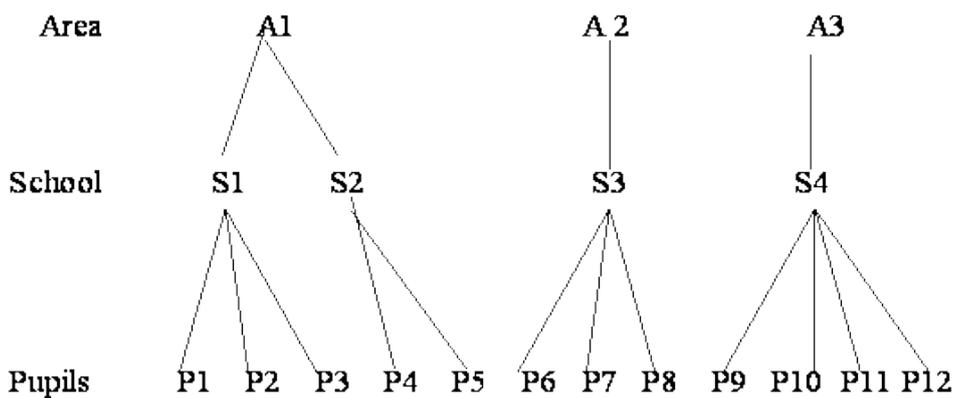
<sup>36</sup> The assumption is that the pupils live in different administrative areas which could be determined according to the postcode of their addresses (for example using the first 3 digits of the postcode)

**Appendix 20. Figure 2. Three level nested model - pupils within cohorts within schools**



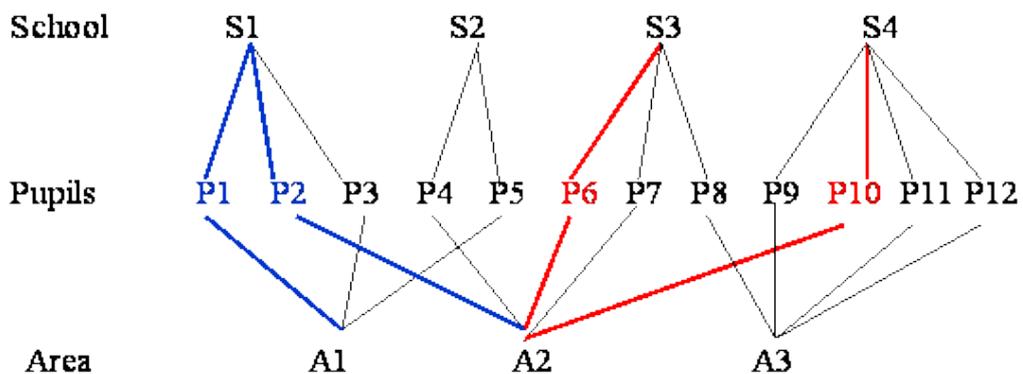
Source: (University of Bristol, 2011a)

**Appendix 20. Figure 3. Three level nested model - pupils within schools within areas**



Source: (University of Bristol, 2011a)

**Appendix 20 Figure 4. Three level non-nested model - pupils nested within school and pupils nested within areas**



Source: (University of Bristol, 2011a)

## **Assumptions**

The advantage of using multilevel analysis instead of multiple regression model is that it gives accurate estimate of standard errors of coefficients. For example, multiple regression model ignores the clustering and as a result standard errors of regression coefficients are underestimated, leading to an overstatement of statistical significance (University of Bristol, 2011a).

Three factors affect the estimates multilevel analysis: number of groups, number of level-one units, and the intra class correlation (Maas and Hox, 2005). The latter will be discussed later. In order to do multilevel analysis two assumptions have to be made. First, the units of data vary randomly according to a distribution (i.e., Normal, Poisson, etc.). Second, the units of data level can be regarded as a random sample from a wider population of units. For example, in the model with pupils within schools, the pupils are a random sample from a wider population of students. Similarly, the schools are a random sample from a wider population of schools (University of Bristol, 2011c).

## **Sample size**

In multilevel studies, an important aspect to be taken into account is usually the sample size at the group level, because the group-level sample size is always smaller than the individual-level sample size (Maas and Hox, 2005). There is some debate in the literature related to the number of units to be sampled. The Centre for Multilevel Modelling in the University of Bristol suggested that at least 20 higher-level units (i.e., schools) are required (University of Bristol, 2011c). Maas and Hox mentioned that in practice 50 groups are usually recommended in organizational and school research, and the smallest acceptable number is 30 (Maas and Hox, 2005). Another important issue is to have sufficient statistical power to find significance (Newsom, 2013). Statistical power in multilevel models depends on effect size and intra class correlations. It is

different for fixed effect model and random effect model, and it changes according to the number of groups and the number of individuals per group (Leeuw and Kreft, 1998). A group size of 30 is normal in educational research, and a group size of 5 is normal in family research and in longitudinal research (Maas and Hox, 2005). Fixed effects, in general, require fewer cases to have sufficient power. 50 groups with 5 cases per group are needed for sufficient power to test fixed effects. Random effects generally require more cases than to test fixed effects. 100 to 200 groups with approximately 10 cases per group are needed for sufficient power to test random effects. Significance tests of intercept variances require fewer cases than variance tests of random slopes (Newsom, 2013). If the number of cases in different groups is unequal, the multilevel estimates or their standard errors are not affected (Maas and Hox, 2005).

### **Variance**

Multilevel regression analysis uses measures of outcome variation to understand contextual determinants of individual health outcome such as social, cultural and economic factors. For example, if the health of the people within a neighbourhood is similar, in comparison to the health of people from other neighbourhoods, it is more likely that the determinants of individual health are directly related to the contextual environment of the neighbourhood and geographical segregation (Merlo et al., 2005b). Contextual phenomenon corresponds to the statistical concept of clustering (Merlo et al., 2005a). Using measures of clustering of individual outcome within neighbourhoods is important to evaluate the relative significance of the neighbourhood effect on outcomes, and consequently to promote interventions at neighbourhood level. This is important to determine the efficacy of intervention on places. When the clustering of individual outcome within neighbourhoods is small, focusing intervention on places is an inefficient strategy (Merlo et al., 2005b).

It has been argued that single level individual analyses as well as ecological studies are not suitable for investigating contextual effects. A single level individual analysis does not consider that there is variability within groups (i.e., neighbourhoods) (Merlo et al., 2005a). In the ecological analysis the units of analysis are groups of people rather than individuals. The results are difficult to interpret because it is not possible to examine directly the explanations for findings (Bonita et al., 2006). For example, the mean of health outcome for each group (i.e., neighbourhood) is estimated from the sample of people in each neighbourhood. These estimated means are used to calculate the ecological variance which corresponds to the between neighbourhood variance of health outcome in multilevel analysis. But, the ecological variance overstates the neighbourhood variance because it also includes variation attributable to sampling error in the estimates of each neighbourhood mean (Merlo et al., 2005a).

In multilevel analysis, cluster effects can be assessed by quantifying and modelling variance (Merlo et al., 2005b). The variations in outcome between groups are assumed to be the same for every individual, whatever their individual characteristics (Merlo et al., 2005c).

In a multilevel model, the individual and the cluster variance components represent the total variance in outcome (Merlo et al., 2005a; Day and Rasbash, 2006). For example, in a two level model with pupils nested within schools, it could be determined how much of the total variation of individual outcome is attributable to school level factors and how much of the total variation of individual outcome is attributable to pupil level factors (Day and Rasbash, 2006).

The multilevel model assumes Normality for the distribution of means of outcome at cluster level and the distribution of the individual values around each mean of outcome at cluster level (Day and Rasbash, 2006). It also assumes that there is independence between the individual and cluster residuals (Merlo et al., 2005b).

### **Multilevel regression model 1 - Intra class correlation**

Intra class correlation (ICC) is a measure of clustering that is correlation between units within a group (i.e., school). Grouped data violate the assumption of independence of all observations. The amount of dependence can be expressed as the ICC (Maas and Hox, 2005). Correlation suggests that the ICC expresses the similarity in outcome between two individuals in the same group (Merlo et al., 2005a). The ICC is quantified in the “empty” model which does not include any explanatory variables. This model does not explain any variance in outcome. It only decomposes the variance of outcome into two independent components (Maas and Hox, 2005).

When data is clustered there are residual components at each level in the hierarchy. A two-level model with children grouped within schools would include residuals at the child and school level. Thus, the residual variance is partitioned into a between-school component (the variance of the school-level residuals) and a within-school component (the variance of the child-level residuals). The school residuals are called “school effects” and represent unobserved school characteristics that affect child outcomes. It is these unobserved variables which lead to correlation between outcomes for children from the same school (University of Bristol, 2011a). This two level model is called variance components model because there is a single residual term for each level, for example student (level 1) residuals and school (level 2) residuals. This model is also called a random intercept model because only the intercept term in the regression equation is assumed to vary randomly across schools (University of Bristol, 2011d). For a two-level model the ICC represents the proportion of variance at the higher level (cluster) (University of Bristol, 2011b) .

To know if the ICC is statistically different from 0 a statistical test of the cluster variance could be used. When the cluster level variance is not significant, there is no justification for computing the ICC (Merlo et al., 2006). If the ICC is close to 0 suggests

that the context defined by the clusters is not important in understanding the differences in outcome at individual level (Merlo et al., 2005b).

### **Multilevel regression model 2 with individual variables**

This is an extension of the empty model which includes individual variables. No cluster variable is investigated (Merlo et al., 2005b). This multilevel model assumes that the explanatory variables are fixed which means that they have a standard normal distribution (Maas and Hox, 2005). From data presented in Table 1 above, I could have included in this model ethnicity as an individual variable.

As in simple regression analysis, the regression coefficients of the individual variables in multilevel regression analysis describe the association between the individual level variables and outcome. The presence of cluster and individual residuals in the model reflects that outcome varies at both levels. The variance is a summary of the differences, and including individual variables in the statistical models allows us to obtain values of variances that are adjusted for those individual variables. The adjusted total outcome variance between people in the city can be partitioned into a variance between clusters and a variance between people within clusters. The cluster variance in this model is the same for all the individuals, whatever their individual characteristics (variables). Cluster differences in mean outcome may be attributable to contextual influences or to differences in the individual composition of cluster in terms of individual variables. By adjusting for individual variables in this model, some part of the compositional differences is taken into account and some of the cluster variance detected in the empty model is explained (Merlo et al., 2005c).

### **Multilevel regression model 3 with individual and cluster variables**

In this model, which is an extension of model 2, individual and cluster variables are investigated at the same time (Merlo et al., 2005b). Two functions are used in multilevel estimation: fixed effects and random effects (Maas and Hox, 2005). Fixed effects are used to model averages (means or regression coefficients) whereas random effects are used to model variance (Merlo et al., 2006). In a fixed effects model, it is not possible to separate out the effects of group variables and the effects of the group dummies, due to observed and unobserved group characteristics. However, this is possible in a random effects model (University of Bristol, 2011a).

### **Multilevel regression model with individual variables and random slopes**

The random slope model allows the explanatory variable to have a different effect for each group. The assumption is that the effect of an individual variable on outcome may vary depending on the cluster context. In other words, for some groups, the explanatory variable has a large effect on the outcome; for others it has a small effect (Merlo et al., 2005c). The random slope analysis examines whether the cluster context as a whole modifies the association between individual variables without specifying any cluster variables (Merlo et al., 2005b).

Multilevel regression analysis could be done using MLwiN software developed by Goldstein's research group (<http://www.mlwin.com>).

## Appendix 21. Documents for ethical approval

### Ethical approval from NRES

**Enclosures:** List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

**Copy to:**

Dr Peter Hedges  
Director of Research Report Services  
University of Warwick  
University House  
Coventry  
CV4 8UW

Mrs Louise Jones  
University Hospitals Coventry & Warwickshire NHS Trust  
Comprehensive Local Research Network  
Executive Suite  
Third Floor Rotunda  
University Hospital  
Coventry  
CV2 2DX

The Committee asked if to have the vaccine parental consent was required. Professor Clarke confirmed that it was.

The Committee mentioned that they felt that conducting focus groups could be a very good method of obtaining information. Professor Clarke agreed but explained that there was concern about disclosure from a focus group of teenagers. In previous research it has been found that things have emerged from focus groups that would otherwise not be known.

The Committee understood that there had been a lot of negativity about vaccines in past years. Professor Clarke explained that they know the national uptake rates but are looking locally in this study.

The Committee thanked you both for attending.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Ethical review of research sites**

##### **NHS Sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

**Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.**

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

##### **Approved documents**

The documents reviewed and approved at the meeting were:

| <i>Document</i>  | <i>Version</i> | <i>Date</i>       |
|--|----------------|-------------------|
| Covering Letter and Response to previous unfavourable opinion from Corina Chivu                |                | 06 September 2012 |
| REC Unfavourable Opinion Letter  |                | 31 July 2012      |
| REC application: 114993/360553/1/566   |                | 07 September 2012 |
| Protocol   | 2              | 26 September 2012 |
| Summary/Synopsis   | 2              | 26 September 2012 |
| Investigator CV: Dr Corina Chivu   |                | 05 September 2012 |
| Investigator CV: Professor Gillian Hundt   |                | 29 May 2012       |
| Investigator CV: Aileen Clarke   |                | 26 September 2012 |
| Letter of invitation to participant: Invitation to Head Teachers                               | 2              | 26 September 2012 |
| Letter of invitation to participant: Invitation to   | 2              | 26 September 2012 |
| Participant Information Sheet: Student Information Sheet                                       | 2              | 26 September 2012 |
| Participant Information Sheet: Parent/Guardian Information Sheet                               | 2              | 26 September 2012 |
| Participant Information Sheet: PSHE Teacher Information Sheet                                  | 2              | 26 September 2012 |
| Participant Information Sheet: Nurse Information Sheet   | 2              | 26 September 2012 |
| Participant Information Sheet: Head Teacher Information Sheet                                  | 2              | 26 September 2012 |
| Participant Information Sheet: Health Professional Information Sheet                           | 2              | 26 September 2012 |
| Participant Consent Form: OPT OUT Form   | 2              | 26 September 2012 |
| Participant Consent Form: Student Consent Form   | 2              | 26 August 2012    |
| Participant Consent Form: Teacher Consent Form   | 2              | 26 September 2012 |
| Participant Consent Form: Head Teacher Consent Form  | 2              | 26 September 2012 |
| Participant Consent Form: Nurse Consent Form   | 2              | 26 September 2012 |
| Participant Consent Form: Health Professional  | 2              | 26 September 2012 |
| Other: Research Plan in support to Q A13 in NHS REC form                                       | 2              | 26 September 2012 |
| Other: Letter to Support the question A 27-5 in NHS REC Form                                   | 2              | 26 September 2012 |
| Interview Schedules/Topic Guides: Individual Interview Topic Guide for Girls                   | 2              | 26 September 2012 |
| Interview Schedules/Topic Guides: Individual Interview Topic Guide for PSHE Teachers           | 2              | 26 September 2012 |
| Interview Schedules/Topic Guides: Individual Interview Topic Guide for Health Professionals in |                | 26 September 2012 |
| Interview Schedules/Topic Guides: Individual Interview Topic Guide for School Nurses           | 2              | 26 September 2012 |

A Research Ethics Committee established by the Health Research Authority

|  |  |                   |
|--|--|-------------------|
| Evidence of insurance or indemnity: MARSH signed John Farrington |  | 02 August 2012    |
| Referees or other scientific critique report: Upgrading Report   |  | 15 May 2012       |
| Letter from Statistician from Dr Kandala Ngianga-Bawkin          |  | 03 September 2012 |

#### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

##### Feedback

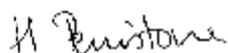
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

|                   |   |
|-------------------|---|
| <b>12/WM/0316</b> | <b>Please quote this number on all correspondence</b> |
|-------------------|---|

With the Committee's best wishes for the success of this project

Yours sincerely



**On behalf of  
Dr Jeff Neilson  
Chair**

**Email:** nrescommittee.westmidlands-blackcountry@nhs.net

A Research Ethics Committee established by the Health Research Authority

NRES Committee West Midlands - The Black Country

Attendance at Committee meeting on 01 October 2012

Committee Members:

| <i>Name</i>             | <i>Profession</i>  | <i>Present</i> | <i>Notes</i> |
|-------------------------|--|----------------|--------------|
| Dr Joseph Arumainayagam | Consultant and Honorary Senior Clinical Lecturer in HIV and GUM                          | No             |              |
| Mrs Chris Bell          | Lay Member   | Yes            |              |
| Dr Nicola Erb           | Consultant Rheumatologist  | No             |              |
| Dr Jeff Neilson         | Consultant Haematologist   | Yes            |              |
| Dr Hilary Paniagua      | Chair of the research ethics committee, School of Health and Wellbeing, Wolverhampton Un | No             |              |
| Mr Nanak Singh Sarhadi  | Consultant Plastic Surgeon   | Yes            |              |
| Dr Julian Sonksen       | Consultant in Anaesthesia and Critical Care  | No             |              |
| Reverend Mark Stobert   | Hospital Chaplin   | Yes            |              |
| Dr David Vallance       | Clinical Biochemist  | Yes            |              |
| Mrs Jennifer Walton     | Retired Research Nurse   | Yes            |              |
| Mrs Veronica A Wells    | Lay Member   | Yes            |              |
| Dr Tony Zalin           | Expert Member  | No             |              |

Also in attendance:

| <i>Name</i>          | <i>Position (or reason for attending)</i> |
|----------------------|---|
| Ms Jo Foxall Dant    | Assistant Co-ordinator                    |
| Miss Helen Penistone | Co-ordinator                              |

## Ethical approval from the NHS Trust in the city of study



01 November 2012

Dr Corina Mihaela Chivu  
Warwick Medical School  
Division of Health Sciences  
University of Warwick  
Coventry  
CV4 7AL

Dear Professor Aileen Clarke

**Project Title:** Factors affecting variation in the uptake of HPV vaccine in secondary schools in the West Midlands

**R&D Ref:**

**REC Ref:** 12/WM/0316

I am pleased to inform you that the R&D review of the above project is complete and NHS permission has been granted for the study at [redacted] Trust. The details of your study have now been entered onto the Trust's database.

The permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

| Document  | Version | Date     |
|---|---------|----------|
| REC Favourable Opinion Letter   |         | 11/10/12 |
| Protocol  | 2       | 26/09/12 |
| Summary / Synopsis  | 2       | 26/09/12 |
| Letter of Invitation - Invitation to  | 2       | 26/09/12 |
| Participant Information Sheet: Health Professional Information Sheet                        | 2       | 26/09/12 |
| Participant Consent Form: Health Professional   | 2       | 26/09/12 |
| Interview Schedules/Topic Guides: Individual Interview Topic Guide for Health Professionals |         | 26/09/12 |

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), to ICH-GCP standards (if applicable) and to NHS Trust policies and procedures. Permission is only granted for the activities agreed by the relevant authorities.

All amendments (including changes to the local research team and status of the project) need to be submitted to the REC and the R&D office in accordance with the guidance in IRAS. Any urgent safety measures required to protect research

participants against immediate harm can be implemented immediately. You should notify the R&D Office within the same time frame as any other regulatory bodies.

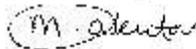
It is your responsibility to keep the R&D Office and Sponsor informed of all Serious Adverse Events. All SAEs must be reported within the timeframes detailed within ICH-GCP statutory instruments and EU directives.

In order to ensure that research is carried out to the highest governance standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors.

You will be sent an annual progress report which must be completed in order to ensure that the information we hold on our database remains up to date, in line with RGF requirements.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely



**Mariam Akhtar**  
**R&D Facilitator**

**Enc:** CI agreement

**Cc:** Mr Peter Hedges, Sponsor Representative, Professor Aileen Clarke, Prof Gillian Hundt

## Topic guide for interview with girls

Version 2  
26<sup>th</sup> of September 2012



**Study Title:** Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands

**Researcher:** Corina Chivu, University of Warwick

### INDIVIDUAL INTERVIEW TOPIC GUIDE FOR GIRLS

**Interview number:**  
**Date:** March – October 2013 .....  
**Site number:**

1. How did you learn about the HPV vaccine? - Did you discuss about HPV vaccine with other people? (mum, siblings, friends)
2. What do you think about HPV vaccine?
3. Did you worry about the HPV vaccine?
4. Who influenced you to receive HPV vaccination?
5. How did you make the decision for the HPV vaccine?
6. Do you think there is any point to have the HPV vaccine?
7. Are there any reasons why people may not wish to have the HPV vaccine?
8. Do you think that parents have views about the HPV vaccine?
9. Do you think that religion or culture may affect people's views of the HPV vaccine?
10. Do you think that having the HPV vaccine will affect the way young people may behave in their relationships?
11. What additional information you would like to have on the HPV vaccine?
12. What is your feeling after being vaccinated?

## Topic guide for interview with nurses

Version 2  
26<sup>th</sup> of September 2012



**Study Title:** Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands

**Researcher:** Corina Chivu, University of Warwick

### INDIVIDUAL INTERVIEW TOPIC GUIDE FOR SCHOOL NURSES

**Interview number:**

**Date:** ...November 2012

**Site number:**

1. What is your job? Is the HPV vaccination your only nursing work?
2. What are your tasks in the HPV vaccination program?
3. How is consent for the HPV vaccination obtained?
4. What is your opinion of the attitude of the schools towards the HPV vaccination?
5. What kinds of barriers do you think there are to taking up the HPV vaccination?  
(i.e., ethnicity, religion, information)
6. How do you feel that these barriers could be overcome?
7. Why do you think that the parents do not consent to the HPV vaccine?
8. Why do you think that the girls do not consent to the HPV vaccine?

## Topic guide for interview with teachers

Version 2  
26<sup>th</sup> of September 2012



Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands

Researcher: Corina Chivu, University of Warwick

### INDIVIDUAL INTERVIEW TOPIC GUIDE FOR TEACHERS

Interview number:

Date: January - June 2013....

Site number:

1. Do you talk to the girls about the HPV vaccination?
2. What do you tell them? (cancer jab, STI vaccine)
3. What kind of materials do you use to prepare this talk?
4. Are there any problems you have faced in attempting to talk about the HPV vaccination to girls?
5. Who else in the school talks to the girls about the HPV vaccination?
6. What facilitates the take up of the HPV vaccine in your view?
7. Are there any barriers to take up of the HPV vaccine? (school, parents, peer pressure)
8. How do you manage parental concerns (if any)?
9. What is the school policy concerning the HPV vaccination?
10. How do you organize the vaccination sessions? (who is involved in the school?)
11. Is it a big effort for the school?
12. Do you think ethnicity has a role in the delivery of the HPV vaccine?
13. Do you think religion has a role in uptake of the HPV vaccine?

## Invitation letter to Head teacher

Warwick Medical School



### INVITATION TO HEAD TEACHERS

Warwick Medical School  
University of Warwick  
Coventry  
CV4 7AL

6/12/2012

Dear Head teacher,

#### Invitation to participate

I would like to invite your school to participate in this research study. I am a female research student and public health specialist with a medical degree and the research is being undertaken for my PhD in Public Health at the University of Warwick about facilitators and barriers to HPV vaccine uptake in secondary schools in the West Midlands.

#### Overview and background

Several European countries have integrated routine and catch-up human papillomavirus (HPV) vaccination in national immunization programmes, aiming at reaching 70% of the target population as recommended by the World Health Organization. European studies conducted between 2007 till the present day show inconsistent results on HPV vaccine uptake in relation to barriers and facilitators.

The purpose of this study is to extend understanding about variation in the uptake of the HPV vaccine among girls from different ethnic and socio-economic backgrounds in Coventry.

#### What is required?

Ethics approval has been obtained from NHS Research Ethics Committee Black Country and all researchers have full Criminal Records Bureau (CRB) clearance for the study.

The research design is that I will be selecting 4 schools in [name city] with varying rates of uptake. In each school I would like to observe one or two PSHE classes in early January 2013. Also, I would like to organize 1 individual interview with one PHSE teacher in January 2013 and another 10 individual interviews with girls aged 12-13 years (in Year 8) between January and March 2013. Each interview will last about 30 – 45 minutes. I will be the interviewer. I will ask interviewees about their views concerning the HPV vaccine.

It is proposed that interviews are organized at a time most convenient for PSHE teachers and girls (i.e., over a lunch time) in order not to affect their work during the school day. The interviews will be tape recorded and transcribed. I have enclosed participant information sheets and consent forms for head teachers, teachers, and girls as well as information sheets and opt out forms for parents/guardians. The information sheets for parents/guardians would need to be sent out by the school if you decided that you would be willing for the school to participate in this study. We will provide you with stamped addressed envelopes.

**Feedback of the results**

The results of the research study will be kept completely anonymized and confidential and no individual feedback on participants will be given to the school or parents or included in publications. The school will not be identified. Clearly if I am told anything in interviews that seemed to indicate that a child was 'at risk' of harm, I would inform you and my supervisors. I will be putting the anonymized results in my thesis, publishing them and presenting them at academic conferences and I will be very happy to send you a summary of the results once the work is finished.

Would it be possible to arrange to come into your school in December 2012 to discuss the study in more detail? If you would like to contact me please ring me (Dr Corina Chivu) on 07517451418 or email me at [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk).

If you would like to speak with my supervisors (Professor Aileen Clarke and Professor Gillian Hundt) you should contact Mrs Hannah Fraser on 02476150063 in the first instance.

I look forward to working with you. Please do not hesitate to contact me if you would like any further information.

With best wishes,

Yours sincerely,

Dr Corina Chivu

PhD candidate in Public Health  
Warwick Medical School  
University of Warwick

## Head teacher information sheet

Version 2  
26<sup>th</sup> of September 2012



### Head teacher information sheet

**Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands**

#### Why are we doing this study?

The purpose of the study is to understand variation in uptake of HPV vaccine and to find out about facilitators and barriers that affect HPV vaccine uptake amongst teenage girls in secondary schools in the West Midlands. This vaccine is given to the girls of 12 up to 18 years old to protect them against cervical cancer later in their life.

#### What does the study involve?

The study involves face to face individual interviews with teachers/pastoral leaders to explore their views about the delivery of the HPV vaccine in school settings and the possible factors which influence girls' access to HPV vaccination. In addition, the study involves face to face individual interviews with approximately 10 girls aged 12 in Year 8 to explore their views and opinions relating to HPV vaccination. Each interview will be tape recorded and will last 30 - 45 minutes.

I will provide full information sheets for pupils and teachers/pastoral leaders to read 2 weeks beforehand and, with your approval, I will arrange for a letter to be sent from the school to all parents or guardians of the pupils involved. The letter will include information about the study and include an opt-out form for parents or guardians who do not want their child/children to participate. Information sheets for parents or guardians include a note that if they do not fill in opt out form and do not return it to the school then their child will be automatically included in the study if their child gives the consent to participate.

Consent to participate will be obtained from teachers/pastoral leaders and pupils on the day of interview.

**Does my school have to take part?**

Taking part in the research is entirely voluntary.

**What happens if I do not want my school to take part?**

There is no pressure to take part. If you do not wish the school to take part, you should just indicate that to me directly.

**Who is paying for this study?**

There is no funding for the study. The University of Warwick is the sponsoring organization of this research and I am supervised by two supervisors – Professor Aileen Clarke and Professor Gillian Hundt at the University of Warwick.

**Does the research have ethical approval?**

The research study has been approved by NHS Research Ethics Committee Black Country and the researcher has full CRB clearance for the study.

**Will we pay you or the pupils for taking part?**

The Ethics Committee does not allow us to offer the participants incentives to take part. But, with your permission I would like to recognize the time that teachers/pastoral leaders and pupils have devoted to the study by giving some chocolates or biscuits to all participants in interviews.

**What will happen to the results of the study?**

The anonymised results of the research study will be used to write my PhD thesis in Public Health at the University of Warwick. In addition, we will write articles in scientific journals and will present the anonymised results at conferences. At the conclusion of the study we will provide you with a summary of the results.

**Could taking part in this study do my pupils any harm?**

Talking about HPV vaccination can be a positive experience but it could also lead to feelings of distress. If your pupils are distressed, they could contact me, their teacher, the school counsellor or nurse if available, or if they prefer they could

- call free ChildLine on 0800 1111 at any time or
- contact Get Connected ([www.getconnected.org.uk](http://www.getconnected.org.uk)) by phone 0808 808 4994 between 1pm and 11pm everyday, by webchat between 1pm and 11pm everyday, by email at any time or by WebHelp 24/7 service

**Can my pupils change their mind after they agree taking part?**

Pupils can change their mind about taking part in the study at any time. They can ring me – Corina Chivu on 07517451418 or email me at [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk) or let the school know.

**Limits to confidentiality**

The confidentiality of information obtained during individual interviews with girls may need to be breached if there is a risk of "serious harm" to the child or someone else.

**Where can I get more information from?**

I will be glad to answer any questions you have about this study at any time. You may contact me by email: [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk) or by phone on 07517451418.

13/03/2013

**Thank you for taking the time to read this information**

## Head teacher consent form

Version 2  
26<sup>th</sup> of September 2012



### HEAD TEACHER CONSENT FORM

**Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands**

1. I confirm that I have read and understood the information sheet dated 13/03/2013 for the above study which I may keep for my records and have had the opportunity to ask any questions I may have.
  
2. I agree that my school can take part in the above study and I am willing to:
  - facilitate the researcher to conduct individual interviews with teachers/pastoral leaders
  - facilitate the researcher to conduct individual interviews with girls aged 12 years old
  
3. I understand that the information from this study will be kept completely anonymous at all times and will be held and processed for the following educational purposes:
  - for a PhD thesis at the University of Warwick
  - articles in scientific journals
  - presentations at conferences
  
4. I understand that the participation of my school is voluntary and that we are free to withdraw at any time without giving any reason and without being penalised or disadvantaged in any way.
  
5. I understand that the names of participating students, teachers, and nurses will be kept STRICTLY CONFIDENTIAL and nobody other than the research team will know what is discussed during individual anonymised interviews. Any future publication from this study will NOT reveal the identities of the participants or the school.

6. I understand that there are limits to confidentiality of information obtained during individual interviews with girls and that this may need to be breached if there is a risk of "serious harm" to the child or someone else.

\_\_\_\_\_  
Name of Head Teacher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking  
consent if different  
from Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Corina Chivu  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Teacher information sheet

Version 2  
26<sup>th</sup> of September 2012



**Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands**

### Teacher information sheet

My name is Corina Chivu. I am a female PhD student at the University of Warwick. I am conducting a research study supervised by two Professors at the University of Warwick.

#### Invitation

You are being asked to take part in this study. I am contacting you based on head teacher's recommendation [name]. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully. Ask me if there is anything that is not clear. My email is: [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk).

#### What is the purpose of the study?

This is part of my doctoral research. The purpose of the study is to understand the factors affecting variation in uptake of HPV vaccine and to find out about facilitators and barriers that influence HPV vaccine uptake amongst teenage girls in secondary schools in the West Midlands. This vaccine is given to the girls of 12 up to 18 years old to protect them against cervical cancer later in their life.

#### Who is paying for this study?

There is no funding for the study. The University of Warwick is the sponsoring organization of this research.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Your participation is on a voluntary basis. You could refuse to participate or you could withdraw at any time during the

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26<sup>th</sup> of September 2012

study without any negative consequences.

If you withdraw during the study, any information you have already provided will not be used and you will not be contacted again about this study. However, if you are happy for the information you have already provided to be used, but do not want to continue to take part, then the information already provided will be used, but you will not be contacted again.

#### What will happen to me if I take part?

I would like to invite you to participate in a face to face individual interview to express your view about the possible factors which influence girls' access to HPV vaccination. The interview will take place in the school and will last 30 - 45 minutes. There are no known benefits or risks for you in this study.

#### Will what I say in this study be kept confidential?

Yes. Information that is discussed between you and me will not be disclosed. Your privacy and your information will be protected at all times.

You are being asked to give me permission to audio record the individual interview. I need to do this so that I know what people actually say. All recordings will be destroyed after use. Anything you say will be completely anonymised in the results so that no-one will be able to identify you. All identifiable information (i.e., name, school) will be removed from the interview transcript or quotations. Research information will be analyzed and reported anonymously so that no person could be identified from these documents. The data will be stored in the University of Warwick and accessed by me and my supervisors in accordance with the Data Protection Act 1998.

#### What will happen to the results of the research study?

The anonymised results of the research study will be used to write my PhD thesis in Public Health at the University of Warwick. In addition, me and my supervisors will write articles in scientific journals and will present the anonymised results at conferences. At the conclusion of the study we will provide you with copies of any reports or other publications arising from your participation. As I have given you assurances about anonymity it will not be possible to send individuals feedback on an individual basis.

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#### Contact for Further Information

I will be glad to answer your questions about this study at any time. You may contact me by email: [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk) or by phone on 07517451418. The research study has been approved by NHS Research Ethics Committee Black Country.

#### Who should I contact if I wish to make a complaint?

Should you have any complaints relating to this study, you should be advised to contact my supervisors:

Professor Aileen Clarke

Division of Health Sciences, Warwick Medical School, University of Warwick, Coventry, CV4 7AL

Email [Aileen.Clarke@warwick.ac.uk](mailto:Aileen.Clarke@warwick.ac.uk)

Telephone 024761 50063

Professor Gillian Hundt

School of Health and Social Studies, University of Warwick, Coventry, CV4 7AL

Email [Gillian.Hundt@warwick.ac.uk](mailto:Gillian.Hundt@warwick.ac.uk)

Telephone 02476 573814

Date 13/03/2013

**Thank you for taking the time to read this information**

# Teacher consent form

Version 2  
26<sup>th</sup> of September 2012



## TEACHER CONSENT FORM

**Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands**

1. I confirm that I have read and understood the information sheet dated 22/04/2013 for the above study which I may keep for my records and have had the opportunity to ask any questions I may have.
2. I agree to take part in the above study
3. I agree to participate in an individual interview
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without being penalised or disadvantaged in any way.
5. I understand that relevant sections of data collected during the study, may be looked at by individuals from the research team, at the University of Warwick. I give permission for the team to have access to my records.
6. I agree to have my interview audio taped
7. I agree to the use of direct quotations in publications provided that anonymity is preserved
8. I understand that my anonymised information will be held and used for the following educational purposes:
  - for a PhD thesis at the University of Warwick
  - articles in scientific journals
  - presentations at conferences

Version 2  
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|   |               |                    |
|---|---------------|--------------------|
| _____<br>Name of Participant  | _____<br>Date | _____<br>Signature |
| _____<br>Name of person taking<br>consent if different<br>from Researcher | _____<br>Date | _____<br>Signature |
| Corina Chivu<br>_____<br>Researcher                                       | _____<br>Date | _____<br>Signature |

## Parent information sheet and consent (opt out) form

Version 2  
26<sup>th</sup> of September 2012



**Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands**

### Parent/Guardian information sheet

#### Dear Parent/Guardian

My name is Corina Chivu. I am a female postgraduate student in the University of Warwick.

#### Invitation

I am inviting girls aged 12 years old from your child's school to take part in a research study I am doing at the University of Warwick. This information sheet tells you more about the study. All data will be anonymous and private.

Please read the following information carefully and ask me if there is anything that is not clear. My email is: [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk) and my phone number is: 07517451418.

#### Why am I doing this study?

I am doing this study to find out why some girls decide to take up the HPV vaccine and others decide not to take it. This vaccine is given to the girls of 12 up to 18 years old to protect them against cancer in the lower part of the womb later in their life and is generally administered at school.

#### Who is paying for this study?

There is no funding for the study. The University of Warwick is the sponsoring organization of this study.

#### Why has my child been chosen to take part?

This study is being conducted in some secondary schools in Warwickshire and your child's school has agreed to take part. I am inviting your child to take part in this research so that I can understand more about girls' views about the HPV vaccination.

**What does the study involve?**

I will come to school in the next 2 weeks. Your child has already been given information about the study and if they are happy to take part, I will ask them to sign a consent form.

Then your daughter may be invited to have an individual interview with me. I will also answer any questions about the research that she might have.

I will not ask your child to share personal stories or anything that she would not be comfortable talking about.

The interview will take place in school. The tape will be kept locked in a secure cabinet in the University of Warwick. The information recorded is private, and no one else except me and my supervisors will be allowed to listen to the tapes. The tapes will be destroyed after I have used them.

**Will what your child say in this study be kept private?**

We will not be sharing information about your daughter outside the research team. The information that I collect from this research study will be kept private. Information about your child collected during the research will be put away and no-one but the research team will be able to see it.

**Does your child have to take part?**

Taking part in the research is entirely up to you and your child.

**What happens if I do not want them to take part?**

**If you do not want your child to take part, please fill in the form at the end of this letter.**

**Can I see my child's answers?**

No, but you will be able to see a blank copy of the interview guide if you wish. Your daughter may choose to tell you about the interview, but she does not have to do this. Because the interviews are private, I cannot share with you the responses your child gives me with you.

**What will happen to the results of the research study?**

The results will have your child's name and the address of the school removed so that individuals or schools could not be identified. The results will be used to write my research paper in Public Health at the University of Warwick. In addition, I and the research team will write articles in scientific journals and will present the results without your child's name and the address of the school at conferences. I will send a summary of the results to the school when I have finished my study.

**Will what your child says affect how he or she is treated at school?**

The head teacher has agreed to the school being involved in the study. The results have your child's name and the address of the school – so whatever your child says will not be reported back to any of their teachers or to anyone at the school.

**Does the study have ethics committee approval?**

This research has been fully approved by NHS Research Ethics Committee Black Country and all the researchers have full CRB clearance for the project.

**Will we pay the pupils for taking part?**

No, but we would like to recognize the time that pupils have devoted to our study by giving a small chocolate bar or biscuits to all girls participating to interviews.

**Can I change my mind if I volunteer now but have second thoughts?**

You can change your mind about taking part in the study at any time. You can ring me – the researcher – Corina Chivu on 07517451418 or email me at [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk) or write to me at Medical School, Division of Health Sciences, University of Warwick, Coventry, CV4 7AL or let the school know.

**What do I do next?**

If you decide that you are happy for your child to take part in this study you will not need to do anything.

**If you do not want your child to take part, please fill in the form at the end of this letter.**

**Contact for Further Information**

I will be glad to answer your questions about this study at any time. You may contact me by email: [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk) or ring me on 07517451418.

**Who should I contact if I wish to make a complaint?**

If you have any further concerns, queries or complaints relating to this study, you should contact my supervisors:

Professor Aileen Clarke

Division of Health Sciences, Warwick Medical School, University of Warwick, Coventry, CV4 7AL

Email [Aileen.Clarke@warwick.ac.uk](mailto:Aileen.Clarke@warwick.ac.uk)

Telephone 024761 50063

Professor Gillian Hundt

School of Health and Social Studies, University of Warwick, Coventry, CV4 7AL

Email [Gillian.Hundt@warwick.ac.uk](mailto:Gillian.Hundt@warwick.ac.uk)

Telephone 02476 573814

Date 5/09/2013

**Thank you for taking the time to read this information**

OPT OUT Form

**Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands**

If you prefer your child **NOT** to take part in the study – please sign the form below and return it to your child’s form teacher at the school.

- 1. I confirm that I have read and understood the attached information sheets relating to my child participating in interview as part of the study dated 5/09/2013.
- 2. I understand that the information from this study will be kept completely anonymous at all times and that any publication from this project will **NOT** reveal the identity of the participant.
- 3. I understand that the participation of my child in this study is voluntary and that he/she can withdraw at any time without giving any reason and without being penalised or disadvantaged in any way.
- 4. I understand that the names of participating students are **STRICTLY PRIVATE** - nobody other than the research team will know what is discussed during individual anonymised interviews.

.....  
I would like to **opt** my child out of participating in this study

***I do not*** give permission to my child to participating in the study

\_\_\_\_\_  
**Name of Parent/  
Guardian**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Name of child**

\_\_\_\_\_  
**Form/ tutor group**

## Student information sheet

Version 2  
26<sup>th</sup> of September 2012



**Study title:** Factors affecting variations in the uptake of HPV Vaccine in secondary schools in the West Midlands

**Researcher:** Corina Chivu, University of Warwick

### Student Information sheet

#### Hello!

I am a female student at the University of Warwick and I am inviting you to take part in a study which I am doing in order to understand more about HPV vaccine for girls in schools. This information explains the study. Please take time to read this information carefully to decide whether you would like to take part. You might want to discuss it with others (teacher, friends, parents). I will treat all information in the strictest confidence and I will keep all information without your name and the address of the school – so no one taking part in the study will be named or be identifiable.

Before you decide whether to take part it is important that you understand why the research is being done and what it will involve.

#### Why am I doing this study?

In this study, I want to see why girls decide to have or not to have the HPV vaccine. This vaccine is given to girls between the ages of 12 - 18 years old to protect them against cancer in the lower part of the womb later in their life.

#### Why have I been chosen for this study?

I am conducting this study in some secondary schools in Coventry and your school has agreed to take part.

I am inviting you because you are the right age to take part in this research.

#### What does an Interview involve?

I will invite you to have an interview with me to tell me what you think about HPV vaccine in general. I will ask you some questions and I will invite you to give your opinions. The interview with me will last for about half an hour. There are no right or wrong answers to any of the questions. You could refuse to give answers to those questions that make you feel uncomfortable.

The interview will be audio-tape recorded. I need to do this so that I know what people actually say. All recordings will be destroyed after use. Anything you say will have your name and the address of the school removed in the results so that no-one will be able to identify you.

You should also know that other girls from your school will be invited to have an interview with me also.

**Do I have to take part?**

No. It is completely your choice whether you take part or not.

Your participation is on a voluntary basis. You could refuse to participate or you are free to stop taking part at any time during the study without giving any reason. If you decide to stop, you will not be penalised or disadvantaged in any way.

**What happens if I don't want to take part?**

If you do not want to take part, the school will arrange another activity for you during that time.

**What will happen to the results of the study?**

The results will have your name and the address of the school removed. The results will be used for educational purposes which means that they will be analysed by the research team and used by me in my research paper. The results will also be published in journals and presented at conferences.

I will send a summary of the results back to your head teacher when I have finished my study.

**Will my answers to the interview affect how I am treated at school?**

No. Your head teacher has agreed that your school can be involved in the study. The results will have your name and the address of the school removed – so neither your teachers nor your parents nor anyone at your school can find out what answers you gave.

**Will what I say in this study be kept private?**

Yes. We will not be sharing information about you outside of the research team. The information that I collect from this study will be kept private. Information about you that will be collected from the study will be put away and no-one but the research team will be able to see it.

**What if the researcher has worries about what I say?**

If what you say in the interview makes me think that you, or someone else, is at significant risk of harm, I would need to tell someone who might be able to help. If so, I will talk to you first about the best thing to do.

**Will I pay you for taking part?**

No – but I would like to recognise your time by giving you some chocolates or biscuits.

**Who is paying for this study?**

There is no funding for the study.

**Could taking part in this study upset me?**

Talking about the HPV vaccine can be a positive experience but it could also make you feel upset or uncomfortable. Although this is unlikely, if you are distressed you could talk to me, contact your school counsellor, or if you prefer you could

- call free ChildLine on 0800 1111 at any time or
- contact Get Connected ([www.getconnected.org.uk](http://www.getconnected.org.uk)) by phone 0808 808 4994 between 1pm and 11pm everyday, by webchat between 1pm and 11pm everyday, by email at any time or by WebHelp 24/7 service

**Can I change my mind if I volunteer now but have second thoughts?**

You can change your mind anytime about taking part in the study. You can ring me on [07517451418](tel:07517451418) or email me at [c.m.chivu@warwick.ac.uk](mailto:c.m.chivu@warwick.ac.uk) or let the school know.

**What do I do next?**

You can keep this information sheet. If you decide to take part, in about two week's time you will be asked to sign a consent form and then invited to take part in an interview.

Version 2  
26<sup>th</sup> of September 2012



**Do my parents/carers know about this study?**

Yes, the school has sent out a letter from me to your parents/carers about this study with the same information sheet.

**Who has reviewed this study?**

Before any research goes ahead, it has to be checked by a Research Ethics Committee. The make sure that the research is fair. The Research Ethics Committee Black Country has checked my study.

**Where can I get more information?**

If you would like to know more about this study or you have any other questions, you can telephone me on 07517451418 or you can email me at [c.m.chivu@warwick.ac.uk](mailto:c.m.chivu@warwick.ac.uk)

5/09/2013

**Thank you for taking the time to read this information**

# Student consent form

Version 2  
26<sup>th</sup> of September 2012



## STUDENT CONSENT FORM

**Study title: Factors affecting variations in the uptake of the HPV vaccine in secondary schools in the West Midlands**

1. I confirm that I have read and understood the information sheet dated 5/09/2013 for the above study which I may keep for my records and have had the opportunity to ask any questions I may have.
  
2. I understand that my participation is voluntary and that I am free to leave the study any time without giving any reason and without being disadvantaged in any way.
  
3. I understand that data collected about me during the study, may be looked at by individuals from the research team, at the University of Warwick. I give permission for these individuals to have access to my records.
  
4. I agree to take part in the above study
  
5. I agree to take part in an individual interview
  
6. I agree to have my interview audio taped
  
7. I agree to the use of my words in publications provided that my name is not mentioned.
  
8. I understand that my information will be held and used for the following educational purposes:
  - for a research paper at the University of Warwick
  - articles in scientific journals
  - presentations at conferences
  
9. I understand if I say something to the researcher that makes her very worried about my safety that she may tell someone who can work out the best thing to do about it.

Version 2  
26<sup>th</sup> of September 2012



\_\_\_\_\_  
Name of Participant      Date      Signature

\_\_\_\_\_  
Name of person taking  
consent if different  
from Researcher      Date      Signature

Corina Chivu  
\_\_\_\_\_  
Researcher      Date      Signature

## Nurse information sheet

Version 2  
26<sup>th</sup> of September 2012

Warwick Medical School



**Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands**

### Nurse information sheet

My name is Corina Chivu. I am a female PhD student at the University of Warwick. I am conducting a research study supervised by two Professors at the University of Warwick.

#### Invitation

You are being asked to take part in this research study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it will involve. Please read the following information carefully. Please ask me if there is anything that is not clear. My email is: [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk).

#### What is the purpose of the study?

This is part of my doctoral research in Public Health. The purpose of the study is to understand the factors affecting the variation in uptake of HPV vaccine and to find out about facilitators and barriers that influence HPV vaccine uptake amongst teenage girls in secondary schools in the West Midlands. As you know, this vaccine is given to girls of 12 - 13 years old to protect them against cervical cancer later in their life.

#### Who is paying for this study?

There is no funding for the study. The University of Warwick is the sponsoring organization for this research.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Your participation is on a voluntary basis. You could refuse to participate or you could withdraw at any time during the

study without any negative consequences.

If you withdraw during the study, any information you have already provided will not be used and you will not be contacted again about this study. However, if you are happy for the information you have already provided can be used, we will use that information, but you will not be contacted again.

**What will happen to me if I take part?**

You are being asked to give me permission to observe you during a vaccination session to understand the logistics and process in terms of preparation and delivery of HPV vaccine.

Also, you are being asked to participate in a face to face individual interview to express your views about the delivery of HPV vaccinations in schools and the possible factors which influence girls' access to HPV vaccination. The interview will take place in the school after a vaccination session in November 2012 and will last between 30 minutes. There are no known individual benefits or risks for you in this study.

**Do I need to be observed and interviewed?**

No. It is up to you to decide either to be observed or to be interviewed or to be observed and interviewed.

**Will what I say in this study be kept confidential?**

Information that is collected during my observation of a vaccination session and that is discussed between you and me will not be disclosed. Your privacy and identity of your information will be protected at all times.

You are being asked to give me permission to audio record the individual interview. I need to do this so that I know what people actually say. All recordings will be destroyed after use. Anything you say will be completely anonymised in the results so that no-one will be able to identify you

or the school. All identifiable information (i.e., name, school) will be removed from the interview transcript or quotations. Research information will be analyzed and reported anonymously so that no person can be identified from these documents. The data will be stored in the University of Warwick and accessed by me and my supervisors in accordance with the Data Protection Act 1998.

#### What will happen to the results of the study?

The anonymised results of the research study will be used for my PhD thesis in Public Health at the University of Warwick. In addition, we will write articles for scientific journals and will present the anonymised results at conferences. At the conclusion of the study we will provide you with copies of reports if you like.

#### Contact for Further Information

I will be glad to answer any questions you have about this study at any time. You may contact me by email: [C.M.Chivu@warwick.ac.uk](mailto:C.M.Chivu@warwick.ac.uk) or by phone on 07517451418. The research study has been approved by NHS Research Ethics Committee Black Country.

#### Who should I contact if I wish to make a complaint?

Should you have any complaints or concerns relating to this study, you should be advised to contact my supervisors:

Professor Aileen Clarke

Division of Health Sciences, Warwick Medical School, University of Warwick, Coventry, CV4  
7AL

Email [Aileen.Clarke@warwick.ac.uk](mailto:Aileen.Clarke@warwick.ac.uk)

Telephone 024761 50063

Version 2  
26<sup>th</sup> of September 2012

Warwick Medical School



Professor Gillian Hundt

School of Health and Social Studies, University of Warwick, Coventry, CV4 7AL

Email [Gillian.Hundt@warwick.ac.uk](mailto:Gillian.Hundt@warwick.ac.uk)

Telephone 02476 573814

Date: 12 November 2012

**Thank you for taking the time to read this information**

## Nurse consent form

Version 2  
26<sup>th</sup> of September 2012

Warwick Medical School



### NURSE CONSENT FORM

**Study title: Factors affecting variations in the uptake of HPV vaccine in secondary schools in the West Midlands**

1. I confirm that I have read and understood the information sheet dated 12/11/2012 for the above study which I may keep for my records and have had the opportunity to ask any questions I may have.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without being penalised or disadvantaged in any way.
3. I understand that relevant sections of data collected during the study, may be looked at by individuals from the research team, at the University of Warwick. I give permission for these individuals to have access to my records.
4. I agree to take part in the above study
5. I agree to be observed during a vaccination session
6. I agree to participate to an individual interview
7. I agree to have my interview audio taped
8. I agree to the use of direct quotations in publications provided that anonymity is preserved
9. I understand that information about me and my work will be held and used for the following educational purposes:
  - for a PhD thesis at the University of Warwick
  - articles in scientific journals
  - presentations at conferences

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking  
consent if different  
from Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Corina Chivu**

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 22. Table 1 Interviews with nursing staff

| Coordinators          | Vaccinators           |
|-----------------------|-----------------------|
| 1 Lead nurse          | 3 Vaccinators         |
| 1 Senior nurse        | 1 School nurse        |
|                       | 1 Health visitor      |
|                       | 1 Practice nurse      |
|                       | 1 Sexual health nurse |
| <b>Total 9 nurses</b> |                       |

## Appendix 23. Table 1 School characteristics

| School                                   |                                      |                                 | Deprivation<br>in the list of 20 schools |                         | Uptake<br>3 <sup>rd</sup> dose<br>all years<br>combined |
|--|--------------------------------------|---------------------------------|--|-------------------------|---|
|  | School size<br>N pupils on<br>roll** | N year 8<br>girls<br>on roll*** | IMD SAP                                  | IMD SCA                 |   |
| School 1*<br>(religious)                 | 1200                                 | 88                              | mid level<br>rank**** 12                 | mid level<br>rank 14    | 87%   |
| School 2* (Academy)                      | 530                                  | 49                              | mid level<br>rank 9                      | mid level<br>rank 13    | 83%   |
| School 3*(Academy)<br>(multiethnic)      | 1400                                 | 97                              | highest level<br>rank 1                  | highest level<br>rank 1 | 76%   |
| School 4*(Academy)<br>(school for girls) | 1350                                 | 175                             | mid level<br>rank 8                      | low level<br>rank 17    | 86%   |

\* The number of the school corresponds to the time the school accepted to participate in the research

\*\*N pupils on roll in 2007/2008

\*\*\*N year 8 girls on roll in 2012/2013

\*\*\*\*rank 1 = highest level of IMD; 20 = lowest level of IMD

## Appendix 24.

### Appendix 24 Table 1. Summary of socio-demographics of 34 girls interviewed

| School 1         |                |   | School 2                           |             |   | School 3      |             |   | School 4            |             |   |
|------------------|----------------|---|------------------------------------|-------------|---|---------------|-------------|---|---------------------|-------------|---|
| Ethnicity        | Religion       | N | Ethnicity                          | Religion    | N | Ethnicity     | Religion    | N | Ethnicity           | Religion    | N |
| White British    | Catholic       | 4 | White British                      | no religion | 1 | White British | Christian   | 2 | White British       | no religion | 1 |
| British African* | Black Catholic | 1 | White British                      | Christian   | 1 | Indian        | Hindu       | 1 | White British Welsh | no religion | 1 |
| British Indian   | Hindu          | 1 | British (mixed Kenya-Malawi)       | Muslim      | 1 | Sri Lankan    | Buddhism    | 1 | British Pakistani   | Muslim      | 1 |
| Nigerian African | Black Catholic | 1 | British Bangladeshi                | Muslim      | 1 | White British | no religion | 6 | Slovakian           | Catholic    | 1 |
| Polish*          | Catholic       | 2 | British Libyan                     | Muslim      | 1 |               |             |   |                     |             |   |
|                  |                |   | British Indian                     | Muslim      | 1 |               |             |   |                     |             |   |
|                  |                |   | British Indian (mixed Kenya-India) | Hindu       | 1 |               |             |   |                     |             |   |
|                  |                |   | Tanzanian                          | Muslim      | 1 |               |             |   |                     |             |   |
|                  |                |   | Pakistani                          | Muslim      | 1 |               |             |   |                     |             |   |
|                  |                |   | Bangladeshi                        | Muslim      | 1 |               |             |   |                     |             |   |
|                  |                |   | Indian                             | Christian   | 1 |               |             |   |                     |             |   |

**Total**

**9**

4 = ethnic non white  
2 out of 4=British non white

\*2 out of 9 = not vaccinated

**Total 11**

9 = ethnic non white  
5 out of 9= British non white

**Total 10**

2 ethnic non white

**Total 4**

2 ethnic non white  
1 out of 2=British non white

**Total**

**17 = ethnic white**  
**17 = ethnic non-white – 8 out of 17 = British non white**

## Appendix 25. Thematic analysis

| Theme               | Category   | Codes  | Source - interviews  |
|---------------------|--|--|--|
| <b>Introduction</b> | A school-based HPV vaccination programme               | 1. local policy nurses<br>2. GP<br>3. data management  | nurses<br>nurses<br>nurses   |
|                     |  |  |  |
| <b>School</b>       | School policy and HPV vaccine                          | 4. school policy<br>5. school attitude<br>6. school attitude<br>7. negative school attitude  | teachers<br>teachers<br>nurses<br>nurses   |
|                     |  |  |  |
|                     | Organization of delivery of HPV vaccination programme  | 8. school-teachers<br>9. school-embarrassment<br>10. tutor<br>11. school-barrier<br>12. school organization<br>13. school nurse<br>14. ethnicity<br>15. school responsibility for HPV vaccination<br>16. organization delivery on the day<br>17. organizer's role (interviewee)<br>18. tutor<br>19. interpreter<br>20. girl-teacher communication<br>21. teacher-parent communication<br>22. teacher-nurse communication | girls<br>girls<br>girls<br>nurses<br>nurse<br>nurses<br>nurses<br>teachers<br>teachers<br>teachers<br>teachers<br>teachers<br>teachers<br>teachers |
|                     |  |  |  |
|                     | Information about HPV vaccine in the schools           | 23. sex education<br>24. no information<br>25. assembly<br>26. school-teachers<br>27. school<br>28. nurses in assembly   | teachers<br>teachers<br>teachers<br>girls<br>girls<br>girls  |
|                     |  |  |  |
| <b>Facilitators</b> | Consent for HPV vaccine                                | 29. parental consent<br>30. girls' competence<br>31. form  | nurses<br>nurses<br>nurses   |
|                     |  |  |  |
|                     | Parental involvement in decision-making on HPV vaccine | 32. girl-parent communication<br>33. siblings vaccinated<br>34. belief - protection from cancer<br>35. girl-family communication   | teachers<br>teachers<br>teachers<br>girls  |

|                 |  |  |  |
|-----------------|--|--|--|
|                 |  | 36. parents' decision or beliefs<br>37. self-management<br>38. own decision<br>39. girl's beliefs - what think about vaccine<br>40. parent-girl communication  | girls<br>girls<br>girls<br>girls<br>nurses   |
|                 | Girls' views about the HPV vaccine               | 41. reassurance<br>42. girl-girls communication<br>43. girl-mother communication<br>44. girl-father communication<br>45. girl-nurse communication<br>46. clinic & NHS<br>47. clinic<br>48. girls-girls communication<br>49. communication<br>50. clinic<br>51. nurse-parent communication<br>52. nurse's role  | girls<br>girls<br>girls<br>girls<br>girls<br>teachers<br>teachers<br>nurses<br>nurses<br>nurses<br>nurses  |
| <b>Barriers</b> | Fear of injections                               | 53. girl's fear<br>54. rumors<br>55. girl's fear<br>56. rumors<br>57. girls' beliefs<br>58. fear<br>59. daughter's refusal   | girls<br>girls<br>teachers<br>teachers<br>nurses<br>nurses<br>nurses   |
|                 | Attitudes about the effectiveness of HPV vaccine | 60. girl's knowledge<br>61. relationships - behavior<br>62. HIV not HPV<br>63. not read letter   | girls<br>girls<br>girls<br>girls   |
|                 | Parental refusal of HPV vaccine                  | 64. religion culture<br>65. parents' beliefs<br>66. religion and culture and language<br>67. parents' knowledge<br>68. parents' decision<br>69. parents' beliefs<br>70. parental refusal<br>71. male dominance<br>72. language<br>73. parents' beliefs<br>74. safety<br>75. husband<br>76. HPV as STI<br>77. parents' education<br>78. girl's health condition | teachers<br>teachers<br>girls<br>girls<br>girls<br>girls<br>nurses<br>nurses<br>nurses<br>nurses<br>nurses<br>nurses<br>nurses<br>nurses<br>nurses<br>nurses<br>nurses |

|                           |                               |                           |        |
|---------------------------|-------------------------------|---------------------------|--------|
|                           |                               | 79. girl's death          | nurses |
| <b>Total<br/>3 themes</b> | <b>Total<br/>9 categories</b> | <b>Total<br/>79 codes</b> |        |

**Appendix 26. Correspondence between the number of a school in quantitative study and the number of the same school in qualitative study**

| <b>Mixed methods research</b>              |   |
|--|---|
| <b>Number school in quantitative study</b> | <b>Number school in qualitative study</b> |
| 6  | 6   |
| 16   | 7   |
| 18   | 14  |
| 19   | 9   |

**Appendix 27. Definition of free school meals**

Free school meals are a statutory benefit and are available to children of parents who start working less than 16 hours per week as well as to children of families who receive income Support, income Based Jobseekers Allowance, an income-related employment and support allowance, support under part V1 of the Immigration and Asylum Act 1999, the Guarantee element of State Pension Credit, child Tax Credit, provided they are not entitled to Working Tax Credit and have an annual income that does not exceed £16,190, Working Tax Credit for four weeks after their employment finishes, during the initial roll out of the benefit, Universal Credit (Coventry City Council, 2014). Children who are on receipt of full-time education or education both before and after the lunch period could benefit from free school meals. From September 2014 all pupils in year 1 and year 2 in state-funded schools in England became eligible for FSMs (Department for Education, 2014) to improve academic attainment and save families money. State-funded schools include academies, free schools, pupil referral units and alternative provision as well as maintained schools (GOV.UK, 2013b). Students at school sixth forms, disadvantaged students at sixth form colleges and further education colleges are eligible for free school meals (GOV.UK, 2013b).

Young children who are educated in a private or voluntary early year's provider – for example a full day care nursery, or play group – or an independent school are not entitled to a FSM even if they meet the eligibility criteria (Department for Education, 2014).

## Appendix 28. Published article based on the national study

Chivu and Reidpath *BMC Public Health* 2010, **10**:473  
<http://www.biomedcentral.com/1471-2458/10/473>



### RESEARCH ARTICLE

### Open Access

# Social deprivation and exposure to health promotion. A study of the distribution of health promotion resources to schools in England

Corina M Chivu<sup>1\*</sup>, Daniel D Reidpath<sup>2</sup>

#### Abstract

**Background:** Area deprivation is a known determinant of health. It is also known that area deprivation is associated with lower impact health promotion. It is less well known, however, whether deprived areas are less responsive to health promotion, or whether they are less exposed. Using data from a national, school-based campaign to promote vaccination against the human papilloma virus (HPV), the relationship between area deprivation and exposure was examined.

**Methods:** Taking advantage of a health promotion campaign to provide information to schools about HPV vaccination, a cross sectional study was conducted to examine the relationship between area level, social deprivation, and take-up of (i.e., exposure to) available health promotion material. The sample was 4,750 schools across England, including government maintained and independent schools. The relationship between area deprivation and exposure was examined using bi- and multivariate logistic regression.

**Results:** It was found that schools in the least deprived quintile had 1.32 times the odds of requesting health promotion materials than schools in the most deprived areas ( $p = .01$ ). This effect was independent of the school size, the type of school, and the geographic region.

**Conclusion:** The relationship between area deprivation and the impact of health promotion may be due, at least in part, to differential levels of exposure. The study was limited in scope, pointing to the need for more research, but also points to potentially important policy implications.

#### Background

The presence of an area level, social gradient in health behaviors and health outcomes has been commonly observed in the literature [1-3]. People who live in more socially deprived areas tend to experience worse health outcomes [4-8], and have a greater prevalence of behavioural risk factors [9,10], than those who live in less socially deprived areas. In the UK, for instance, people living in more deprived areas tend to have less healthy diets, higher rates of smoking, and lower levels of physical activity [11,12]. All of these behaviors are known risk factors for poor health outcomes. The international picture is somewhat similar [9,13-15]; although, the

exact nature of the relationship between area deprivation and health has been found to vary by context [16].

Differences in the rates of health damaging behaviors, such as smoking, form at least a part of any explanation for variations in health outcomes between areas of different levels of deprivation. There is also an area level social gradient in the impact of health promotion efforts, whereby the impact of health promotion tends to be less in more deprived areas. For instance, people living in more deprived areas tend to have lower rates of smoking cessation [13], lower rates of childhood vaccination [17], and lower uptake rates of screening services [18].

Explaining the relationship between area deprivation and health remains an active field of research. Explaining the relationship between area deprivation and the impact of health promotion activities has been the focus of far less research. Broadly, however, two kinds of

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explanation present themselves. The first kind of explanation relates to the receptiveness of people living in more deprived areas to health promotion messages. People in more deprived areas may "choose" to ignore the health promotion messages more than those in less deprived areas [19]. A second kind of explanation is that people living in more deprived areas are just as receptive to health promotion messages, but they are less likely to be exposed to health promotion messages than their counterparts in less deprived areas. It is this latter kind of explanation that is explored in this paper.

In June 2007 the UK Department of Health (DH) accepted (in principle) the recommendation of the Joint Committee on Vaccination and Immunization to introduce a national, school-based, human papilloma virus (HPV) vaccination campaign, targeting girls [20]. The long-term goal of the campaign was to reduce the incidence of cervical cancer [21]. In England the vaccination campaign commenced in September 2008 - the beginning of the school year [22]. The vaccination was provided free of charge and on a voluntary basis, initially to 12 and 13 year old girls in schools, but the program was to be expanded to capture older female students (up to 18 years) who would otherwise miss out. In June 2008, prior to the commencement of the vaccination campaign, the Royal Society for Public Health (RSPH) developed and distributed to schools a series of health education resources on the HPV vaccine and cervical cancer [23]. The resources were developed in response to the government initiative, and were designed to support the vaccination campaign. The RSPH anticipated that, by providing schools with HPV related, health education resources which were integrated with the regular school curriculum, students (and through them, parents) would be made aware of the risk of HPV, the benefits of vaccination, and ultimately choose to have the vaccination [23].

The distribution of the educational resources to schools by RSPH created the conditions of a "natural experiment" allowing us to examine the effect of area level deprivation on the exposure to health promotion messages. It was a particularly pertinent campaign on which to focus, because cervical cancer is known to be unequally distributed in England, with the most deprived areas having twice the incidence of cervical cancer as the least deprived areas [24]. By analysing the uptake and distribution of the educational resources (i.e., the reach of health promotion), it was possible to measure the extent to which deprivation affected exposure to health promotion messages. If deprivation was associated with a lack of exposure, then one would anticipate that schools in more deprived areas would be less likely to receive HPV educational resources than would schools in less deprived areas.

## Methods

In March 2008, a letter was mailed by the RSPH to 5,715 schools across the UK inviting them to receive the HPV health education resources. The schools were drawn from a comprehensive database of UK secondary schools provided to the RSPH by a third party. Of the schools to be sent a letter, the majority (4,750, or 83.6%) was located in England, and it was these schools that formed the sample for the present analysis. The remaining 965 schools in Scotland, Wales and Northern Ireland were not included in the analysis, because of difficulties in matching the schools with equivalent measures of area deprivation. For each school additional limited data were available about the type and size of the school.

## Measures

The **outcome** measure, exposure to health promotion materials, was operationalised in terms of the take-up by schools of the RSPH educational resources. The requests for materials were recorded by the RSPH for all 4,750 of the schools included in the initial mail-out in England. The cut-off date for recording the requests was 29 July, 2008.

The **independent** variable, area deprivation, was measured using the Index of Multiple Deprivation 2007 (IMD) for England [25]. The IMD combines 37 indicators related to a range of economic, social and housing issues, into a single area deprivation score with the most deprived areas having the highest scores. The IMD has been used extensively to examine the relationship between area deprivation and health in England [11,26]. In the present analysis, the geographical location of each school was determined using the postcode to which the initial letters were sent. Each postcode was associated with an IMD score using the online GeoConvert facility [27]. The IMD scores for all the schools in the sample were then divided into quintiles of deprivation.

The **covariates** included in the analyses were school size, school type, and the geographic region within England where the school was located. School size was a dichotomous variable capturing the smallest 20% of schools, in terms of the size of the student body, versus the rest. The decision to dichotomize this variable and choice of cut-point was determined empirically during data exploration and cleaning. Schools type was a dichotomous variable capturing government maintained schools (i.e., schools receiving state aid) and independent schools. The geographical region was based on the 9 government office regions (GORs) of England. From North to South, these regions were the: North West, North East, Yorkshire and the Humber, West Midlands, East Midlands, East London, South East, and South West. Matching a postcode to a GOR was, again, performed using the online GeoConvert facility [27].

**Data Analysis**

Logistic regression was used to examine the relationship between area deprivation and the take-up of the HPV health educational resources. The approach involved standard progressive modeling whereby each of the possible unadjusted effects for the covariates was also examined. Then the effect of area deprivation adjusting for school size, school type, and region was estimated in a multivariate logistic model. When reporting the results of the logistic regression, the base category of the covariates was selected so that improvement in the take-up of the HPV educational resources was reflected as an odds ratio greater than 1.

The protocol for the study was approved through the formal ethics review processes of Brunel University.

**Results**

Of the 4,750 schools sent a letter about the HPV health educational resources, 1,327 schools (27.9%) requested a copy. Table 1 shows a break down of the characteristics of schools that did and did not request the health education resources.

The take-up of the educational resources varied across the quintiles of deprivation. Schools located in the most

(and second most) deprived areas had take-up rates around 25%, while the schools located in the least deprived quintile had take-up rates around 32%. A test for trend showed a significant increase in the take-up of the educational resources as deprivation decreased ( $z = -3.99, p = .000$ ). School size was significantly associated with the take-up of the HPV educational resources, with odds of larger schools taking up the educational resources more than twice that of the smallest 20% of schools (OR = 2.11, 95%CI: 1.76-2.53). Significantly more government maintained schools requested materials (32%) than independent schools (27%) (OR = 1.44, 95%CI: 1.22-1.69).

There was substantial regional variation in the take-up of the educational materials. London and the North East had the lowest take-up rates (~20%). The West Midlands and the South East had take-up rates around 27%. The North West and Yorkshire and the Humber had take-up rates around 30%. The East Midlands, the South West, and the East had larger take-up rates around 33%. All regions, with the exception of the North East had take-up rates significantly higher than that of London, with odds ratios ranging from 1.5 up to 2.1.

The multivariate logistic model shows the association between area deprivation and the take-up of the educational materials after adjusting for school size, school type, and the regional location of the school (Table 2).

After adjusting for the covariates, there remained a significant association between area deprivation and the take-up of the HPV educational resources. Schools in the least deprived areas had odds 1.32 times greater than schools in the most deprived areas of requesting the teaching resources ( $p = .01$ ). After adjustment, there remained a significant trend, with decreasing levels of deprivation associated with increasing take-up rates of the educational resources ( $p = .001$ ) [28]. The interpretation of the covariates, post adjustment, was generally the same as the interpretation prior to adjustment. Larger schools were significantly more likely to take-up the teaching resources than smaller schools (OR = 2.16, 95%CI: 1.74-2.68). Geographical region also remained significantly associated with the take-up of the educational resources - indeed there were only minor variations in the odds ratios pre- and post adjustment. The major variation in the results was that the type of school (government maintained or independent) was no longer significantly associated with take-up post adjustment.

**Table 1 The request for educational resources broken down by IMD, school size, school type, and geographic region**

|                          | Received |      | Not Received |      | Unadjusted OR (95% CI) |
|--------------------------|----------|------|--------------|------|------------------------|
|                          | %        | N    | %            | N    |                        |
| <b>IMD quintiles</b>     |          |      |              |      |                        |
| 1 (Least Deprived)       | 31.7     | 301  | 68.3         | 648  | 1.38 (1.13-1.69)       |
| 2                        | 30       | 284  | 70           | 664  | 1.27 (1.04-1.56)       |
| 3                        | 28.4     | 269  | 71.6         | 679  | 1.18 (0.96-1.45)       |
| 4                        | 24.7     | 235  | 75.3         | 715  | 0.98 (0.8-1.21)        |
| 5 (Most Deprived)        | 25.1     | 238  | 74.9         | 709  | 1 (Base)               |
| <b>School size</b>       |          |      |              |      |                        |
| Smallest 20%             | 17.3     | 167  | 82.7         | 798  | 1 (Base)               |
| Remaining 80%            | 30.6     | 1160 | 69.4         | 2625 | 2.11 (1.76-2.53)       |
| <b>School type</b>       |          |      |              |      |                        |
| Independent              | 22.5     | 235  | 77.5         | 808  | 1 (Base)               |
| Government Maintained    | 29.5     | 1092 | 70.5         | 2615 | 1.44 (1.22-1.69)       |
| <b>GOR</b>               |          |      |              |      |                        |
| London                   | 19.9     | 145  | 80.1         | 584  | 1 (Base)               |
| North West               | 29.1     | 180  | 70.9         | 438  | 1.66 (1.29-2.13)       |
| North East               | 20.9     | 53   | 79.1         | 201  | 1.06 (0.75-1.51)       |
| Yorkshire and the Humber | 29.8     | 131  | 70.2         | 308  | 1.71 (1.30-2.25)       |
| West Midlands            | 27.3     | 142  | 72.7         | 379  | 1.51 (1.16-1.97)       |
| East Midlands            | 32.8     | 104  | 67.2         | 213  | 1.97 (1.46-2.65)       |
| East                     | 33.7     | 173  | 66.3         | 340  | 2.05 (1.58-2.65)       |
| South East               | 27.4     | 240  | 72.6         | 635  | 1.52 (1.20-1.93)       |
| South West               | 33       | 158  | 67           | 321  | 1.98 (1.52-2.57)       |

Unadjusted odds ratios and 95% confidence intervals are also shown.

**Discussion**

In 1986 the *Ottawa Charter for Health Promotion* detailed the basic goals and objectives for health promotion [29]. One of the goals was to achieve equity in health, and one of the strategies for doing this was to ensure equality of access to information. The motivation

**Table 2 The adjusted odds ratios for requesting educational resources including 95% confidence intervals and approximate p-values**

| Variables                | Adjusted odds ratio | 95% CI    | p-value |
|--------------------------|---------------------|-----------|---------|
| <b>IMD quintiles</b>     |                     |           |         |
| 1 (Least Deprived)       | 1.32                | 1.06-1.63 | .011    |
| 2                        | 1.25                | 1.01-1.54 | .037    |
| 3                        | 1.16                | 0.94-1.43 | .166    |
| 4                        | 0.95                | 0.77-1.17 | .608    |
| 5 (Most Deprived)        | 1 (Base)            |           |         |
| <b>School size</b>       |                     |           |         |
| Smallest 20%             | 1 (Base)            |           |         |
| Remaining 80%            | 2.18                | 1.75-2.7  | .000    |
| <b>School type</b>       |                     |           |         |
| Independent              | 1 (Base)            |           |         |
| Government Maintained    | 0.97                | 0.80-1.18 | .790    |
| <b>GOR</b>               |                     |           |         |
| London                   | 1 (Base)            |           |         |
| North West               | 1.57                | 1.21-2.02 | .001    |
| North East               | 1.02                | 0.71-1.46 | .913    |
| Yorkshire and the Humber | 1.63                | 1.24-2.15 | .001    |
| West Midlands            | 1.45                | 1.11-1.9  | .005    |
| East Midlands            | 1.83                | 1.36-2.48 | .000    |
| East                     | 1.88                | 1.44-2.45 | .000    |
| South East               | 1.45                | 1.14-1.85 | .003    |
| South West               | 1.9                 | 1.45-2.48 | .000    |

behind the strategy was the view that people can make healthier choices (in this case choose to be vaccinated), if they have appropriate information [30]. It is this issue of equality of access to information that lies at the heart of the present study. In an environment in which it is known that the most deprived areas have twice the incidence of cervical cancer as the least deprived areas [24], the most deprived and the least deprived areas should have, at a minimum, the same level of exposure to health relevant information. Indeed, as a matter of policy, it may be preferred for those areas with the highest incidence to have an even greater exposure to relevant information than those less deprived area with a lower incidence.

As anticipated, schools in the least deprived areas were significantly more likely to request the educational resources than schools in the most deprived areas; furthermore, this association held even after adjusting for school type, size and geographical region. Although the relationship between area deprivation and request for teaching resources was not particularly strong (OR = 1.32), given the association between deprivation and

incidence of cervical cancer, any significant trend in exposure to health promotion material in the wrong direction is cause for concern and further investigation.

One explanation for the finding that less deprived areas had a higher take up rate of the educational resources may relate to the "inverse equity hypothesis" [31,32]. According to this hypothesis, higher socioeconomic status groups pick up interventions quicker than lower socioeconomic status groups. This increases the health differences between the groups in the short term. However, with the passage of time, the lower socioeconomic groups begin to pick up the intervention, which then reduces the health differences between the groups. It may be that schools in less deprived areas are better placed to take advantage of the freely available educational resources, explaining their quicker take up. Assuming the hypothesis is correct, and given continued availability of the materials [33], the difference in the take up rate may reduce over time.

In addition to the modest deprivation effect, there was a regional effect, with schools from some regions (the East and South West) having almost twice the odds of requesting the education resources as schools in London or the North East (with the highest percentage of small deprivation areas in the most deprived area quintile [25]). There was also a school size effect, with the smallest 20% of schools half as likely to request the materials as the larger schools.

It is tempting to speculate why factors such as area, school size, or indeed school type might be significantly associated with the take-up of the health promotion resources. One might speculate for example that religion could underpin school size or school type effects; perhaps with more religious (and possibly conservative) schools less supportive of the HPV vaccination program. Alternatively, it might be that smaller schools, with fewer staff, simply lack the capacity to take advantage of support offered through external initiatives. Unfortunately, the data are such that none of these questions can be adequately disentangled, and any response remains purely speculative.

There are two important limitations to the findings. The first limitation relates to the operationalisation of exposure to health promotions materials. The relationship between an individual's exposure to the health promotion materials and a school's request for materials is essentially unknown in this study. It may be that schools that did not request the materials from the RSPH but obtained the materials through a secondary source. Nor is it sufficient simply for school to request the materials, they have to be integrated into the curriculum which could be constrained by competition with other topics [34], school policy or local culture [35]. The extent to which materials are integrated into the curriculum will

also affect individual's exposure. Nonetheless it is reasonable to assume that, on average, students in schools requesting the materials had a higher exposure to those materials than students in schools that did not request the materials. The second limitation relates to the design. As a "natural experiment" there was no control, and a range of unmeasured (and unknown) possible confounders, making any inference about a causal relationship impossible.

There is, *prima facie*, a third limitation, which on reflection is unfounded. The "third limitation" is that the area deprivation of a school does not reflect the area deprivation of the students within the school. This makes less sense when it is actually drawn out. The argument would be that, on average, students attending schools located in the most deprived areas are no more likely to live in most deprived areas than students attending schools in least deprived areas. It is true that students attending independent (privately funded) schools may travel considerable distances to attend school. Schools in receipt of government aid, however, tend to draw their student body from their local area. So the area level of deprivation of a government aid school is going to be similar (the data were in quintiles) to the area in which the students live. The adjustment in the analysis for school type was particularly pertinent to this argument; and even after adjustment, students attending schools in more deprived areas were significantly less likely to be exposed to the health promotion material.

Notwithstanding the limitations, the findings support the central idea that more deprived areas are likely to have a lower exposure to health promotion messages than less deprived areas. The effect is not strong, but the accumulation of weak effects over time, can have important ramifications for population health [36], and for the disparity in the health of more and less socially deprived groups. The interaction between the level of exposure, the level of area deprivation, and the individual response to health promotion messages would be a fruitful line of future inquiry.

### Conclusions

There was a social gradient associated with schools' response to the opportunity to receive educational resources supporting the HPV vaccination campaign. Schools in the most deprived areas were less likely to request materials than schools in less deprived areas. This was independent of other significant associations, such as school size and geographical region. This has important implication for the level of exposure to health promotion messages that people from more and less deprived areas are likely to experience.

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### Authors' contributions

CC conceived the study, analysed and interpreted the data, drafted and edited the manuscript. DR contributed to the conception of the study, provided assistance with the analysis and interpretation of the data and edited the manuscript. Both authors read and approved the final manuscript.

### Competing interests

The authors declare that they have no competing interests.

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