

# **ATTITUDES, UNDERSTANDING AND COMPLIANCE WITH CERVICAL SCREENING IN EASTERN EUROPEAN MIGRANTS IN ENGLAND**

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by

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## **ABSTRACT**

### **Attitudes, Understanding And Compliance With Cervical Cancer Screening In Eastern European Migrants To England**

**Hersha Patel**

#### **Introduction**

The incidence of cervical cancer in England, in the 25-34 year old age group is rising but screening coverage is falling. It has been hypothesised that this might be in part due to the effect of migration of Eastern European (EE) women to England. This thesis explores the attitudes, understanding and behaviours of migrant EE women in England towards cervical cancer prevention strategies, focusing on the effect of migration. Further to assess cervical cancer prevention as an entirety the understandings and attitudes of EE adolescents and healthcare professionals in England have been investigated.

#### **Methods**

Five studies, using a combination of qualitative, quantitative and systematic review research methodologies were conducted to assess the aims. The studies were conducted in England and Latvia.

#### **Results**

Comparison of the English and Latvian studies revealed that both the native Latvian women and migrant EE women had lower levels of understanding of the process of cervical screening than the native English women. The largest influence on cervical screening behaviours both prior to and after migration was the women's overall perception of the healthcare system. The migrant EE women held negative attitudes towards the healthcare system in England. Minimal changes occurred in attitudes and behaviours towards cervical screening after migration.

Practice nurse smear takers in England were found to lack adequate awareness of current cervical screening protocols or HPV vaccination and not all were confident in providing HPV related patient education.

Awareness of primary prevention of cervical cancer in the Latvian adolescent population was suboptimal, although they appeared to be partaking in high-risk behaviours.

### **Conclusions**

The uptake of cervical cancer prevention modalities in the migrant EE population appears to be influenced by their pre-existing knowledge of cervical screening and cervical cancer and their perception of the healthcare system and healthcare professionals in England.

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Finally, I would like to acknowledge my beautiful daughter Serena. Who would have thought I could have baby and write my thesis all in one year, Serena you have made it really easy.

This is for you Serena, Love you always x

## **STATEMENT DETAILING WORK PERSONALLY PERFORMED**

### **Study 1: Behaviours, Attitudes And Knowledge Of Cervical Cancer Prevention Strategies In Migrant Eastern European Women To England**

I wrote the final study protocol, applied for ethical approval and research and development approval for all the participating sites.

I developed the study questionnaire and interview topic guide. Colposcopy clinic staff and community groups helped with the distribution of the questionnaires and recruitment of participants from the community setting. I conducted all the qualitative interviews. I conducted all the final data analysis; Dr Susan Sherman provided guidance for and helped develop the initial set of codes for the qualitative data.

### **Study 2: Cervical Cancer Prevention; A Mixed Methods Study Evaluating The Knowledge, Behaviours And Attitudes Of Latvian Women**

This study was conducted in collaboration with colleagues in Latvia. I designed the study protocol, study questionnaire and interview topic guide. The Latvian collaborators obtained ethical approval for the study and distributed the questionnaires. I conducted all the interviews and all the final data analysis; Dr Susan Sherman provided guidance for and helped develop the initial set of codes for the qualitative data.

### **Study 3: Knowledge, Attitudes And Awareness Of The Human Papillomavirus Amongst Primary Care Practice Nurses: An Evaluation Of Current Training In England**

I developed the concept and the protocol for the study. I developed the study survey in collaboration with Dr Karen Mistry and the local Public Health England screening team. I analysed all the data from this study and prepared the published manuscript.

### **Study 4: Knowledge Of Human Papillomavirus And The Human Papillomavirus Vaccine In European Adolescents**

I conducted the literature search to identify the eligible studies and formulated summaries. Dr Esther Moss and myself performed the critical appraisal of the studies

and Dr Yadava Jevu performed the meta analysis. I performed the meta synthesis of the qualitative studies and prepared the published manuscript.

**Study 5: Adolescents' Awareness Of HPV Infection And Attitudes Towards HPV Vaccination 5 Years Following The Introduction Of The HPV Vaccine In Latvia**

This study was conducted in collaboration with colleagues in Latvia. I designed the study protocol and study questionnaire. The Latvian collaborators obtained ethical approval for the study and distributed the questionnaires. I conducted all the data analysis and prepared the published manuscript.



## **PUBLICATION AND PRESENTATIONS**

### **Original Articles:**

**Patel H**, Jevs YB, Sherman SM, Moss EL. Knowledge of human papillomavirus and the human papillomavirus vaccine in European adolescents: a systematic review *Sex Transmitted Infections* 2016;92:474-479.

**Patel H**, Austin-Smith K, Sherman SM, Tincello D, Moss EL. Knowledge, attitudes and awareness of the human papillomavirus amongst primary care practice nurses: an evaluation of current training in England. *Journal of Public Health (Oxford, England)*. 2017;39(3):601-8.

**Patel H**, Pcolkina K, Strazdina K, Viberga I, Sherman SM, Tincello DG, et al. Awareness of HPV infection and attitudes toward HPV vaccination among Latvian adolescents. *International Journal of Gynaecology and Obstetrics*. 2017;137(2):138-44.

**Patel H**, Moss EL, Sherman SM. HPV primary cervical screening in England: Women's awareness and attitudes. *Psycho-oncology*. 2018 Mar 9. Doi: 10.1002/pon.4694. [Epub ahead of print]

### **Oral Presentations:**

**Patel H**, Pcolkina K, Strazdina K, Viberga I, Sherman SM, Tincello DG, Redman CW, Rezeberga D, Moss EL. “Adolescents’ awareness of HPV infection and attitudes towards HPV vaccination 5 years following the introduction of the HPV vaccine in Latvia”. BMOGS, Stoke-on Trent Oct 2016

**Patel H**, Pcolkina K, Viberga I, Sherman SM, Tincello D, Redman C, Zodzika J, Jermakova I, Rezeberga D, Moss EL\*; “Utilization, attitudes and awareness of cervical cancer prevention strategies in Latvian women”. BMOGS, Riga April 2017

\* presenting author

**Patel H**, Sherman SM, Tincello D, Moss EL; “Primary HPV testing- is it an acceptable test for women in England?”. BS CCP, Cardiff, May 2017

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**Patel H**, Sherman SM, Tincello D, Moss EL; “The impact of migration on cervical screening behaviour”. Eurogin, Amsterdam, Oct 2017

**Poster Presentations:**

**Patel H**, Gupta M, Freeman H, Walker C, Brown L, Moss EL, Kirwan P; “Cytological and birth outcomes following treatment for high-grade cervical intraepithelial neoplasia following fragmentary large loop excision”. 15<sup>th</sup> World Congress for Cervical Pathology and Colposcopy, London 2014

**Patel H**, Jevé Y, Moss E; “Knowledge of Human papillomavirus and the Human papillomavirus vaccine in European Adolescents- A Systematic Review”. BS CCP, Nottingham, April 2015

**Patel H**, Pčolkina K, Viberga I, Sherman SM, Tincello D, Redman C, Zodzika J, Jermakova I, Rezeberga D, Moss EL; “Cervical cancer prevention: A mixed methods study evaluating the knowledge, behaviours and attitudes of Latvian women”. IGCS, Lisbon Oct 2016

**Patel H**, Sherman SM, Tincello D, Moss EL; “An “Abnormal Result” Receiving an abnormal smear result-The expectations, emotions and knowledge of the management of abnormal smears”. BS CCP, Cardiff, May 2017

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## ABBREVIATIONS

CASP	Critical Appraisal Skills Programme
CEBM	Centre for Evidence Based Medicine
CIN	Cervical Intraepithelial Neoplasia
CSP	Cervical Screening Programme
EE	Eastern European
EU	European Union
GP	General Practitioner
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
HPV	Human Papilloma Virus
hrHPV	High Risk Human Papilloma Virus
HSIL	High Grade Squamous Intraepithelial Lesion
LSIL	Low Grade Squamous Intraepithelial Lesion
MSM	Men who have sex with men
NHS	National Health Service
NIHR	National Institute for Health Research
NP	Nurse Practitioner
PHE	Public Health England
PN	Practice Nurse
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta Analysis
SPSS	Statistical Package for Social Sciences
STI	Sexually Transmitted Infection
TOC	Test of Cure

# **1 INTRODUCTION**

## **1.1 CERVICAL CANCER**

Cancer of the uterine cervix, cervical cancer, is largely a preventable disease that affects young women. However, with early diagnosis it is treatable with good overall survival rates and long-term quality of life. Furthermore, the implementation of effective secondary prevention measures, in the form of cervical screening and more recently primary prevention, with the introduction of the Human Papillomavirus (HPV) vaccine, have resulted in a significant decline of cervical cancer incidence and mortality.

### **1.1.1 Epidemiology**

Globally cervical cancer is the fourth most common cancer in women and it ranks seventh of all cancers worldwide(1). In 2012 there were an estimated 528,000 new cases of cervical cancer and 266,000 deaths from the disease(2). Developing countries disproportionately harbour the majority of the disease burden (3, 4), with 88% of all cervical cancer deaths occurring in a low resource country(5). This is largely the result of poor access to healthcare and lack of established cervical screening and HPV vaccination programmes(6, 7).

In the European continent the highest incidence of cervical cancer exists in Central and Eastern European (EE) countries(8), of which Romania is at the top(9) (refer to figure 3.1, page 41). The crude incidence rate of cervical cancer in Romania in 2012 was 39.4 per 100,000 women per year, compared to 21.7 in Eastern Europe and 15.1 worldwide(10). Cervical cancer ranks third in incidence of all cancers affecting females in Romanian, Lithuania and Moldova(9). Unlike the rest of Europe, which has seen an overall decrease in cervical cancer incidence rates over time, the age standardised incidence of cervical cancer in EE, is continuing to show a rising trend(11).

The incidence and mortality figures for cervical cancer have decreased considerably over the 20-year period from 1989 to 2010, in England. Incidence rates have fallen by a third and mortality has been reduced by 60%(12). This represents the success of the National Health Service (NHS) Cervical Screening Programme (CSP), which was

introduced in 1988. Nevertheless cervical cancer remains the most prevalent cancer in women under the age of 35years, in the UK and in the 25-34year old group there has been an rise in the incidence rate(13). It has been hypothesised that this is due to a number of factors. Firstly it is believed that this reflects the higher burden of HPV infection and smoking prevalence in this cohort(14), secondly participation with cervical screening has declined over the last ten years(15) and lastly it has been debated that the change in the screening commencement age from 20years to 25years that took place 2003, has had an effect(16-19). Migration of women, particularly from EE countries is also felt to play a part(20), although this effect has not previous been quantified.

Cervical cancer is known as the two-peak cancer as it has two age specific incidence peaks. The first is in women aged 30-34years and the second in women aged 80-84 years. In the England the lifetime risk of developing cervical cancer is 1 in 134(1).

### **1.1.2 Risk Factors**

Persistent infection with high risk HPV (hrHPV) is the main aetiological factor that is responsible for both pre-malignant and malignant disease of the cervix(21, 22). Factors associated with increased susceptibility to acquiring HPV infection will therefore also increase the risk of cervical cancer. This includes age at first sexual intercourse, those who first have sexual intercourse under the age of 18 years are twice as likely to develop cervical cancer compared to those who are over 21 years old at sexual debut (23). Multiple sexual partners(23) and also the male partner's sexual activity, particularly the number of sexual partners and female prostitutes as sexual partners, have been identified as key determinants of cervical cancer risk(24), whereby men act as the transmission vector for hrHPV. Male circumcision has been associated with a reduced risk of penile HPV and in this group, the current female partners of men who have had multiple sexual partners will carry a lower risk of cervical cancer compared to partners of uncircumcised men(25). Previous infection and co-infection with herpes simplex virus type 2 and chlamydia have also been recognised as predictors of cervical cancer(26, 27). In addition, immunosuppression as a result of infection with human

immunodeficiency virus (HIV) (28) or iatrogenic immunosuppression following an organ transplant(29) results in a greater risk of developing HPV related cancers.

Smoking has been identified as a risk factor for cervical cancer, even after allowing for exposure to HPV infection. Smoking duration is positively correlated with increasing risk; however, more importantly smoking cessation for at least 10 years halves the risk(30), emphasising the benefit of smoking cessation.

The combined oral contraceptive pill has been linked with an increased risk of cervical cancer; the risk increases with duration of use and doubles after 5 years(31). There is a decline in risk with time from last use and after 10 years of no use it is similar to that of never users(32).

Thus far there is a lack of evidence supporting the genetic nature of cervical cancer and studies, which have explored familial aggregations, have failed to clearly discriminate between shared environmental and genetic effects(33).

### **1.1.3 Pathophysiology**

#### **HPV**

HPV is a small non-enveloped double stranded DNA-virus that infects epithelial cells of cutaneous and mucosal surfaces(34). The viral genome is divided into three functional regions early (E), late (L), and a long control region (LCR or noncoding region [NCR])(35). The early region has viral proteins which have a regulatory role in the infected cells, the late region encodes for two proteins (L1 & L2) that form the viral capsid and the LCR contains sequences which control viral replication and transcription(36). There are over 160 types of HPV that have been identified(37), each correlating to epithelial infection at a specific site(38). The most clinically relevant group of HPV is known as the alpha-papillomaviruses, this group contains all the HPV sub-types responsible for genital and mucosal infection(39). This subset is further divided into high-risk oncogenic and low risk types(40).

HPV is the most common viral infection of the reproductive tract(41), however the prevalence of cervical HPV worldwide varies significantly (42). In addition, there is

evidence of regional differences in HPV sub-types in women with low-grade squamous intraepithelial lesions (LSIL)(43) and also in those without any cytological abnormalities(42). The ARTISTIC trial, which evaluated the effectiveness primary HPV screening within the NHS CSP in Greater Manchester, showed that the most prevalent hrHPV subtypes across all ages were HPV types 16 (3.3%), 52 (1.5%), 18 and 31 (both 1.3%), 51 (1.2%) and 39 (1.1%)(44). A review of HPV prevalence and type distribution across Central and Eastern Europe found that HPV 16 was the most prevalent hrHPV subtype in women with normal cytology (2.8%) and the combined HPV 16 and 18 prevalence was 4.0% (range 3.3–21.0%)(45). Further HPV 16 and 18 were found in 75.7% (range in individual studies 47.1–90.5%) of all cervical carcinomas(45).

Transmission of genital HPV is principally through genital skin-to-skin contact primarily during sexual activity(46).

### **HPV and Cervical Cancer**

Professor Zur Hausen first identified the role of HPV in cervical cancer in 1983(47); he was later awarded a Nobel prize for his discovery. It is now known that HPV is prevalent in 99.7% of all cervical cancers(48).

High-risk HPV gains cell entry by infecting the cervical epithelium at the squamo-columnar junction that exists between the endo and ecto cervix or by binding to receptors on the basement membrane, infecting the basal epithelium(36). Following cell entry, the virus commences replication and progresses to the surface epithelium with basal cell differentiation. The production of the E6 and E7 viral oncoproteins deregulate the host cell growth cycle. E6 binds to the tumour suppressor protein p53 and E7 to the retinoblastoma gene product, pRB(49). Stimulation of cell growth, prevention of differentiation and chromosomal instability as a consequence of increased E6 and E7 activity result in tumorigenesis(36).

The development of cervical cancer occurs over many years in a stepwise fashion following sexual acquisition of oncogenic HPV(50). The first of which is viral persistence, in the majority HPV infection is transient and in most the virus will be

spontaneously cleared by the body's immune system after 6-12 months(51). However, it is when there is persistent infection with hrHPV that cervical cancer may develop(40). It is believed that multiple factors may be responsible for persistent HPV infection. These can be divided into host, environmental and viral factors. Host factors include any condition that results in immunosuppression. Smoking more than 20 cigarettes per day(52) and the use of oral contraceptives(53) are environmental factors that have been found to correlate with the increased risk of viral persistence. In addition, the various types of HPV will have differing patterns of persistence, HPV type 16 is more prone to generate a persistent infection of longer duration than other hrHPV types and as a result is the most oncogenic (54).

Persistent infection may progress to the precancerous lesion, cervical intraepithelial neoplasia (CIN)(55), progressing from LSIL or CIN 1 through to high-grade squamous intraepithelial lesions (HSIL) or CIN 2/3 (56). However more recent theories on the natural history of cervical cancer question this stepwise progression from a low-grade lesion to a high-grade one and instead propose that they are two separate entities(57). The Bethesda classification system is used to describe the degree of cytological and histological abnormality(58). Low-grade lesions are likely to spontaneously regress in immune-competent women without any treatment in up to 58% of women over 24 months(59). For high-grade disease (CIN2/3) it is more difficult to accurately determine the spontaneous regression rate, as treatment is usually recommended for these lesions. An unethical study conducted by Dr Herb Green showed that untreated CIN3 has a high propensity to progress to cervical cancer(60). It was found that in the group of women who only underwent a diagnostic biopsy (punch or wedge) and received no further treatment for CIN3, 31% developed cervical cancer over 30 years(61). Furthermore, in the subset who had evidence of persistent disease following the initial biopsy, during follow up period (6-24 months), 50% developed cervical cancer over 30 years(61). However, spontaneous regression rates for high-grade lesions have been found to be as high as 58% and 47% for CIN 2 and CIN 3 respectively, over a six-month period(62).

## **1.2 CERVICAL CANCER PREVENTION**

### **1.2.1 Primary Prevention**

#### **1.2.1.1 HPV Vaccine**

Four prophylactic vaccines against high-risk HPV have been developed for the primary prevention of cervical cancer: the monovalent vaccine (HPV 16)(63), the bivalent vaccine (HPV 16/18)(64), the quadrivalent vaccine (HPV 6/11/16/18)(65) and the nonavalent vaccine (HPV 6/11/16/18/31/33/45/52/58)(66). The bivalent and quadrivalent vaccines were licensed for clinical use in 2006/2007; they provide protection against hrHPV 16/18 thought to be responsible for 70% of cervical cancers(67) and the quadrivalent vaccine provides additional protection against low risk HPV 6/11, which are causative for 90% of genital warts(68). Furthermore, the newer nonavalent vaccine is believed to increase the protection conferred by the vaccine from 70% to 90%(21, 69). It has been approved for use in the European Union(70) but it is not currently available as part the national HPV immunisation programme in England.

The vaccine is most effective when it is given to HPV naïve women(65); hence it is recommended that adolescents be vaccinated prior to becoming sexually active. This would require vaccination to occur approximately between the ages 9-13 years(71). The median age of first sexual intercourse, in Britain, in women aged 16-24 has been reported as 16 years (10th, 90th centile: 14, 20 years)(72). In an adolescent sample of 27,702 from 17 European countries, stated that overall 13.5% of girls and 15.4% of boys initiated sexual activity before the age of 15(73). However, vaccination at an early age has raised concerns regarding long-term vaccine efficacy particularly as the adolescent becomes sexually active, increasing their risk of exposure to HPV. Nevertheless, a recent a study has demonstrated sustained vaccine efficacy up to 9 years post vaccination(74).

The beneficial effects of the vaccine are already evident in countries with established vaccination programmes, with significant decreases in prevalence of vaccine HPV types(75), reduction in high-grade cervical disease(76) and incidence of genital warts(77). The main outcome measure reported for vaccine efficacy is the development of high grade CIN (CIN 2+) rather than cervical cancer, however in view of the natural



history of cervical cancer (described previously); it is logically to assume that by reducing the risk of development of the pre-cancerous lesion that the risk of cervical cancer is also in turn reduced. Additionally the recommendation by the World Health Organisation to assess HPV vaccine efficacy, was to look at the development CIN2+ lesions as the main endpoint(78). Cervical cancer as an endpoint was believed to be unethical.

A systematic review assessing HPV vaccine efficacy concluded that in women aged 15-26 who were HPV negative, the vaccine reduced the risk of CIN2+ (from 164 to 2/10,000 [RR 0.01 (0 to 0.05)], CIN3+ and adenocarcinoma-in-situ associated with HPV 16/18 (CIN2+ from 164 to 2/10,000 [RR 0.01 (0 to 0.05)], CIN3+ from 70 to 0/10,000 [RR 0.01 (0.00 to 0.10)] and adenocarcinoma-in-situ from 9 to 0/10,000 [RR 0.10 (0.01 to 0.82)](79). With regards to vaccine related adverse effects, no increase in serious adverse effects was noted and pregnancy outcomes such as miscarriage and terminations were also not affected(79).

In England HPV vaccination commenced in 2008 as part of the national vaccination programme. Currently it is offered to all adolescent girls aged 12-13years and is available to men-who-have-sex-with-men (MSM) aged 16-40 years, via sexual health clinics(80). Vaccine delivery in adolescents is through school based programmes and vaccine coverage for the two dose regimen reached 85% in 2015/2016(81).

#### **1.2.1.2 HPV Vaccination in Eastern Europe**

The implementation into a national immunisation programme and funding for HPV vaccination has varied across Eastern Europe (Table 1.1). In some countries despite the availability of free of cost HPV vaccination, uptake has been poor, reaching a maximum of only 54% in 2012 in Latvia and 55% in Slovenia in 2011/2012(82). In Romania there have been several attempts to introduce a national HPV vaccination programme. Initially in 2008 a school-based vaccination programme was implemented but was suspended within the first year due to low uptake(82). It was then re-launched following an information increasing campaign in 2010, however, uptake still remained low at <5% (83). Currently the vaccine is recommended for 11-14 year old girls but is not fully funded(84). However, due to the paucity of up-to-date data on vaccine coverage and

lack of standardised reporting it is difficult to fully evaluate and compare the various vaccination programmes.

**Table 1.1 HPV vaccination in Eastern Europe**

<b>Country</b>	<b>Population vaccine recommend for</b>	<b>National vaccination programme</b>	<b>Funding/ Target population/Delivery</b>	<b>Coverage</b>
<b>Bulgaria(82)</b>	12-26years Females	Since 2012	Fully state funded 12 year old girls Health centres/primary care	14%*
<b>Czech republic(82)</b>	9-25/26 years Females	Since 2012	Fully covered by General health insurance Paediatricians 13 year old girls	N/A
<b>Estonia(82)</b>	12 years and above Females	Not implemented	-	-
<b>Hungary(85) (86)</b>	9 years and above Females	2014	Fully state funded School based vaccination 12-13year old girls	N/A
<b>Latvia(82)</b>	12 years Females	2010	Fully state funded School based vaccination 12year old girls	53.4% (2012)
<b>Lithuania(84)</b>	-	-	-	-
<b>Poland(82)</b>	12-13 years Females	-	-	-
<b>Romania(82, 83)</b>	12-24 years Females	2008 2010	Not funded Recommended for 11-14year old girls(84)	<5%
<b>Slovakia(82)</b>	12 years Females	Recommended only for 12 year old females	Partial reimbursements of costs (89% of the total price of the bivalent vaccine and 92.5% of the total price of the quadrivalent vaccine. 12 year old girls	-
<b>Slovenia(82)</b>	9-26 years old Females	2009/2010	Fully state funded School based vaccination 11-12year old females	54.9 (2011/2012)

## **1.2.2 Secondary Prevention**

### **1.2.2.1 Screening**

Screening in the context of medicine is a method of identifying healthy individuals who may be at an increased risk of developing a particular condition. Wilson and Jungner in 1968, defined a set of screening criteria to aid the selection of conditions which would be amenable to screening(22). The following were identified as key principles of a screening test/ screening programme(87):

- The condition sought should be an important health problem.
- There should be an accepted treatment for patients with recognized disease.
- Facilities for diagnosis and treatment should be available.
- There should be a recognizable latent or early symptomatic stage.
- There should be a suitable test or examination.
- The test should be acceptable to the population.
- The natural history of the condition, including development from latent to declared disease, should be adequately understood.
- There should be an agreed policy on whom to treat as patients.
- The cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
- Case-finding should be a continuing process and not a “once and for all” project

### **1.2.2.2 Cervical Screening**

Dr George Papanicolaou in the 1940s described a staining technique of vaginal cells, which he claimed could identify precancerous cells of the cervix(88). Although this discovery was initially met by scepticism by some(89), it has permitted the development of cervical screening programmes all around the world. It was believed that in the absence of stopping the whole population from smoking, cervical cytology was the only way of significantly reducing the burden of cervical cancer(90). Cervical screening meets the criteria for an effective screening programme described by Wilson and Jungner above; it has recognisable pre-malignant stage(88), a long latent phase in

which pre-malignant or early invasive disease can be recognised and treated(50) and the screening programme has been found to be cost effective(91).

In 1988 the NHS CSP was launched in England and in the subsequent two decades cervical cancer incidence rates fell by over one third and mortality was reduced by 60%(92). However, between 2008- 2009 there was a transient increase in the incidence rate; it was thought that this was secondary to the publicity that resulted from the diagnosis of cervical cancer in and the subsequent death of a major TV celebrity(93, 94), prompting increased attendance for cervical screening and hence diagnosis of cervical cancer. The screening decisions of younger women and those from a lower socioeconomic background were influenced by this story to a greater extent than older women and those from a higher socioeconomic background(95).

Currently the NHS CSP provides screening for a target population of 14 million women aged between 25-64years old(96). The age of screening commencement changed from 20years to 25years in 2003. This rationale for this change was that the prevalence of HPV infection and the associated low grade changes are high, in women below 25 years, and are likely to spontaneously resolve(97). Additionally, there is a risk of increased anxiety levels in these women(98) and the negative consequences of potentially unnecessary treatment, such as increased risk of preterm labour(99). There is no evidence to support that screening women below 25 years reduces the mortality from cervical cancer and additionally women screened aged 20 to 24 are at no lower risk of cervical cancer than non screened women of the same age(100). The women are invited for cervical smears at 3 yearly (between 25-49 years) and 5 yearly (50-64years) intervals(101). A UK audit of screening histories of women aged 20-69years with invasive cervical cancer (n= 1,305) and age matched controls (n= 2,532) showed that, screening was less effective at preventing cervical cancer in younger women (<40 years) and that annual screening offered minimal additional protection over the 3 and 5 yearly screen intervals (102). Over the last ten years there has been a gradual but steady fall in the screening coverage rates, in 2015 73.5% of all eligible women had been adequately screened. The lowest screening coverage was in the 25-29 year old age group in which only 63.5% were screened in 2015, followed by the 30-34 year old group which had a screening coverage rate of 70.4%(103). Conversely it is in the 25-34

year age group that there has been a overall increase in cervical cancer incidence rate of ~ 52% since 2000-2002(1). Furthermore, the peak number of new diagnoses of cervical cancer between 2009-2013 was observed in the 25-29 year old age group followed by the 30-34 and 35-39 year old groups(96). In the 25-29 year old group 28% had had no prior cytology compared to 16% of controls but reassuringly 65% of the 25-29 years had micro-invasive disease, stage 1A(96) at the time of diagnosis. However it has been predicted that with the HPV vaccinated cohort commencing screening and with the introduction of primary HPV screening (see below), that the peak age of cancer diagnosis will change from 25-29years between 2011-2015 to 55-59 years between 2036-2040(104).

#### **1.2.2.3 HPV Triage and Test of Cure (TOC)**

HPV testing in the form of “HPV triage” and “TOC” were introduced into the NHS CSP in England in 2011(105). All women with a screen result of borderline nuclear changes or mild dyskaryosis now undergo testing for hrHPV. Those who are negative for hrHPV return to routine recall, where as those who are positive require further investigation in the form of colposcopy. HPV triage permits earlier return to routine recall of approximately one third of women, reducing the anxiety and physical discomfort associated with colposcopic examination(106). Additionally HPV triage is more sensitive for the detection of CIN 2 +, compared to repeat cytology(107). HPV TOC consists of high-risk HPV testing six months post treatment in all women who have a negative/borderline/mild dyskaryotic result on cytology. HPV testing post treatment (TOC) has a higher sensitivity and similar specificity at picking up residual disease than follow-up cytology alone(108). Previous studies have demonstrated that TOC at six months post treatment results in a 10-year risk of developing CIN 3 + of 2.1% (if negative for high-risk HPV), 2.8% (if cytology negative) and 1.4% (if both high-risk HPV and cytology-negative)(108).

#### **1.2.2.4 Primary HPV Screening**

In light of the strong causative association between HPV infection and the development of cervical cancer, primary HPV screening has been proposed as an alternative to screening with cytology. Primary HPV screening has been shown to be more sensitive

at detecting CIN 2+ disease and may permit extended screening intervals(108, 109). HPV testing, as well as having greater sensitivity is more reproducible and less prone to human error, as it does not require human interpretation(110). However, it is acknowledged that HPV infection is very common and in the majority the infection is transient(111), without any clinical implication and therefore there is a risk of over investigation and possibly overtreatment.

Currently in England primary HPV testing with cytology triage is being piloted at six sites. Preliminary results from the pilot study in England have shown an overall HPV positive rate of 12.9% and referral rate of 4.3%. Both the HPV positivity rate and referral rate declined with increasing age. On the whole, results thus far demonstrate that primary HPV screening is superior in detecting CIN 2+ disease with a slightly higher referral rate compared to primary cytology screening(112). Following a review of the results from the six pilot sites for primary HPV testing in England and the adoption by other countries such as Australia and the Netherlands, the UK National Screening Committee in January 2016 announced that it should be adopted nationally(113) and there are plans for it to be rolled out across the whole of England by 2019(114).

Prior to full implementation, consideration will need to be given to the acceptability issues surrounding HPV testing. A study amongst Hindu women in the UK found that they would prefer cytology screening due to the stigma associated with testing positive for HPV and the possible implications it may have on their relationships(115). Women from other ethnic backgrounds in the UK have raised similar concerns regarding HPV testing but these have been found to be especially pertinent to women from South Asian backgrounds(116). Muslim women fear that HPV testing may provoke questioning of trust and fidelity within their marriages(117).

#### **1.2.2.5 Cervical Screening in Eastern Europe**

As a consequence of the various political and economic changes that took place in the post-communism transition period, preventive healthcare suffered and in some countries cervical screening programmes that were previously supported and subsidised by the

state were dissolved(118-120). Many of the cervical screening programmes that currently exist in EE are very primitive and lack rigorous quality assurance. Contemporary data on screening practices and screening coverage is difficult to obtain, in part due to the lack of robust databases and also because of the large proportion of women choosing to have cervical smears in the private sector outside an organised programme (118, 121). There is a concern that by accessing screening outside an organised programme that a small minority of women are being over-screened, whilst the majority remain under-screened.

In many EE countries there is a traditional practice of annual “gynaecological screening” consisting of a full pelvic examination, smear test and colposcopy(122), which tends to be favoured over organised cervical screening. It is a practice that is promoted by gynaecologists and expected by the public(123). The most recent figures available show that screening coverage rates within EE, with the exception of Slovenia, are low ranging from <10%-59%(118, 121, 124). The main method of screening is conventional cytology, with HPV triage and TOC only being adopted by a few (Table 1.2).



**Table 1.2 Cervical screening in Eastern Europe**

<b>Country</b>	<b>Type of screening/ Start date</b>	<b>Screening age/interval</b>	<b>Screening Test</b>	<b>Quality Assurance</b>	<b>Coverage*</b>	<b>Funding</b>
<b>Bulgaria (118, 119, 124)</b>	Opportunistic Mid 1990's	30-59 years 3 yearly	Conventional cytology	No	N/A	Only for those with health insurance
<b>Czech Republic (118, 121, 124)</b>	National organised screening 2008	26-60 years Annually	Conventional cytology HPV triage/TOC	Yes	55%	Public health insurance
<b>Estonia (118, 121)</b>	National organised screening 2006	30-59 years 5 yearly	Conventional cytology	No	35%	Health insurance
<b>Hungary (118, 121, 124)</b>	National organised screening 2002	25-64 years 3 yearly	Conventional cytology	Yes	<10%	Health ministry/ National health insurance
<b>Latvia (118, 121, 124)</b>	National organised screening 2009	25-70 years 3 yearly	Conventional cytology	Yes	59%	State funded
<b>Lithuania (118, 121, 124)</b>	National organised screening 2004	25-60 years 3 yearly	Conventional cytology	No	40%	Health Insurance
<b>Poland (118, 121, 124)</b>	National organised screening 2004	25-59 years 3 yearly	Conventional cytology HPV triage	Yes	25%	State funded
<b>Romania (118, 121, 124, 125)</b>	National organised screening 2012	25-64 years 5 years	Conventional cytology	Yes	8.1%	Ministry of health
<b>Slovakia (118, 121, 124, 125)</b>	Opportunistic 1980's	23-64 years 3 yearly	Conventional cytology HPV triage/TOC	Yes	N/A	?
<b>Slovenia (118, 121, 124, 125)</b>	National organised screening 2003	20-64 years 3 yearly	Conventional cytology HPV triage/TOC	Yes	72%	Health Insurance Institute of Slovenia

\* Latest reported figures

### **1.3 HEALTH BEHAVIOURS**

Health behaviour may be defined as “any activity undertaken by a person who believes himself to be healthy, for the purpose of preventing disease or detecting it in an asymptomatic stage” (Page 531)(126). It refers to personal attributes (beliefs, expectations, motives and perceptions) and actions relating to health maintenance, restoration and improvement(127, 128). The health belief model (HBM) has been proposed as an aid to explain and/or predict health related behaviours. It has been argued that one limitation of the HBM is that there is an unrealistic emphasis on rationalising health behaviours and that it actually lacks predictive value(129). However, as the HBM focuses on the belief-based psychological factors in relation to health decisions/behaviours, it identifies factors that might be amenable to change as apposed to demographic factors that cannot be changed(130). The key principles underpinning the HBM are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy(131, 132). Additionally, demographic and socio-psychological variables such as age, gender, race, ethnicity, social class and personality have also been identified as health modifying factors(133).

#### **1.3.1 Cervical Screening Health Behaviours**

Factors affecting cervical screening behaviours have been extensively studied and many of the identified elements fit into the categories specified in the HBM. Consequently, they identify features prevalent in the “non-attender” group but do not necessarily provide predictive information. Listed below are common variables that have been found to influence participation with cervical screening. The rationale governing one’s screening behaviour is multifaceted; therefore, it is likely that these variables do not act independently and that complex interactions exist between them. Similarly, interventions to improve screening uptake would need to involve multiple strategies, rather than a single intervention.

## **Ethnicity**

When interpreting data on ethnicity it is vital that the way in which ethnicity is defined and ethnic groups are divided is considered. The concern is that the heterogeneity that exists within ethnic groups can be missed. Yet, it is known that the ethnicity of the women can affect screening uptake (134). In addition to the overall affect on screening behaviours that ethnicity and cultural background have; they can also influence the other independent variables that impact screening uptake, this will be discussed in detail under each of relevant variables.

Women from non-white ethnicities in England are less likely to be screened(135, 136), however, it is possible that this might be due to practical barriers rather than ethnicity alone(137). Women of Black and Asian ethnic minority groups have lower screening uptake and this finding persists even after accounting for socioeconomic status(138). Their low self-perceived vulnerability and language barriers could provide an explanation for low uptake(138). Additionally, poor knowledge and their underlying cultural and health beliefs form further barriers(139). Interventions thought to promote screening uptake in the Asian ethnic population include increasing cultural awareness in healthcare professionals through a combination of training and outreach work(140) and the use of culturally tailored online resources(141). The use of media campaigns and mailed material in isolation have been shown to be ineffective(140). A Swedish study has proposed the use of doulas that are of the same cultural background as the migrant population, as a mode to close the gap between service users and healthcare professions and hence promote screening(142).

Whilst the cervical screening behaviours of the non-white ethnic groups have been extensively explored(138, 143, 144), there is limited data available on white ethnic minorities, such as the migrant EE population. Their individual needs can go unrecognised as they are often aggregated in the general “white ethnic group” category. However, in England they are a growing migrant group and have some of the highest cervical cancer incidences rates within Europe(145). Cervical screening programmes in many EE countries, where available, are relatively new and lack rigorous quality assurance and validation. It has been postulated that this results in the development of poor cervical screening health behaviour, which is maintained even after migration. The

prevalence of hrHPV has been found to be high in the migrant EE population(146), reflecting the increased incidence in their country of origin. Additionally, in England higher rates of smoking and sexual ill-health have been witnessed in this group compared to the national population(147). UK data from the Midlands has revealed that 15% of cervical cancers occurred in women born outside the UK and 15% (10/67) of these were from EE(148). Furthermore, in Leicestershire specifically migrant EE women were over represented in the cervical cancer cohort, they accounted for 7.4% of cervical cancers in 2013 compared to a background EE population in Leicestershire of only 2.6%. In these women, the median duration of stay in the UK prior to diagnosis was 5 years (range 2-8 years) and none had participated in the NHS CSP despite numerous invitations(148). This pattern of behaviour has also been noted in other Western European countries; a study conducted in Spain found that migrant women from EE were less likely to have cervical screening compared to the native population and that 74.2% perceived themselves to be in good health and therefore lacked appreciation of the need for preventive medicine(149).

The limited work that has been done in this group of women in the UK has demonstrated that, similar to other ethnic minority groups, language is a major barrier in accessing healthcare for these women(150, 151). This results in communication issues and having to be reliant on interpreters. Furthermore, when interpreters are not available, these women may have to use friends or relatives to interpret, this can result in them having to share personal and possibly sensitive information which some women may be uncomfortable doing.

There is a lack of awareness of the structure of the healthcare system in the UK and they do not fully appreciate the differences between primary, secondary and emergency care services(151). They can also experience difficulties with registering with a GP, as a result of not being able to produce the relevant documents required for this process(151). Delay in registering with a GP can result in delays in accessing preventative health care(152), such as cervical screening. Migrant EE are also often a transit mobile population, moving houses frequently and so failure to inform their GPs of changes of address can further perpetuate the problem(150).

With regards to cervical screening, even those women who appear to appreciate the importance of cervical screening do not fully participate with the NHS CSP(150). 90% of cervical cancers diagnosed in migrant EE women have been shown to be associated with non-compliance, compared with only 46.7% in the UK-born(148). There is frustration regarding the perceived “long” smear interval in the UK of three years, compared to the annual smears offered in some EE countries(147). This along with the above-mentioned reasons may deter women from participating with the NHS CSP. However, there have been no large scale studies exploring the rationale governing cervical screening behaviours, cervical cancer and HPV awareness in this expanding, heterogeneous group in the UK.

### **Age**

The data on age have been inconsistent, with some studies showing that older age correlates with an increased likelihood of attending for cervical screening compared to younger age(135, 138, 153), whereas the reverse has been demonstrated in other studies(137, 154). It has also been argued that younger age in itself as a causative factor is a fallacy and in fact it is the practical barriers that younger women face which inhibit them from participating with screening(155). Furthermore, younger women are more likely to be geographically mobile and hence primary care trusts may not have updated lists, resulting in a falsely lower screening coverage rate, as the patient may not have been removed from the database(135).

Self-perceived vulnerability has been found to vary with age due to differences in the causal understandings of cervical cancer(129); younger women are more likely to identify the risk of cervical cancer with sexual promiscuity, compared to older women who have linked it to smoking or a virus(156).

### **Socioeconomic status**

Lower socio-economic class and social deprivation are associated with lower uptake of screening(157, 158) and women experiencing adverse economic conditions are less likely to participate with preventative health measures(159). Higher social class may imply greater educational level and hence a better understanding of preventative health(129). Therefore, those of a higher socioeconomic status may be said to have

greater health motivation for screening. Lack of funds to access healthcare services in countries where state funded healthcare is not available may further perpetuate the problem. This is particularly applicable to many of the EE countries, where a small number of women are over screened in the private sector, whilst overall coverage in the general population is low(118).

### **Education**

Higher level of education has been correlated with greater screening attendance (136, 138, 160). However, in Hindu women it was found that even amongst the highly educated cohort, screening attendance was lower than that in the general population(115). This suggests that in some instances cultural influences outweigh the benefits of higher educational background. Applying the principles of the HBM, it may be argued that those with a higher educational level have a better understanding of cervical screening. Consequently, they have a greater appreciation of the seriousness and susceptibility, as well as believing that screening will identify disease prior to the onset of clinical symptoms and that early detection is beneficial(129). Increased knowledge of cervical cancer and cervical screening specifically, rather than higher education in general has been suggested to promote uptake of screening in women from different cultural and ethnic backgrounds (161-163).

### **Emotional Factors**

Cervical smear examinations are a sensitive and intimate procedure. Perceptions, such as pain, fear and embarrassment, can deter women from participating. Referring to the HBM, these can be seen as psychological barriers, which may outweigh the perceived benefits of screening and hence prevent participation. Embarrassment at having the procedure performed has been found in non-attenders(137) and it is a concern that is shared amongst women from different ethnic backgrounds(138, 150). Due to the nature of the examination many women associate the feeling of pain with it, presenting another barrier against attendance(115). The perception of pain might be a result of actual pain experienced during a previous smear examination or it could be the anticipation of potential pain(137). Lastly women can fear the screen result and dealing with the potential implications of it(137, 138). Not all women fully comprehend the difference between the terms “pre-cancerous” and “cancerous” which can evoke emotions of fear

and anxiety(164, 165). The absence of or a limited social support network may make the decision of prioritising one's own health more difficult(166). It has been shown in the UK, that women from ethnic minority groups have a greater fear of the screen result compared to the general population(115), potentially making them less likely to participate with cervical screening.

### **Practical Barriers**

As described above, for some women the rationale for not attending screening is more pragmatic. For instance not having time to attend for screening due to work or childcare commitments or experiencing difficulties in obtaining appointments at a convenient time(137). The potential of losing income as a result of taking time off work is not a risk that some women can afford to take(150). The cost/benefit argument is applicable here, where the cost is loss of income and the benefit may not be as easily apparent, as the women feel well in themselves and are asymptomatic.

For some it is as simple as they "just do not get around to going" and it has been noted that women from ethnic minority groups in the UK are more likely to cite this as a reason for non-attendance(138). This again demonstrates that the benefit of screening is not fully appreciated and hence not prioritised. Lack of knowledge of cervical cancer pathology and screening could be a contributing factor(167). Misconceptions regarding the clinical manifestation of early stage cervical cancer may falsely reduce self-perceived vulnerability and the perceived benefits(168).

### **Examiner Characteristics**

Screening attendance can be influenced by examiner characteristics(135). The gender of the practitioner can be important for some, either due to cultural and/or religious beliefs or due to the intimate nature of the examination, whereby female gender is preferential and the fear of encountering a male practitioner acts as a barrier against participation(115, 169). Some women have described feeling ashamed talking to male practitioners about this topic and believe that females would be better able to empathise with them, as they can relate to the same experiences(170). Female practitioners have been shown to have a patient-centred communication style(171) and have higher overall

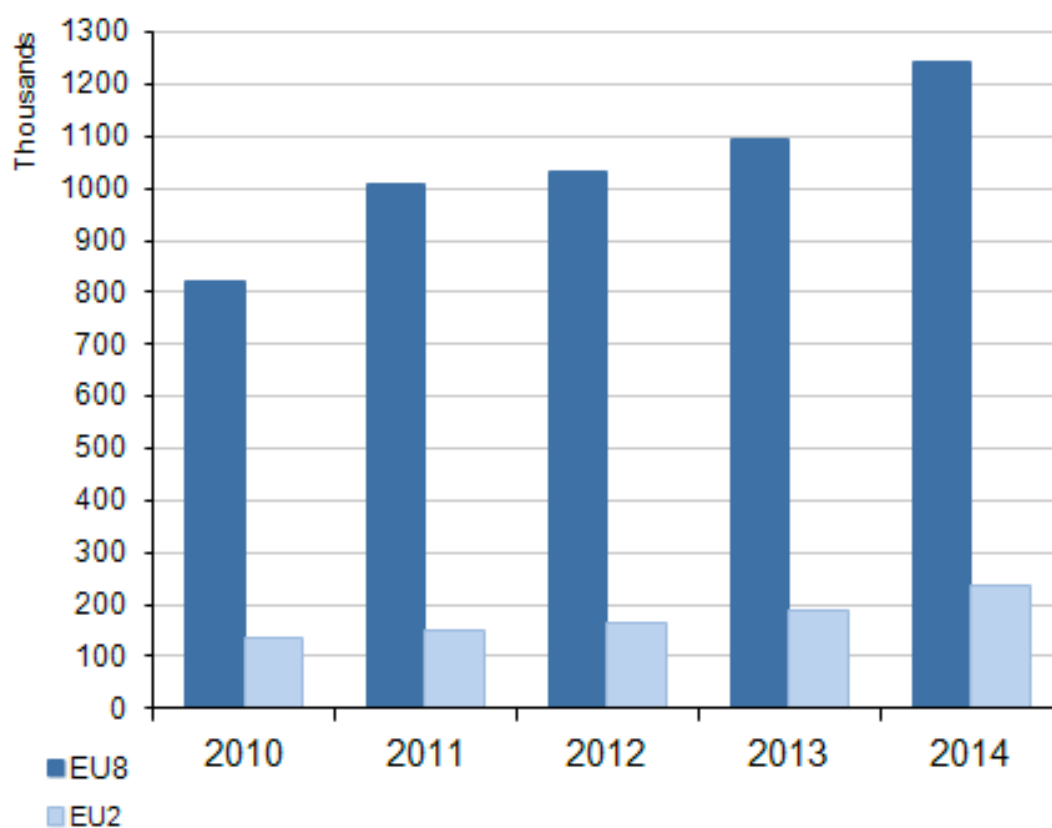
screening rates compared to their male colleagues; this finding was not limited to gender-specific screening tests(172).

However, the gender of the practitioner is not important for all women, some have no particular preference in terms of gender but are more concerned about their professional role (primary care doctor/general practitioner (GP), nurse practitioner (NP) or gynaecologist)(173). Many women prefer to have gynaecological examinations(173) and cervical screening performed by a gynaecologist rather than a GP or NP(150). Nevertheless, GPs play a vital role; they can either positively or negatively influence the women's perception of screening(174). It is debatable which of these two factors is more important to the women; one study has found that gender is superior particularly in the group of women who are reluctant to participate in screening(175). However, the choice between gender and role may not be a simple one and factors such as personal preferences, past experiences, cultural and religious beliefs are likely to have an impact.



## 1.4 MIGRATION PATTERNS

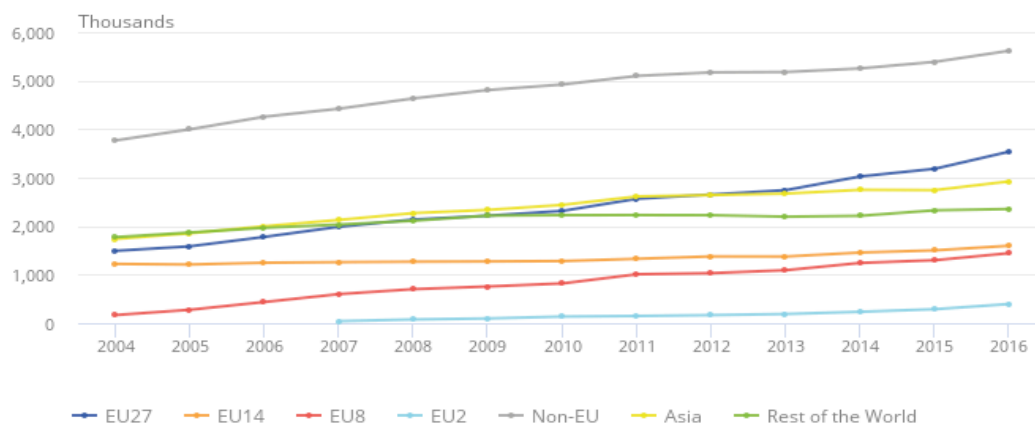
The Population by Country of Birth and Nationality Report: August 2015, showed that there has been a significant increase in the migrant EE population to the UK; between 2013-2014 the UK population from the 2004 European Union (EU) accession countries (Czech Republic, Estonia, Poland, Hungary, Latvia, Lithuania, Slovakia and Slovenia) had increased from 1,092,000 to 1,242,000(176). Romania and Bulgaria joined the EU on 1<sup>st</sup> January 2007. Since 2007 the numbers of UK residents from these two countries has increased substantially from 42,000 in 2007 to 235,000 in 2014(176). Figure 1.1 shows that from 2010 to 2014 the migrant populations overall from both the 2004 (EU8) and the 2007 (EU2) accession countries have grown at a substantial rate.



**Figure 1.1 EU Accession population resident in UK, by country of birth, calendar years 2010 to 2014**

Source: Annual Population Survey, ONS(177) (Contains public sector information licensed under the Open Government Licence v3.0.)

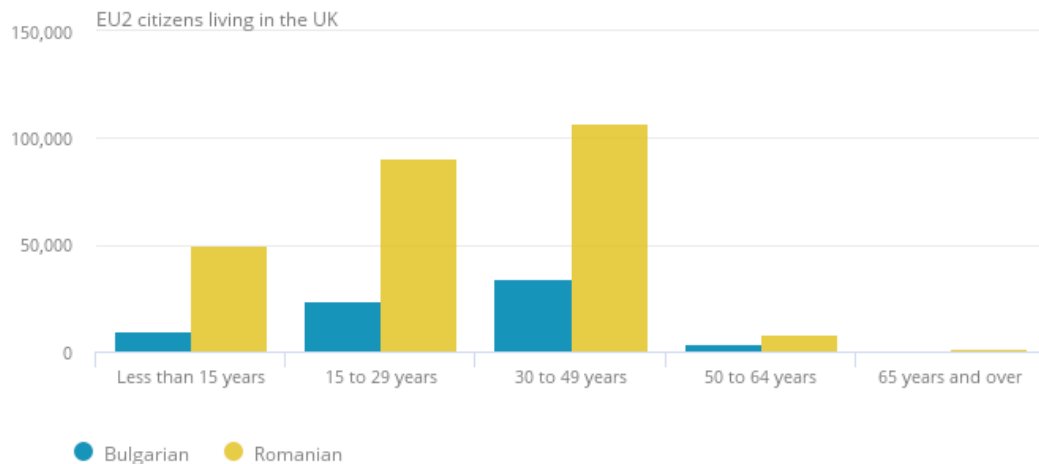
The most recent Annual Population Survey report showed that for the year ending 2016, the most common non-UK country of birth was Poland and the most common non-British nationality in the UK was Polish(178). Additionally in 2016 there was a statistically significant increase in the populations from the EU8 and EU2 countries (Figure 1.2), supporting a continued trend of growth in population from these countries.



**Figure 1.2 Estimates of the non-UK born resident population of the UK by country of birth, 2004 to 2016**

Source: Annual Population Survey, ONS(178) (Contains public sector information licensed under the Open Government Licence v3.0.)

Data adapted from the last UK census report in 2011 showed that, of the migrant Polish population 51% was female and the average age at migration 30.1 years(179); a detailed breakdown for the other EE countries was not provided in this report. However more recent data has shown that 73% of the EU8, 81% of Bulgarian and 77% of Romanian citizens living in the UK, are aged between 16-49 years(180). Figure 1.3 shows a breakdown of the ages of the Bulgarian and Romanian populations in the UK. Although this data does not provide information on the gender of these groups, it does inform us that the migrating population from these countries largely falls within the cervical screening age limits in England.



**Figure 1.3 Age of EU2 citizens living in the UK, 2014 to 2016**

Source: Office for National Statistics, Annual Population Survey, pooled data, 2014 to 2016(180) (Contains public sector information licensed under the Open Government Licence v3.0.)

The full effect that the vote to leave the EU will have on the EU8 and EU2 populations with regards to both migrations to and from the UK is yet to be seen. However in the latest migration statistics report the following was quoted *“The first full year of data since the EU referendum vote in 2016 shows a decrease in the number of people coming to live in the UK and an increase in the number leaving, resulting in a fall in net migration of 106,000”* (Page 3)(181). Nevertheless, it was acknowledged in the report that the reasons for migration are multifaceted and “Brexit” alone might not be the only determining factor. The results of this study will still be of relevance to the large EE population that is already residing in the UK and it is probable that the groups of EE population who have established roots (employment or family etc.) are unlikely to migrate back to their country of birth. Furthermore, it is not known when the UK will actually leave the EU and in the interim there is still a large EE population who are part of the healthcare system in England and have the potential to contribute to the predicted increasing incidence of cervical cancer (projected to rise by 43% in the UK between 2014 and 2035, to 17 cases per 100,000 females by 2035)(182).

## **1.5 THESIS AIMS**

1. To investigate the health beliefs, cervical screening behaviours, knowledge of cervical screening and the Human papilloma virus, of women born in an Eastern European country (from the 2004 and 2007 EU accession countries) who have migrated to England
2. To compare the behaviour, beliefs and knowledge of the migrant EE population with that of indigenous, White British, English-born women
3. To identify the barriers which prevent or discourage migrant EE women from participating in the NHS CSP

To evaluate the research aims, relevance of research goals and the proposed mixed methods study protocol of survey questionnaires and semi-structured interviews, two patient and public involvement groups were held. The findings of the patient and public involvement groups are discussed in Chapter 2.

## **2 PATIENT AND PUBLIC INVOLVEMENT & METHODOLOGY OVERVIEW**

### **2.1 PATIENT AND PUBLIC INVOLVEMENT**

#### **2.1.1 BACKGROUND**

The use of patient and public involvement (PPI) in healthcare research is expanding and is advocated by the National Institute for Health Research (NIHR)(183). PPI in research is believed to help prioritise research, improve research quality and relevance, as well as permitting those who are affected by the research to have a voice(184). INVOLVE, an organisation in the UK that supports and promotes PPI work, has defined PPI in research as “research being carried out with or by members of the public rather than to, about or for them”(Webpage) (185). Patient participation and engagement can be falsely labelled as PPI. Additionally, there is a danger of adopting a tokenistic approach to PPI, merely to satisfy regulator requirement(186).

When considering using PPI in research the potential benefits and disadvantages need to be explored. The way in which the lay perspective will be evaluated and how it will be incorporated into the research require thought too. Currently there is no robust method of measurement of the impact that PPI work has on health research(187) and the evidence which is available is weak(188). A recent review exploring if PPI work “is worth doing” concluded that in order to answer this question increased attention needs to be given to the context in which the PPI work takes place and the way in which it was conducted(189). The researcher’s account of PPI work allows access to new “knowledge in context” through direct engagement; this provides valuable data for others to learn from(189). The emphasis is placed on the researcher’s own skills and the detail in which their findings are reported(189). One of the challenges of using existing patients as research partners or collaborators is that there can be confusion regarding the two separate relationships/identities: the “patient-doctor” and “research partners”. Patients may deal with this by compartmentalising the two roles, for example by referring to the clinician by their title in a clinical situation and by their first name during research meetings(190). Similarly clinicians need to ensure that they maintain patient confidentiality and do not broach clinical discussions during research meetings(190).

In the context of cancer research it has been suggested that greater PPI in research, particularly of those people who have been affected by the disease, is fundamental to enhancing public confidence in cancer research(191). The development of an organised PPI infrastructure within cancer networks is believed to help facilitate consumer involvement, permitting PPI at all stages of research(192). A group of patients from the UK with a variety of cancer diagnoses identified the following as cancer research priorities: the impact on life, how to live with cancer and related support issues, risk factors and causes and early detection and prevention (193).

PPI may be utilised during various stages of the research process: conceptualising a research idea, undertaking research activity and dissemination of outcomes.

### ***Conceptualising a research idea***

The connotation of doctors and/or researchers as “experts” of what research is required has been challenged(194). Instead it is argued that lay people are better placed to identify and prioritise the research agenda(195). The lay population are the ones who will be affected and/or are the benefactors of research outcomes and therefore can provide a unique perspective(196). However, if the opinions of the researcher and the PPI group differ it can result in scientific and ethical conflicts(197). This can result in the researcher having to compromise on the academic/scientific quality of the study to ensure that the study is acceptable to the public(198). There has to be mutual respect between the two parties for PPI work to succeed.

### ***Undertaking research activity***

PPI work can aid with the development and piloting of data collection tools. With regards to questionnaire design specifically, PPI can help with validation of the questions in terms of appropriateness and language, which can result in an improved response rate(199). Additionally, PPI work can provide access to hard-to-reach communities and increase recruitment(200). However, the lay group may not have the required knowledge about research methodology and ethics to be able to comment or their views may breach these principles(198).

### ***Dissemination of outcomes***

This is an important area for PPI activity, PPI groups can advise on how best to disseminate the data so that it is both relevant and acceptable to the target audience. PPI groups have been successful in helping with the development of patient information leaflets, raising awareness and the development and delivery of education(201).

#### **2.1.2 METHODS**

Two pre-protocol PPI focus groups were set up, one for the native English population and one for the migrant EE cohort. The participants were identified from a combination of patients attending the colposcopy clinic at University Hospitals Leicester and through the adoption of snowballing(202) recruitment. The later method was used to a greater extent for the migrant EE group, who had been identified as a “hard to reach” cohort. The selected participants were sent an invitation letter, which was followed up with a telephone call to confirm participation. Those who agreed to take part then received a pack containing a draft project protocol and a draft questionnaire, for review prior to attending the meeting.

For the native English group out of the 12 women invited 5 attended and in the migrant EE group 4 out of the 11 invited women attended. A further two women from the migrant EE group who were not able to attend the focus group session assisted with questionnaire validation at a later stage. Participant characteristics of the women who attended the focus group sessions can be found in Table 2.1. The focus groups took place in a meeting room at the local hospital as this was deemed to be the most convenient place for the majority of women to meet. Each session lasted approximately one hour and the sessions were audio recorded, with the permission of all participants. The participants received a £20 thank you gift voucher and travel expenses were reimbursed. A PPI award was granted from the NIHR East Midlands Research Design Team, to enable this work. At the end of the session, the women were asked if they would like to have continued involvement with the study, those who agreed were sent the amended and translated versions of the questionnaire to assess validity.

**Table 2.1 Participant characteristics**

<b>Age/years (median/range)</b>		<b>36 (27-43)</b>
<b>Ethnicity n(%)</b>	<b>British</b>	5 (56)
	<b>Romanian</b>	2 (22)
	<b>Polish</b>	2 (22)

The aims of the PPI groups were:

1. To ascertain if the proposed area of research was thought to be significant among those women who had been affected by the disease. What were their specific concerns and what study outcomes did they feel were important?
2. To determine if the study goals were achievable with the proposed study design.
3. To assess the appropriateness and content of the study questionnaires.
4. To identify potential recruitment issues and to provide solutions.
5. To aid with dissemination of study results

### **2.1.3 FINDINGS**

#### **2.1.3.1 Migrant EE group**

##### **Their own experiences with cervical screening and access to health care in the England/ Initial thoughts on project proposal**

All participants agreed that the project proposal was an important and relevant area. Emphasis was placed on increasing awareness about the benefits of cervical screening, early detection and treatment of cervical cancer. The participants explained that some of them had underestimated the significance of cervical screening and therefore had ignored multiple screening invitations. Commitments such as work and childcare took precedence and they had no time in which to attend for smear tests. The PPI group felt that knowledge of cervical screening in EE women is poor as in many EE countries cervical screening is not very popular. Some of the EE women described that on migration to England they were unaware of how to access healthcare services in England and therefore could not participate with screening despite wanting to.



Preventative health care is largely viewed as something that is mainly accessed by the educated and/or wealthy. They envisage that these beliefs are maintained on migration and therefore they believed that studying women in their home country would be an important aspect of this study, to ascertain screening behaviours and knowledge prior to migration and how/if they change.

As a result of their own personal experiences the group felt that this is an extremely important area of health research. They articulated that the delays in their treatments could have been avoided if they had been better informed.

### **Review of study questionnaire**

The group felt that the questions were relevant and the language used was appropriate for the lay population. The group were informed that the questionnaires were going to be translated into different languages to accommodate the multilingual groups being studied; this information was well received. The group expressed that having the questionnaires in the participant's native language would result in a greater response rate and would also enhance their understanding of the questions.

### **Recruitment of participants**

None of the women in this PPI group were aware of or part of any EE community groups in the locality however, they were able to provide information about areas where many EE resided and where speciality shops were based. They felt that these would be good areas from which to recruit participants for the study. Recruiting from primary and secondary care alone would exclude those women who have difficulties in accessing healthcare in the first instance. It was highlighted that there may be difficulties in recruiting from this community, as they can be a closed group. They feel there is a lot of stigma associated with the migrant EE population, this may in part, be due to the way they have been represented in the media(203), this might stop them from fully integrating with society. From their own experiences of when they first arrived in England, they described that some EE women might be sceptical about taking part in something that do not fully understand. Additionally, many of them will not be able to take time off from work for the interviews, without incurring a financial penalty.

### **Dissemination of study results**

As well as the distribution of information flyers in their native languages, they felt that having someone from within their own communities to promote screening would be beneficial. They explained how they had used their own experiences to encourage family and friends to attend for screening. The consensus was that the message was taken more seriously if it came from someone you knew or could relate to.

#### **2.1.3.2 Native English group**

##### **Their own experience with cervical screening/Thoughts on project proposal**

The women in the group described the project proposal as “very interesting”. All women in the group felt that this was an important area for medical research. Within the group there were a mixture of women who had been fully compliant with screening and those who had missed some screening calls. It was those who had been fully compliant with screening who were the most “angry” with the system. They expressed that it had not been made clear to them that screening is not a diagnostic test and therefore they felt that increasing the screening frequency would have prevented them from getting cervical cancer.

They articulated that they had experienced difficulties in understanding the principles of screening and they do not even have to contend with any language barriers, therefore, it must be very difficult for the migrant population. The women questioned the knowledge of healthcare professionals, many of the women felt that they were not provided with adequate information, particularly about HPV when they attended for screening.

Having knowledge about HPV seemed to be quite important to them; even those who had undergone treatment for cervical cancer felt that they still did not have a clear understanding of what it was. They defined themselves as being “the generation of the transition period” where they have minimal awareness of HPV and are affected by it but do not know enough about it. They questioned the level of HPV awareness in teenagers/adolescents, what are they told, how much do they know about HPV or the HPV vaccine? It was evident that they felt more effort should be made to increase awareness from an early stage. The PPI group recommended that as part of this study

the level of understanding and awareness of HPV in the adolescent group should be explored. They explained that the experience of having to conduct research about HPV on their own was frightening.

### **Review of study questionnaire**

Overall, they felt that the content was relevant and sensitively presented. Queries were raised about the questions being closed questions and if more open questions need to be incorporated. However, following discussion it was concluded that the questionnaire is quite lengthy and that having too many open questions may deter women from completing it. It was felt that the survey was factual, with mainly “tick box” answers and therefore easy to complete.

It was explained to the group that, where possible pre-validated questions were used to ensure data quality and to permit meaningful comparisons of study data. Clarifications were sought on the relevance of some of the questions, for example educational level, it was explained that we were looking for correlations between education and screening behaviours and knowledge. There was some debate about additional questions being included, for example about the stigma attached with the diagnosis of HPV but the consensus was that more detailed and perhaps more sensitive questions would be better reserved for the interview stage of the study. A few women voiced that focus groups as well as one-to-one interviews should be used as some participants may find the interviews intimidating and prefer to participate in a group environment.

### **Dissemination of study results**

This group struggled to provide suggestions on how to disseminate results specifically to the migrant EE group. However, general suggestions included having a group of trained educators to disseminate results at community centre, schools and GP surgeries. It was believed that women would be more receptive to women from a similar ethnic background to themselves. More overt advertising, in the form of posters, flyers and increased use of media were suggested to increase awareness and remove the stigma associated with talking about the topic in public.

#### **2.1.4 LIMITATIONS**

The PPI work has been extremely beneficial in validating the study proposal, study material and recruitment. However, it is acknowledged that there were some limitations associated with the PPI work conducted. Firstly, for both the PPI groups the participants involved had all been through some form of cervical cancer screening and/or treatment and therefore it could be argued they do not truly represent the whole of the lay population. In the migrant EE group, women from only two of the ten EE countries of interest were represented. This is a heterogeneous group and it would be wrong to assume that they all share similar views and experiences.

None of the women had any prior training in research methodology; hence they may have struggled to offer any substantial critique. However, efforts were made to provide explanations for the rationale governing certain study design choices and the study design has been kept simple.

The two relationships of research collaborators and patient-doctor were on, occasions, muddled. Many of the women, particularly from the native English PPI group, wanted to talk about their own experiences and concerns. They requested factual information and reassurance from myself as a clinician.

## **2.2 REVISED AIMS AND OBJECTIVES**

As a result of the pre-protocol PPI work conducted the following aims were added to the ones previously stipulated:

1. To assess cervical screening practices, knowledge of cervical screening and HPV and HPV vaccine knowledge in EE women in their home countries.
2. To evaluate current HPV training and knowledge of HPV in practice nurse cervical smear takers involved in the NHS CSP
3. To assess the current level of HPV and HPV vaccine knowledge in European adolescents

It was felt that, the aim of assessing cervical screening practices, knowledge of cervical screening and HPV and the HPV vaccine knowledge in EE women in their home countries, was difficult to achieve due to the funding and time restrictions of this research project. The research team has established collaborations with University of Latvia and Riga Stradiņš University; therefore the study was replicated in Latvia. It is acknowledged that this will not provide a comprehensive comparison to the migrant EE group being studied in England, which is a heterogeneous group that comprises of ten EE countries. However, it will provide an insight into the possible effect of migration on the screening practices of one of the studied groups.

To address all of the research aims the following studies were conducted (details of the individual studies are provided in the individual study chapters). Study 1 was the initial mixed methods study proposal and the other studies were added following the PPI consultation.

**Study 1-** Behaviours, attitudes and knowledge of cervical cancer prevention strategies in migrant Eastern European women to England

**Study 2-** Cervical cancer prevention; a mixed methods study evaluating the knowledge, behaviours and attitudes of Latvian women

**Study 3** - Knowledge, attitudes and awareness of the human papillomavirus amongst primary care practice nurses: An evaluation of current training in England

**Study 4-** Knowledge of human papillomavirus and the human papillomavirus vaccine in European adolescents: A systematic review

**Study 5-** Adolescents' awareness of HPV infection and attitudes towards HPV vaccination 5 years following the introduction of the HPV vaccine in Latvia

## **2.3 METHODOLOGY OVERVIEW**

Described here are the main research methodologies that have been utilised for the above stated studies. Tailored adjustments to the methodology are detailed for each individual study in the relevant chapters.

### **2.3.1 Data collection methods**

#### **2.3.1.1 Mixed methods**

The use of mixed methods research in healthcare is growing. It involves the integration of quantitative and qualitative research methods, exploiting the strengths of both, to address a research question, where one method alone would be inadequate(204, 205). The benefits of using of a mixed methods design in preventative health research is that quantitative data collection provides generalizable results and the qualitative methods provide an insight into the rationale governing certain health behaviours(206).

The aims of Studies 1 and 2 consisted of two main parts; firstly, there was a need to establish existing screening practices and knowledge of cervical cancer prevention measures in the target groups and secondly, more in-depth exploration of their health behaviour choices was required. A mixed methods approach was therefore believed to be the most suitable.

#### **2.3.1.2 Questionnaires**

Questionnaires are useful in obtaining data from large populations and they permit coverage of greater geographical areas, without being too resource intensive(207). In order to obtain as large a sample as possible the Study 1 was conducted in three centres across the Midlands (details provided in Chapter 3) and therefore the use of questionnaires allowed standardised data collection from a large sample. In addition, it was felt that a greater volume of factual information could be acquired with the use of questionnaires particularly for the studies that were assessing HPV knowledge (Studies 3 & 5).

Anonymous, paper (Studies 1, 2 & 5) and online (Study 3) questionnaires were used for data collection.

The use of paper-based surveys has been shown to result in a higher response rate compared to computerised surveys(208). Additionally, it would not have been possible to access the cohort (lay population) of interest in the relevant studies via online measures. However, using a web-based survey tool permits access to groups who may be difficult to access, as well being cost and time efficient(209), such as healthcare professionals working across multiple institutes. The debate on the superiority of anonymous vs. confidential surveys, with regards to the quality of the data obtained, is still on going. An anonymous survey is one in which respondents are not allocated ID numbers and cannot be identified in any way and a confidential survey is one in which the respondents may be identified with a unique ID number used to link responses back to an individual(210). Some studies investigating sensitive issues have found little difference between the two approaches(211-213), whereas others have indicated that anonymous surveys may be superior(214, 215). It is believed that the perceived sensitivity by the participant of the topic being investigated, may help explain some of these discrepancies(215). One of the shortcomings of anonymous data collection is that non-responders cannot be tracked and hence, cannot be sent prompts to complete the survey, resulting in a lower response rate(216). However, the subject being investigated in this thesis has been identified as a sensitive one by the PPI groups, therefore an anonymous survey is likely to yield in a higher response rate.

#### **2.3.1.3 Qualitative interviews**

To identify the attitudes, motivations, and perceptions that influence health behaviour decisions, qualitative data collection needed to be incorporated(217). This was achieved through the use of semi-structured interviews and focus group work. The option of participating in a focus group rather than a one-to-one interview was added following feedback from the PPI groups. Focus groups reverse the power balance from the researcher to the participants(218) and thus the participants might be more inclined to engage in discussion. An American study comparing one-to-one interviews with focus groups, in a group of African-American men concluded that more sensitive data was disclosed in the focus group session(219). However, disclosure of sensitive information was incidental and not elicited or in direct response to the research question. Furthermore, other research has argued that in a focus group setting participants are less



likely to discuss sensitive or socially deviant topics(220). A potential disadvantage of the focus group is that the participants can influence each others opinions, whereby the process of negotiation and renegotiation occurs in attempt to make “collective-sense” of the subject(218). This can result in those with stronger opinions dominating the group. The topic of research in this study is a sensitive one and therefore a focus group might not be appropriate for all the women. Nevertheless, focus groups are usefully in exploring the perspectives of culturally and linguistically diverse groups(221).

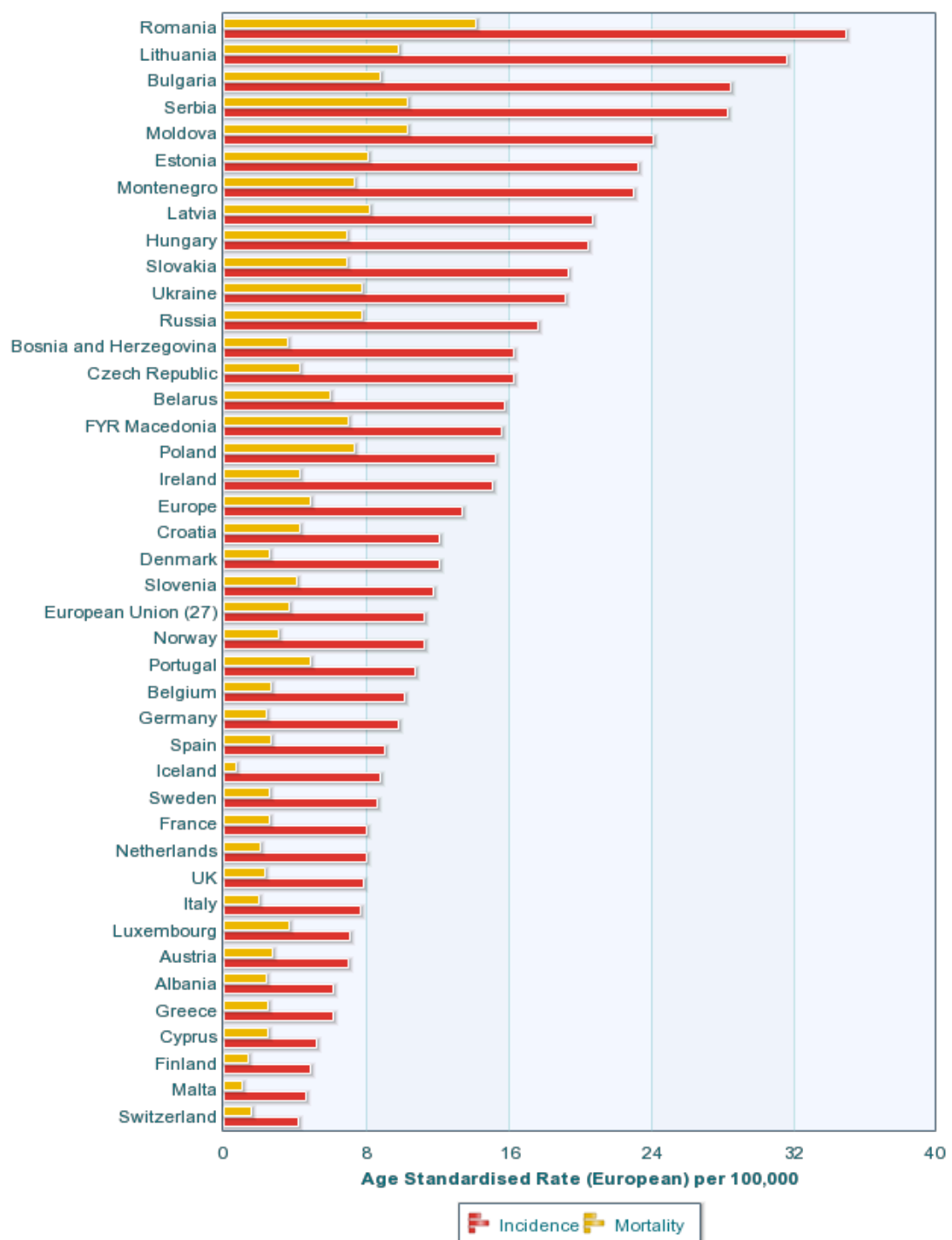
### **3 BEHAVIOURS, ATTITUDES AND KNOWLEDGE OF CERVICAL CANCER PREVENTION STRATEGIES IN MIGRANT EASTERN EUROPEAN WOMEN TO ENGLAND**

#### **3.1 INTRODUCTION**

Cervical cancer is a largely preventable cancer that affects young women. Between 2012-2014 more than half of the cases of cervical cancer in the UK were diagnosed in women below the age of 45 years(1). Further the incidence of cervical cancer in women aged 25-34 in the UK is increasing(1), whereas the age appropriate screening coverage in England has fallen from 73.7% in 2011 to 70.2% in 2016 among women aged 25-49 years(222). Within Europe, Romania, Lithuania and Bulgaria have the highest cervical cancer related incidence and mortality and seven EE, EU accession countries feature in the top ten (Figure 3.1)(145). As discussed in the introduction chapter the availability, quality and uptake of cervical cancer prevention strategies in EE is variable.

It has been hypothesised that the reduction in screening coverage noted in England might be in part due to the effect of migration of women from EE(20), where the incidence of cervical cancer is high but uptake of screening is suboptimal. Assessment of the cervical screening histories of migrant EE women from around England has shown that in Pan-Midlands between 2005-2009, 9 out of 10 EE-born women, diagnosed with cervical cancer, were non-compliant with screening(148). Unpublished data by Moss et al found that in Leicestershire in 2013 migrant EE women were over-represented with regards new cases of cervical cancer, EE women accounted for 7.4% of cervical cancers compared to a background population of only 2.6%. More recent unpublished data by Collins et al, showed that in Northwest London between 2007-2016 EE women were similarly over represented, they accounted for 28.2% of cervical cancers compared to a background population of only 6.2%. Further 90% of EE women had not previously had a smear test performed in the UK prior to their diagnosis, compared to only 52% of UK born women.

The aims of this study were to determine the cervical screening behaviours of migrant EE women to England and explore their knowledge and attitudes towards the NHS CSP, HPV and the HPV vaccine.



**Figure 3.1 Estimated incidence and mortality from cervical cancer in Europe in 2012**

Source: World Health Organisation- EUCAN(145)

## **3.2 METHODS**

### **3.2.1 Sampling Frame**

The sampling frame was defined as all women, within the defined study period and geographical area (specified later), who fall within the English cervical screening age (25-65years), from two population groups; migrant EE (nEE) (from the 2004/2007 EU accession countries), the study group, and native English Caucasian (nEN), the comparison group. The comparison group helped to identify health behaviours, which are independent of country of origin.

### **3.2.2 Data Collection Methods**

A mixed methods approach was used to assess the aims of this study and data collection took place between April 2015-December 2016.

#### **3.2.2.1 Questionnaires**

##### **Questionnaire Development**

The aim of the survey was to explore the existing screening behaviours, identify the level of knowledge of cervical cancer, cervical screening and awareness of HPV and the HPV vaccine, in the two study populations. The survey was conducted using an anonymous, paper based, self-administered tool.

The survey tool was divided into five main sections; socio-demographics, general health behaviours, cervical screening knowledge and practices, HPV and HPV vaccine knowledge and screening behaviours in country of birth for the nEE group. The final questionnaire consisted of 33 items. (Appendix I)

##### ***Socio-demographics***

Socio-demographic factors that were assessed included the following; age, gender, marital status, education, employment status, ethnicity, country of birth and language barriers. These have all been identified in literature (previously described) as variables, which may affect women's cervical screening behaviours.

Questions on age, gender and marital status were based on the wording and format found in the national UK census survey(223). The UK educational system was used to formulate the question on educational level. It was acknowledged that the educational systems might differ in the EE countries that were being studied. This was accounted

for in the translated versions of the questionnaires by adapting the wording to suit the educational system for each country. However, efforts were made to ensure that the overall education level categories (trade/vocational/school leaver qualification/ higher qualification/ under graduate degree/post graduated degree) were maintained, so that meaningful comparisons could be made.

Employment status question was developed through a combination of review of existing surveys tools and feedback received from the PPI groups. Further sub-division of the employment option into self-employed and whether they were working for a salary or not, were thought not to be relevant. The consensus within the supervisory team and the PPI group was that it would not add much in terms of the overall research aim and would make the survey appear lengthier.

Assessing ethnicity can be complex; it is multidimensional and can include elements of a person's cultural identity, religious beliefs, language and physical appearance(224). Using a "closed" tick box approach to assess ethnicity has been criticised, it has been argued that it limits the respondent's flexibility of self-identity and that they can be forced to conform to the available options(225). However, the impracticalities of coding open responses for large studies are also appreciated and a balance between the two (closed approach with adequate options for the population being studied) is preferential(225). The options for the assessment of ethnicity were based on the categories specified in the UK census survey(223) and a additional category was inserted for the white EE group. The choices for ethnicity in this group were broad but covered the ten EE countries that were being explored in this study and were deemed to be appropriate by the PPI group.

The questions on country of birth, length of time in the UK and frequency of visits to their home country were included to provided information on; if their health behaviours modify with increased frequency of visits to their home country and the length of time in the UK.

Language was assessed in multiple ways, was English their first language, which language did they mainly speak at home, could they speak/understand English and could they read English. The nEE PPI group had commented that some women are able to speak and/or understand English but cannot read or comprehend written information.

### ***General Health Behaviours***

This section established if the participant had initiated contact with the English healthcare system and how long after migration it had taken them to do so. One of the concerns highlighted by the nEE PPI group, was that there is a delay after migration in accessing healthcare in the UK. The reasons for delay are also explored; selections provided for this question have been adapted from the anecdotal evidence obtained from PPI work.

### ***Cervical Screening Knowledge and Practices***

General awareness of the NHS CSP, the availability of free cervical screening, screening commencement age, smear interval and the purpose of cervical cancer screening were examined. Personal screening behaviours, age and country of first and most recent smear tests and regular attendance for screening were surveyed.

### ***HPV and HPV Vaccine Knowledge***

It was apparent from both the PPI groups that there was considerable anxiety surrounding HPV and that overall awareness and understanding of it was poor. The aims of this section of the survey were to determine existing levels of awareness and to determine if it correlates with overall screening practices. Various tools in the literature have been used to assess HPV and HPV vaccine knowledge in different populations(226). Waller et al have developed a validated measure of HPV knowledge, which has been tested across different countries and covers a wide range of concepts(227). With the authors permission this tool has been incorporated into our survey to determine HPV and HPV vaccine in our cohort.

### ***Screening Behaviours in Country of Birth for the Migrant EE Group***

Knowledge of the available screening and HPV vaccination programmes in their country of birth were considered. Anecdotal evidence from clinical practice has revealed that many nEE women return to their home countries for cervical screening. Their screening practices, in terms of country and frequency of attendance and the reasons underpinning these choices were questioned.

## **Quality Assessment of Questionnaire**

Pre-validated questions, where possible, were incorporated into the survey tool. The overall face validity of the instrument was confirmed by peer review from experts within the speciality and the PPI groups. Construct validity may be inferred as this instrument measures concepts similar to other tools in literature. The final survey tool had a high (80.9) Flesch Reading Ease Score, indicating high readability and on review by the PPI groups, it was deemed to be sensitively worded and relevant.

Test-retest reliability was assessed on a pilot group of 10 women, all of white British ethnicity, who completed the survey on two occasions two weeks apart. Reliability could not be measured with the translated versions of the survey due to difficulties in recruiting sufficient participants from all the countries of interest.

## **Translation of Questionnaires**

The final version of the questionnaire was translated into the various languages of the ten EE countries that were being studied. Cultural and linguistic differences need to be considered during the process of translation, to ensure the meaning of the question is not lost(228). In this study, although there were language differences, the cultural context in which the study was conducted was universal for all the participants. For example, all the participants were currently living in England and it was their perception/knowledge of the English healthcare system that was being assessed. Where there were differences, such as with educational attainments and the varying educational systems, the questions were adapted following consultation with collaborators who were indigenous to the culture. One-way translation of questionnaires was conducted; the limitation of this method is that it has low reliability and validity and relies on the skills and knowledge of the translator(228). Back translation would have been the preferred method(229) but resource limitations, in the context of a multilingual study, did not permit this. However, bilingual collaborate members from The European Federation of Colposcopy verified the accuracy of the translations.

## **Recruitment of Patients for Questionnaire Study**

### Sample size

A total sample size of 1300 for each group was calculated using the sample size calculation for proportion ( $N = P (100\% - P) \div (SE)^2$ )(230). This was based on an

assumed proportion of 50%, as no previous data was available for this particular research subject and an estimated response rate of 30%. This would require that 390 surveys be completed for each of the two study groups for the data to be representative. Data were collected from two settings, secondary care (colposcopy clinics) and community groups. Consent was implied on completion of the survey.

### Colposcopy Clinics

Data were collected from three sites in the Midlands; University Hospitals Leicester, Northampton General Hospital and University Hospitals of North Midlands. A non-random consecutive sampling approach was adopted. Patients attending colposcopy clinics who met the study eligibility criteria were presented with a study pack, containing the survey and a participant information sheet. Assessment for study eligibility was made from review of the patient's age and recorded ethnicity in their records. If the information on ethnic background was not available, then the default process was to provide the patient with a study pack and inclusion in the study would then be based on their response to the ethnicity question. The patients were asked to complete the surveys prior to their seeing the nurse or doctor, as they may be provided with information about the tested subject during their consultation. For the same reason, for the nEN group, only new patients (first time attendees to colposcopy) were invited to take part. Unfortunately, due to the substantially smaller number of nEE women attending colposcopy clinics the same consideration could not be afforded to this group.

### Community Groups

A snowballing approach(202) has been utilised to identify local migrant EE community groups. Snowballing sampling is a non-probability sampling method that has been shown to be an effective recruitment technique for "hard-to-reach" populations(231, 232). One group, which was identified through this approach, is the Czech and Slovak club in Birmingham. This is a community group that runs a supplementary language school and nursery for children of Czech and Slovak descent and organises cultural and social events. Participants were recruited for the survey component of the study during an annual sports day. Mothers of the children attending the sports day were asked to complete the survey; they were given the option of having the survey in English, Czech



or Slovak. They could either complete the survey on the day or return it by post in the stamped return envelopes that were provided.

### **Data Analysis**

The surveys were pre-coded and a dataset has been created using the statistics programme, Statistical Package for Social Sciences (SPSS), IL, USA, version 22. Descriptive statistics were generated for the responses and correlation co-efficients to describe the relationship between two continuous variables. Chi-square and multivariate analysis were used to further explore relationships between variables. All reported p-values were assessed using two-sided tests and statistical significance was taken as a cut-off of  $p < 0.05$ . Each question was analysed individually to account for missing responses.

#### **3.2.2.2 Semi-Structured Qualitative Interviews**

Participants were asked to self-volunteer at the end of the survey to be involved in the interview stage of the study. The participants were given the choice of either partaking in one-to-one interviews or a focus group session. The aim of the semi-structured interviews was to obtain a detailed understanding of the thought process behind particular screening behaviours and choices. In addition, perceptions about the NHS CSP and screening in their country of origin were explored. Themes that have emerged from the survey and issues surrounding HPV testing, HPV vaccine and the perceived stigmatism of the association between sexual behaviour and HPV, were further investigated. The topic schedule for the semi-structured interviews (Appendix II) was determined by the findings of the PPI group and from review of existing literature on the subject. The same topic schedule was utilised for the one-to-one interviews and the focus group session. A consecutive non-random sampling method was utilised to select participants from all those who had volunteered and interviews were conducted until data saturation was reached. To ensure standardisation and consistency between the interviews I, the chief investigator, conducted them all. An interpreter, if required, was offered to be present for the interviews with the nEE women and I underwent formal training in qualitative interviewing techniques. The interviews were conducted either in a meeting room at the hospital or in the community at a location of their choice; the

participants decided on the meeting place based on convenience. All the participants were provided with a £10 gift voucher and were reimbursed for travel expenses. The participants were provided with participation information sheets and written consent was obtained from all the participants prior to the start of the interviews.

### **Data Analysis**

The analysis of qualitative data can be challenging and methods of analysis have been criticised due to lack of clarity and rigor(233). The process of coding and derivation of findings need to be reported in sufficient detail to withstand external interpretation and critique(234). Inductive framework method of analysis was used to analyse the data for this study(235). One advantage of framework analysis is that it allows one to address specific questions and therefore is beneficial in research related to informing policy or practice(235). Furthermore in framework analysis the process of coding is transparent thus permitting others to observe how findings were derived(234). The audio-recorded interviews were professionally transcribed. A member of the supervisory team (SS) and I reviewed the transcribed data. The two reviewers assigned open codes with explanatory notes to the data of four transcripts. Following review of the 4 transcripts the two reviewers compared codes and agreed on a set of codes to form the initial analytic framework. I reviewed the remaining transcripts and the analytic framework was applied, new codes were sought for and the analytic framework was revised accordingly. The transcripts were reviewed regularly; this enabled the exploration of any new themes in subsequent interviews.

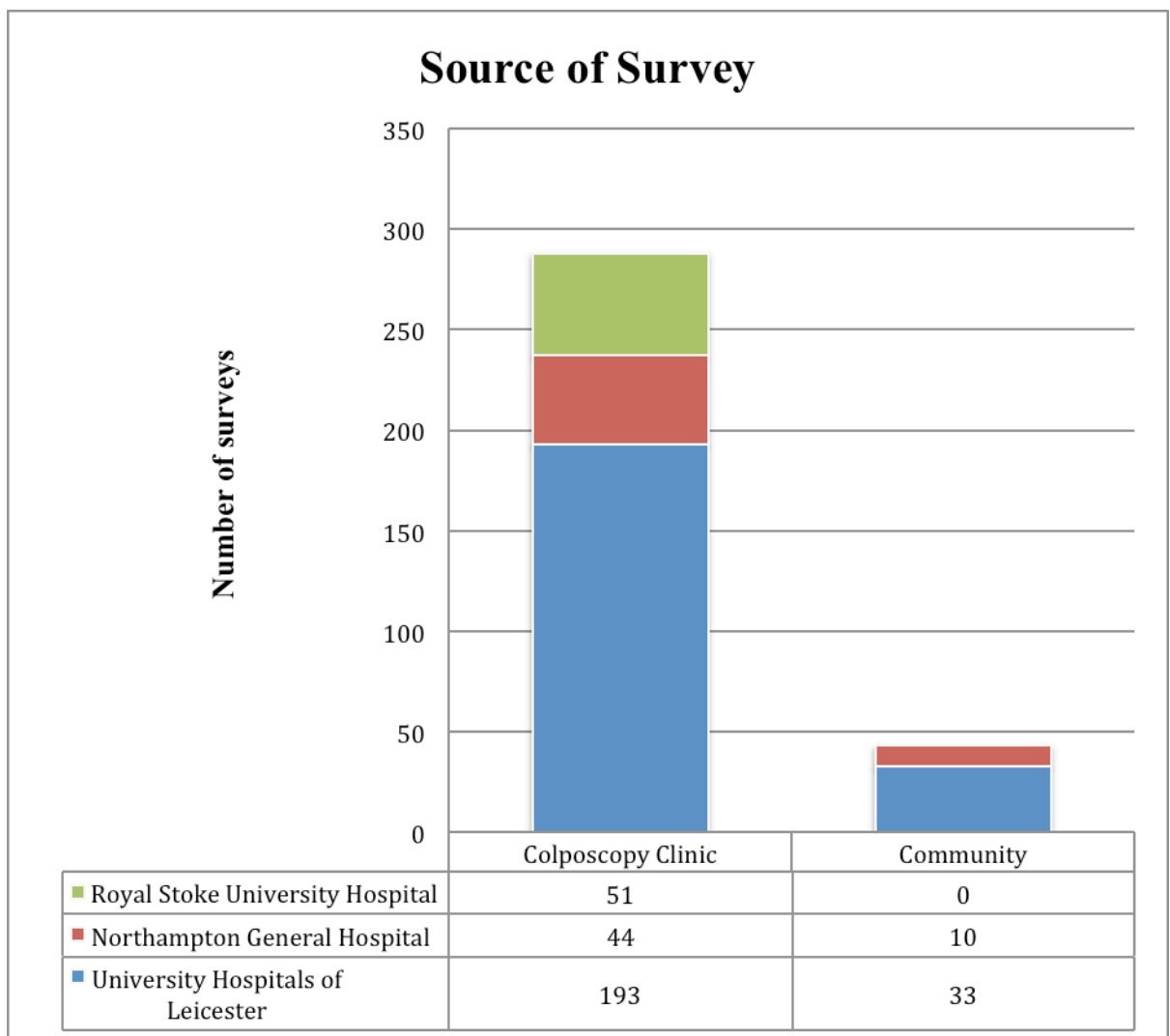
The final analytical framework was applied to all the transcripts with the aid of NVivo (software used to aid qualitative data analysis). The final sets of codes were grouped into themes.

Ethical approval for the study was obtained from the London Bromley research ethics committee (15/LO/0249).

### 3.3 RESULTS

#### 3.3.1 Part 1 Questionnaire Data

In total 331 questionnaires were completed out of the 400 that were distributed over the three participating sites, resulting in a response rate of 83%. The distribution of surveys completed at each site and in the two settings can be seen on Figure 3.2. The majority of completed surveys for both the settings came from University Hospitals Leicester/ Leicester city community (67%[n=193] hospital, 77%[n=33] community). In view of the minimal of number of surveys completed in the community setting and at the other two sites (Northampton General Hospital and Royal Stoke University Hospital) all the surveys were combined for analysis purposes.



**Figure 3.2 Source of completed surveys**

The median age of the participants was 31 years (range 24-64); the majority of women were either married (n=102 [31%]) or in a relationship (n= 102 [31%]). Women from the nEE group were found to have a greater level of educational attainment than nEN women ( $p<0.01$ ). Most (n=267[81%]) of the participants were in some form of employment (Table 3.1) and although the differences in the employment status of women from the two groups (nEE and nEN) did not reach statistical significance ( $p=0.08$ ) there was a greater proportion of nEE women in full time employment (63% vs. 49%). With regards to ethnicity and country of birth, 75% (n=249) described themselves as of English ethnicity and were born in England. Of the 25 % (n=82) born in an EE country, the distribution of country of birth shows that Poland (n=39 [12%]) was the most common country of birth followed by Slovakia (n=17 [5%]), with the other countries accounting for the rest of the participants (Table 3.1).

### **Pattern of migration and behaviours for nEE population (Table 3.2)**

The median length of time that the nEE participants had lived in England was 7 years (range 1-15 years). Most of them declared that they spoke (n=69 [85%]) and read (n=70 [85%]) English despite English not being the first language for almost all of them (n=80 [99%]). All the EE participants were registered with a general practitioner (GP) in England aside from one, who cited that they did not have any health concerns, as the reason for not registering. Further 76% (n=58) had registered with a GP within one year of migrating to England.

### **Cervical screening behaviours and knowledge (Table 3.3)**

There was confusion over the exact purpose of the cervical smear test, the majority of women from both groups nEN (n=278[85%]) and nEE (n=55[71%]) correctly recognised that it is a test to identify pre-cancerous cervical cells but significantly more nEN women were aware of this fact ( $p < 0.01$ ). Half the women overall assumed that it might be a diagnostic test for cervical cancer, with no difference noted between the two groups. nEE women were more likely to believe that cervical smear tests were performed as part of a full gynaecological examination (46% vs. 21%,  $p<0.01$ ). Overall most of the women (n=319[97%]) were aware of the availability of free cervical screening in England and their main sources of information included the GP (n=158[49%]) and the smear invitation letter (n=164[51%]). More nEE women than

nEN (6% vs. 2%,  $p=0.04$ ) quoted other sources of information however these were not specified on the survey responses. There was a discrepancy between the two groups regarding the recommended screen frequency in England, nEE women were more likely to believe that cervical smears are performed on annual basis than nEN women (18% vs. 4%,  $p<0.01$ ). Almost all the women ( $n=317[96\%]$ ) in this cohort had previously had a cervical smear test and 35% ( $n=26$ ) of the nEE women had their first smear in England. In addition, 71% ( $n=52$ ) of the nEE women had undergone their most recent smear examination in England and 92% ( $n=294$ ) of women overall claimed to always attend for cervical screening, with no significant difference noted between the two groups.

**The specific cervical screening behaviours and awareness of current cervical screening in their country of birth for the nEE women (Table 3.4)**

Just over half (55% [ $n=40$ ]) the women from this sub-cohort reported to have smears in England only, the remainder either had all their smears in their country of birth or had smears in both their country of birth and England. The main reasons for returning to their birth country for cervical smears were that the smear tests were performed by a gynaecologist/doctor (61% [ $n=17$ ]) and that it included a full gynaecological examination (68% [ $n=19$ ]). The nEE women appeared to be aware of the cervical screening programmes in their birth countries but not of the availability of HPV vaccination.

**HPV and HPV vaccine knowledge (Table 3.5)**

Overall 68% (221/324) of the women stated that they had previously heard of the HPV virus, 8% (26/324) were not sure and 24% (77/324) had not heard of it. nEN women were more likely to have heard of HPV than nEE women (73% [ $n=179$ ] vs. 53% [ $n=42$ ],  $p<0.01$ ). When general HPV knowledge was assessed in the group of women who had heard of HPV, the median overall knowledge score was found to be 9 out of a maximum of 15 (range 0-15). Four (2%) participants achieved the maximum score of 15 and 13 (6%) participants scored zero. The median score for this category for the nEN women was 10 (range 0-15) and for the nEE women was 9 (range 0-14).

In the group of women who had heard of HPV, 78% (169/216) were aware that HPV is tested for at the same time as the smear test. Looking at two cohorts separately; 81% (142/175) of nEN women and 66%(27/41) of nEE women were aware of this fact ( $p=0.03$ ). The median score for the HPV testing knowledge questions was 5 out of 6 (range 0-6); 16% ( $n=27$ ) scored zero and 27%( $n=46$ ) achieved the maximum score of 6. The median scores for the two groups (nEN and nEE) individually were 5 (range 0-6).

Of the women who had heard of the HPV virus, 63% (138/219) had heard of the HPV vaccine. This included 65% (115/178) of nEN women and 56% (23/41) of nEE women ( $p=0.31$ ). Further in the subgroup of women who were aware of HPV, 7%(16/218) had received the HPV vaccine, 5%(10/218) were not sure and 88%(192/218) had not. All 16 women who had received the HPV vaccine were nEN born. Overall HPV vaccine knowledge was assessed in the subgroup who had heard of both the HPV virus and the HPV vaccine, this showed that the median score was 4 out of a maximum of 7 (range 0-7). The maximum score of 7 was only achieved by 1% ( $n=2$ ) and 19% ( $n=26$ ) scored zero. The median scores for the HPV vaccine knowledge category for the both the groups (nEN and nEE) were 4 (range 0-7).

### **Associations between socio-demographic factors and understanding of cervical cancer prevention methods**

On univariate analysis younger age was found to be associated with greater HPV vaccine related knowledge overall ( $p= <0.0.1$ ) but when the results were analysed for each group individually; the association was only statistically significant in the nEE group ( $p= <0.01$ ). Higher level of educational attainment was associated with the general HPV and HPV testing knowledge categories both overall and individually in the two groups (Table 3.6). However, higher educational attainment was only significant for the knowledge of the purpose of cervical smears category for the nEE group ( $p=0.03$ ) and HPV vaccine category for only the nEN group ( $p=<0.01$ ). There was no effect noted with the number of years in England for the nEE group. General HPV knowledge varied with employment status overall and in the nEN group. Further analysis of employment status for the total cohort and the nEN group individually, revealed that being in some form of employment was the most advantageous (Table 3.7). This was confirmed by the Mann Whitney U Test analysis when employment (full

and part time) was compared to no employment (unemployed, housewife, retired),  $p < 0.01$  for both the total cohort and the nEN subgroup.

Multivariate analysis using linear regression for the whole cohort showed that none of the socio-demographic factors were significant for knowledge of the purpose of cervical smears. Higher educational attainment remained significant for all three HPV knowledge categories (general, testing and vaccine). Lower age persisted to show a significant association with HPV vaccine knowledge (Table 3.8)

**Table 3.1 Socio-demographic characteristics**

		<b>Total</b>	<b>nEN</b>	<b>nEE</b>
<b>Age in Years (median/range)</b>		31 (24-64)	31 (24-64)	31 (24-55)
<b>n= 330 (nEN= 248, nEE- 82)</b>				
<b>Relationship status; n(%)</b>	Married	102 (31)	77 (31)	25 (30)
	Widowed	1 (0)	0	1(1)
	Divorced	12 (4)	10 (4)	2 (2)
	Separated	8 (2)	7 (3)	1 (1)
	In a civil partnership	2 (1)	1 (0)	1 (1)
	In a relationship	104 (31)	75 (30)	29 (35)
	Co-habiting	45 (14)	37 (15)	8 (10)
	Single	57 (17)	42 (17)	15 (18)
<b>Education; n(%)</b>	No formal Qualifications	23 (7)	22 (9)	1 (1)
	Trade/technical /vocational	27 (8)	14 (6)	13 (17)
	GCSE's/O Levels or equivalent	92 (29)	75 (30)	17 (22)
	A Level or equivalent	83 (26)	68 (28)	15 (20)
	First degree	53 (16)	39 (16)	14 (18)
	Post Graduate degree	45 (14)	29 (12)	16 (21)
<b>Employment Status n(%)</b>	Employed full time	173 (52)	121 (49)	52 (63)
	Employed part time	94 (28)	77 (31)	17 (21)
	Unemployed	32 (10)	27 (11)	5 (6)
	Retired	5 (2)	5 (2)	0
	Housewife	27 (8)	19 (8)	8 (10)
<b>Ethnicity n(%)</b>	English	249 (75)		
	Bulgarian	1 (0)		
	Czech	7 (2)		
	Hungarian	4 (1)		
	Latvian	6 (2)		
	Lithuanian	4 (1)		
	Polish	39 (12)		
	Romanian	4 (1)		
	Slovakian	17 (5)		
<b>Country of Birth n(%)</b>	England	249 (75)		
	Bulgaria	1 (0)		
	Czech	7 (2)		
	Hungary	3 (1)		
	Latvia	6 (2)		
	Lithuania	4 (1)		
	Poland	39 (12)		
	Romania	5 (2)		
	Slovakia	17 (5)		



**Table 3.2 Pattern of migration and behaviours for nEE population**

<b>Years in the England (median/ range)</b> <b>n=77</b>		7 (1-15)
<b>Frequency of visit to home country</b> <b>n=79</b> <b>n(%)</b>	Once a month	2 (3)
	2-3 times a year	38 (48)
	Less than once a year	39 (49)
<b>First Language English</b> <b>n=81</b> <b>n(%)</b>	Yes	1 (1)
	No	80 (99)
<b>Do you speak English?</b> <b>n=81</b> <b>n(%)</b>	Yes	69 (85)
	No	4 (5)
	Not very well	8 (10)
<b>Can you read English?</b> <b>n=82</b> <b>n(%)</b>	Yes	70 (85)
	No	4 (5)
	Not very Well	8 (10)
<b>Home language</b> <b>n=79</b> <b>n(%)</b>	English	18 (23)
	Bulgarian	1 (1)
	Czech	6 (8)
	Hungarian	2 (3)
	Latvian	4 (5)
	Lithuanian	1 (1)
	Polish	32 (40)
	Romanian	2 (3)
	Slovakian	12 (15)
<b>Registered with a GP in England</b> <b>n=82</b> <b>n(%)</b>	Yes	81 (99)
	No	1(1)
<b>Length of time with current GP (median/range, in years)</b> <b>n=66</b>		3 (0-9)
<b>Time taken, after migration to England, to register with a GP (Years)</b> <b>n=76)</b>	0-3 months	39 (51)
	3-6 months	13 (17)
	6-12 months	6 (8)
	More than 1 years	18 (24)

**Table 3.3 Cervical screening behaviours and knowledge**

			<b>Total n (%)</b>	<b>nEN n (%)</b>	<b>nEE n(%)</b>	<b>P value</b>
<b>Why are cervical smears tests preformed? (select all true options) (n= 327)</b>	Diagnose pre- cancerous cervical cells	Correct	278 (85)	223 (90)	55 (71)	<b>&lt;0.01</b>
		Incorrect	49 (15)	26 (10)	23 (29)	
	Diagnose cervical cancer	Correct	163 (50)	131 (53)	32 (41)	0.07
		Incorrect	164 (50)	118 (47)	46 (59)	
	Pick up STD's	Correct	253 (77)	199 (80)	54 (69)	0.05
		Incorrect	74 (23)	50 (20)	24 (31)	
	As part of a full gynaecological examination	Correct	239 (73)	197 (79)	42 (54)	<b>&lt;0.01</b>
		Incorrect	88 (27)	52 (21)	36 (46)	
<b>Aware of free cervical screening in England (n=330)</b>	Yes		319 (97)	243 (98)	76 (94)	0.10
	No		11 (3)	6 (2)	5 (6)	
<b>Source of information about smear tests (n=322)</b>	GP		158(49)	114 (47)	44 (57)	0.10
	Friends		15 (5)	10 (4)	5 (6)	0.38
	Smear invitation letter		164 (51)	131 (53)	33 (43)	0.10
	Other		9 (3)	4 (2)	5 (6)	<b>0.04*</b>
<b>Recommended screening commencement age in England (median/range) (n=279)</b>			25 (13- 40)	25 (15- 40)	25 (13- 40)	n/a
<b>Recommended screen frequency in England (n=314)</b>	Every 6 months		5 (2)	0	5 (7)	<b>&lt;0.01</b>
	Every year		23 (7)	10 (4)	13 (18)	
	Every 3 years		285 (91)	229 (95)	56 (76)	
<b>Have you ever had a smear test? (n=328)</b>	Yes		317 (96)	242 (98)	75 (93)	0.07
	No		9 (3)	4 (2)	5 (6)	
	Not sure		2 (1)	1 (0)	1 (1)	
<b>Age of first smear test (median/range) (n=296)</b>			24 (15- 55)	24 (15- 40)	21 (15- 35)	n/a

<b>Country of first smear test (n=311)</b>	England	262 (84)	236 (100)	26 (35)	n/a
	Bulgaria	1 (0)			
	Czech	7 (2)			
	Hungary	2 (1)			
	Latvia	3 (1)			
	Lithuania	1 (0)			
	Poland	28 (9)			
	Romania	3 (1)			
	Slovakia	4 (1)			
<b>Timing of most recent smear test (n=322)</b>	Never had one	7 (2)	4 (2)	3 (4)	0.12
	0-3 years	302 (94)	232 (95)	70 (89)	
	4-5 years	10 (3)	7 (3)	3 (4)	
	More than 5 years	3 (1)	0	3 (4)	
<b>Country of most recent smear test (n=310)</b>	England	289 (93)	237 (100)	52 (71)	n/a
	Bulgaria	1 (0)			
	Czech	3 (1)			
	Latvia	2 (1)			
	Poland	13 (4)			
	Romania	1 (0)			
	Slovakia	1 (0)			
<b>Always attends for a smear test (n=321)</b>	Yes	294 (92)	221 (91)	73 (94)	0.78
	No	23 (7)	19 (8)	4 (5)	
	Cannot remember	3 (1)	2 (1)	1 (1)	

**Table 3.4 Cervical screening behaviours and knowledge of cervical cancer prevention in their country of birth for the nEE women**

		<b>n(%)</b>
<b>Screening programme available in their country of birth</b> <b>n=74</b>	Yes	57 (77)
	Not sure	17 (23)
<b>Cervical screening behaviours</b> <b>n=73</b>	Attends for smears only in country of birth	7 (10)
	Attends for smears in England only	40 (55)
	Attends for smears both in country of birth and England	26 (36)
<b>Reason for attending for smears in their country of birth (select all that apply)</b> <b>n=28</b>	More convenient	1 (4)
	Smears performed more often	7 (25)
	Performed by a gynaecologist/doctor	17 (61)
	Includes full gynaecological check-up	19 (68)
	Distrust of English doctors	5 (18)
<b>Frequency of attendance for smears in country of birth</b> <b>n=25</b>	Every 2-3 years	7 (28)
	Every year	14 (56)
	More than once a year	4 (16)
<b>Is the HPV vaccine available in their country of birth</b> <b>n=68</b>	Yes	25 (37)
	No	2 (3)
	Not sure	41 (60)
<b>Is the HPV vaccine part a national vaccination programme in their country of birth</b> <b>n=68</b>	Yes	6 (9)
	No	13 (19)
	Not sure	49 (73)

**Table 3.5 HPV and HPV vaccine knowledge**

	Total		nEN		nEE		P Value
	Correct N (%)	Incorrect N (%)	Correct N (%)	Incorrect N (%)	Correct N (%)	Incorrect N (%)	
General HPV knowledge questions (n=208)							
<i>HPV is very rare</i>	198 (95)	10 (5)	160 (96)	7 (4)	38 (93)	3 (7)	0.42*
<i>HPV always has visible signs or symptoms</i>	195 (94)	13 (6)	158 (95)	9 (5)	37 (90)	4 (10)	0.29*
<i>HPV can cause cervical cancer</i>	165 (79)	43 (21)	128 (77)	39 (23)	37 (90)	4 (10)	0.06*
<i>HPV can be passed on by genital skin-to-skin contact</i>	101 (49)	107 (51)	83 (50)	84 (50)	18 (44)	23 (56)	0.51
<i>There are many types of HPV</i>	112 (54)	96 (46)	94 (56)	73 (44)	18 (44)	23 (56)	0.15
<i>HPV can be passed on during sexual intercourse</i>	146 (70)	62 (30)	118 (71)	49 (29)	28 (68)	13 (32)	0.77
<i>HPV can cause genital warts</i>	98(47)	110 (53)	86 (51)	81 (49)	12 (29)	29 (71)	<b>0.01</b>
<i>Men cannot get HPV</i>	194 (93)	14 (7)	154 (92)	13 (8)	40 (98)	1 (2)	0.31*
<i>Using condoms reduces the risk of getting HPV</i>	101 (49)	107 (51)	83 (50)	84 (50)	18 (44)	23 (56)	0.51

<i>HPV can be cured with antibiotics</i>	193 (93)	15 (7)	158 (95)	9 (5)	35 (85)	6 (15)	<b>0.04</b>
<i>Having many sexual partners increases the risk of getting HPV</i>	117(56)	91 (44)	84 (50)	83 (50)	33 (80)	8(20)	<b>&lt;0.01</b>
<i>HPV usually doesn't need any treatment</i>	50 (24)	158 (76)	45 (27)	122 (73)	5 (12)	36 (88)	<b>0.05</b>
<i>Most sexually active people will get HPV at some point in their lives</i>	104 (50)	104 (50)	92 (55)	75 (45)	12 (29)	29 (71)	<b>&lt;0.01</b>
<i>A person could have HPV for many years without knowing it</i>	168(81)	40 (19)	138 (83)	29 (17)	30 (73)	11 (27)	0.17
<i>Having sex at an early age increases the risk of getting HPV</i>	57 (27)	151 (73)	46 (28)	121 (72)	11 (27)	30 (73)	0.93
<b>HPV testing knowledge questions (n=142)</b>							
<i>An HPV test can tell how long you have had an HPV infection</i>	131 (92)	11 (8)	110 (92)	9 (8)	21 (91)	2 (9)	1*
<i>If a woman tests positive for HPV she will definitely get cervical</i>	141 (99)	1 (1)	118 (99)	1 (1)	23 (100)	0	1*

<b>cancer</b>							
<b><i>An HPV test can be done at the same time as a Smear test</i></b>	130 (92)	12 (8)	110 (92)	9 (8)	20 (87)	3 (13)	0.41*
<b><i>HPV testing is used to indicate if the HPV vaccine is needed</i></b>	126 (89)	16 (11)	106 (89)	13 (11)	20 (87)	3 (13)	0.73*
<b><i>When you have an HPV test, you get the results the same day</i></b>	133 (94)	9 (6)	110 (92)	9 (8)	23 (100)	0	0.35*
<b><i>If an HPV test shows that a women does not have HPV her risk of cervical cancer is low</i></b>	60 (42)	82 (58)	46 (39)	73 (61)	14 (61)	9 (39)	0.05
<b>HPV vaccine knowledge questions (n=113)</b>							
<b><i>HPV vaccines require two doses</i></b>	49 (43)	64 (57)	41 (43)	55 (57)	8 (47)	9 (53)	0.73
<b><i>The HPV vaccines offer protection against all sexually transmitted infections</i></b>	107 (95)	6 (5)	91 (95)	5 (5)	16 (94)	1 (6)	1*

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<i>The HPV vaccines are most effective if given to people who have never had sex</i>	64 (57)	49 (43)	53 (55)	43 (45)	11 (65)	6 (35)	0.47
<i>Someone who has had HPV vaccine cannot develop cervical cancer</i>	108 (96)	5 (4)	91 (95)	5 (5)	17 (100)	0	1*
<i>The HPV vaccines offer protection against most cervical cancers</i>	68 (60)	45 (40)	57 (59)	39 (41)	11 (65)	6 (35)	0.68
<i>One of the HPV vaccines offers protection against genital warts</i>	14 (12)	99 (88)	10 (10)	86 (90)	4 (24)	13 (76)	0.22*
<i>Girls who have had the HPV vaccine do not need to have smear tests when they are older</i>	111 (98)	2 (2)	94 (98)	2 (2)	17 (100)	0	1*

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**Table 3.6 Associations between socio-demographic factors and knowledge of cervical cancer prevention**

	Purpose of cervical smears			General HPV knowledge			HPV testing knowledge			HPV vaccine knowledge		
	Overall	nEN	nEE	Overall	nEN	nEE	Overall	nEN	nEE	Overall	nEN	nEE
	Spearman's rho correlation coefficient (p value)											
Age	0.04 (0.53)	-0.00 (0.96)	0.14 (0.21)	-0.08 (0.17)	-0.09 (0.17)	-0.04 (0.72)	-0.08 (0.14)	-0.1 (0.13)	-0.02 (0.83)	<b>-0.15</b> <b>(&lt;0.01)</b>	<b>-0.18</b> <b>(&lt;0.01)</b>	-0.09 (0.44)
Educational level	0.09 (0.11)	0.65 (0.31)	<b>0.25 (0.03)</b>	<b>0.23</b> <b>(&lt;0.01)</b>	<b>0.22</b> <b>(&lt;0.01)</b>	<b>0.29</b> <b>(0.01)</b>	<b>0.2</b> <b>(&lt;0.01)</b>	<b>0.19</b> <b>(&lt;0.01)</b>	<b>0.26</b> <b>(0.02)</b>	<b>0.17</b> <b>(&lt;0.01)</b>	<b>0.17</b> <b>(&lt;0.01)</b>	0.22 (0.06)
N° of years in England (nEE group)	n/a	n/a	0.15 (0.21)	n/a	n/a	0.03 (0.78)	n/a	n/a	0.03 (0.77)	n/a	n/a	-0.09 (0.44)
	Kruskal-Wallis Test P value											
Relationship status	0.25	0.17	0.58	0.32	0.29	0.15	0.07	0.08	0.12	0.42	0.8	0.23
Employment status	0.56	0.6	0.49	<b>&lt;0.01</b>	<b>&lt;0.01</b>	0.96	0.26	0.11	0.70	0.29	0.1	0.72

**Table 3.7- Sub analysis of the association of employment status with general HPV knowledge score, for the total and nEN groups**

<b>Employment Status</b>	<b>Mean (95% CI)</b>		<b>Median (Range)</b>	
	<b>Total</b>	<b>nEN</b>	<b>Total</b>	<b>nEN</b>
<b>Employed full time</b>	6.72 (5.98-7.46)	7.17 (6.27-8.08)	7 (0-15)	8 (0-15)
<b>Employed part time</b>	7.93 (6.95-8.90)	8.38 (7.37-9.38)	9 (0-15)	9 (0-15)
<b>Unemployed</b>	5.38 (3.3-7.45)	5.30 (2.98-7.61)	4.5 (0-15)	4 (0-15)
<b>Retired*</b>	0	0	0	0
<b>Housewife</b>	5.74 (3.82-7.66)	5.84 (3.25- 8.43)	6 (0-15)	6 (0-15)

\* All 5 retired participants were from the nEN group and scored zero for the general HPV knowledge category questions

**Table 3.8 Multivariate analysis models for the associations between socio-demographic factors and knowledge of cervical cancer prevention**

<b>Model 1- Purpose of cervical smears; <math>R^2 = 0.02</math>, Adjusted <math>R^2 = 0.01</math></b>			
<b>Variable</b>	<b>Standardized Co-efficient Beta</b>	<b>P Value</b>	<b>95% CI</b>
Age	0.08	0.21	1.52-3.13
Education	0.09	0.14	-0.01-0.02
Relationship status	0.05	0.41	-0.02-0.17
Employment status	-0.08	0.17	-0.19-0.03
<b>Model 2- General HPV knowledge; <math>R^2 = 0.07</math>, Adjusted <math>R^2 = 0.06</math></b>			
<b>Variable</b>	<b>Standardized Co-efficient Beta</b>	<b>P Value</b>	<b>95% CI</b>
Age	-0.1	0.10	-0.11-0.01
Education	0.22	<b>&lt;0.01</b>	0.41-1.22
Relationship status	0.03	0.62	-0.26-0.16
Employment status	-0.03	0.56	-0.62-0.34
<b>Model 3- HPV Testing knowledge; <math>R^2 = 0.05</math>, Adjusted <math>R^2 = 0.04</math></b>			
<b>Variable</b>	<b>Standardized Co-efficient Beta</b>	<b>P Value</b>	<b>95% CI</b>
Age	-0.04	0.51	-0.04-0.02
Education	0.17	<b>&lt;0.01</b>	0.12-0.55
Relationship status	0.09	0.14	-0.03-0.19
Employment status	-0.05	0.37	-0.37-0.14
<b>Model 4- HPV vaccine knowledge; <math>R^2 = 0.05</math>, Adjusted <math>R^2 = 0.03</math></b>			
<b>Variable</b>	<b>Standardized Co-efficient Beta</b>	<b>P Value</b>	<b>95% CI</b>
Age	-0.15	<b>0.01</b>	-0.07- (-) 0.01
Education	0.12	<b>0.03</b>	0.02-0.41
Relationship status	-0.04	0.47	-0.14-0.06
Employment status	-0.04	0.47	-0.31-0.14

### **3.3.2 Part 2 Interview Data**

A total of 40 one-to-one semi structured interviews were conducted, 20 were with women from the nEN group and 20 from the nEE group. The women were recruited from a mixture of community and hospital settings (Table 3.9). In addition, one focus group consisting of six women from Czech and Slovakian backgrounds was conducted. The analyses of the interviews and the focus group have been conducted together owing to the fact that there was only one focus group and the same interview schedule was utilised for both. Details of the participant characteristics are demonstrated in Tables 3.9 and 3.10.

There were 14 theme categories and 45 codes in total (Appendix III). A description of the theme categories and the top-level codes within each group, along with the main findings are provided below. Details in the parentheses following the quotes represent the participant's identification number and recruitment setting (PC= Community, PH=Colposcopy clinic, FG= Focus group), age (in years) and ethnicity.

#### **1. Perceptions of the healthcare system and healthcare providers in England versus their country of origin**

*Opinions on the provision versus availability and access to healthcare in England compared to their country of origin; Differences/similarities in relationships with the healthcare provider*

##### **Registration with a GP**

The views of the interviewed women were split regarding the process of registration with the GP. Some of the women commented that they found the process “easy”. Factors that transpired to aid registration included having family or friends already living and/or settled in England, if they were part of an educational institution (e.g.- university) and if they already spoke and/or understood the English language.

*“Yes, here already yes, so I think I asked my friend and she said like, “oh you have to go to nearest GP practice and they going to like register you”, so yeah” (PC14, 29, Polish)*

*“..my sister was already in England, so we just... we had to give where we lived and other stuff, but it was fairly easy indeed..... I did speak English already.”* (PC2, 37, Lithuanian)

*“...so I personally cannot recall having any problems because I went to uni, so I went to the surgery there, the university had one on the campus. So that was kind of easy, they didn't question anything because I was a student...”* (PC25, 29, Polish)

Difficulties were encountered with registration with the GP due to not being able to produce the relevant and requested documentation, such as proof of address, bills etc. and language barriers.

*“I think registration with GP was very difficult at start, especially because we didn't have, like you have to get the bill to get into surgery and we didn't have bill at start and it was a bit difficult because we just moved in a new apartment..”* (PC1, 34, Latvian)

*“..she lives here for three months and she's not registered with a GP because she says, “I can't speak English.” And the doctor's told her, “We can't register you if you don't speak English.””* (PC3, 30, Romanian, in reference to a friend)

Delay in registration from time of migration to England ranged from 2 months to 2-3 years. The main reasons stated for this delay were that they did not require the GP, they did not know how important it was, they could self medicate for minor illnesses, they had not settled down in one location and that they had waited until they actually needed medical assistance.

*“...until we really got sick we didn't register with GP.”* (PC1, 34, Latvian)

*“In England, the first two years I didn't have a GP. And then when I, because I've been moving from town to town”* (PH12, 30, Latvian)

Factors that prompted registration included becoming pregnant, the need for contraception and because it was required by their employer or educational institution.

*“I think it’s just because of the work that I was doing as well, they were asking for GP details ... and then after a year and a half I got pregnant with the youngest one, and then from there pushed me.”* (PH12, 30, Latvian)

*“I was forced by the university while doing PhD, to be registered with GP as a common practice, but my attitude towards seeing doctors was I can only go if I’m dying, so if I’m not dying I can cope myself with very simplistic drugs”* (PH1, 35, Lithuanian)

With regards to the amount of information offered about the availability of healthcare services at the GP practice, several women commented that they were simply supplied with an application form to complete but no actual information was provided. It was felt by some that offering information at this point would be too much to take in, whilst others felt that this was a missed opportunity, especially for those women who could not communicate very well in written English.

*“I register to GP, the GP make appointment for me, 10 minutes for ask me a couple of questions, I can tell him, if not, I just fill up that form I give back, nobody know if I have something wrong, because you can’t write down, if my English is not good, I can’t write many things.”* (PH4, 34, Hungarian)

### **Access to healthcare in England**

The migrant women tended to access emergency care, in the form of accident and emergency departments or urgent care centres. This was particularly the case soon after migration to England and prior to registration with a GP. Some had even come with their own medications to avoid having to interact with the healthcare system in England if possible.

*“Yes, they have to go to a walk-in centre every time they have some problem..”* (FG, Czech/Slovak)

*“..I came to the UK equipped with a massive box of drugs for all possible outcomes.”* (PH1, 35, Lithuanian)

Overall, women from both the groups, nEN and nEE commented on the difficulties in accessing GP services. The main issues were around trying to get appointments within a timely manner and at suitable times. Conversely a couple of migrant women stated that in their experience they found access to the GP easy/ easier than their home country.

*“I think you can’t get a GP appointment for anything anyway, and I think people have that perception anyway, that they find it hard to get a GP appointment”* (PH5, 25, English)

*“...if you need an appointment on the same day you have to ring very early, otherwise you may be told that sorry but we don’t have any appointments, the next one available is, for example in a week time..”* (PC24, 33, Polish)

Frequency of access to the GP was an emergent theme. The women remarked that they did not visit the GP on a frequent basis; again this finding was noted in both groups of women. The reasons for this behavioural pattern varied from not needing to go to fear of wasting the doctor’s time.

*“I think my first trip to a GP was 10 years later. I didn’t go to the GP, they had to call me and chase me to see that I’m still alive and want to be registered and so on.”* (PH1, 35, Lithuanian)

*“...you know I just don’t believe in running to the doctors if you get a cough or an ache. You know they are busy enough aren’t they without worrying about you getting too many headaches or your legs hurting to be quite honest with you.”* (PC16, 40, English)

In contrast to the apparent “lack of need” to engage with the GP, the migrant group held largely negative views about GP and/or doctor attitudes. There was a feeling that symptoms were not taken seriously and that there was often a “wait and watch attitude”. This was described as *“lack of responsibility towards patients and it’s pretty much natural selection process”* (PH1, 35, Lithuanian). As a result, some of the women, adopted the method of embellishing the length/severity of their symptoms as a way

around this attitude. Others took to seeking advice from a doctor from their home country prior to seeing the GP in England so that they were going to the GP with a diagnosis and plan for treatment, and would only be requiring a prescription.

*“I will go to my Latvian doctor to ask for a reason my kids are sick and then I would go to GP and say she has this problem, I need these things....”* (PC1, 34, Latvian)

The perceptions about GP attitudes in England were a driving factor for going back to their home countries to access healthcare. Two main benefits about accessing healthcare in their home country were, firstly, that their complaints were taken more seriously and secondly, they had direct access to specialist care. It was perceived that these benefits were greater than the cost of going home and that of having to pay for treatment. In addition, if there was a choice there was a preference to seeing a doctor who was from the same country as them.

*“..you felt almost helpless and you thought it’s much easier to book a ticket and go back to one of those countries, pay privately, and at least they do something.”* (PH1, 35, Lithuanian)

*“Here it’s different, if you go to GP and you ask about something they always send you to the nurse, that’s why a lot of people say, “I will leave it and when I go to Poland I will check it out.””* (PH3, 30, Polish)

Limited comments were made about private versus state funded care in England. One participant had strong views and felt that the standard of care in the private sector was much greater, whilst another did not believe that there was a difference.

*“In England if I need anything to do with my health I will always go private. It is much nicer, the doctors have more time for, they are not working under as much pressure as in the NHS”* (PC26, 35, Slovenian)

Barriers to engaging with healthcare in England circled back to previous themes, such as their complaints not being taken seriously and difficulties in getting appointments.



Further it was expressed that if they had originated from a rural area, in their home countries, they might not be accustomed to engaging as actively with healthcare as is the case in England.

*“Yes exaggerating symptoms just to be heard and seen and it’s quite sad really but it is psychological yes, people worry, they don’t understand how serious or not serious.”* (PH1, 35, Lithuanian)

*“My little girl she got infection in her ear, on Monday 10 times nobody answer the phone, the GP I tell to them the message, “Can I see the doctor?” “Yeah, the doctor is going to ring you.” Today is Wednesday and I’ve still not had him ring me.”* (PH13, 42 Polish)

### **Access to healthcare in Eastern Europe and general health behaviours**

In comparison to access to healthcare in England many references were made regarding the private sector in relation to healthcare in EE. The migrant population who still utilised healthcare in their home countries tended to mainly access healthcare privately. There was the perception that private healthcare was superior and some of the advantages of it included shorter waiting times and quicker turnaround of test results. The treatment received in private care was also believed to be better. For some as they were no longer residing in EE and not contributing to health insurance or health taxes they were not entitled to state funded healthcare. It was also easier for them to access private healthcare during their “short” trips back home due to the limited availability of time. The financial implications of returning home and paying for healthcare did not appear to be a concern for this group of women. However, there was an appreciation that not all of the population who were still living back in their countries of birth could afford private healthcare. Further there wasn’t an absolute need to access private healthcare as state funded healthcare was still available to those with health insurance.

*“I’m not really registered with a doctor over there now, if I go there and I want to see a doctor I go privately.”* (PC24, 33, Polish)

*“doctors and the nurses in hospitals not in private clinics, they don’t treat you how they should,..... whereas privately, when you go to a private clinic, then those people are paid enough, they are nice to you, they are kind, they are respectful and you feel like going.” (PC7, 30, Romanian)*

*“So yes hospital is so busy, typically, they don’t give you any advice. If you stand at the door and cry and beg maybe they will...” “Private clinics are completely different, obviously, private clinics in Lithuania you are seen and you are looked after very well but people can’t afford going private most of them.” (PH1, 35, Lithuanian)*

The threshold for accessing healthcare in EE was thought to be lower and it was felt that the pressures on the healthcare care services were not as great. Several comments were made on the availability of direct access to specialist care, rather than the GP acting as the gatekeeper. This set up was seen to be advantageous. Greater utilisation of the pharmacist was also described, whereby the pharmacist would be approached for advice on self-medicating prior to seeing the doctor.

*“...you would go even if you have a minor illness,” (PC1, 34, Latvian)*

*“...because there is much less pressure in a hospital in Lithuania, sometimes you can get hospitalised to have tests done.” (PC2, 37, Lithuanian)*

*“...when you’ve got a baby you go in straight to the...Gynaecologist.”*

*“Specialist. We don’t have general practitioners. We have specialists for everything.” (FG Czech/Slovak)*

The themes that emerged about general health behaviours were that it was “cultural” to have regular health checks and that they were more conscious about their health, with a greater emphasis on prevention. There was more awareness about health in the form of adverts and through the use social media forums. Further healthcare professionals themselves were more likely to conduct investigatory tests and prescribe medications.

*“..if you put the TV on every other ad is about some kind of pills, tablets, self medication” (PC24, 33, Polish)*

*“I know that in Hungary we tend to jump on everything and we are more, I think we are more conscious about health, and in Hungary the doctors seem to prescribe more medication probably not necessary or they will send you off for a test even if you have the slightest symptoms or you have some concerns.” (PC4, 43, Hungarian)*

*“Yes, we were brought up to go to the doctors, weren’t we?” “I think most of, you know, like, our culture they do that.” (FG Czech/Slovak)*

*“....as I said in Lithuania and many other Eastern European... pretty much entire Soviet Union, if you go to the doctors there will be something wrong with you, even if there is nothing wrong with you they will find something wrong with you... Yes and then the person feels satisfied, they found something....” (PH1, 35, Lithuanian)*

### **Trust in the English healthcare system and attitudes towards the differences**

Opinions regarding trust in the healthcare system in England were split. Some women were “happy” with the healthcare provided in England; they believed it to be superior to that provided in their countries of birth. The fact that healthcare is fully funded in England was seen as a positive and as aforementioned in England free healthcare did not necessarily equate to poor quality for all. Other women had very little trust in the English healthcare system and perceived the quality to be better in their country of origin. The reasons for this lack of trust were multiple and included previous bad experiences which, had resulted in a missed diagnosis, delay in referral to specialist care and failure of the doctors to provide an adequate explanation about management plans, in particular if this included “waiting and watching”.

*“So I’m very happy with everything, absolutely everything; the... the level of care..” (PH2, 36, Slovak)*

*“I find that health care might be a little bit better in Latvia because they care more” (PC1, 34, Latvian)*

*“I think. I do still think the healthcare provided back in the Czech Republic might be a little better.... here you have to just go through your GP to go anywhere and I think it’s just for the patient it’s kind of...a waste of time..” (PC23, 33, Czech)*

*“It is much better in Slovenia, here no one listens to you. You can’t see a specialist you always have to go to the GP first. There is a really long wait to get an appointment with the GP.” (PC26, 35, Slovenian)*

Theses bad experiences reinforced the negative preconceptions that they already held about the British healthcare system. One participant explains how there is a lot of negative publicity about the healthcare in England in other countries.

*“I think it’s a trust issue because unfortunately outside the UK, the NHS system is portrayed as not very knowledgeable or experienced and quite ignorant..... but when you go and see GP the only solution they typically give you is Paracetamol or Ibuprofen which is not uncommon..” (PH1, 35, Lithuanian)*

The last group of women were those who described bad experiences or questioned the care provided but still declared that they were “happy” with the system.

*“I’m surprised how the doctor can sort you on the phone.....” “I like the system. I’ve born just one baby in England, but if I could choose I would born another 10.....” (PC13, 42, Polish)*

Comparing the provision of healthcare in England with that in their country of origin, concerns regarding the inability to directly access specialist care and the “wait and watch” attitude were echoed again. References were made to the ease of access to specialist care in their own countries as well as how symptoms were more likely to be treated with antibiotics sooner.

*“..if you have any concerns then it’s a long-winded process to go through and it’s much easier just to go back and access your normal gynaecologist.” (PC4, 43, Hungarian)*

*“..in Poland for example, if you have fluid they always give you like antibiotics, here they try to treat you with like paracetamol or something.” (PC14, 29, Polish)*

Views on the role of the GP as triaging system and as a gatekeeper to specialist referral were divided. One participant felt that the fact that GP in England is able to assess multiple problems was an advantage over their home country. Whilst many of the women in the Czech/Slovak focus group disagreed and questioned how one professional could have sufficient knowledge about all the various organs of the body.

*“quite like that you can have a lot of things done at the GP, I don't know, contraception, diabetes and everything checked, at home it's mainly just if you feel unwell and for something else you go to specialist place. So I actually prefer this.” (PC6, 28, Hungarian)*

*“Even if you see a general practitioner ...she's not going to deal with your acne problem, for example.”*

*“Here you just see a GP and he can solve your eyes, your...”*

*“...skin, your...”*

*“Everything, yes...whatever.”*

*“Here it's quite different” (FG, Czech/Slovak)*

The women felt that in England it was all *“all about statistics about how many people you have referred and if you have referred too many people that's bad for your practice”* (PC1, 34, Latvian). In contrast in their home countries they described that the doctors had more time, when they went to see the doctor they would discuss all your concerns, you did not need to limit one problem for one appointment and there was no need to book a double appointment slot. In addition, there was the benefit of continuity of care as you could see the same doctor (specialist/GP) on each occasion and on initial registration with the GP they would physically review you and discuss any pre-existing medical problems.

*“...because you have a whole appointment with a doctor and you can discuss everything else to do with your health and so other problems you may have, it's just a*

*little bit like extra that you get when you go for an appointment in Poland.”* (PC25, 29, Polish)

*“In my country I can sit with my doctor for half an hour if it’s necessary.”*

*“...then here it’s like, ‘Oh yes..... now your time is up. See you later.’”* (FG, Czech/Slovak)

*“In Romania if you register to GP, the GP take time, 10, 15 minutes with you when you take the form back and ask you if you have some intolerance or if you allergic or if you have something.”* (PH4, 34, Hungarian) (participant was born in Hungary but lived in Romania)

However, there was an appreciation that due to the large population size in England that the pressures on time and demand for healthcare are greater. Therefore the same freedom in terms of time during consultations may not be affordable here.

*“That being said it’s not necessarily the most cost effective thing to do on a large scale if you were to provide this sort of appointment to every single person.”* (PC25, 29, Polish)

*“...maybe it’s here because there’s more people here, that’s why they don’t have the time”* (PC14, 29, Polish)

Finally, two polish women described conflicting comparisons of the healthcare in Poland compared to that in England. One believed it to be better in Poland and felt that the doctors provided more comprehensive explanations of treatment plans, whereas the other describes *“the atmosphere in the hospital everything is nice here, in Poland everything is stressed, everybody get stressed you know, it’s different.”* (PH13, 42, Polish). These differing opinions may be explained by how each them access healthcare in Poland, the initial participant makes reference to the fact that *“I’m going to like receive better treatment because I’m paying for it, so.”* (PC14, 29, Polish). This may imply that the difference in judgement that is being portrayed here by these two women is actually a reflection of private versus state healthcare in Poland.

### **Relationship with the doctor**

The relationship with the doctor in their home countries was described as one of “trust” and “familiarity”. They felt that the doctors know more than they do therefore they trusted them. Further there was the sense of familiarity with the doctor, as usually the same doctor would have treated other members of the family. One participant described a more negative doctor-patient relationship, whereby the doctor held a more authoritative role; *“if you come and they don’t find anything they will shout at you and say you’re taking their time, you shouldn’t be coming, if you come and there is something they shout at you that took too long to come as well and now its complex, so it’s not a pleasant welcoming environment.”* (PH1, 35, Lithuanian)

*“They are used to doctors know a lot and they know better than I do, so you trust them because they know better.”* (PC1, 34, Latvian)

*“..we have a saying that the dentists and the gynaecologists are like very close family friends because you have to be at trust with them”* (PC4, 43, Hungarian)

Overall the relationship with the GP in England was referred to one as that lacked trust. One participant who tend to refer to her sister in law, from Latvia, for medical advice prior to consulting her GP, comments on how *“sometimes they just Google in front of me and... ..I feel like they’re not competent enough.”* (PC1, 34, Latvian). As aforementioned the lack of trust is also related to the fact that the GP in England deals with pathology of the entire body and is not a specialist. The familiarity that they have with the doctors in their home countries cannot replicated in England as they may end up seeing a different doctor each time. In addition, it was mentioned that they would prefer to see a doctor who originated from their own country and that often women would seek them out from neighbouring towns. The lack of continuity was an issue for the English-born women too.

*“...they’re choosing Peterborough, London and they’re choosing Polish doctors that can... so they’ve got the practice here, I don’t know, they’re coming to every few weeks*

*for two and three days and they're doing this private here if they cannot go to Poland.*  
(PC5, 34, Polish)

*"...because you don't always see the same GP and you don't have that rapport with the GP,..."* (PH5, 25, English)



## **2. The social interactions of the migrant Eastern European population**

### ***The interactions, priorities and accessibility issues of the migrant Eastern European group from their perspective***

#### **Access to the migrant population and integration of the migrant group with society, barriers and facilitators**

The participants from the migrant EE cohort expressed differing opinions when they were asked about issues regarding accessibility to them (the migrant EE population), for the purposes of health promotion. The women commented that on initial migration it would be difficult for researchers/healthcare professionals to identify migrant EE women, *“you never know if a woman moves here, if she’s moving here you never know, she is here”* (PC3, 30, Romanian). Furthermore specific to healthcare if they are not registered with a GP, identifying and/or accessing the migrant EE group for health promotion would be very difficult. In the groups of migrant EE women who move to England as family, it is usually the husband/male partner that goes out to work whilst the women stay at home with the children and therefore this presents another barrier to accessing the women.

*“But what if someone is not in GP, how you can find, I dunno.”* (PH6, 26, Polish)

*“Some people come and stay with families, it might be a husband who is working, or partner is working, and the females just stay with the children,..”* (PH1, 35, Lithuanian)

Integration with society as a whole may be limited, as they tend to “stick” together in their own communities. In view of this it was suggested by some that a method of access might be through community groups, such as a “polish church”, through Facebook groups and community-specific mother and baby groups, all of which can be found through Internet search engines. However, in contrast to these suggestions, one Lithuanian participant who had attempted to assemble a group of Lithuanians from the local community for a church service described the difficulties that she experienced in achieving this. Despite the presence of a large Lithuanian population in her target area and leaving advertisement leaflets in community specific shops, in Lithuanian, she was unsuccessful. She commented on how the Lithuanian community is “normally” a

religious one and therefore this would have been of interest to them and it would also have been an opportunity to meet other people from the same community. Their priorities on migration may not necessarily be to integrate with any society (English or their own), instead their priorities were described as finding accommodation, obtaining a bank account and a national insurance number. If they were approached for the purposes of health promotion they would probably *“just say like oh just don’t talk to me, like, no, no, no, I was like, it’s alright I haven’t got time, I’m just in a rush or something...”* (PC14, 29, Polish).

*“Quite, yeah I think it’s quite typical in every single community that people like try to stick together and it’s like it’s hard to just reach them...”* (PC14, 29, Polish)

*“...we posted on a Lithuanian website to the Lithuanians in Northampton and information and also left leaflets in the Eastern European shops where they definitely go into, and Lithuanians are quite religious, well Catholics, but I'm afraid we didn't get a lot of response.”* (PC2, 37, Lithuanian)

*“...the first thing you would go, you would find an apartment and then you would get an account, maybe banks...”* (PC1, 34, Latvian)

Some cited social isolation and the stigma experienced as a “migrant” as barriers to integration. Their personal and social circumstances at the time of migration appear to determine whether these were a concern for them or not. For example, those women who had come to England for education purposes or had family or friends already in England did not comment on these adverse experiences. This was compared to the group of women who were in a difficult social environment at the time of and/or prior to migration. A Polish single mother describes how her partner was recently released from prison following charges for domestic violence. Her perception was that she is treated “differently” both at work and by the doctor as she is not British. Further as previously described social isolation may result from not leaving the house due to childcare commitments and only their partner being employed.

*“I would feel like they treat me differently because I am Polish...”* (PC14, 29, Polish)

*If that people to keep me just in house, never take me out for see, for learn, for nothing.....if I take you with me, in Hungary or Romania, I keep you just in house, the people don't know who is there, how can somebody help you if they don't see you never? (PH4, 34, Hungarian)*

### **Employment**

It was apparent that getting into employment was a priority for many of these women. They commented that for some Eastern Europeans the main aim was not to integrate with society but to earn money quickly and to go back home. There was a sense of judgement on the kinds of employment that the migrant group may end up in, with descriptions such as *“low quality works, like au pairs or collecting strawberries and those kinds of things”* (PC1, 34, Latvian). This was coupled with the sense of disassociation of some of the women from this “other” group of the migrant population, with the possible implication that their behaviours and views may differ. In addition, lack of employment or the loss of employment would increase their financial burden as some of these women described they were only just financially surviving. In the context of these financial burdens preventative healthcare was not a priority.

*“While people are coming just, ‘I want to earn some pocket money and I want to get back,’ they are not bothered to register.” (FG, Czech/Slovak)*

*“There are people who are thinking, I’m going to come here, I’ll just do a couple of years work, I’m going to go back and they don’t see the point, why do I need to learn English and all that stuff.” (PH12, 30, Latvian)*

*“I don't want to sit on a high horse, but I know people who have a profession, I don't know that people who probably working in factories what sort of take they have on this.” (PC4, 43, Hungarian)*

### **3. Knowledge, awareness and understanding of cervical cancer and the cervical screening programme.**

*The level of understanding and knowledge that exists about cervical cancer and screening in the two groups and their perception of population knowledge*

#### **Cervical cancer**

Awareness about cervical cancer was limited and some justified their limited awareness by the fact that they did not know of anyone who had been diagnosed in their circle of friends or family. The majority of women felt that more awareness surrounding cervical cancer was needed, whilst others commented that there was “enough” awareness about it and that they had seen adverts on the television, as well as in magazines.

*“....it’s been very quiet, I haven’t read anything for a long time about it. I’ve got to say I don’t think there’s enough out there.” (PC13, 56, English)*

*“I don’t know anybody actually friends or friends of friends who had it and I don’t know how common it is or if it’s very rare, but I’d never heard about it since that celebrity.” (PH14, 36, Lithuanian)*

*“I think you give enough information out there, I think I’ve seen TV... do you put adverts on the television” (PH10, 63, English)*

Triggers mentioned by the women, for recollection of cervical cancer included, the introduction of HPV vaccination and “Jade Goody”. Jade Goody (a reality TV star) was by far the most commonly mentioned association of cervical cancer in this cohort of women. The women expressed that the publicity received by Jade Goody resulted in increased awareness of cervical cancer and for some of the women this was the only time that they had heard of the disease. Although the English-born women more commonly referenced Jade Goody, the EE-born women had also heard of her story.

*“As far as I well I only know about because of that Jade Goody to be quite honest with you apart from that I have never really...” (PC16, 40, English)*

*“..then obviously Jade Goody died because of cervical cancer, so I think that was 2009 yeah..... I think obviously I’m sure that thousands and thousands of people have died of it before, but because it was such a public and such a quick, ...”* (PC23, 33, Czech)

An emergent theme during discussions about cervical cancer awareness was that of “breast cancer”. References were made about breast cancer in comparison to cervical cancer, particularly in regards to the increased awareness about breast cancer that exists. It was felt that breast cancer has a higher profile, that it is more advertised and that people feel more comfortable talking about it. Information about breast cancer is more readily available and appears to be more prevalent. The population are aware of how to perform a self breast examination and the signs to monitor for, the same level of awareness does not exist for cervical cancer.

*“I think breast cancer’s a lot more there than cervical cancer, yes. “I’m doing this for breast cancer,” “I’m doing this for breast cancer,” there’s a lot of charities about breast cancer, a lot of things on the TV about breast cancer – so breast cancer is more there in your face isn’t it a little bit more than cervical cancer I think.”* (PC18, 40, English)

*“Like the awareness of breast cancer you just go everywhere and people are happy to talk about it and everything, so why is it so different for cervical cancer, so...”* (PC23, 33, Czech)

*“Because you can hear on the TV all the time about breast cancer, breast cancer, breast cancer, but you never hear about the private stuff..”* (PH13, 42, Polish)

Additionally, there was a perception that people do not like to openly talk about cervical cancer compared to breast cancer and it was referred to as a “private part of the body”.

*“..because that is private and people don’t talk out loud.”* (PH13, 42, Polish)

Knowledge about cervical cancer was also fairly limited and there was no difference in the two groups of women (nEN and nEE). It was believed to be a rare cancer and this may be linked to the poor awareness of it. Theories on whom this cancer may affect included that it was a mixture of younger and older women. However, some women commented that usually when they think of cancer they generally think of older women and that as a young woman you don't think about cancer. On learning that it is associated with a sexually transmitted infection (STI) through the interview process, remarks were made that young women would be more vulnerable as they can have more sexual partners and that as long as you were sexually active you could get cervical cancer at any age. Further the fact that cervical screening is commenced at a young age led them to the conclusion that young women must also be affected.

*"I haven't known anybody with it and I've known lots of people with lots of different types of cancer so maybe it is rarer than others.." (PC8, 32, English)*

*"I think erm... that the young people don't thinking about erm... problem about cancer." (PH6, 26, Polish)*

*"As long as you're sexually active you can get it at any time in your life, either if you are 16 or 30 or 50." (PC7, 30, Romanian)*

There was uncertainty regarding the causes of cervical cancer, some believed it to be hereditary, some were unaware and one participant thought it was related to the male partner's genital hygiene. None identified the link with HPV infection without some prompting, however one participant did identify the association with sexual activity/behaviours, commenting that *"I did hear when I was younger that if you had sex before the age of 16 you increased your chances of cancer.." (PH10, 63, English)*

*"Yeah, I've always believed it was hereditary, but then no one else in my family has ever had abnormal smear tests, so maybe it's not, but that's what I always thought." (PH11, 45, English)*

*“I read that if the male partner doesn't wash his genitals properly then it can cause, in the long run it can cause cancer to the female..” (PC4, 43, Hungarian)*

In terms of symptoms of cervical cancer, on the whole the women appreciated that it can be asymptomatic. One participant even used this as a reason to justify more regular smears/ gynaecological examinations. However, a smaller proportion felt that you would experience symptoms if you had developed cervical cancer.

*“Also, cervical cancer, there aren't really many symptoms, so it's hard to realise, find out unless you go to the doctor that you have cervical cancer. So, it's peace of mind if you go once a year that some specialist looked at you, rather than go every three years.” (FG, Czech/Slovak)*

*“I think so, I think you'd feel something like, I don't know exactly which one you would be able to feel, but I mean if it's cancer or whatever, but if something wrong with your body then it lets you know, like leaks, like maybe blood or itchiness.” (PC7, 30, Romanian)*

The participants' perception of population knowledge about cervical cancer was that knowledge levels and awareness were deficient. References were again made to Jade Goody, stipulating that the publicity that arose from her, temporally heightened awareness in the general public but since then it has died down. The association of cervical cancer with HPV, an STI, was not felt to be public knowledge.

*“...something like Jade Goody's case, which is a very public celebrity comes then people's mentality changes and they go but I think they take it for granted later again.....But not cervical cancer specifically; I don't think people understand.” (PH1, 35, Lithuanian)*

*“I don't think a lot of people do, “She's got cervical cancer,” “Oh what a shame,” they don't say, “Oh right, you aware of the fact that that's because she's caught it...” you know.” (PC18, 40, English)*

### **Cervical screening**

There was a divide between those women who were born in England and the migrant group with regards to awareness about cervical screening or “smear tests”. Women born in England claimed to have heard of screening, some even recalled that they knew about it prior to their first smear invite and that there was a lot of awareness about it at school. Whereas in the migrant group many women admitted that they did not know exactly what it was prior to migration to England. This is despite most of them attending for annual gynaecological reviews in their home countries which on reflection they acknowledged included having a smear test. This is discussed in more detail later.

*“...so I think before I needed them I think I was aware of them..”* (PC10, 33, English)

*“...when I was in school there was a lot of awareness because of that.”* (PH5, 25, English, in response did you know about smears tests prior to receiving your invitation letter)

*“To be honest I never heard of smears screening until I came to the UK.”* (PH1, 35, Lithuanian)

Women from both groups commented on the lack of publicity and/or information available about cervical screening.

*“ I mean I’ve never seen anything on the television with people who’ve had it showing you what they do..”* (PC13, 56, English)

*“... when I moved here I didn't have any information about it and even in GP practice they didn't, like in the walk-in clinic they didn't even suggest me anything like that, so it's like there isn't any information and there isn't any education about it either.”* (PC1, 34, Latvian)

Knowledge of the actual screening programme itself was good. Most of the women correctly identified that the age of commencement of screening in England is 25 years, with some who believed it to be 18 years and others who did not have any idea.



Similarly, women from both groups were aware of the screen frequency in England of every three years. The terms “cancer” and “pre-cancerous” were often used interchangeably when the women spoke about the actual purpose of the smear test. Overall it was evident that the women had some understanding that the purpose of the smear test was to detect “abnormal” cells and that the main advantage was early diagnosis and treatment. Some of the women had a more in-depth appreciation that the aim was to detect pre-cancerous changes and to prevent the development of cancer. A smaller group were not clear on the purpose of the smear test, with suggestions including, *“To check if everything is okay or not.”* (PH6, 26, Polish), *“..that they are looking for most probably sexually transmitted diseases or something but I was not really...”* (PH14, 36, Lithuanian) and *“Just, like I think certain part of my body, like for example if my ovaries they are fine, it’s like, if everything is alright, like inside I think..”* (PC14, 29, Polish). Almost all of the women who were not clear about the purpose of the smear test were born in an EE country. Women from both groups (nEN and nEE) spoke only briefly about screening for HPV during the smear test. There were uncertainties about the indications for a smear test expressed for example, *“I wonder if a girl’s a virgin, they can’t have the smear can they? Or can they still have a smear?”* (PC12, 61, English).

*“Well it’s basically checking that some of the cells they are not cancerous, that’s what I thought it is.”* (PC1, 34, Latvian)

*“Yes, I believe. I think it’s testing cells in the lining of your cervix for any abnormal cells for the start and looking at the change that could potentially lead to cancerous cells and obviously you need to have a smear test to check for any changes in the cells so treatments start to prevent it turning in to cancer.”* (PC11, 36, English)

*“It’s to diagnose the cervical cancer cells in the womb or wherever that is in the genitals...”* (PC2, 37, Lithuanian)

There was limited appreciation about what a screening test means and the possibility of a false negative result. Only one participant spoke about the procedure itself and she

denied any knowledge of what it involved and admitted that she “..went on the Internet goggled it..” (PC7, 30, Romanian).

There were divided opinions regarding population knowledge/awareness about screening. nEE women considered that other women would perceive screening just as a routine check-up and that although they would appreciate that its “mandatory” they would not really understand why. Further they thought that the general public believe that screening is diagnostic and that not many women would have heard about it. In contrast to this English-born women felt that there was good awareness of screening in the population and that if they were attending for the smear test then they were aware of the risks of getting cervical cancer. The differing opinions may relate to whom the women are referring to when they talk about the “general population” for the nEE women it is likely many of them are referring to other women like themselves who have migrated to England. Compared to the English-born women, who are more likely to be referring to other native English women.

*“I think a lot of people know that it’s mandatory, but I don’t really know why.... I think they think it’s more of a check-up.”* (PC1, 34, Latvian)

*“...you know the woman just doesn’t know about smear test, for example.... many ladies don’t know nothing, they’re not hearing about test, you know what I mean?”* (PH13, 36, Polish)

*“Yes I think that’s what they expect; they expect a smear test to tell them definitely this is a cancer or this is not a cancer,..”* (PH1, 35, Lithuanian)

*“I think on the whole it’s very good and people do... it’s out there and people know about it.”* (PH10, 63, English)

### **Information provided at the time of the smear test**

The main content of the information provided to the women at the time of the smear test were details about the procedure itself and the process of obtaining/receiving the results. Some women recalled that they were given information about what they were looking

for i.e. abnormal cells. Others experienced that unless they asked questions, the practitioner volunteered very little information. One participant describes her recollection of her first and only smear test, where she felt very minimal information was provided and recalls a specific comment made by the nurse at the time; *“..let’s hope it comes back clear then I don’t need to see you for the next few years, and that’s the only thing she emphasised; we didn’t go into any details.”* (PH1, 25, Lithuanian). This participant was diagnosed and treated for cervical cancer.

*“Well briefly, they just said they were looking for abnormalities or something like that. They didn’t go too much into detail; they mainly explained what is going to happen, how to say it and what they would do, but not exactly what they were looking for.”* (PC6, 28, Hungarian)

*“Yeah I think she told me, yeah I think so, I think I knew what we were doing and what would happen afterwards.”* (PC10, 33, English)

The participants explained that the smear taker did not educate them about symptoms that they should monitor for. Nevertheless, they were all in agreement that this is vital information that should be provided at the time of the smear. An English-born interviewee describes that she did experience abnormal vaginal bleeding in between normal smear tests and had to “Google” it to discover that she needed further medical attention, she was then found to have abnormal cervical cells, which required treatment.

*“...I mean, it’s all over the internet if people looked for it, it says exactly that, you know, if you get anything that’s not usual after you’ve had intercourse or anything like that, you should go and see your GP but you just go for the smears, the nurses obviously think, they’ve probably heard this a million times before I don’t need to keep repeating the same thing.”* (PC22, 31, English)

The majority of the women expressed that they were not informed about HPV testing during their most recent smear test. As the interview progressed and they learnt about the role of HPV in cervical cancer pathology or through their own experiences, the women felt that being informed about HPV testing at the time of the smear is essential.

In the limited scenarios where it was mentioned no specific details were provided. Further, receiving a results letter stating that you are HPV positive without any prior knowledge to the fact it was being tested could cause undue anxiety.

*“No, I’ve not heard anything about it, nothing about it, ever. ....I would have liked to have known at the time, yeah.”* (PC18, 40, English, in response to *“Do they tell you that they may check for HPV now during your smear test?”*)

*“I was told by the nurse when she did the smear test that she was going to test for it but I wasn’t quite sure what it is...”* (PC7, 30, Romanian)

*“Umm... I suppose you’d be a bit worried if it... if you hadn’t been told beforehand and you received that. You’d maybe think it was... means that you were going to get cancer or something, so it would be a good thing that... for them to actually say.”* (PC21, 31, English)

As aforementioned the women were informed of the processes of obtaining results, however information on what happens if the results are abnormal was scarce. Internet search engines were utilised to gain further details of the next steps. However, some women considered it not to be necessary to be informed about the next step until/if they get there. In addition, women who had had their follow up schedule altered due to the introduction of HPV TOC felt that they were not provided with sufficient information as to why this change had occurred. They had gone from 6 monthly/ annual smears back to three yearly over a short time.

*“I didn’t feel... my nurse particularly wasn’t greatly helpful, ...prior to me having the abnormal cells and asking questions about what happens when you get to hospital and it was a bit dismissive almost in her responses..”* (PH7, 25, English)

*“I think it would be... I imagine there must be a reason why, but I don’t know what the reason is.”* (PC25, 29, Polish, in response to a question about, if is she knew the reason for a change in the follow-up regimen)

There were mixed views, from women from both the groups (nEE and nEN), on whether the amount of information provided was adequate or not. One group of women were completely satisfied with the quantity and quality of the information they were offered, they “trusted” the healthcare professionals. Whereas others felt that for their current situation, where the test results were negative, adequate information had been supplied but if they had abnormal results they would like to know more. Then there were those who considered that the level of information provided was insufficient. One woman commented that she thought that knowledge was being withheld due to the fear that it may be misinterpreted.

*“Well I suppose if they’d not found anything I’d be satisfied, but if they found something I suppose I would want a bit more but...”* (PC15, 36, English)

*“...like to be aware, so I’d like to be told more, whereas I know, I think the culture here or the impression I get is not to tell people too much because they will misinterpret the information and get the wrong impression.”* (PC25, 29, Polish)

The main barrier to providing more information was quoted as lack of time. The women considered that there was not enough time during the consultation to give an exhaustive explanation of the test and procedure. The pressures of service provision to get through adequate number of patients limited the time for discussion and this also discouraged the women from asking questions. These feelings of time pressures during the consultation were more pronounced in the nEE women, reflecting the differences in their experience of healthcare in England compared to their home countries.

*“Like here in England, if you are going to go for a test, if it’s going to take 20 minutes to explain, it’s ... I don’t think they just, they don’t have the time for it. But I would like to know ...”* (PC14, 29, Polish)

*“You know why, I will tell you why because we have 10 minutes? You don’t want to bother them.”* (FG, Czech/Slovak)

*“...but every time when I ask an explanation or if I can speak a couple of minutes with nurse, no, no, is busy, busy, busy.” (PH4, 34, Hungarian)*

The other factor to consider was the ability to retain information. The women commented that they might have had things explained to them but that they cannot recall them. The procedure itself caused worry and preoccupied their minds and therefore they were unable to take in any information at that point. For some it's an experience that they want to block out as soon as it is over and therefore they cannot retain the information. Further getting the balance of giving the “right” amount of information is important, some expressed that having any more information would actually create more anxiety.

*“.. And then she started that test, so I haven't got... I can't remember that she... she gave some information.” (PH6, 26, Polish)*

*“Yeah, I think so. I think... I usually block it out fairly soon afterwards, but I'm, pretty sure that they explain what they're doing and why, yes.” (PC20, 31, English)*

#### **4. Access to information about cervical cancer and screening and the adequacy of currently available information.**

##### ***The current sources of information about cervical cancer and screening and potential need for increased information***

##### **Sources of information about cervical cancer and screening**

As discussed above the level of awareness and knowledge about cervical cancer/cervical screening was limited in this group. Therefore, they had limited sources of information. The story of and the publicity that surrounded Jade Goody were quoted as a source of information by many of the women. They recall that there was a lot of publicity on the television and news stories about cervical cancer as a result of her illness. With regards to magazines and newspapers the women recollect that when there was a celebrity/high profile public figure or a young person who had been diagnosed with cervical cancer, there would be more information available about it for a short period only. There was this perception that news about cervical cancer was more prevalent in the media if a young person rather than an older person had been affected. The participants admitted to “googling” for information but acknowledged that not all the information found on the internet is accurate and sometimes it can do more harm than good. The NHS website was thought be a good source of more accurate information that was available through the internet. Some women had heard about cervical cancer from charitable organisations. Other sources of information included posters, the media, school and the GP. However, overall it was evident that many of the quoted sources of information were available only for a limited time and seemingly coincided with the Jade Goody story. When the interviewees spoke about their sources of information the majority referenced Jade Goody. This suggests that current sources of information are limited.

*“Yes, I Google to check what it is and what it is for” (PC24, 33, Polish)*

*“.. because on internet sometimes you just, even like they saying you have some symptoms and you are just doing like research and it’s like, oh my gosh you got cancer and it’s just like headache.” (PC14, 29, Polish)*

*“Well that is what I’ve read about lately you know that’s when you get it in the papers is when young people get it..”* (PC13, 56, English)

### **Need for more information**

This was briefly touched upon in the earlier section. However, an emergent theme in the interviews was that when the participants were asked specifically about their need/requirement for more information, most of them felt that would like more. This is in contrast to some of the statements that they were satisfied with the level of information provided by the practitioner at the time of the smear test. This brings into question the relevance of the forum at which the information is shared. The other explanation is that the interview may have highlighted gaps in their knowledge, which they were not aware existed. For example, many of the participants felt that they would like more information on HPV testing, what it is, what it means and the consequences of a positive result. The participant’s knowledge about HPV and HPV testing is discussed in detail later, however as mentioned earlier the women in this group were not even aware that it was being tested for.

*“Yeah, you need to know the virus I would think, because abnormal cells, I mean that’s not a lot of information, if you knew what actually caused the abnormal cells in the first place, it being the HPV, yes, so I had no idea about that,..”* (PC18, 40, English)

*“Because if I am tested for something I should know what I’m tested for.”* (PC1, 34, Latvian)

*“..so many different levels or categories of HPV virus and strains, I think it would be nice to know, are they only testing you for the ones that make you more prevalent to get cervical cancer..”* (PH7, 25, English)

More information was also sought on the symptoms or the lack of that one should monitor for. It was felt that by explaining that the patient may not experience any symptoms the importance of regular smears could be emphasised.



*“And to tell people what they should be looking out for or anything at all, or maybe there aren’t any symptoms and that’s why you should go for a smear test.” (PC22, 31, English)*

The information needs of the two groups (nEN and nEE) did not appear to differ, they both equally expressed the requirement for more information particularly with regards to HPV testing.

The benefits of increased knowledge or information sharing were quoted as *“if you know more about something you’re less scared of it.” (PC24, 33, Polish), “so more information available I’m happier and I feel more relaxed and secure rather than me asking questions and worry that I haven’t asked something crucial..” (PH1, 35, Lithuanian)*. Greater knowledge was also thought to help reduce anxiety and frustration and possibly allow the women to make lifestyle changes that may reduce their risk of developing cervical cancer.

*“If you knew that there were ways that you could even just lifestyle changes possibly that would reduce your risk of developing cervical cancer, then yes I do think that information should be available..” (PH5, 25 English)*

With regards to the avenues through which information sharing should occur a variety of suggestions were made. Some thought that leaflets would be good, whereas others felt that leaflets are less likely to be read and therefore face-to-face discussions would be more useful. Use of media and social media, along with larger awareness campaigns, similar to the ones used for breast cancer, were also suggested.

*“As long as you explain it to them, perhaps it might be better face to face with somebody rather than just...Because you get a letter and think I’ll read that later and it’s put away....” (PH10, 63, English)*

*“I don’t know maybe like just awareness campaigns because we all know so much more about breast cancer because there is always campaigns for it..” (PC15, 36, English)*

**5. Knowledge, awareness and understanding of cervical cancer and the cervical screening programme in their country of birth prior to migration.**

*The level of understanding and knowledge that exists about cervical cancer and screening prior to migration and their perception of population knowledge in their home countries*

**Cervical screening and cervical cancer**

Awareness about cervical screening programmes in their country of birth varied amongst the women. Many had very little awareness or were not sure of the details of the screening programme or the smear test itself. Some of the women rationalised their lack of knowledge by the fact that they were too young, prior to migration to England, to be involved with screening in their home countries, therefore did not know much about it. The other reason quoted was that they had been in England for such a long time that they no longer had a recollection of the current situation in their home country. Knowledge of the details of the actual smear test were lacking, for example what was being tested for and what it involved. In contrast, a smaller group of women felt that it was “quite common” for women in their home countries to be aware about cervical screening and they were able to provide a clear description of their respective programmes. Perceptions about population knowledge were similar to the women’s own awareness, i.e. if they felt they did not know much they assumed that population knowledge in their home countries was also scarce. Some comments were made about the differences in population knowledge between more rural areas compared to more urban areas. The assumption was that women from more rural areas may not have as an in-depth an understanding and/or knowledge of cervical screening.

*“I knew it because in Latvia that’s quite common and you know and everybody would know....” (PC1, 34, Latvian)*

*“That time I was like 18 so I didn’t really like have any information about it. I knew what it did something but I just, I didn’t read about it, I wasn’t interested at all.” (PC14, 29, Polish)*

*“I felt like there isn’t much information in the rural area as much as it is in the towns so women in villages don’t, even if they know about it, they probably don’t know enough about it and the importance of it.” (PC7, 30, Romanian)*

Awareness specifically about cervical cancer was thought to be poor, both at a personal and population level. Comments were made that unless one knew of a relative or a close friend that had suffered with cervical cancer; there would be little awareness of it. There was no publicity in the news or newspapers and it was felt that ovarian cancer was the more “dominant” female cancer.

*“I would say 50% never heard of smear or cervical cancer in the first place because typically when you think about gynaecological cancer you think ovarian, not even womb, womb was not very common, so yes I would ovarian is the dominating one...” (PH1, 35, Lithuanian)*

### **Information provided**

Observations about the amount of information provided by healthcare professionals about screening and/or smear tests were that some women perceived that the level of information provided was not sufficient. Only basic information was shared and more in-depth, detailed explanations were withheld. No information was provided about the availability or the lack of HPV testing and the women desired more information.

*“I think in Latvia you get in, you get it done, you get out – it’s very... They don’t tell you much details and they try not to go into it unless you really ask them and then they will tell you, even though they don’t really want to tell you.” (PH1, 34, Latvian)*

*“When I done this test I just done it once in Poland, the person just said all we are going to just check it, if you don’t have any cancer and everything. But it was just like basic, he just tell me the basic thing, he didn’t went really deep..”(PC14, 29, Polish)*

In contrast another group expressed that ample information about the test being performed as well as potential results was being offered. The last group of women were

in between the two described above, they remarked that if you had questions and wanted information that the healthcare professionals would happily oblige.

This later group also commented on the fact that education about gynaecological procedures/ checks commence when you are a teenager, a gynaecologist would visit the school and provide an educational session on the topic. Therefore implying that they already have a foundation of basic knowledge on the subject. Another participant further reinforced that education about smears tests starts at school level; hence there is greater awareness of it in the population in their home country. However, this same participant was also one that felt that the healthcare professionals did not provide adequate information.

Two participants who were both from Poland expressed conflicting views, this again could represent the forum in which healthcare is accessed private versus state, although they do not explicitly comment on this here.

*“The doctor explained how this worked, what this is and what they are looking for and when the results came he just explained everything is normal, nothing here.”* (PC5, 34, Polish)

*“I remember they used to, back in Slovakia when I used to be a teenager, I don’t remember how many of them there were but in the school we had the gynaecologist coming over and speaking with us.”* (FG, Czech/Slovak)

## **6. Cervical screening; from the invitation to the smear test.**

*The process from receiving the initial smear invitation letter, access to screening services, screening behaviours and the actual smear test*

### **Smear invitation letter**

The majority of the participants had recollection of receiving the smear invitation letter and for many these acted as a prompt to actually go and get screened. It meant that they did not have to take the responsibility to remember when their next smear was due, as they would simply wait for the next letter to arrive. This removal of responsibility from themselves was welcomed. Various comments were made about the actual content of the smear invitation letter, some felt that the letter was very “generic”(PH5, 25, English) and that it stated basic facts such as the age and frequency of screening. Others thought that the letter did not emphasis the importance of screening, with more importance being given to the rarity of one being affected by cervical cancer. The women recalled that there was no information on HPV testing in the letter but it did state that the test was free of cost and that “..it’s a horrible...nobody wants to do it but it’s not that bad and it’s better to just get it done.” (PC10, 33, English). It was suggested that rather than having separate information leaflets that the key facts were incorporated into the letter itself. Only one of the EE-born women commented on the language of the letter and described how she had to translate the letter in order to understand its content. However, they did identify a potential problem in actually receiving the smear invitation letter for the EE group, they are a mobile population and they may not change their address with GP on moving and therefore the letter might not reach them.

*“Well perhaps if for example, I’m just thinking of the letter you get sent out, it said it’s time for your regular blah blah blah, this applies to you if you’re aged between such and such and sexually active.” (PC20, 31, English)*

*“I would not know when my last smear test was, but then I know I’m going to get the letter and it’s just up to me to go and get it sorted, but at least I know that there is a database..” (PC23, 33, Czech)*

*“..it wasn’t very obvious to me from that letter I was receiving how important it is and how high risk actually it is because obviously they emphasise that it’s extremely unlikely then and so on and so on, so..”* (PH1, 35, Lithuanian)

*‘..these people they are moving often, they are not saying in one place, so even if they register one address, they are not bothered to change their address in their GP surgery.’* (FG, Czech/Slovak)

The reminder letters were thought to be beneficial as many commented that they had received them and without them it would be quite easy to forget about booking the smear test. One participant who herself had not been for a smear test despite receiving many reminder letters suggested that an actual appointment is sent with the reminder letter. This last comment may relate to issues with accessing screening services and barriers, which will be discussed later.

*“so if I don't get those letters and if I forget about them and if GP doesn't mention it I won't do it probably.”* (PC1, 34, Latvian)

*“..if you got the reminder with the appointment...” “I think I... it’s the fact of you only ever get the reminder and it’s the fact of it’s just something you just don’t get around to doing.”* (PC16,40, English)

Two main themes emerged about the information leaflet that accompanies the smear invitation letter. The first was around if the women actually read them and second regarding the content of them. With regards to the first point, it was apparent that most women did not read the information leaflet. One reason specified for not reading it was that they might have read it when they went for their first smear test but subsequently they did not feel the need to, as they knew what to expect from the test. They expected that information would be provided at the time the smear test. The few who admitted to reading it confessed that they did not retain the information, which they had read. Others just screened the information leaflet for any new information or changes. One participant felt that it was related to her age, now that she is relatively older she was

conscientious about her health and therefore she was more likely to read it. Pregnancy in addition was another prompt to read the leaflet; this was mainly to ascertain if a smear test could be conducted during pregnancy.

*“Not, not now but I used to when it first came.”* (PC13, 56, English)

*“No I have never read the leaflet oh God it’s terrible isn’t it..”* (PC16, 40, English)

*“I do just to see if there’s any more updates or anything, then five minutes later it’s out of my head...”* (PC17, 34, English)

*“Possibly probably first time and then I will just screen through it, if there is anything that catch my attention that has changed, but yeah.”* (PC24, 33, Polish)

With regards to the content of the information leaflet, it was felt that the overall level at which it was pitched was correct. It was simple to read and understand and “straight forward”. However, some of the women felt that if it was your first smear invitation and you had not done any of your own research it would not be clear from the leaflet exactly what the smear test involved. They felt strongly that there is no mention of the fact that it is a private and intimate examination and that one may bring someone with them for support. Of interest it was only nEN born women who had made comments on the inadequacy of the information provided. This may suggest that either due to language barriers, comprehension of the information was impeded in the nEE group and therefore they could not comment effectively on the adequacy or that their information needs were not as great as the nEN group. Only in the focus group did the participants have recollection of receiving information on HPV in the leaflet. Some felt that the content of the letter and the leaflet *“..can be quite scary still.”* (PH7, 25, English)

*“They normally have a leaflet saying what exactly the test is, why they do it and what it involves. Yeah, it was brief, it didn’t go into too much detail, but it was enough to feel comfortable to go.”* (PC6, 28, Hungarian)

*“...especially as if it’s your first one, there’s not much information to say, you know, like, it doesn’t say that you can take someone with you, it doesn’t say that it’s an intimate thing, that it’s quite a personal thing..” (PH5, 25, English)*

*“I didn’t even know yeah how they did it and what instruments they used and whether it would be uncomfortable and whether I was covered up or whether I was just kind of laid bare..” (PC8, 32, English)*

### **Access to cervical screening services**

Opinions regarding the ease of accessibility to screening services were split. One group of women had experienced difficulties in obtaining appointments to have their smear test. They described problems with appointments being cancelled on multiple occasions or even booking an initial appointment within a timely fashion. Getting through to the GP surgery over the telephone was thought to be more difficult than physically going to the surgery. However, problems with getting an appointment to fit in around working hours was not thought to be isolated to the GP surgery, NHS or even just smear tests, comparisons were made to obtaining hairdresser appointments.

The other group of women were those who found it relatively easy to access screening services. Some commented that they utilised “drop in” clinics which permitted them a degree of flexibility. Nevertheless, one of the quoted disadvantages of drop in clinics was that there was the potential to “put off” going on the day, as no real commitment had been made to attend, i.e. other things may take priority at the last minute. When a specific appointment time was provided, arrangements to ensure that they were free at the time could be made beforehand. It was easier for some women as their GP surgeries had extended opening hours or appointments could be booked online. It was also highlighted that women may not be aware that the smear test can be taken at places other than just the GP surgery, thus permitting more flexibility. The perception of what constituted a delay in getting an appointment for a smear test differed between the two mentioned groups. In the group who felt that access to screening services was “easy” the women appreciated that this was a non-urgent procedure and did not mind waiting a period of weeks. In comparison for the other group waiting a few weeks for a smear test appointment was deemed to be too long.



There was no difference noted between nEE and nEN born women in terms of their perception and/or experiences with regards to accessing screening services in England.

*“It was very hard for me to get the latest appointment because they just don't... it's really bad with appointments in this surgery, so I've tried to get it twice already and every time they had to cancel it somehow and, yeah, I'm still due for one.”* (PC1, 34, Latvian)

*“This time around I have found it really difficult so like I said it's the fourth time they've cancelled,..”* (PC10, 33, English)

*“It wasn't bad at all. I think I didn't even have to wait too long.”* (PC7, 30, Romanian)

*“.. there are other places that they can go that isn't necessarily their own GP. I think people just think they have to have it at the GP.”* (PH5, 25, English)

### **Cervical screening behaviours**

The women's recollection of the age at which they started cervical screening varied. In those who could remember there was a divide in the starting smear age between the women born in an EE country and those born in England. For the English-born women most stated that they had their first smear test aged between 20-25years, whereas the EE-born women tended to have started earlier at 18years of age. Women from both the nEN and nEE groups suggested that the screening age in England should be lowered. The perception was that girls are becoming sexually active at a younger age and therefore they are at a higher risk and that the screening start age should be lowered to reflect this. There was little understanding of why the screening age had been increased from 20 to 25, with monetary reasons quoted by some.

*“...that all tests or... or something should be early yeah, so that should start at eighteen years because how I say, they started the sex about fifteen/sixteen years yeah all so I think it's pretty young.”* (PH6, 26, Polish)

*“I thought it was a money thing.”* (PC3, 30, English)

With regards to their actual screening behaviours the majority of the interviewed women claimed to be regular screen attenders. Furthermore, they were confident that they had not missed any smear invites and repeated comments were made about the smear invitation letter acting as a good aide-memoire. EE-born women had mainly had their initial smear in their home countries and the subsequent ones in England and/or in their home countries. In contrast a smaller group of women admitted that they did not attend for regular smear tests, one such was an English-born woman who had only had two smear tests in her lifetime that were 15 years apart and her last one was an abnormal smear 7 years ago. Another was an EE-born lady who on migration to England had “ignored” several smear invitation letters for almost ten years before attending for her first smear test. The specific barriers to screening are discussed later on.

*“.....personally I always go because, you know, it’s something if you get it, you need to catch it quick.....No, never missed one, no, no.” (PC13, 56, English)*

*“I mean said I had mine done 7 years ago and I got the abnormal cells that I had to have the laser treatment and haven’t been back after that.” (PC16, 40, English)*

The above-described screening behaviour was not in keeping with that of the other EE-born women. It emerged that the EE-born women had a heightened sense to protect one self, which resulted in them having more frequent smears in their home country. Although this was not true for all EE-born women, the women who did chose to return home for smears stated that they used it as a “double check” mechanism, that they trust their own more and that when they go home they have a gynaecological check-up and a smear test will be performed as part of this. The perceived prolonged smear frequency in England was also a strong motivator for returning home. It was not seen to be disadvantageous to have more frequent smears in two different countries. However, some had experienced that English doctors did not accept abnormal results from abroad and this caused frustration particularly if there was a discrepancy in results from the two countries. Smear tests performed in England, their country of birth and in the private sector in either country, were assumed all to be of the same quality and hence the

annoyance that tests performed elsewhere were not accepted. There were also the group of nEE women who had started off having smears tests in their home countries but were now committed to having smears in England only.

*“I know it’s going to sound a little bit harsh but I trust more, like, Polish ... if I’ve done the test here and if I’ve done it in Poland at least I double check if you know what I mean.”* (PC14, 29, Polish)

*“Because the previous one showed some irregular cells, this one was absolutely fine, normal, so I felt that there is a discrepancy, so just to be on the safe side I would double check with a gynaecologist.”* (PC4, 43, Hungarian)

Overall the women correctly identified the three yearly cervical screen frequency in England. There was some awareness that the screen frequency did change at some point to five yearly but knowledge of the exact circumstances when this would happened was lacking. For example, one participant commented that it might correlate to geographical location; *“Whenever I get the letter, when I lived in London I think it was every three years, but I think it’s every five years here in Northampton..”* (PC15, 36, English).

Knowledge of the rationale behind the three or five yearly smear interval was absent from both groups (nEE and nEN). However, it was the EE-born women who were concerned about the smear interval in England, which they perceived to be too long. It was felt that over three years one could develop cancer without necessarily being aware of it or having any specific symptoms. This fear related back to their deficient knowledge about cervical cancer development, many of them were not aware if it was a rapidly progressing disease or not. Some of the women believed that it was due to cost implications that more frequent smears were not routinely performed. As aforementioned it was not seen to be harmful per se to have more frequent smears but some did understand that there might be clinical reasons for the current smear interval, for example a comparison was made to excessive vaginal examinations during pregnancy resulting in infections.

*“.. having a smear test done twice a year, I don't think it's dangerous..”* (PC23, 33, Czech)

*“I'm not very sure if the cervical cancer is kind of an aggressive cancer, how fast it actually develops. And if this gap is actually short enough gap to detect it early.”* (PC24, 33, Polish)

*“..because a pregnant woman, for example, she's not close to getting any infection if someone's just checking all the time down there. Maybe this could be the reason for these checks as well, to do it just every three years, not too necessary just going in there constantly and checking every...don't know.”* (FG, Czech/Slovak)

### **Influences, barriers and motivation for cervical screening**

Age was deemed to be a significant influential factor of screening behaviours and/or uptake and nEN women commented on this more than the EE-born women. They believed that the older, more mature woman was more likely to comply with screening, whereas younger women would feel that it is not something that really affects them. Older women have a greater appreciation of the risk to their health, compared to the young who may believe themselves to be immune. It was thought to be analogous to smoking, when the young take up smoking they do not worry about getting lung cancer when they are young. Further it was thought that younger women would be more embarrassed by the procedure than older women.

*“I think when you're younger, you never think you're gonna get anything anyway even if they say, you think oh well I'm young I'm okay. But when you're older, you realise “oh gosh I could get these things””* (PC13, 56, English)

*“It's like people who smoke 20 a day, they don't worry about getting lung cancer when they're young”* (PC18, 40, English)

The biggest motivator for cervical screening emerged to be fear or concern about self-health, either directly for themselves or for their children. They feared the diagnosis of cancer, the belief that it was preventable or detectable at an early stage was deemed

sufficient to motivate them to attend for screening. There was awareness that they may not have any symptoms, which further perpetuated their fear of getting cancer without knowing about it. There was also a sense to take care of one's body by attending for these recommended checks. The sense to protect one self was for a personal benefit but for those women with children it was more than that, they emphasised that they were doing it for their children, they didn't want to leave them without a mother/parent. The concerns about developing cancer and preserving their health were equally shared by both groups of women (nEE and nEN).

*"So that's what always done me, I think the word cancer scares you."* (PH9, 52, English)

*"It's important for my kids, just because of my kids, that's the most important part because I don't want them to stay without somebody."* (PH12, 30, Latvian)

Triggers to initiate cervical screening included receiving the smear invitation letter, which has previously been discussed, commencing a sexual relationship, developing symptoms and doctor recommendation. Having a cervical smear test was thought to be part of a sexual health check that they may have at the start of a new sexual relationship. This belief was mainly prevalent amongst the EE-born women. However, one UK born woman who was non-compliant with screening described that the only time she attended was following her partner cheating on her. Her concern was that she wanted to be checked for sexually transmitted infections and the smear test was a part of this.

*"...I started to have sexual intercourse and I thought that it would be good to do the whole... err, gynaecological.."* (PC5, 34, Polish)

*"Well I really went then because of a nasty divorce and I found out my husband was sleeping around so I only really went for the fact that to make sure he hasn't given me anything to be quite honest with you,..."* (PC16, 40, English)

The development of symptoms such as irregular bleeding, "not feeling right" and the discovery of a suspicious mass led to some women seeking professional advice, which

then resulted in them having a smear test. Doctor recommendation also played a part in smear test initiation; often this was when the women had attended for other concerns, for example to have the coil fitted.

*“..when I told him that I’d never been for a test myself he literally forced me and he literally forced me so..”* (PH1, 35 Lithuanian)

*“But originally everything came from that, because I was planning to fit in the coil.”* (PH12, 30, Latvian)

Prior awareness and/or knowledge of cervical cancer were also motivating factors for them to attend. The women commented that they knew how important it was to attend either from knowledge that they held themselves, that they had obtained from family and friends or the information contained within the smear invitation letter. Lastly some women stated that they were simply brought up to attend for regular check-ups and if something was recommended by the doctor they would comply, without questioning it.

*“..but as I said I probably was brought up the way that if something comes from the doctor it’s important, so that was my... I didn’t think twice to go or not to go.”* (P14, 36, Lithuanian)

Personal and perceived population barriers to cervical cancer screening included feeling “healthy” and being asymptomatic. If they did not feel unwell, have any symptoms or believed that they were of good health, there was no justification to seek medical help. Comparisons were made to having regular/routine dental checks, where they would only go with the onset of symptoms and there was a reluctance to attend merely as a preventative measure. These views were shared amongst both nEE and nEN women.

*“Do you see what I mean, there’s obviously nothing wrong. It’s like going to the dentist, a lot of people don’t go until they have an issue.”* (PC22, 31, English)

Embarrassment, preservation of dignity and privacy also appeared to be of concern. These were seen as deterrents for screening attendance; the thought of having an

examination of a personal area was too much for some women. The emotion of embarrassment was felt to be greater with younger age and with advancing age it was believed that there is a greater appreciation of risk that overrides the fear of embarrassment. The phrase “it's a private thing” was frequently mentioned with regards to smear tests. The participants commented on how if the test included examination of a less private or an already exposed area of the body (the arm or the hand) they would be more comfortable with it. However, the same degree of vulnerability was not associated with the breasts, one participant acknowledged that breasts are also a private part of your body but that she would still feel more comfortable talking about them and breast-feeding in public, where her breasts may be exposed.

*“...we're happy to openly breast feed, whereas you wouldn't openly have a smear test anywhere done, that would be inappropriate.” (PC19, 33, English)*

*“...just because it's kind of intimate procedure and, you know.....it's quite private” (PC24, 33, Polish)*

The anticipated fear of the procedure and a ‘bad’ experience were further mentioned as barriers. Fear was described in two forms, one of the procedure itself, that is was going to be painful and hurt and secondly fear of getting the diagnosis of cancer. The later went back to the notion of “what you don't know won't hurt you”, particularly if they were asymptomatic. A bad experience with a smear test could reinforce existing concerns and deter attendance in the future.

*“..you know once you are diagnosed with it you are on a timer for how long you have got, what you don't know don't do you no harm if that makes sense.” (PC16, 40, English)*

*“Potentially, because it was, for me, it was uncomfortable and painful, so that coupled with the fact my nurse wasn't particularly approachable or personable, I was a bit unsure are we finished are we not, can I start getting re-dressed again, it wasn't pleasant and if you're reluctant about going I think it can curtail you ever going again almost.” (PH7, 25, English)*

Knowledge of cervical cancer has been previously discussed; poor knowledge levels resulted in the participants having a low self-perceived risk of developing cervical cancer and therefore they were less likely to participate with screening. Others had declared themselves to be low risk due to certain lifestyle choices, for example they were not sexually active and hence felt that they did not require screening. Some simply had no explanation or could not recall any specific reason for non-attendance.

*“I don’t have a reason why I didn’t go for the smear test first and then...”* (PH12, 30, Latvian)

*“I’m not sure why I didn’t go for the first one to be honest. I was young and I kind of disregarded it I guess.”* (PC20, 31, English)

The other group of barriers were the practical ones: no time, difficulties in accessing the GP surgery and having the smear test during at the appropriate time in the menstrual cycle. As the smear could only be performed at certain points of the menstrual cycle it was felt that there was limited opportunity to get it booked, this could lead to delays. Fitting in an appointment around a busy life, particularly if they had children and were working could be difficult.

*“Yeah I do feel a bit like because there’s only a little amount of time every month that you can do it it’s dragged on..”* (PH10, 63, English)

*“..reasons like lack of time, kids maybe, I don’t know, mums for example, they have their hands full or the job is taking a big part of their lives..”* (PC7, 30, Romanian)

Lastly it was a question of priority, for some of the women had other events in their lives that were of greater priority. This meant that they would end up forgetting about the smear invitation letter, resulting in unexpected delays. This was particularly relevant for the EE-born women in whom the priority on migration would be to find accommodation, work and school placements for their children.



*“..extremely busy life, I was juggling with both PhD and going through some personal difficulties, so I just completely ignored it.” (PH1, 35, Lithuanian)*

*“...but at that moment I set my priority more for the kids and other things that I needed to do, just because we moved, I needed to change the kids schools..” (PH12, 30 Latvian)*

Language barriers were the main concern for the EE-born women. Their level of comprehension of spoken and written English varied at the time of migration to England. Some of the women commented that their level of English comprehension was relatively good, as they had learnt it in school prior to migration. However, it was identified that the English, which is taught in schools in EE countries is more formal English and may not be practically useful. Understanding the meaning of medical terminology even for those women who had relatively good English language skills was a challenge. Language barriers inhibited completion of even simple tasks such as ringing up the GP surgery to make an appointment. Some of the EE-born women were more resourceful and utilised Google or family/friends to translate or requested a translator to aid their understanding and facilitate them. It was apparent that the interviewed EE-born women did not have an expectation for information to be always provided in their native language. They were keen to and some already had made the effort to evolve and learn the English language but they required support initially. Although they did refer to a group of EE-born women who do not plan on remaining in England for a prolonged period; these women were less likely to be motivated to learn English.

*“There might be medical stuff that I wouldn't know the English words of..” (PC25, 29, Polish)*

*“I came here I understand English and I speak English, but I don't know any medical terms..” (PC3, 30, Romanian)*

*“Well, I think you have to call them and book an appointment, and the phone call is sometimes a big barrier because people on the other side of the line don't understand what you're saying, and you don't understand them.” (FG, Czech/Slovak)*

*“...but slowly, slowly I learn the language, I make my own document everything.”*  
(PH4, 34, Hungarian)

### **The smear experience**

The anticipation of having a smear test was worse for the group of women who knew very little about it themselves or had heard about the unpleasant experiences of friends or family. Emotions such as “nerve wracking” were used in relation to this. There was also the fear that when they attended that they would be in a vulnerable position and may not be able to ask the questions that they wanted to. In comparison the group of women who had had other gynaecological procedures previously, did not have the same level of anticipation anxiety, as they knew what to expect.

*“I suppose it was a bit nerve wracking because I didn’t know what to expect...”* (PC15, 36, English)

*“I didn’t feel I could go along and ask and then say actually I don’t want it because I’d feel like I wasted their time so I just didn’t press on to the matter.”* (PC8, 32, English)

*“...so I kind of was not new to the gynaecology and I knew what could happen but I didn’t know what they were going to do exactly.”* (PH14, 36, Lithuanian)

Their actual smear test experience fell into three categories; it met their expectations and it was no worse or better than what they had expected, it was overall a positive experience and it was an overall bad experience. On the whole, the women who felt the experience met their expectations commented that it was not a pleasant procedure to have done but that would not deter them from participating. Those who described a positive experience felt the following factors contributed, the procedure was quick and easy, they were made to feel at ease, they had the opportunity to ask questions and their dignity was preserved. A positive experience encouraged attendance for screening in the future. Additionally, those women who had children felt that after going through childbirth this was much more acceptable. Factors that contributed to a negative

experience were the converse of the above, the procedure was painful, the feeling of being rushed and the feeling of being in a vulnerable state.

*“So yes, I went for the first one, it wasn’t bad at all so that’s why I am going for the next.”* (PC24, 33, Polish)

*“...think it’s just the idea of being semi naked in front of somebody and it’s a really vulnerable position to be in and like kind of... it’s not a part of your body that ever share with anybody that you don’t know really intimately, and so the idea of just getting up on a bed and being with a stranger made me feel uncomfortable..”* (PC8, 32, English)

There was importance placed on the actual person performing the smear in terms of the woman’s overall smear experience. The personal characteristics with regards to their attitudes and personality played a vital role. In addition the gender of the practitioner was significant, the majority of participants if given a choice would prefer to have a female practitioner. The reasons for this were that they believed that females would have more empathy for them and would be able to relate to their situation more as they would have probably gone through the experience themselves. Nevertheless, the women quoted that they would not decline a smear test purely on the basis that it was a male practitioner, they would just be uncomfortable and would prefer a female if given a choice. Some of the women said that they have *“heard that males are even better”* (PC14, 29, Polish).

*“I guess if a female did it they may be a bit more understanding if they have for instance gone through it themselves..”* (PC11, 36, English)

*“I think to be honest I think I’d do the British thing and suck it up and sit there and be uncomfortable. But yeah, I think I definitely would prefer a female.”* (PC8, 32, English)

The role of the practitioner, if they were a nurse or a doctor, appeared to be of less importance than the gender. On the whole, the women did not mind that it was a nurse that would review them and perform the smear test. They considered that the doctor

would not be able to provide any further information than the nurse until the test results were back anyway. The smear test was compared to blood tests, which need to be sent to the laboratory prior to any useful information being available and therefore anyone who was trained could obtain the sample. When it came to receiving treatment there was a preference for it to be performed by a doctor. The women felt that the main advantage with a nurse practitioner was that they were more likely to have built up a rapport with the nurse, due to seeing them for other things such as contraceptive advice. With the doctor it was improbable that you would see the same doctor more than once, whereas as they were more likely to have the same nurse each time. The EE-born women were more concerned with the role of the practitioner, many comments were made about the surprise that they felt when they found out that in England it would be the nurse who performed the smear test. However, after the initial shock, with regards to trust in the nurse's ability there were mixed feelings. Some found it strange having a nurse rather than a doctor but still trusted the nurse whilst others questioned the skill and ability of the nurse and would have preferred a doctor.

*"So it's about the treatment I need I would most probably want to hear it obviously from a doctor ..."* (PH14, 36, Lithuanian)

*"here it's nurse, you know it's not a big difference but for me it was like strange experience, but I do trust... but actually if that nurse is good trained... so what's the difference? It was just strange for me that in Poland it's different practice, but it's probably the country's regulations.."* (PC5, 34, Polish)

*"The gynaecologists, so, you know, there is more studying involved. I don't want to sort of underestimate or underrate the nurses here, but it's more comfort, it being done by a doctor."* (FG, Czech/Slovak)

## **7. An “Abnormal Result” Receiving an abnormal smear result**

### ***Receiving an abnormal smear, the expectations, emotions and knowledge of the management of abnormal smears***

#### **Abnormal results**

Women who had been through the process of receiving an abnormal result spoke of their experience. It has been previously commented upon that the interviewed women claimed not to have received a great amount of information regarding the process that follows an abnormal result. The need for information varied, some only wanted information when or if they received an abnormal result, others preferred for information to be provided beforehand. Their existing knowledge of the process that follows an abnormal result was vague and they referred to the experiences of friends to complete the gaps in knowledge.

*“I.... I know a friend did so I know that she had to go back for like... I don’t know whether it was a second smear test or whether it was maybe a small biopsy, that sort of thing, but I’ve not had... I’m not really exactly sure what it was...”* (PC21, 31, English)

The abnormal result letter was thought to be unclear and ambiguous, both in terms of the content and the wording. There was confusion over what the abnormal result actually meant and what the next step would involve. Some of the women had received the letter inviting them for a colposcopic examination prior to receiving the results letter, which resulted in anxiety and confusion. The gap between receiving the results letter and seeing a clinician was perceived to be too long. This period of waiting and uncertainty resulted in undue worry. For the EE-born women their understanding of the results was inhibited further by language barriers and receiving the results in a letter form only exacerbated this. For some their understanding of written English was not as good as that of spoken English.

*“...think I got the letter for the colposcopy before I got the result back from the smear. ....just got this scary letter saying you’re coming for a colposcopy and I thought it was something really bad..”* (PC11, 36, English)

*“Yes the smear test, be low grade and high grade cancers but I don’t understand if it’s low or high.” (PH4, 34, Hungarian)*

*“...so I had a positive HPV and abnormal cells, so at the doctor’s, like, I wasn’t told, or the nurse, I wasn’t told what HPV would mean, what abnormal cells would particularly mean, she did say, I think you’ll be alright, which obviously then turned out not to be alright, which is quite scary for your first smear test..” (PH7, 25, English)*

The emotions associated with receiving an abnormal smear result included shock, being frightened and the feeling of being scared. The fear was associated with their initial thought that they had cancer and that *“oh my God, I’m going to die”* (PC23, 33, Czech). One participant describes such heightened levels of anxiety that she required medication for it; another simply wanted someone to talk through the results with. The levels of anxiety appeared to be worse in the EE-born women and this appeared to be related to their limited understanding, poor social support in England and lack of resources from which to seek further information.

*“I went through such severe anxiety, I had to go back and ask for some medication, Diazepam and so on, I just couldn’t cope with my nerves, I was so nervous, it was beyond everything” (PH1, 35, Lithuanian)*

*“When I got bad result and everything I really wanted to talk to somebody” (PH13, 42, Polish)*

### **Colposcopy**

The women used the terms “fear” and “scared” to describe their experience of colposcopic examination. Although they claim to have received information during the consultation at the colposcopy clinic for some inadequate information was provided and some even felt rushed out of their consultations. In others their mind was too pre-occupied with the procedure that was being performed that they were unable to absorb any information. More information about HPV was provided at the colposcopy clinics compared to when the smear was taken, which helped relieve the women’s anxiety. The women who actually underwent treatment had limited appreciation of the procedure that

they had undergone. They were able to regurgitate the immediate postoperative instructions that they had been given but lacked understating of the long-term treatment implications. The result of this was that they did not appreciate the implications of multiple treatments.

*“Yeah, they did go through it with me, but it was so fast and so rushed it sort of didn't sink in and I had questions I wanted to ask, but before I knew it I was in the next room”*  
(PH11, 45, English)

*“The nurse at the hospital reassured me, like I said, that it's almost unavoidable, whereas before I was sitting there reading the leaflet thinking, I don't understand.”*  
(PH7, 25, English)

*“Yeah. That one... err... one thing I... I didn't know for example when I had that operation aah... I actually asked them that time whether it's gonna affect me somehow in the future and I've been told that it shouldn't affect me at all. But now when we're pregnant, someone told me that err... they need to keep checking the baby; whether it's growing properly because err... of... because of that operation.”* (PH2, 36, Slovak)

## **8. Human Papillomavirus- Awareness and attitudes towards HPV**

### ***Knowledge, awareness, attitudes and sources of information about HPV***

#### **Awareness and knowledge of HPV**

The awareness of HPV was mixed in this group, whilst the majority of women had not heard of HPV, the few who had remarked that they had a vague recollection of it but could not remember any details. There was confusion about what HPV actually was. Is it a virus? Is it the same as HIV?

*“That... that HPV sounds familiar, but I don’t have... I wouldn’t know what it was. I’ve not... no I’m not sure exactly what it is.”* (PC19, 33, English)

*“Is it a virus or something?”* (PC25, 29, Polish)

*“I think it doesn't, because if you wrote HIV I would understand that.”* (PC3, 30, Romanian)

Some women commented on the asymptomatic nature of the virus. With regards to transmission of HPV, some women were clear that it was transmitted through sexual contact and others were not. One participant believed that it was having sex itself that caused the abnormal cells rather than the transmission of the virus. In those women who appreciated that HPV was sexually transmitted, they also understood that men could be affected by it to. The extent to which men were affected was not clear, some women saw them merely as carriers or transmitters of the virus, whilst others believed that they may also be at risk of sinister pathology. Multiple sexual partners was mentioned as a risk factor for acquiring HPV. Although, the women were not aware if HPV was a common infection or not, they commented that knowing it was a common infection would make it more acceptable to them. Possible treatment options for HPV were debated and included antibiotics.

*“...it’s not a sexually transmitted disease.”* (PH5, 25, English)



*“It could be a sexually transmitted disease and it could just happen to people.”* (PC2, 37, Lithuanian)

*“And I know that is the ... you can actually get it from the sexual contact and that’s it.”* (PC24, 33, Polish)

The link between cervical cancer and HPV was poorly understood and some women were unaware of it altogether. The women raised questions about whether HPV always resulted in cervical cancer and were shocked to hear that cancer can be caused by a sexually transmitted infection. One participant who had already been diagnosed and treated for oral-pharyngeal cancer, which was secondary to HPV, had a greater appreciation for the causative association between HPV and cervical cancer. Another participant who works as a midwife believed that the consequence of HPV infection was infertility, applying the knowledge she held for STIs such as chlamydia. Overall in terms of personal knowledge and awareness of HPV there were no differences noted between EE-born and English-born women.

*“I think the only implication it could have is infertility.”* (PH5, 25, English)

Population knowledge and awareness of HPV was perceived to be deficient. One of the interviewed women described the conversations that she has with women about HPV. She explained that there was a lot of ignorance surrounding HPV in the general public and how many women do not have an in-depth understanding of what HPV is and the consequences of acquiring the infection.

*“... there’s lots of ignorance; it’s educating the population about issues, nobody understands what HPV is and how it affects..”* (PH1, 35 Lithuanian)

### **Sources of HPV-related information**

The participants referred to their sources of HPV-related information in terms where they had first heard of or seen HPV mentioned. For some women coming across “HPV” in the survey component of this study, had triggered them to conduct their own research to obtain more information. In the group of women who had had a previously abnormal

result, their first awareness of HPV was in the smear results letter. Others who had teenage daughters had first come across it when their daughters had been invited for the HPV vaccination. A few women recall reading about it in an information leaflet and one had even come across it in a film that she had recently viewed. The internet was a popular source of information, however there were conflicting views between two of the Polish women regarding the NHS website. One referred to it for all her HPV-related information and trusted the site. The other felt that the NHS website was not good and that the presented information might be inaccurate and even biased, therefore she preferred to refer to the polish government website. This further demonstrates distrust of the English healthcare system, however here it does not appear to be universal.

*“I got the smear test results when it came back it mentioned that HPV...”* (PH12, 30, Latvian)

*“Yes, but mainly because it was introduced to girls aged 13 or something like that, so my daughter got the vaccination.”* (PC4, 34, Hungarian)

*“NHS website doesn’t give much information to be honest..... So I normally look at the Polish websites and the government websites more than the NHS website....”* (PC24, 33, Polish)

### **Attitudes and emotions**

The women expressed strong emotions about the HPV virus, particularly after learning more about it through the interview process. The knowledge that an STI could cause cancer was met by shock and fear. One participant commented on how she would have changed her lifestyle particularly with regards to having unprotected sexual intercourse had she been aware of this. Feelings of being uncomfortable and embarrassed were expressed, when the women had conducted their own research on HPV.

*“..I started reading about it and yes you feel a bit embarrassed and yes you feel a bit uncomfortable..”* (PH14, 36, Lithuanian)

*“...it probably would change my sex life and everything, then there would be no way that I would even risk like having unprotected sex.” (PC23, 33, Czech)*

### **Sexually transmitted infection**

The acknowledgement of HPV as an STI led to the women seeking explanations of how one might acquire the infection. This was more of a concern for those women who were in a long-term relationship. *“...can you get it just from your long-term partner or is it just sleeping about?” (PH9, 52, English)*. If they were in a long-term relationship they questioned if this was something that would be of relevance to them especially if both partners were monogamous. This group of women perceived themselves to have less to fear about than other women who may still be on the “dating scene” or who were unsure of their partner’s sexual history. Additionally, questions were raised concerning the wellbeing of their partners, did they need to be more careful? One participant who had been vaccinated, describes being questioned by her mother about how she acquired HPV if she had received the vaccine, had she been sexually active prior to this? She was unable to provide a valid explanation. Past relationships were being questioned and attempts were made to try and pinpoint when the infection might have been transmitted. The women were starting to see cervical cancer as a shared responsibility, between themselves and their partners in view of the fact that it is associated with an STI.

*“..I mean it’s kind of irrelevant now I mean I’m married and only having sex with one person and hopefully that will stay that way..” (PC8, 32, English)*

*“Well it is with every other STI, so yes. I would say it’s a shared responsibility..” (PC22, 31, English)*

*“I’m married to my husband and I’ve only ever had sex with my husband, so I suppose in many respects that’s... it might be different, you might fear more if you’d had other sexual partners that you weren’t so sure of their history.” (PC19, 33, English)*

The women questioned that if HPV is a STI, is it the same as any other STI such as Chlamydia? This then raised the issue of presumed sexual promiscuity. For some women it was a case of self judgement: *“.. I don’t think I could have done anything*

*safer, I couldn't have done anything more restrictive..*" (PH7, 25, English). Other women feared judgement from others; they recalled of how Jade Goody's lifestyle choices were gossiped about and even blamed for her disease. There was also an appreciation from some of the women that although we might live in a more permissive society, the implications of having a STI-related disease in some cultures and religions would be significant.

Lastly, the theme of stigma emerged with regards to HPV as an STI. The women described cervical cancer as a disease that has not occurred through natural changes but that one has bought on themselves and hence there would be greater stigma attached to it. The degree of stigma felt was thought to vary by age; however the women had conflicting views. Some believed that the "younger" generation would be more concerned about the stigma than the older, whereas others thought that for the young it is now the norm to have multiple sexual partners and have regular STI checks. Comparisons were made to attending a family planning clinic to commence the oral contraceptive pill. The women assumed that if there was greater awareness amongst the general public regarding how common HPV infection is then the stigma associated with it would be lessened.

There was no difference in the emotions associated with HPV as an STI between nEE and nEN women. However, those women who were in a long-term relationship portrayed a sense of superiority and were more open to discussion as they felt it was something that did not and would not affect them. They spoke of other people's experiences in the third party, as they themselves had not been in that situation.

*"I mean a couple of my friends are a lot younger than me I mean if they've gone out and had a drink and had a one night stand, their next stop is to go down and get checked and there isn't a stigma on it how there used to be, I mean I would die of embarrassment for my age group.."* (PC16, 40, English)

*"I think because sexually transmitted diseases were always kind of a taboo.."* (PH14, 36, Lithuanian)

*“.. it reflects badly on you and I think that’s what many females are mostly scared of, if they admit that, their partner or anybody else will start making assumptions about their sexual life.” (PH1, 35, Lithuanian)*

*“I don’t know ‘cause I’ve never been to one of these places ‘cause there’s, I know there’s one in Northampton ‘cause their friends go and we’ve discussed having tests and things so... but I don’t know.” (PC13, 56, English)*

## **9. Human Papillomavirus Vaccine**

### ***Awareness, vaccination status and attitudes towards HPV vaccination***

#### **Awareness and knowledge of the HPV vaccine**

Awareness of the HPV vaccine was overall deficient, very few women had heard of it. Some women had a vague recollection of the name but could not recall details and others claimed to have heard of the cervical cancer vaccine and did not appreciate that this was actually the HPV vaccine. With regards to detailed HPV vaccine knowledge many of the women admitted that they did not know very much. Knowledge about the function of the vaccine was superficial, the women had a vague idea that it was to prevent “cancer” but how it did this was not clear. There was confusion over if the vaccine prevented cancer directly or indirectly through the prevention of acquiring HPV infection. One participant attempted to provide a more sophisticated explanation and spoke about antibodies that would fight off the virus. There was limited comprehension of the level of protection offered by HPV vaccination. Women commented that they believed they would be protected for life, that it was a cure and if you were vaccinated you could not develop cervical cancer. This resulted in confusion regarding the need for smear tests following vaccination. However, there were some women who appreciated that the vaccine was not 100% protective and that smear tests were still required and that other precautions would still need to be taken. Knowledge of the age at which the vaccination is recommended in England varied from 12 years to 18 years and only a few women appreciated that it needed to be administered prior to the onset of sexual activity. In keeping with the overall poor HPV vaccine knowledge, there was no awareness of the fact that there had been more than one HPV vaccine available in England that provided protection against different HPV types and genital warts. The most commonly mentioned source of information for the HPV vaccine for the news and other media outlets. The women recall the debates that took place at the time of vaccine introduction. Other sources included friends or family members talking about it as their daughters had been offered the vaccine and the health visitor, as it was listed as one of the recommended vaccines.

*“Yeah it’s got antibodies and you know, and to fight off the virus before it gets in there.” (PC24, 33, Polish)*

*“Yes, because, okay I’ve had a vaccine, but it’s not 100% as there’s always that chance that I could have cervical changes, so the only way to find out is to do a smear test.”* (PH5, 25, English)

*“.. my perception was that it was like a, like a cure if you’ve got it, then if you got the vaccination, that maybe you couldn’t get cervical cancer..”* (PC20, 31, English)

### **Vaccination status**

Very few of the interviewed women themselves or their daughters had received the HPV vaccine. Of concern was that some of the women could not actually recall if their daughters had been vaccinated or not. The women’s recollection of the information provided to them at the time of vaccination (either for themselves or to provide consent for their daughters) revealed that they were provided with an information brochure. The amount of information provided was deemed to be inadequate by some whereas other women admitted to only reading the first few lines prior to making a decision. Remarks were made about the accuracy of some of the information that they had come across. For example, one woman had heard that it could cause infertility in the future; this misinformation planted a seed of doubt in their minds about vaccination.

A suggestion made for improving information sharing at the time of vaccination included, small group discussions with the teenage girls rather than just the provision of an information leaflet. It was felt that teenage girls were less likely to read information leaflets. Similarly, for the parents an educational evening with the school nurse was proposed. There was a strong sense that both the child and the parent should have greater awareness about the HPV vaccine rather than it just being another routine childhood vaccine.

*“Yeah, you know what we’re like, we’re, well I don’t...perhaps you’re different but you read a bit and ooh that sounds good, you know, and you don’t read the last bit, you know.”* (PC12, 61, English)

*“....the child and their parents should be educated rather than just having a vaccine because that’s what they think they should do for their child.”* (PH5, 25, English)

### **Attitudes towards HPV vaccination**

Most of the women held positive vaccine attitudes; this included both nEE and nEN women. They rationalised their positive attitudes with statements such as *“I usually trust that if the main population is vaccinated then kids won’t get sick.”* (PC1, 34, Latvian) and *“People have obviously spent a lot of time and money to develop sort of thing, so...”* (PC21, 31, English). The women had a sense to protect their children in the future as they could not be sure of the lifestyle choices that they may go on to make. There was an understanding of the fact that herd immunity would be required to obtain maximum vaccine benefits. Their positive attitudes were reinforced if they knew of someone who had already been vaccinated and not suffered any adverse effects, and also if they had had an abnormal smear themselves. A minority of women were still undecided about the vaccine and wanted to conduct more research of their own prior to approving it. One Polish participant held strong negative views about the HPV vaccine mainly due to the misconception that it was associated with future infertility. Although overall she claimed to believe in vaccinations in general, she did not feel that the HPV vaccine had been around long enough for there to be adequate information available on its side effect profile. She went, as far as to say that the potential risk of infertility for her daughter was more of a concern than the prevention of cervical cancer. In the Czech/Slovak focus group there were some strong negative views expressed, these were again related to adverse effects of the vaccine that they had heard about. This time the adverse effects included “serious illness” and even “death”. They felt that vaccines in general were a relative new invention and that previously people would survive illnesses without any vaccinations.

*“No, because I don’t what choices she’s gonna make later in life, so I would rather she had the option...”* (PC19, 33, English)

*“..but it’s like, I think vaccinations work best when everyone is vaccinated, which is the crazy thing about antivaxers...”* (PC9, 33, English)

*“Yeah, but I don’t want her to come one day and say, oh it’s because you give me a vaccine, now I can’t have kids.”* (PC24, 33, Polish)



*“So, now because I saw the research a few years ago and now all the young bodies being injected, most of them suffer very serious types of illnesses or some of them, they are dead.” (FG, Czech/Slovak)*

Overall the age of vaccination was felt to be appropriate by the interviewed women. There was a general consensus between the interviewed women that teenagers were becoming sexually active earlier. Therefore, if the vaccine is most effective prior to commencing sexual activity then this was an appropriate age. Further it was felt that they should be fully informed about what the vaccination is for, i.e. a STI, not only that it protects against the development of cervical cancer. It was largely EE-born women who felt that the current age of vaccination was too young; they felt that the girls would not be in a position to make an informed choice. There was also a slight undertone that EE-born women felt that girls were sexually active earlier in the England than in their countries of birth, hence the greater need for protection. There were mixed views surrounding the message that would be portrayed by being vaccinating against a STI. Some women felt that the teenage girl may interpret it as permission to commence participation in sexual activities, as now that they were “safe and protected”.

*“No, because they’re so active nowadays these young ones, they look older than what they are and whatever, but they’re more forward than what we were years ago, so yeah. I don’t think they’re too young to be told.” (PH9, 52, English)*

*“I think it is really young, especially if you tell them what it is..” (PC23, 33, Czech)*

*“To be honest with you a little bit too early to start about sex, about everything, I’m surprised because at that age nobody talked to me about sex, because kids being kids not adults, baby in skin, you know it’s baby but in her head it’s adult already – that’s wrong.” (PH13, 42, Polish)*

*“No I think it’s the right age and especially that I live hear in the UK” (PH14, 36, Lithuanian)*

HPV vaccination of boys was considered and the women were not clear about how HPV affects males and therefore their need to be vaccinated. However, some women used either their pre-existing knowledge or the knowledge that they had gained through the interview that HPV is sexually transmitted and rationalised that at the very least they would be carriers and transmitters of HPV. In view of this, HPV vaccination of males was felt to be reasonable, although they questioned that if this was the case why are they not being tested or vaccinated already? One participant felt that presently the majority of responsibility for protection against STIs falls on the female and by vaccinating both sexes this responsibility could be shared. The group of women who were against the HPV vaccine still held negative views about vaccinating boys too, they questioned that if boys do not have a cervix then they will merely just pass on the virus, is this sufficient to be vaccinated?

*“Do they not test boys for it then if it’s with boys as well then?” (PC13, 56, English)*

*“I think there’s a lot more pressure on girls to be more aware of things like sexually transmitted infections... I think it probably would be a good idea and then everybody is vaccinated, rather than just it being girls.” (PH5, 25, English)*

*“Well, they don’t have a cervix.*

*If the vaccine can be a danger for girls, it can be a danger for boys as well.*

*No, they don’t have a cervix. We are talking about cervical cancer.*

*Yes, but they wouldn’t pass it on to the girls?*

*They just can pass it on, they cannot possibly develop cervical cancer.” (FG, Czech/Slovak)*

## **10. Human Papillomavirus Testing**

### ***Awareness and attitudes towards current HPV testing. Williness to participate with primary HPV testing in the future***

#### **Awareness and attitudes towards current HPV testing**

The vast majority of women were not aware that HPV testing was already incorporated into the current NHS cervical screening programme. One participant believed it to part of a routine STI screen and commented on how her daughter and her friends have all been tested for it. Some women were only aware that they had been tested for it when they received the results letter with a positive HPV result. When the women were questioned if they would still attend for screening if they knew that they might also be tested for HPV, they held contrasting opinions. Some women compared it to pregnancy when you are happy to undergo tests for conditions that you know it is unlikely that you have. Others did not mind as they were in a long-term relationship and were confident that nothing would be discovered. Lastly there were the group of women who would be discouraged from attending.

*“My daughter’s been tested for it and so have all her friends, they’re all quite into being tested for that.”* (PC13, 56, English)

*“Yeah, even like when you’re pregnant you get tested for all sorts of things you probably don’t think you’ve got.”* (PC19, 33, English)

The potential of receiving a positive HPV result evoked mixed emotions. For the group of women who had not actually had a positive HPV result they hypothesised that they would handle it in very pragmatic terms. However, for those who had previously tested positive for HPV it was a different scenario. The women explained how it had not been present on previous smears tests. They would then attempt to identify when or how they could have acquired the infection. Could they have made different lifestyle choices? Was it something they did? This process was especially difficult for those women who were in committed long-term relationships. The women expressed emotions of shock, fear and embarrassment. These were coupled with an element self blame for putting ones self into a high-risk situation. Other women feared explaining the diagnosis to their

partners. The main trigger for their emotional responses was the fact that they were either not aware that were being tested for HPV and/or they did not have adequate information about HPV. It was suggested that having a face-to-face discussion with the GP or practice nurse regarding the HPV test result would lessen the level of anxiety. Directly seeing a clinician would permit the sharing of accurate information and allow preparation for future management options.

*“..it was almost three years back when I had a long-term partner and when I think oh my God, yes, at that time we were not using condoms, we were using contraceptives but not condoms..” “I mean it was a big hurdle to overcome I suppose because then you suddenly realise oh my God, you start blaming yourself, because yes it’s your fault”* (PH14, 36, Lithuanian)

*“I’ve been with the same partner for 10 years, I haven’t slept with anybody else, I don’t understand where it’s come from..”* (PH7, 25, English)

*“ I was shocked, I was thinking how I’m going to say to my husband, what he’s going to think, what is that and then embarrassed as well a little bit, because I didn’t know as well what is going to be outcome from all that.”* (PH12, 30, Latvian)

*“I’d probably want to make an appointment to talk to somebody face to face to find out if there was a treatment or what implications that has on me and then my general health..”* (PH5, 25, English)

### **Views, attitudes and perceptions about primary HPV testing**

Participation with primary HPV testing was a contentious subject. There was a group of women who still perceived it as cervical screening and for the benefit of their own health claimed that they would still participate. This group were very matter of fact, commenting that they were sexually active and therefore were at potential risk of acquiring the infection and this was a test to prevent cancer, which could be life threatening. Women who were in a committed long-term relationship, viewed it in two ways, firstly that they might have acquired the infection from a previous relationship and secondly that although one would hope to fully trust their husband you might not be

able to do so. The other group of women who were in favour of participation were those who had already had an abnormal smear result, for them it was more important that the abnormality was detected and treated rather than what was actually being tested for.

*“..so for me I would still go for it because I’m thinking well what if it’s laid dormant for a while and I got it before I met my husband” (PC8, 32, English)*

Normalising HPV testing was thought to reduce the associated stigma, as this would be a screening test that all women who were of certain age would be invited for, therefore some women believed that the stigma might not be as great. When the same women who were initially in agreement to participate with primary HPV testing, thought more in-depth about HPV testing and the implications it may have on their relationship, they started to change their minds about participation. Being tested for an STI, even if was a screen to prevent cervical cancer, was not as simple as it had initially appeared, particularly with regards to the implications it would have for trust in their relationship. Other women felt it was not a test that was “appropriate” or “applicable” to them due to their age or lifestyle choices.

*“Maybe I would be less likely to do it, I don’t know. When it gets down to nuts and bolts, like, when you put it like that, yes, it puts a question mark over things.” (PC9, 33, English)*

*“Yeah. Because it’s one of those things where it’s not really appropriate to me or it doesn’t apply.” (PC22, 31, English)*

Women in long-term committed relationships felt that their relationship status would be a barrier against participation with primary HPV testing. Their self-perceived risk of acquiring or having the HPV infection was thought to be non-existent, hence they felt there was no need for them to be tested for it. Further, if the women themselves had only had one sexual partner they believed that there were not at risk and their partner’s previous relationships did not appear to be of concern. Women who reported religious

affiliations also felt that if this was now a test for an STI that it would not be of relevance to them.

*“I think because I’m married and I know that we don’t sleep with other people I wouldn’t think there’s any chance of me getting an STI so I would think oh well there’s no point in me having that..”* (PC10, 33, English)

The wording of the smear invitation letter for primary HPV testing was thought to be important. If it was worded as “you are being invited to be screened for cervical cancer”, it may not be viewed any differently to how it is currently. However, if it mentioned that screening would involve being tested for HPV and then somewhere in the letter it was mentioned that HPV is an STI, this could deter women from attending. Even if in the letter it did not specifically quote that HPV is an STI, the women were concerned that as soon as the word HPV is entered into an internet search engine that would be the first piece of information to appear. Currently having a smear test is not associated with an STI. It was apparent from the discussions around the enclosed information leaflet with the smear invite that they rarely read it; therefore the role of them in providing information and reassurance would be limited. The stigma of being tested for HPV was thought to be lessened if men were also offered routine testing, as is the case for other STIs.

*“Yeah, I think some people would not feel comfortable being tested for a sexually transmitted disease, you know having a smear test is not linked with that as far as people are aware, all they’re going for is a routine smear test.”* (PC18, 40, English)

There was a fear that primary HPV testing might result in women being divided into two groups by society, those who attend for screening will be thought of as having adopted a more high-risk lifestyle in comparison to non-attenders. Having a screening test to prevent cervical cancer would be viewed as synonymous with being screened for an STI. All the interviewed women however did not share this view and they believed that this would be more of an issue for the younger generation in the future.

*“Some people who think that their husbands are unfaithful or are promiscuous and people who aren’t, yes...” (PC9, 33, English)*

*“Potentially yeah, especially with maybe younger people and the generations that are coming up now..” (P21, 31, English; In response to a question about the potential stigma of attending for HPV testing)*

*“.. but I can see that maybe younger people would feel it’s more to do with the lifestyle choice.” (PC15, 36, English)*

The actual or hypothesised feelings of their partners regarding HPV testing in general or about receiving a positive HPV result were debated. There were mixed reactions, some women found that their partners were very supportive and were only concerned about the wellbeing of the women. These partners did not raise questions about previous relationships. However, other women believed that their partner’s reaction to a positive HPV result would be to start questioning the faithfulness of the woman. One Latvian lady who had had a positive HPV result previously became distressed during the interview when discussing her partner’s response; she felt that since the diagnosis he was distant from her. The partners were felt themselves to have very little knowledge of HPV and how it affects them. The women proposed that the male partners would have a greater appreciation of their own risk and knowledge of HPV if they were tested for it too. This would relieve some of the pressure from the female partner. The male partner in some instances was thought to be a barrier to participation with primary HPV testing whereas others believed it was not their decision to make.

*“Yeah, yeah very supportive. Yeah, nothing came up about previous it was just... he was worried..” (PC11, 36, English)*

*“oh you have done something, the partner has done something wrong. That’s like maybe you have been somewhere else with somebody else. I think that’s the first thought what man would think.” (PH12, 30, Latvian)*

*“Yes, he didn’t get it either. He was like, does that mean I’ve got it as well and I was like, I don’t know, do men get it, does it get passed on, I’m not sure.”* (PH7, 25, English)

*“He’d probably be like, “you don’t need to... why are you going?””* (PC22, 31, English)

Another theme that emerged was that once they had obtained a negative HPV result and if they were in a monogamous relationship would they still need to continue attending for screening? Further if they did attend does it imply lack of trust in their relationship and what would be the implications a subsequent positive result? The women thought that this might cause confusion and that other women may start to question their need for repeated screening.

*“I would know that assuming I hadn’t been unfaithful that Mike must have got it from somewhere and it doesn’t just appear does it? It’s got to be got from someone and also then, gosh this is a bit of a moral maze isn’t it, and then...or vice versa, like if he’s.”* (PC9, 33, English)



## **11. Cervical cancer prevention in their country of birth for the nEE group**

### ***The participants' perception of current availability of cervical cancer prevention in their country of birth***

#### **Cervical screening**

The women described that to their knowledge in their countries of birth, the process of receiving a formal smear invitation letter did not exist. The main method of learning about smear tests or having cervical screening was through direct contact with the doctor. This could be either the GP or the gynaecologist and meant that if they did not see the doctor then they would not be aware of the need for cervical screening. In addition, comments were made about the provision of healthcare, i.e. in terms of receiving smear invitations, might be different in larger cities compared to the more rural areas.

*"..if you don't go to the doctor, you're not going to know about that thing. If you're not going to even ask, but there might be in Riga in the hospitals, Riga GPs, maybe they have."* (PH12, 30, Latvian)

*"I don't think we get letters as such.."* (PC1, 34, Latvian)

Screening behaviours prior to migration to England included never having been for a smear test, attending when they were pregnant as part of a general check and attending private clinics on the advice of family members. The frequency of smear tests for these women varied, some were still only attending every two/three years whilst others attended annually or even more frequently. It was apparent from the descriptions by the interviewed women that they were in control of how often they had screening, particularly in the private sector.

*"In Poland you can go when you want yeah so.."* (PH6, 26, Polish)

The practice of "annual gynaecological examinations" was thought to be part of and/or synonymous with cervical screening. The women described how from the age of 16-18 years all girls in their country of birth attended for annual gynaecological reviews. In

some countries it was compulsory and in others family members recommended attendance. Often the women were asymptomatic and did not have a justified reason for participating with this practice. In addition, there was little appreciation of what was being examined or tested for; “*..they just had a look if everything looks okay.*” (PC23, 33, Czech). However, the women recalled that on each occasion they were offered and in some cases recommended to have a smear test. Most of the women felt that as they were undergoing a gynaecological examination that they might as well have a smear test. The women did not believe that there was any harm in having more frequent smear tests or being tested in two different countries. Conversely it was viewed as an advantage, they would have a record in both countries and it served as a double check mechanism. The full gynaecological review was considered as beneficial and was “missed” by the nEE women when they migrated England.

*“The system before was at 16 years old, it’s compulsory, in Lithuania it used to be compulsory every single year to go for general health checks for every single one which would the trip to the gynaecologist as well.”* (PH1, 35, Lithuanian)

*“Yeah, it’s like, it’s the same as you know how you are recommended to go once a year to have your teeth checked, your eyes, everything, and in Czech Republic it’s a common thing to go once a year to have your parts checked as well.”* (PC23, 33, Czech)

*“And it is kind of a popular, the girls are going for a check-up like every six months to a year, even when nothing happens other than not even pill or anything, just for a check-up.”* (PC24, 33, Polish)

The women’s perception of uptake of cervical screening services in their countries of birth was that uptake is variable. In some countries uptake was regarded to be poor and in others they had no concept of what the uptake might be. Similar to the way in which access to healthcare in general (described earlier) was dependent on multiple factors so was access and utilisation of screening services. Factors identified to influence screening uptake choices included, affordability, knowledge and self perceived risk. One participant shares how her own mother and other women she knew had never been for screening in Romania but participated with screening on migration. She felt that the

rationale behind this behaviour was firstly that it was offered to them so they were made aware of it and secondly because it was free of cost, in the country that she had migrated to.

*“.. why do I need it then, why should I spend, I don’t know, X amount for something that I might not need to have..” “Never done it in Romania, but as soon as they went to another country, they’ve done it there.” (PC7, 30, Romanian)*

Knowledge of the management of abnormal results in their countries of birth was vague. Although a few of the interviewed women declared that they had had abnormal smear results in their countries of birth, they were unable to describe the management they had undergone for these. One participant who had had a colposcopic examination and treatment in England and was then found to have an abnormality in a subsequent smear that she had performed in Slovakia (during a holiday). She explained that there was no formal facility as a colposcopy clinic there and the same gynaecologist who performed the initial smear test would manage the abnormality. However, even though this participant had been happy to have a smear test in her country of birth she had chosen to return to England for treatment.

### **HPV vaccination**

Awareness about the availability of the HPV vaccine in their countries of birth was deficient. Some of the women had a vague recollection that it may be available but were not able to share any details regarding the age or to whom it was offered. HPV vaccine attitudes were mixed; relatives and friends who were still residing in Eastern Europe had shared concerns regarding the safety of the vaccine. Further, the interviewed women expressed that they felt the vaccine attitudes of the population in their home countries had changed since they have moved away. They believed that their home populations were more sceptical of the benefits and the need for vaccination, were more fearful of the adverse effects and there appeared to be a greater freedom of choice with regards to consenting for vaccination available to them now compared to previously. One participant commented that in view of the cultural differences that she believes to exist between England and her country of birth, vaccinating against HPV at 12-13years would be too early. She remarked that in her culture not very many 12-13year olds

would be sexually active therefore it would be better to defer it until they were 16 years old and above.

*“They think that, well because some kids maybe have side-effects and they are fearful that their kids is going to have a side-effect like that.....nowadays it's more...you've got free of choice, more than you have in the past or maybe in the past you were more scared of things than they are nowadays.” (PC7, 30, Romanian)*

*“Because that age, our culture is very different and at that age, it's maybe 5% 12 to 13, that they're having sex with somebody else at that age... but just thinking about that, I would be 14, 15 and having sex with somebody, No.” (PH12, 30 Latvian)*

## **12. The affect of influences imposed by family and friends on cervical prevention behaviours**

*The extent to which the participants cervical prevention behaviours and beliefs have been influenced by family and friends*

### **Mother/Daughter/sister**

The screening behaviours of the mothers for a majority of the interviewed women had a direct affect on their own screening practices. The concept of cervical screening was introduced to many of the women by their mothers. Their mothers were in addition a motivating factor for initiating and continuing with screening. Knowledge of cervical cancer and screening was acquired from their mother and their mother's experiences. However, the role of the mother did not extend into ensuring that they actually attended for all their smears.

For the nEE women the practice of annual gynaecological reviews was something that had been passed down from their mothers. Women whose mothers had been affected by cancer of any origin had a heightened sense of concern for their own health and were more likely to partake with any form of cancer screening.

*"Like I say my mother always went for them, you know, so I just, you know, took notice of what she done, you know, and she said "well you should go just to be on the safe side".. " (PC12, 61, English)*

*"... maybe she assumes I'm responsible enough and make sure I go for myself. Or maybe it's because I've mentioned I've been? Erm... but she doesn't check, no she's never checked.." (PC19, 33, English)*

*"But I don't know, it was one of those things that my mum, my sisters do it and I was like, okay I'll go as well to see if everything's okay, but obviously it was there." (PC23, 33, Czech)*

*"(Crying) My mum was 53 when she died from cancer and after I got now, yeah I've got it in the head, of course I'm scared." (PH13, 42, Polish)*

The detail in which discussions surrounding the topic of screening that took place between the interviewed women and their mothers were variable. Some women commented that they spoke to their mothers about everything and others felt that this was not the norm for them. There was a greater reluctance to discuss abnormal results, particularly prior to finding out what they meant. The women claimed that it was not because they were embarrassed to discuss abnormal results with their mothers but more that they did not want to cause them undue worry. Similarly, the mothers would not follow-up on smear results, it was assumed that they would be informed if a result was concerning.

Two women who had both received positive HPV results spoke of their contrasting experiences with regards to the discussions that took place with their mothers. One explained that she did not explicitly inform her mother that her pathology was HPV-related and that this was an STI. The other participant had had a more open discussion and her mother in return had asked her questions about her and her partner's lifestyle, which she could not respond to. The nEE women appeared to be less comfortable than the nEN women about having an open detailed discussion with their mothers. It was suggested by one of the nEE women that when she was growing up it was not "normal" to have discussions of such nature with their mothers.

With regards to the HPV vaccine, a participant describes that her mother informed her that she was going to have the vaccine "*just because you're a girl..*" (PH5, 25, English). Nevertheless, she feels that her mother would have been better informed about the vaccine but did not feel the need to share this information with her at the time, as it was not an easy topic to broach.

*"..but it's not because I'm embarrassed or anything it's just purely for her not to worry unnecessarily really, so because it came out fine therefore I told her and she didn't care."* (PC11, 36, English)

*"I spoke to my mum about it and she was saying, oh does that mean my other half should be more careful, does that mean you should be more careful, what does it actually mean and I couldn't really answer it either.."* (PH7, 25, English)

*“..even me now I don’t think I would be able to go to my mum and say oh look actually you know the surgery that I had it was not just because something happened, it was because of sexually transmitted disease;”* (PH14, 36, Lithuanian)

When the situation was reversed and the women discussed their own relationship with their daughters, it was apparent that over the generations the mother-daughter relationship had changed. In terms of screening behaviours some women explained that their daughters did not attend despite they themselves (the mothers) attending and them emphasising the importance of them.

*“Yeah, I think it was when my elder daughter had her first child and she hadn’t been, she hadn’t had a smear test, I said it’s important to go, at 26, you go for your smear test.”* (PC18, 40, English)

*“One’s got a partner in the... I mean they’re both in their early 30s, so they should really go.”* (PH8, 55, English)

In addition the mother-daughter relationship had developed into a more open one, this was also the case for the nEE women. The women confessed that they could talk to their daughters openly about HPV vaccination and topics, such as sex, were not a taboo. However, the final decision for or against HPV vaccination did not always appear to be a joint one, the women felt that their daughters were not necessarily mature enough to make that decision.

*“Yeah, it was okay, we have quite an open relationship with her, so sex is not a taboo and all these things..”* (PC4, 43, Hungarian)

*“I just told her that she has to get it, because at this age they argue about everything.”* (PC1, 34, Latvian)

The influential affect of sisters was less clear, many of the women were not aware of their siblings screening practices or beliefs. This was mainly due to screening not being

an obvious topic of discussion between them and the geographical distances. Some women spoke of the memories of their elder sisters attending for gynaecological reviews and/or smear tests in the past but not of current practices.

### **Other family members**

Other family members were divided into two main groups: their parents as a unit and the extended family. In reference to their parents they mainly discussed their upbringing and how this had influenced their health seeking behaviours. It was evident that the nEE group of women felt more uncomfortable discussing private health matters with their parents, it was not common practice. One participant who does not attend for cervical cancer screening explained that this was due to the influence of her parents, *“we are just not brought up to go to doctors or anything like that to be quite honest with you.”* (PC16, 40, English). The participants felt that if the child had a more open relationship with their parents, they were more likely to participate with both cervical screening and HPV vaccination. However, they appreciated that this is not the situation for all children.

*“Parents, I don’t know if it’s the generation thing or it was education thing, same, they never ever spoke about things like this.”* (PH14, 36, Lithuanian)

With regards to the extended family members they referred largely to the female members and commented on their screening practices. The screening practices of the extended family members (nieces, cousins, aunts etc.); did not appear to influence their own screening choices. Nevertheless, if anyone in the family had suffered with cancer of any origin this heightened the need to look after one self. Similarly, if they had healthcare professionals in their families they were more aware of preventative medicine.

*“I’ve got lots of doctors and nurses in family and it’s important in my family..”* (PC5, 34, Polish)



## Friends

The screening behaviours of the participants' friends did not appear to have a direct affect on their own screening choices. However, some of the women justified their own behaviours by referring to their friends who shared the same practices. If their friends were non-attenders and they had/were participating with screening they would attempt to encourage their friends to attend too. Further, if the women themselves had had an abnormal result they felt very strongly about encouraging their friends to attend. nEE women described how their friends would assist them with translation of the smear invite letter and provide one another with support in case of an adverse result. Although this was only the case for those women who had friends in England, some of the nEE women did not have any family or friends in England. This later group felt isolated and did not have the same level of social support as the native population. The nEE also commented how some of their friends still go back to their country of birth for more frequent smear tests, it was not clear if/how this influenced their own behaviours.

*"Yeah to be quite honest with you out of all my friends and family I don't know any of them that go and have it done to be honest with you. No, I think they've all got my sort of attitude or I've got theirs.." (PC16, 40, English)*

*"I told her what it is and I said "go on and have it done" and she went, "oh but I don't like it, they're going to put something in me", I'm like "never mind, you better go and do that". " (PC24, 33, Polish)*

*"In here I've got friends so err... they say that it's after three years and err... as well they need to go probably to Poland and doing that test early yeah." (PH6, 26, Polish)*

The smear experience of the interviewees' friends had an impact on their own attitudes. If a friend had a bad experience then the participant herself was more anxious about her own smear test whereas positive experiences helped alleviate anxiety. Further, if more than one friend in their circle had had an abnormal result it helped reduce any associated stigma, as this meant that they were not alone. The level of comfort that the interviewed women felt discussing smear tests and the results with their friends was dependent on the closeness of the individual relationships. Some of the women declared that they

spoke about this topic openly whereas other women said they did not but that perhaps they should, as this would “normalise” the topic. In a similar manner the HPV vaccine was described as “normal” by one of the participants who had been vaccinated, as all her friends in school had received it.

*“..because from what I’ve seen of my friends, there’s a lot of us who haven’t been normal and had to go back for further tests and we can’t be the special ones..”* (PH7, 25, English)

*“Yes, I remember all of my friends had it. Yes, I don’t remember anybody not having it.”* (PH5, 25, English)

### **13. Discussing cervical cancer prevention**

*The extent to which and the settings in which the participants were “comfortable” discussing cervical cancer prevention measures*

#### **Discussing the smear test**

The interviewed women held mixed opinions on how comfortable they were about bringing up the topic of smear tests. It appeared that the group of women who described themselves to be generally “very open” were the most comfortable. Some women expressed that it is something that all women have to go through and therefore it is not a “secretive” topic. The main trigger for initiating a conversation on smear tests was the receiving of a smear invitation letter or a pending appointment to have the smear test performed. This would then expand to conversations about when each of them had last attended and any positive and/or negative experiences would be shared. Some of the women were happy to talk to anyone about smear tests, i.e. colleagues at work, friends and family, whilst others would only have such discussions with those they considered to be close family and/or friends. Although this group of women claimed not to be embarrassed discussing smear tests as it was something that all women did, sharing or posting about it on social media was considered to be a step too far. Nevertheless, these same women expressed that having more open discussions about smear tests would be beneficial, it would remove the embarrassment associated with them and encourage more women to attend.

For the nEE women, it was after they had undergone treatment for an abnormal result that they felt the need to share their experiences with friends and family. If they had not had an abnormal result then they were more reluctant to discuss it as it was felt to be a private topic. In those women who did not discuss smear tests openly their main reasons for this behaviour were that; they did not believe that this was a common/normal topic of discussion, that it was an intimate thing and that they were embarrassed to talk about it.

*“I mean I feel comfortable talking about it and I talk about it, I mean I’ll be at work and, “I’ve got a doctor’s appointment for a smear test,”” (PC18, 40, English)*

*"I think it would be ... it's got to be like open, it's like not keeping secret, yeah. More women would go." (PC14, 29, Polish)*

*"Err... to be honest, err... since I had that problem, I try to everyone... I try to advise every one of my friend to go for smear test." (PH2, 36, Slovakian)*

*"..it's quite private but to be honest with you if I was supposed to sharing with my friends just like that, I don't think I would feel comfortable.." (PC24, 33, Polish)*

### **Discussing HPV testing and treatment**

Discussing HPV testing was a more contentious subject. If HPV was thought of as an abstract term rather than specifically as an STI, the interviewed women declared that they would be more comfortable discussing it. Further their own perceived risk of testing positive for it affected how openly they would discuss the topic. For example, one participant described that she would be less open if she thought her partner had been cheating or if she had had an affair. There was fear that discussing HPV testing in the context of it being a STI would result in further questions or speculations on their sexual health. Discussing cervical screening was thought to be more acceptable than talking about HPV testing in isolation.

*"..think I'd be maybe less open if I thought Mike's been cheating or if I'd had an affair, then I might not be quite so open about it for fear of being pressed on it.." (PC9, 33, English)*

*"I don't think so, maybe perhaps I can see if they asked me any questions about the sexual activities as well to do with this or not.." (PC25, 29, Polish)*

### **Forums in which discussion about cervical cancer may occur**

The interviewed women suggested mother and baby groups as a forum where they believed that discussions about cervical cancer prevention might be appropriate. The women described that at the mother and baby groups many women discuss breast feeding and screening for breast cancer. They commented that although the breasts are

also a private and intimate body part there is less embarrassment/stigma associated it with them. The women believed that *“people go topless and people wear low cleavage tops so you can acceptably talk about breasts and breast cancer..”* (PC8, 32, English) however, you only share your pelvic organs with those whom you are in an intimate relationship with and therefore it less socially acceptable to discuss openly. Conversely there is a lot of publicity promoting breast-feeding and to make it more publically acceptable. Whereas cervical cancer has not been mentioned at the groups attended by the interviewed women, they felt that this was a good place to raise awareness of cervical cancer/screening since there is a captive audience and attendance of women from diverse backgrounds.

Reasons as to why women did not discuss cervical cancer or screening openly ranged from ‘it simply has not come up’ to *“the whole vagina business it’s still, even the word people hate and it’s still kind of taboo..”* (PC23, 33, Czech).

*“I’ve never heard anyone talk about cervical screening there, but I’ve never...yes, people don’t seem to chat about it.”* (PC9, 33, English)

#### **14. Increasing the uptake of cervical cancer prevention**

##### ***The views and perceptions of the participants on how the uptake of cervical cancer prevention methods might be increased***

##### **Media, leaflets and social media outlets**

The use of adverts and advertising were believed to increase general awareness of cervical cancer and this was thought to result indirectly in increased participation with cervical cancer screening. The outlet used for the advertisements was an area of debate, some women suggested utilising public transports and commented how this is already being used for other STI's. Television adverts were a popular suggestion, it was felt that powerful messages could be portrayed over a relative short time period through this medium since most households have access to and watch television. One participant proposed that if they advertised on news channels the message would be taken more seriously. It was also compared to the stop smoking adverts that have been appearing on the television, these were felt to have been successful and something similar for cervical cancer was advised. Further, through television women would also be able to see what the procedure involves and this may help reduce the anticipation anxiety associated with smear tests. Other women argued that television adverts might not be the most productive as there is an increasing trend to watch programmes on catch up TV, where one may skip over adverts or there may not be any adverts on them in the first instance.

*"...on public transport you do get quite a lot of, not a lot, but you do get these adverts for STD checks and everything for young people, so maybe go the same route.." (PC23, 33, Czech)*

*"I normally watch the news and if it comes through the news channel then I'm more likely to pick up on it.." (PH14, 36, Lithuanian)*

*"Maybe if they show on telly, you know they show operations on telly. I've never shown, seen anybody said well you know this lady's got the cells and this is what we're going to do, look how easy it is.." (PC13, 56, English)*

Many women recommended social media as a powerful tool of increasing awareness. It was felt to be particularly useful in reaching the younger generation, who utilised it as part of their daily routine. References were made to social media campaigns that have been successful in increasing awareness for other medical and non-medical issues. The women felt that they would be able to appreciate their own risk of being affected by cervical cancer if real life testimonies were shared through social media. Through the use of social media it was proposed that participation with cervical cancer prevention strategies could be made to be more “normal” and light hearted, thereby removing the secretiveness of women attending for smear tests.

*“.....Social Media, advertising, something that’s accessible to young people which young people are always on like Facebook, Snapchat, Instagram, Twitter...” (PC21, 31, English)*

*“.. like testimony, like you know like people’s stories ‘cause that... for me that’s what makes me feel “it can happen to them, it could happen to me”.” (PC19, 33, English)*

Magazines adverts were not a popular choice and were mentioned predominantly by the older women in the group.

*“Especially to women ‘cause women do tend to pick up magazines don’t they and just read them and I think that would..” (PC13, 56, English)*

The use of information leaflets was felt to be beneficial if they were distributed at the doctor’s surgery, it was believed that here they would be read whilst waiting to be seen. If the leaflets were distributed through other outlets then it was felt that they would simply be disposed of and not read. The additional limitation identified with leaflets was that of language for the non-English reading population.

*“I think they tend to, well they should be given one at places like this or say you go for your smear, or even in the doctors’ waiting room, I think leaflets they tend to read them then.” (PH9,52, English)*

*“Leaflets, yeah they are okay but if you, sometimes when you hand them out to people the first thing they do is just put them in the next bin, so.”* (PC24, 33 Polish)

### **The importance of the content of screening uptake promotion material**

Providing factual information in simple lay terminology was believed to be an important factor. The women remarked that they would be more likely to get involved in awareness campaigns if they had more information about the condition. Further focusing on the fact that with early detection cervical cancer can be preventable would reduce the fear associated with the diagnosis of cancer.

*“..pushing the fact that it’s preventable with early detection, I think that would be the big key”* (PC11, 36, English)

There were mixed opinions about using scaremongering techniques to encourage participation with cervical screening. Some women felt that this would work well, by informing women that many young women are affected by it whereas others believed that scaremongering would deter women from participating, as they would switch off and not take in the information. The other suggested approach was that of taking away the element of choice, for example one participant suggested that as part of the recruitment process for a job, the employer should ensure that all women working from them are up to date with their smears. This was thought to be of particular relevance to women who were born in an EE country.

*“I think sometimes you have to scare them into it a little bit don’t you that, you know, this is happening to so many..”* (PC13, 56, English)

*“I would find that more... well ‘cause I think sometimes I switch off with scaremongering..”* (PC19, 33, English)

*“If you don’t give them the choice, because as I say what differs the UK from many other countries, in those countries people are raised with no choice, you’re always told*



*and you know exactly what you're expected to do from early childhood, so nobody like it, medical procedures, but to say you have to do it, they do it..” (PH1, 35, Lithuanian)*

Another approach was instead of having generic letters and adverts, it was suggested to make them more personalised. How this would be achieved in reality was not discussed in detail. However, references were again made to including real life case studies, it was felt that women would be able to relate to these more than just random facts and figures. Another suggestion for making things less generic was if the doctor spoke directly to the women about smear tests, if and when they attended for another medical problem. The doctor was felt to be in a position of power and someone who would be listened to.

*“I guess it's finding ways to get the message to them more personally...if you know that it's more of a kind of a mass mailing type thing I think a lot of people do just ignore them don't they?” (PC10, 33, English)*

*“..whereas if a doctor mentioned I'd be able to go oh what's that and how often and what are the risks and blah blah blah, and just that two minute conversation I'm more likely to go..” (PC8, 32, English)*

The interviewees commented that the information preferences and needs of different groups of women would vary. Thought would need to be given to the requirements of the individual population groups at whom the information is targeted and the one-size fits all approach might not be appropriate.

*“I think it depends on the age group, if we were targeting the young woman, possibly most of them is using the internet, so maybe some kind of campaign going through that.” (PC24, 33, Polish)*

### **Increasing uptake for EE-born women**

Language was perceived to be the main barrier; suggestions were made to produce information in the native languages of these women. Further, targeting advertisements at specialised supermarkets or community centres was thought to increase awareness and hence participation. The women disclosed that many women on arrival to England

would go to recruitment agencies therefore this would be another place where there would be a captive audience, to increase awareness.

Having a cervical smear promotion bus attending communities, which are occupied by EE-born women, was also suggested. The idea was that these women could then be offered smear tests on the promotion bus if they were due one. Taking away the pressure of women having to arrange an appointment with the GP, additionally this would raise awareness for cervical cancer. The EE-born women appreciated that catering for the language needs for all women would be difficult, as identifying their native language might not be a simple task. The provision of information needed to be in a manner that was culturally sensitive; again they appreciated that identifying the various cultural differences might not to be always possible. As aforementioned, taking away the element of choice was also suggested, it was felt that this was what the EE-born women were accustomed to.

*“Yes, maybe like some, like when you have like Polish shop or Polish restaurant, maybe just to leave some leaflets or something..” (PC14, 29, Polish)*

*“And again another place that a lot of people go to when they first arrive here to work is recruitment agencies.” (PC25, 29, Polish)*

## **Education**

The word or phrase “education” was frequently mentioned in reference to increasing awareness and uptake of cervical cancer prevention. The overall impression was that there was not enough education on cervical cancer and its prevention at the school level. This resulted in an increased expectation that the parents should educate the next generation, however it was believed that not all parents were equipped to undertake this and as a result these children would miss out. Having education on smear tests and HPV incorporated with general sex education was felt to be the most beneficial, with reference being made to the concept of normalising the topic. This might eliminate the factor of embarrassment experienced as an adult. The women referred to taking away the “Britishness” from the subject, that we don’t speak about certain things, being more open about it from an young age and making it more of an acceptable subject. The

parents would also then indirectly be informed as the interviewed women supposed that the children would discuss what they have learnt at school with their parents and hence educate them. Women from the focus group described how in their country of births at school they would have a healthcare professional, perhaps even a gynaecologist, talk to the female students about cervical screening. They felt that this was beneficial and that something similar should be implemented here in England. However, there was some debate if the children should be spoken to alone or with their parents. The nEE women requested more control over what was being taught to their children and thought it would be better to have these discussions together. This was in comparison to the nEN women who were happy for their children to be educated in isolation from them.

The suggested age at which education on cervical cancer and its prevention should commence varied from as early as 10 years up to 13 years. The women felt that as soon as a girl starts menstruating it is appropriate to commence education on STIs and cervical cancer prevention. Further, they felt that the earlier education was commenced the more it would be perceived as a normal process and the sooner it would be accepted as something they will have to participate in later life.

*“And there isn't much education... any education about it either.”* (PC1, 34, Latvian)

*“I don't think the school should rely on the parents to always have, you know, to make that conversation, because if the parent isn't going to talk to them about it, who is..”*  
(PH5, 25 English)

*“..they'll probably learn as an adult it's not an embarrassment, it's something that's got to be done.”* (PC17, 34, English)

The consensus between the interviewed women was that education on cervical cancer prevention should be aimed at both male and females, especially as it associated with a STI. This would enable the teenage boys to appreciate their role and also reduce the stigma that the females have to face thereby promoting a culture of shared responsibility. In addition, if the male students had knowledge of the risk of cervical

cancer they are more likely to encourage their female partners or even family to attend for screening.

*“Well because the virus, the sexually transmitted, is two people, so the boy/the man carrying that and passing it, so yes really.”* (PC18, 40, English)

*“..I’ve not heard you mention this to their sister or to their mum or their girlfriend or their partner because it’s important that they support the females in their life as well..”*  
(PC8, 32, English)

**Table 3.9 Interview participant characteristics**

<b>Participant ID</b>	<b>Age (Years)</b>	<b>Ethnicity</b>	<b>No of years in England</b>	<b>Occupation</b>	<b>Relationship status</b>
PH1	35	Lithuanian	13	Employed	In a relationship
PH2	36	Slovak	10	Employed	In a relationship
PH3	30	Polish	10	Employed	In a relationship
PH4	34	Hungarian	3	Employed	Married
PH5	25	English	n/a	Employed	In a relationship
PH6	26	Polish	4	Employed	Single
PH7	25	English	n/a	Employed	Married
PH8	55	English	n/a	Employed	Married
PH9	52	English	n/a	Employed	Married
PH10	63	English	n/a	Retired	Married
PH11	45	English	n/a	Employed	In a relationship
PH12	30	Latvian	7	Employed	Married
PH13	42	Polish	8	Employed	Single
PH14	36	Lithuanian	11	Employed	Married
PC1	34	Latvian	5	Employed	Married
PC2	37	Lithuanian	9	Employed	Single
PC3	30	Romanian	2	Employed	In a relationship
PC4	43	Hungarian	10	Employed	Married
PC5	34	Polish	9	Employed	Married
PC6	28	Hungarian	9	Employed	Single
PC7	30	Romanian	6	Employed	Married
PC8	32	English	n/a	Employed	Married
PC9	33	English	n/a	Employed	Married
PC10	33	English	n/a	Employed	Married
PC11	36	English	n/a	Employed	Married
PC12	61	English	n/a	Employed	Married
PC13	56	English	n/a	Employed	Married
PC14	29	Polish	10	Employed	Single
PC15	36	English	n/a	Employed	Married
PC16	40	English	n/a	Unemployed	Single
PC17	34	English	n/a	Employed	Single
PC18	40	English	n/a	Employed	In a relationship
PC19	33	English	n/a	Employed	Married
PC20	31	English	n/a	Employed	Married
PC21	31	English	n/a	Employed	In a relationship
PC22	31	English	n/a	Employed	In a relationship
PC23	33	Czech	14	Employed	Single
PC24	33	Polish	8	Employed	Married
PC25	29	Polish	9	Employed	Single
PC26	35	Slovenian	5	Employed	Married

PC= Recruited from Community Setting

PH= Recruited from Colposcopy Clinic

**Table 3.10 Focus group participant characteristics**

<b>Participant ID</b>	<b>Age (Years)</b>	<b>Ethnicity</b>	<b>No of years in England</b>	<b>Occupation</b>	<b>Relationship status</b>
<b>FG 1.1</b>	32	Czech	2	Employed	Single
<b>FG 1.2</b>	48	Czech	10	Employed	Married
<b>FG 1.3</b>	34	Czech	4	Employed	Married
<b>FG 1.4</b>	29	Slovak	9	Employed	In a relationship
<b>FG 1.5</b>	34	Slovak	9	Housewife	In a relationship
<b>FG 1.6</b>	30	Slovak	8	Housewife	In a relationship

### **3.4 DISCUSSION**

This mixed methods study shows that the barriers preventing cervical screening in England, identified in the nEE, were not exclusive to them and some were shared with nEN women or other women in general(236, 237). The larger issue that has been revealed in this study is the way in which nEE women access healthcare services and their trust in healthcare/healthcare professionals in England.

#### ***Access to Healthcare in England***

Registration with the GP is the first step in accessing preventative healthcare in England. In the studied group 99% were registered with a GP in England at the time of the study but only half of nEE women had registered within 0-3 months of migration and in the interviews participants reported taking up to 3 years. The median time taken to register with a GP following move of residence within England has previously been found to be 4 months and in the quoted study by Millett et al, no difference was found between the various ethnic groups(152). However, the number of participants included from the different ethnic groups was small and ethnicity was defined based on race rather than country of birth. In another much larger study, a difference was noted between different nationalities and the likelihood of them registering with a GP in England(238). Language proficiency issues, lack of availability of relevant documents and resorting to self-medicating were barriers to registration in our cohort; these have also been found to be prevalent in other migrant groups to England, such as the Burmese(239). Delays or difficulties in engagement with primary care can have an impact on the burden on emergency care services(240). The nEE group in the current study described increased utilisation of emergency care facilities in preference to primary care initially on migration. This behaviour can help resolve immediate health concerns but will result in delay in accessing preventative healthcare, such as cervical screening(152). The rationale for such behaviours may relate to how healthcare is accessed in their country of birth, the participants in this study described direct access to secondary care and shorter waiting times. However, when the nEE women spoke of their health behaviours prior to migration, they appeared to have a lower threshold for seeking medical advice and greater appreciation for preventative healthcare. Therefore the health seeking behaviours of the nEE women in England are likely to relate to their of lack of knowledge of and trust in the English healthcare system. The stigma

associated with the connotation of “health tourism” and unawareness of their entitlement to healthcare in England may further prevent engagement(241). A UK based study found that, amongst women from differing ethnic groups, the overall level of trust in the healthcare system was low and there was a level of distrust expressed about healthcare professionals, especially pertaining to the following concepts “patients are taken seriously” and “patients get enough attention”(242). White and black Caribbean ethnic groups in this study were associated with a greater level of overall trust(242). In comparison to this a high level of trust in the NHS (both primary and secondary care) in England has been reported in the British South Asian population(243). The differing levels of trust amongst the various ethnic groups described in the present study and the studies quoted above might be explained by their individual expectations of healthcare, which are likely to be influenced by their experiences of healthcare in their country of origin.

The relationship that the nEE had with the GP in England was described as one lacking trust. Factors found to enhance the doctor-patient relationship are when the doctor meets their expectations, involves them in decision-making and appears to be interested and listens to them(244). These were qualities that the nEE women felt were deficient in GPs in England. However, a study exploring the depth of the GP-patient relationship, where the participants were of white ethnicity, found that a deeper relationship between the two parties did not equate to increased emphasis on preventative health(245). The authors rationalise this finding by the fact it was a cross sectional study or that the GPs might be concerned by the negative impact imparting lifestyle advice might have on the doctor-patient relationship. Others have found that a strong doctor-patient relationship will serve as a strong motivator for change(246). Nevertheless, the above studies refer to lifestyle changes in general and not specifically to the uptake of cervical screening.

### ***Access to the Migrant EE Population in England***

Access to the nEE population for the purpose of health promotion would be difficult in the absence of them registering with a GP. The nEE women described that unless they had established relationships and/or contacts in England they can live in isolation and no one would be aware of their presence in England. It has been suggested that to increase public participation in health promotion active efforts to engage with



educational institutes and religious/cultural centres might be beneficial(247). However, the nEE women in the current study described that due to the social isolation they sometimes faced, they failed to integrate even with members from their own community groups.

### ***Knowledge of Cervical Cancer and Information Needs***

Awareness and knowledge of cervical cancer was overall poor and there was no difference noted between the two groups nEE and nEN. Further, both groups referenced the reality celebrity Jade Goody as their trigger for awareness of cervical cancer. The mass media attention received by Jade Goody when she was diagnosed with cervical cancer, witnessed a transient increase in the uptake of cervical screening(248). However, it was argued that this opportunity was not maximised with regards to improving public health knowledge of cervical cancer; when media articles were analysed they were found to lack factual information(249, 250). This might explain the low knowledge levels in the studied group despite some awareness of cervical cancer. The content of tabloid/popular versus broadsheet newspapers covering the Jade Goody story did not vary, therefore women from all socio-economic classes and cultural backgrounds had access to the same level of information(251). This is apparent in this study, as even nEE women recalled Jade Goody. The so-called “Jade Goody” effect has not been replicated; in 2011 when a popular British TV soap ran a story where one of the characters was diagnosed with cervical cancer. This story did not appear to have the same effect on increasing awareness or uptake of cervical screening(252). Real life stories compared to fictional might have a greater impact on increasing awareness, many of the interviewed women referred to people that they knew of who had been diagnosed with cancer as a source of their knowledge for that particular disease.

Knowledge of the cervical screening programme and the purpose of a smear test was greater in the nEN group (90% vs. 50%) and more of the nEE women believed that a smear test formed a part of a full gynaecological examination (46%vs 21%). Being born in the UK has been found to be associated with greater knowledge of cervical screening(144). The exact reason for this observation is not known but it has been found to persist independent of potential language barriers that non UK born women may have(253). One possible explanation is that the lower knowledge levels observed in the

nEE women relate to their level of knowledge prior to migration to England. Many of the nEE women reported low levels of knowledge in their country of birth both at a personal and population level. Variation in knowledge levels between the nEE women might be rationalised by socio-economic inequalities that existed in their country of birth prior to migration. Socio-economic inequalities have been shown to be associated with lower knowledge levels independent of the effect of ethnicity(253). The resulting effect would be lower baseline knowledge at the time of migration to England. The affect of knowledge on actual screening behaviours is discussed later. The limitations of a screening versus a diagnostic test were not well understood by either group. This has been shown to result in overestimation of the benefits of screening and possible misinterpretation of a negative result(254, 255). There is a danger of significant symptoms being dismissed in the presence of a negative smear result(256). Furthermore, an abnormal result may be interrupted to be synonymous with the diagnosis of cancer(257). Information sharing at the time of the smear test may help alleviate a number of these misunderstandings and is essential for informed consent(258). Initially some of the women in this study had described satisfaction with the level of information provided but as gaps in their knowledge became apparent during the interview process, they declared the need for further information. At primary care level it has been noted that both GPs and practice nurses differ on how they prepare women for a smear test and information of the reliability of the test and the process that follows an abnormal result are often omitted, instead the focus is on the practical side of the procedure(259). The medium through which information was shared was important; the studied cohort suggested the use of information leaflets and face-to-face consultations. Leaflets in isolation have been found to be of little benefit but in combination with verbal communication can improve the patients' experience(260). Mass media campaigns similar to those used for breast cancer awareness were also recommended, these have been found to be effective in increasing uptake of cervical screening when combined with personalised patient and healthcare professional education(261). The information leaflet, which accompanies the smear invite letter, is another source of information, however the participants admitted that they did not read it, especially if they had had a smear test previously and consequently knew what to expect. Therefore, any new updates in the leaflet, for example regarding HPV testing would be missed. There was a discrepancy of opinions between the nEN and nEE

women regarding the content of the information leaflet, in those women who had read it. This might relate to language barriers and limited comprehension by the nEE women of the information provided. The provision of detailed information with limited ability to comprehend can result in inequalities in participation, discouraging those with a lower educational background(262). Based on the same principle nEE women may also be discouraged due to language barriers impeding understanding.

### ***The Smear Invitation***

The smear invitation letter was valued in this study as a useful reminder tool for attendance to screening and has been proven to increase participation with screening in other populations(263). The main limitation of it was for women who did not have a valid postal address. This was of particular relevance for the EE migrants to England who are known to have high rates of mobility following migration(264). The content of the smear invitation letter was believed to be sparse and the participants requested for more factual information. A longitudinal study by Duggal et al., showed that the clarity of the smear invitation letter, in those without any language barriers, over a time period has improved, however it is less reassuring and less friendly(265). Even though the quoted study is out-dated and therefore the relevance of the findings to the current screen invite are limited, it highlights the importance of the factual content with regards to patient anxiety and relates to the findings of the current study. The reminder letters were also felt to be beneficial by the studied group, reminder letters have been shown to increase screening attendance by 9% but if the initial invitation is followed up a telephone reminder rates are increased by 31%(266). The benefit of a telephone reminder is that an appointment may be scheduled at the same time. One of the participants in this study who was a non-attender felt that if an appointment was sent with the reminder letter then she would be have been more likely to attend.

### ***Cervical Screening Behaviours***

The age for commencing screening in England was correctly estimated by both the nEN and nEE women in the survey, however the in-depth interviews revealed that the nEE women had started screening at a younger age in their home countries. This is likely to be reflective of access to healthcare and health seeking behaviours that exist in their country of births. In most of the EE countries included in this study the national

proposed age for commencement of screening is between 23-30 years(45). This suggests that the smear tests were performed outside any screening programme that may exist in their country of births. The frequency of smear tests in England was an area of concern particularly for the nEE women, who were of the belief that cervical screening is offered on an annual basis in England and believed that the three yearly interval was too long. The “prolonged” screen interval was a motivating factor for some to return home for more frequent smear tests, for the vast majority access to screening more frequently would have been again outside any national programme(45). However, annual cervical screening has not been shown to add significant protection over the 3 or 5 yearly screen intervals(102) and there is a risk of overtreatment of lesions that may have spontaneously regressed(267). Women have been found to prefer active management even with low-grade cytological abnormalities(268). The personal beliefs of nEE women on the screening programme in England and their screening behaviours prior to migration appear to dictate their current screening behaviours, with women falling into one of the following groups; those who did not participate with any screening; those who attended screening in England only; those attended for screening their country of birth only and those who attended for smears in their country of birth and in England. The main reasons quoted for returning home for smear tests are that a gynaecologist performs the test and it involves a full gynaecological examination. Preference for a gynaecologist, rather than a nurse practitioner or a GP for gynaecology-related care has been noted in other population groups(173). The strongest predictor for preferring a gynaecologist was having had a gynaecologist for their last pelvic examination(173). Gynaecologists perform the majority of cervical screening in EE countries, therefore it is likely that the nEE women’s preference is governed by what is perceived to be standard practice for them.

Motivation has been argued to be the first step in determining certain behavioural performances(269). The two studied groups of women (nEN and nEE) shared similar motivating factors for participation with cervical screening. Referring to the principles of the health belief model; the motivators related to their perceived susceptibility and the perceived severity of the diagnosis of cervical cancer. However, the evidence for the association of risk appraisal and cervical screening uptake is not clear, some studies have shown a positive association(237, 270), whilst in others the association was not a

significant one(271). Nevertheless, it would be sensible to assume that an element of risk to ones self must exist for them to seek out preventative measures. It has also been suggested that proposed “motivation” in itself may not result directly in subsequent uptake of screening(271). In order to calculate self-risk the women are required to have baseline level of knowledge of cervical cancer and higher knowledge levels have been associated with increased participation with cervical screening(162). Knowledge either acquired directly or through family members was also a motivator for screen attendance in this study. The belief that smear tests were preformed as part of a routine sexual health check was to an extent held by both nEE and nEN women, but was more prevalent in the former group. Therefore, the commencement of a new sexual relationship acted as motivator to have a smear test performed. There is a danger that this may result in attending for a routine sexual health check and the assumption that a smear test has been performed when it may not have or the reverse, having a smear test without a full sexual health screen. Misconceptions of what a cervical smear test involves in nEE group may stem from the practice of annual gynaecological reviews that was described by nEE women to occur in their country of births. Similar misconceptions on the purpose of the smear test have been described in other populations where the practice of annual pelvic examinations is prevalent. Patients have been found to hold false beliefs such as pelvic examination are required for STI screening, used as a screen for ovarian cancer and are necessary prior to the commencement of contraception(272). Of concern is that physicians have been found to hold similar beliefs and they do not support prolonging the interval of these routine examinations(273).

Doctor recommendation was quoted as a motivator for screening uptake by the participants in this study but has also been shown by others to be an important determinant for screening uptake, particularly in ethnic groups(274). Lack of appreciation of the preventative nature of cervical screening can in itself act a barrier to uptake; the lack of symptoms or the belief of being “healthy” was described as barriers in this study. These findings relate back to knowledge and the concept perceived susceptibility. Emotional barriers, such as embarrassment and fear, were in the current study shared by both groups of women (nEE and nEN), however others have found that they can be greater in ethnic minorities(275) and this can result in a delay with seeking

medical assistance(276). The main limitation of the quoted studies is that ethnicity was split into white and non-white, with some further segregation of the non-white group but not of the white women and therefore the findings are not strictly comparable to that of the current study. Age appeared to be an important factor for both emotional and practical barriers of cervical screening. Practical barriers have been shown to be greater in younger women, whereas in older women the perception of risk is greater(277). The idea of perception of risk may not directly relate to that of cervical cancer in itself but generally to adverse health with advancing age and hence the emotion of embarrassment is overridden. The screening uptake figures in England from 2016 are reflective of this, screening uptake was the greatest in the 50-64 year age group at 78%(278).

The prioritisation of other tasks despite having a positive attitude towards cervical screening can result in a delay in attendance(236). This was of particular relevance to the NEE women who prioritised finding accommodation, employment and school placements for their children. This behaviour may be reinforced in the absence of any symptoms and the sense of being in good health. Oscarsson et al., found that some women believed participation with preventative healthcare could result in stress and anxiety tipping the equilibrium more towards ill health rather than good health(236). Language has been identified as a barrier to screening in many ethnic groups(150, 279-281), similar to the current study findings. Language barriers may pose to be problematic at many stages of the screening journey from registering with the GP(241) to understanding the smear invite letter(280). Communicating with the GP to make an appointment and even the use of public transport to access the surgery can be impeded by language barriers(282). Further, a proportion of the women were unaware of their entitlement to have an interpreter present for consultations. The NHS states that “Patients must be able to access primary care services in a way that ensures their language and communication needs do not prevent them receiving the same quality of healthcare as others” (Pages 2-3) and that translation/interpretation service should be provided free at the point of delivery(283).

The personal attributes of the healthcare professional performing the smear test appeared to be important in determining their perception of the overall smear

experience. As previously discussed the role of the practitioner was more of a concern for the nEE women, however gender was significant for both groups. Female gender has been found to be important not only for smear tests specifically but for any gynaecological-related examination(284). Nevertheless, a male practitioner would not per se serve as a barrier to attendance in the studied groups, but if the overall smear experience was negative it can affect future screening practices(275).

The detrimental effects of receiving an abnormal cervical screen result have long been documented from studies dating back to 1986(285). Similar concerns to that found in the current study have previously been noted and include; fear that the abnormality indicates that they have cancer(286) and shock(287). The fact that women still have the same negative emotional responses to receiving an abnormal smear result may indicate that patient education and understanding of cervical screening has not improved over time. For the studied group their emotional responses had been triggered by their lack of understanding of what the abnormal result means in real terms. What is the difference between low and high-grade changes? Previous work has shown that women can incorrectly interpret all abnormal screen results to be synonymous with a diagnosis of cancer(288). In addition, levels of anxiety associated with a low and high-grade cytological abnormality have been found to be similar(289), supporting the theory of poor patient understanding of the various grades of abnormal smear results. Lack of understanding of the smear result is a risk factor for heightened levels of anxiety in women who have had an abnormal screen test(290). In the nEE group language barriers further impeded their understanding of the smear result and others had poor social support; these resulted in amplification of the negative emotional responses. The affect of ethnicity on anxiety levels following an abnormal result has not previously been explored specifically for the EE group but when the “white” group has been compared to the “non-white” group no significant difference has been shown(289). Increased anxiety levels associated with an abnormal smear result have not been shown to affect compliance with follow up(291) and adherence did not differ by race or ethnicity(292). Nevertheless, increased anxiety levels and the fear of cancer can be long lasting and have been shown to be present at two years following an abnormal smear result(293).

### ***HPV/ HPV Vaccine Knowledge and Attitudes***

nEN women were more likely to have heard of HPV than nEE women (73% Vs. 53%), this is likely to be explained by the fact that in many of the EE countries, HPV triage/ TOC and/or HPV vaccination are either unavailable as part of national state funded cancer prevention programmes, have only recently become available or there is low uptake of them (Chapter 1). However, in spite of this the survey study revealed that in those women who had heard of HPV; nEN and nEE women had comparable median HPV knowledge scores (10 and 9 out of 15, respectively). The level of HPV knowledge demonstrated in the qualitative interviews in both the groups appeared to be lower than in the survey. A potential disadvantage of using closed questions within a survey tool is that they can be suggestive and hence place ideas into the respondent's mind or encourage the participant to respond even though they do not necessarily know the answer. This may explain the discrepancies in HPV-related knowledge observed in the two parts of this study. Higher educational attainment was associated with significantly greater HPV and HPV vaccine knowledge in the current study. Other researchers have also shown that higher educational levels are associated with greater HPV vaccine knowledge but vaccine acceptance has been higher in those with lower educational levels(294). Furthermore it has been suggested that the provision of HPV related information can increase HPV knowledge levels but this does not translate into increased parental vaccine acceptance(295). Vaccine attitudes appear to be of greater importance(295). In our cohort it was only nEN women who had been vaccinated and the qualitative interviews revealed that it was mainly nEE women who held strongly negative HPV vaccine attitudes. nEE women had also remarked that in their countries of birth there was more fear of adverse effects and scepticism about vaccination. The HPV vaccine has not been found to be associated with any serious adverse effects and there is no strong evidence to support any causative association with infertility(79). Nonetheless, the strength or even the existence of any association between vaccine attitudes and vaccination status cannot be commented upon from the current results. However, studies from Romania, where HPV vaccine uptake is poor(82, 83), have shown that HPV vaccine views of Romanians are negative and reflect their broader opinion about science and mistrust of their healthcare system(296, 297). This would suggest that in order to increase vaccine acceptance in the nEE group, the focus should



be on increasing their trust with the healthcare system and healthcare professionals in the England.

The nEE women contested that the age of HPV vaccination in England was too early, as they believed that in their country of births girls do not engage in sexual activities as early as they do in England. It may be inferred from this that nEE women feel that they are at lower risk of acquiring HPV and subsequently developing cervical cancer. Studies exploring sexual behaviour in both in the UK and Europe (including Eastern European countries) have shown that a significant proportion of adolescents engage in sexual activity under the age of 15 years(72, 73). The prevalence of HPV infection in Eastern Europe has been found to be 21.4-29.1%, compared to a global prevalence of 10.4-11.7% and Northern Europe (including UK) prevalence of 7.9-10%(298, 299). The nEE women appear to be underestimating their risk of acquiring HPV infection; the women in this study believed that it was due to their cultural beliefs that their sexual behaviours might differ. It possible that the younger generations of EE women might not share the same the cultural beliefs but fear of their behaviours/choices not being culturally acceptable may prevent them from discussing them openly. The nEE participants referred to the fact that is was not usual behaviour to have discussion of such nature with their parents.

### ***HPV Testing Knowledge and Attitudes***

HPV testing in the form of HPV triage and TOC has been shown to be an acceptable test in hypothetical situations(300). However, in the current cohort it was evident that the women were unaware that it is even being tested for or what it means. The concept of informed consent is questioned in this situation and whether the test is acceptable because they do not have adequate information. Similar to the findings of the present study, knowledge about HPV in various population groups has been found to poor(226). The question of if they would still attend for screening knowing that it might include a HPV test related back to their self perceived risk of testing positive for HPV and/or their understanding of the test. It is the testing positive rather than undergoing HPV testing in itself that causes increased anxiety(301). In common with other studies the negative emotions associated with a positive HPV result included states of anxiety and

distress(302), embarrassment and concerns about past and future sexual relationships(303).

Participation with primary HPV testing was discussed in hypothetical terms and the views of the participants in the current study appeared to be governed by their personal knowledge, experience and again their self-perceived vulnerability of acquiring the infection. In those women who had previously had an abnormal smear result (with/without HPV) or had undergone treatment for abnormal cytology the fear of developing cancer was worse than the test being performed to look for it. O’Conner et al., found that overall concerns over the discovery of abnormal cytology and treatment outweighed any concerns regarding HPV status(301). The way in which primary HPV testing is marketed was thought to influence participation with it; normalising HPV testing by promoting it as a test for all women was believed to lessen the stigma associated with it. The current cohort considered focusing on the prevention of cervical cancer rather than testing for HPV per se would help increase participation and others have found that it may similarly reduce any adverse psychological effects associated with HPV testing(304). Hence the content and the phrasing of the smear invitation letter have a vital role in this. For primary HPV testing to be acceptable it will need to be seen as a screening test for the prevention of cervical cancer and not merely as a test for an “STI”. The later has the danger of dividing society into the attenders who might potentially be judged to have adopted a certain/ high-risk lifestyle compared to the non-attenders. The response of the male partners to disclosure of the HPV result varied in the current study and negative responses can limit normal support channels. Revealing a positive HPV result to a partner has been shown to be affected by their own knowledge of HPV and their social and cultural norms as well as their relationship experiences(305). The varied actual or hypothesised partner responses in the current study are likely to be explained by this.

The need for continued screening following an initial negative HPV test result for those women who were in a monogamous relationship was questioned. The more information the women had about HPV and its transmission resulted in more questions and the situation was not as clear as it initially appeared. Similar confusion existed for some women following HPV vaccination.

### ***Attitudes Towards Discussing the Topic of Cervical Screening***

The women in this study believed that discussing the topic of cervical screening more openly, would help raise awareness about cervical cancer and increase participation with screening. However, not all of the women felt comfortable talking about this topic, especially the nEE women. The nEE women similar to women from other ethnic groups in England, described cervical screening as a “private” topic(275) and therefore would not routinely talk about it. The emotion of “embarrassment” was quoted as reason why some women in this study were not comfortable conversing about cervical screening; it is not clear if “embarrassment” in itself will serve as a barrier to screening, as this emotion has been described both by attenders and non-attenders(138). nEE women who had experienced an abnormal result wanted to share their experience and encourage other women to attend. One possible explanation for this could be that through the process of receiving the abnormal result, they gained factual knowledge/were educated about cervical screening which allowed them to overcome the factor of embarrassment(306).

### ***Increasing Participation with Cervical Screening***

The use of television adverts was suggested as a method of increasing participation with cervical screening in England. The main advantage of this method was that women from all socio-economic backgrounds were thought to have access to a television. An Australian study reported an increase in cervical screening participation across all socio-economic groups with the use of a mass media campaign (including television, radio and poster advertisements)(307). This Australian study was conducted in 2005 and therefore might not be of relevance for the modern era of online/catch-up television. It has been argued that, as more viewers are utilising the catch-up function; online television adverts might not be as effective. For the younger generation the use of social media was recommended. Social media has the potential to reach a large number of people and has been successfully used to raise funding and awareness about Amyotrophic Lateral Sclerosis, through the “Ice Bucket Challenge”(308). A similar campaign, called “Smear For Smear” was launched for cervical screening in 2015 during the cervical cancer prevention week in England. This was prior to the current study being conducted, however none of the interviewed women recalled it. This topic would have been especially of relevance to the women in this study who had had a

previous abnormal smear result. Additionally, there are many videos on cervical cancer available on “You Tube”, however not many of these originate from reputable healthcare organisations(309) and the studied women did not mention any awareness of these either. This suggests that although social media campaigns are a powerful tool to promote healthcare messages, they need to be utilised properly to achieve maximum effect (308, 310).

The use of personalised letters, as was suggested by the women in this study, has been shown in a Spanish study to increase participation by approximately 25% and up to 30% if an appointment time was also included with the invitation letter(311). The limitations with this approach outside a funded study setting, include not having adequate resources to facilitate personalised invitation letters signed by the women’s own healthcare professional. Further, there is the potential for wasted appointments, with the large number of women who might not attend/cancel and this is all in the context of an already stretched NHS in England. Nevertheless the final analysis of this Spanish study showed an overall increase of 20% in screening participation with the use of individual contact methods and fixed screening dates(312). An increase in screening uptake of this extent would be beneficial especially if it is balanced against the implications for resources that are placed by women not participating with screening.

Suggestions made to increase cervical screening uptake in the nEE group specifically, included removing the element of choice and making screening mandatory. From the interview part of the study it transpired that for a proportion of nEE women the concept that some health practices (such as the annual gynaecological reviews) are “compulsory” was normal, as was the practice in EE countries such as Latvia during the soviet era(313). The implementation of compulsory screening saw a reduction in cervical cancer incidence in Latvia from 16.8 to 8.9 per 100,000 women(313). In addition, one participant made reference to the fact that not having the element of choice is what they would be accustomed to. This would not be possible in the England where patient choice and informed consent are central principles of the practice of medicine, therefore it may be assumed that some of the nEE women do not appreciate the importance of cervical screening, as it is not mandatory.

Language-specific targeted adverts were suggested to increase screening uptake in the nEE population. The use of ethnic radio stations in Australia has been shown to increase participation with screening in women from non-English speaking minority groups(314). The validity of the effect of the intervention in this study is limited, as a larger general screening campaign, in English, was also on-going at the time of the study. In other ethnic groups, the use of community targeted media education campaigns have proven to increase awareness and intention to attend for cervical screening but this has not necessarily translated into improved attendance for a smear test(315). In contrast, another study exploring cervical screening community development work amongst an ethnic minority group in England, did find an increase in screening attendance(316). Increasing awareness of cervical cancer might not be sufficient in all ethnic groups to induce behavioural changes. The nEE women recommended that to encourage women to have a smear test, the use of mobile cervical screening buses/units attending areas with a large nEE population would work. This would remove any practical barriers and help with the transmission from the contemplation of having a smear test to the action of actually having one. Mobile units have been shown to be successful in increasing actual screening uptake in rural areas(317), where access and awareness may act as barriers. The studies referenced here are somewhat out-dated, despite this more recent work has drawn the same conclusions; community outreach work in a culturally and language appropriate way is a strong method of increasing awareness and potentially uptake of screening in minority ethnic groups(275).

### *LIMITATIONS*

This study has limitations, a non-random consecutive sampling method was utilised to recruit participants for the questionnaire component therefore the recruited sample might not be representative of the population. However, due to the scale of the study and the relatively low population of nEE women in the study area, this was the most achievable method of recruitment. Even though a non-random sampling method was used, participants were recruited from a large geographical region and multiple institutions. The number of recruited participants, for the questionnaire component, fell short of the original sample size calculation in both the nEE and nEN groups. Mid-study analysis revealed that recruitment was not progressing as anticipated due to low number

of participants, particularly from the nEE group, attending the colposcopy clinics. The referral rate of patients to colposcopy clinics had reduced significantly over the study time period as a result of HPV testing (HOV triage and TOC). Difficulties were also experienced in identifying and engaging nEE participants in the community. A lower sample size will reduce the representativeness of the data; however, the difficulties experienced in recruitment of the nEE women highlight the challenges in accessing this group for the purpose of health promotion. This in itself is an important finding of the study.

The majority (87%) of surveys were completed by women attending colposcopy clinics and it may be argued that by default these women are already engaging with cervical screening. However, they provide an insight into to what motivated them to participate rather than just focusing on the barriers, which is just as important(174). The initial research protocol included recruiting participants (nEE and nEN) from primary care, this would have given access to those women who might not have participated with cervical screening. Unfortunately due to information governance issues and difficulties encountered with local primary care trusts this was not possible. An attempt was also made to access participants through the national screening database, this would have allowed access to all women who were eligible for screening from the two groups of interest. However, again due to information governance and data protection regulations it was not possible to access this database. Nevertheless, recruiting participants from the community setting did permit sampling women who might not have participated with cervical screening and also those who might not have engaged with any healthcare services in England. Community participants only completed a minority of the surveys but 69% (n= 18/26) of the nEE interview participants were recruited from the community setting. The interview data provided a greater insight into the rationale behind their screening health behaviours. In this study the cervical screening behaviours and attitudes of women who had actually been diagnosed with cervical cancer were not specifically explored. It is possible that these women might not have participated with any cervical screening either in their country of birth or in England and therefore have different attitudes and/or represent a different demographic. The exact clinical histories of the women who participated in the study were not elicited as it was felt that the participants would feel uncomfortable disclosing such details. However, some of the

interviewed women did self-disclose that they had undergone treatment for cervical cancer and hence their views were expressed. A further study specifically exploring women with diagnosed cervical cancer from the two groups would be more informative. By using a snowballing approach to recruit nEE women from the community there is a danger that the same group of friends who share similar views and educational background may have been recruited, however the participant responses and characteristics did not support this. nEE women who have not joined community groups or integrated with the community were not sampled, and it could be argued that this is the group that we need to target.

For the interview component of the study, the participants were asked to self-volunteer, these women might represent the group of women who are already more engaging with health promotion. Nevertheless, some of the women had not always participated with cervical screening or engaged with healthcare services in England. This group of women provided an insight into what induced a change in their health behaviours and what their barriers were prior to this.

It is acknowledged that the nEE group is a very heterogeneous group and not all the countries of interest were represented due to difficulties with recruitment. In view of this, the findings of this study might not be representative of the whole of the nEE group (as it was initially described). In addition, qualitative work lacks generalizability and although EE is a geographically defined region, it would be unfair to assume the populations are entirely the same. This study did show that many of the views and health behaviours were shared amongst women from the various EE countries.

### **3.5 CONCLUSIONS**

The cervical screening behaviours of the nEE population to England appeared to be, in part, governed by their perception and/or level of trust overall in the English healthcare system. This prevents them from wholly accepting the advice and/or recommendations of it. From the point of migration there is a delay in interacting with screening services in England, as many of the nEE women delay registering with a GP and this is the first step to being on the screening register. Their priority appears to be to resolve acute health problems and not preventative healthcare.

Further, their pre-existing knowledge of cervical cancer and their screening behaviours prior to migration also impact on their screening behaviours on migration. To increase uptake in this high-risk group of women (nEE), targeted education should be provided at the initial point of contact with healthcare services in England, (either when they register with the GP or when they first make contact with emergency care services). Healthcare professional have a vital role to play in the provision of education to increase both awareness and participation with cervical cancer prevention methods.



## **4 CERVICAL CANCER PREVENTION; A MIXED METHODS STUDY EVALUATING THE KNOWLEDGE, BEHAVIOURS AND ATTITUDES OF LATVIAN WOMEN**

### **4.1 INTRODUCTION**

Latvia has a high incidence of cervical cancer(318), and efforts to reduce it have not been successful or accepted by all. Cervical screening in Latvia has undergone considerable reforms since it first became available in the early 1960s(313). Initially screening was performed as part of a preventative gynaecological examination but there was no formal organised programme. In the 1980s screening became compulsory, as part of the broader system for the prevention and treatment of disease for all citizens, and consequently a significant reduction in the cervical cancer incidence rates was observed(313). In 1989 however, due to political and economic changes compulsory screening was ceased, resulting in a rise in incidence. Thereafter cervical screening remained opportunistic until 2009 when a fully funded national cervical screening programme was implemented. Similar to many other Eastern European countries, data on both cervical cancer screening and HPV vaccine uptake are scarce and somewhat out-dated. Screening coverage has been reported to reach a maximum of 59%(121) and HPV vaccine uptake of 53.4%(82). The aim of this mixed methods study was to explore the knowledge, behaviours and attitudes regarding cervical cancer prevention strategies in Latvian women.

### **4.2 METHODS**

#### **4.2.1 Sampling Frame**

The sampling frame was defined as all Latvian women aged 20 years and above attending the colposcopy clinics and the GP surgery at the selected institutes over the study time period. The sampling frame was intentionally kept broad to ensure that a good mixture of women who do and do not partake in cervical cancer screening were included. We did not restrict the sample to the age limits (25-70 years) recommended in the national Latvian screening programme, as preliminary research had shown that many women who do not fulfil the national screening criteria were still having opportunistic screening outside the programme(313), and it was felt to be important to include this group in order to assess their motives for such behaviours.

#### **4.2.2 Data Collection Methods**

A mixed methods study consisting of questionnaire surveys and in depth one-to-one semi-structured qualitative interviews.

##### **4.2.2.1 Part 1 Questionnaires**

###### **Questionnaire Development**

In order to permit comparison with the main study that was conducted in England the same questionnaire was used for this Latvian study (Chapter 3). Minor alterations were made to ensure it was appropriate for the Latvian population; for example the wording of questions was changed from “England” to “Latvia” for relevant questions. Questions referring to the length of time in England were excluded and replaced with questions asking about living outside of Latvia for any period. Similarly questions about proficiency with the English language were removed, although all knowledge-based questions remained the same. The survey tool was developed in English and then translated into Latvian by our Latvian collaborators.

The final survey consisted of four main sections: socio-demographics, general health behaviours, cervical screening knowledge and practices and HPV and HPV vaccine knowledge. The final questionnaire consisted of 28 items (Appendix I)

###### **Recruitment for Survey Study**

A convenience sampling approach was adopted, whereby only the time period for recruitment was determined. The aim was to recruit patients from two settings (primary and secondary care) to ensure that those women who had and those who had not attended for cervical screening were equally represented. All women aged 20 years and above attending colposcopy clinics in Riga East Clinical University Hospital, a state funded hospital in Riga and a state funded GP surgery in Riga, between September and October 2015 were asked to complete the survey. State funded institutions were chosen for recruitment, as women from all different socio-economic backgrounds are more likely to access these as compared to private providers.

The women were asked to complete the survey prior to their consultation with the healthcare professional. Completed surveys were placed in a sealed envelope and handed back to the healthcare professional.

### **Data Analysis**

The surveys were pre-coded and a dataset was created on the statistics programme, SPSS, IL, USA, version 22. Descriptive statistics were generated for the responses and Chi square test or Fisher exact test as appropriate were used for univariate analysis. All reported P-values were assessed using two-sided tests and statistical significance was taken as a cut-off of  $p < 0.05$ . Each question was analysed individually to account for missing responses.

#### **4.2.2.2 Part 2 Semi-Structured Qualitative Interviews**

Participants were asked to volunteer at the end of the survey to be involved in the interview stage of the study. A consecutive non-random sampling method was utilised to select participants from all those who had volunteered and interviews were conducted until data saturation was reached. The aim of the semi-structured interviews was to obtain a detailed understanding of the thought processes behind particular screening behaviours and choices. In addition, perceptions of the national Latvian screening programme and access to healthcare in Latvia were explored. Themes that were explored in the questionnaire study (part 1) and issues surrounding HPV testing, HPV vaccine and the perceived stigmatism of the association between sexual behaviour and HPV, were further investigated. The topic schedule was kept the same as the English arm of the study with minor alterations to ensure that it was appropriate for the Latvian population (Appendix II).

To maintain standardisation and consistency, I conducted all the interviews myself and an interpreter was offered to all the participants. The interviews were conducted either in a meeting room in the hospital or at the GP surgery, as this was deemed to be the most easily accessible place for the participants. All the participants were provided with a €10 gift voucher and were reimbursed for travel expenses. The participants were

provided with a participation information sheet and written consent was obtained from all the participants prior to the conduction of the interviews.

### **Data Analysis**

The interviews were audio recorded with permission and transcribed verbatim into English (in the interviews where there was a interpreter present, it was the interpreters speech that was transcribed verbatim in English). Inductive framework method of thematic analysis was used for analysis of the transcripts(235). The merits of this method and a detailed description have been provided in Chapter 3. NVivo which is a software used to aid qualitative data analysis, was used for analysis. Two reviewers reviewed the initial two transcripts independently and agreed on an extensive list of codes. I reviewed the remaining transcripts and applied the codes. Any new emerging codes were added to the analytic framework and the final framework was applied to all the transcripts. The final set of codes was grouped into themes.

Ethical approval for the study was obtained from the University of Latvia ethics commission board (13/08/2015).

## **4.3 RESULTS**

### **4.3.1 Part 1 Questionnaire Data**

Overall 158 surveys were completed, 25 from primary care and 133 from secondary care. In total 200 surveys were printed and distributed resulting in an overall response rate of 79%. As so few surveys were completed from primary care, surveys from both the settings were analysed together. The median age of the participants was 36 years (range 21-71 years), almost half of them were married and the majority (72%) were in full time employment (Table 4.1). All of the women apart from one were registered with a GP in Latvia. The reason stated by the single participant for not being registered with a GP was that she did not know how to register.

### **Cervical screening behaviours and knowledge (Table 4.2)**

Most of the women (67%, n=105) appreciated the purpose of a cervical smear test as a screening tool, to identify pre-cancerous cervical changes and that it lacks diagnostic

(72%, n=113) ability. Just over half (53%, n=83) accurately selected only the true options for the question “Why are cervical smear tests performed?”, 23% (n=36) considered that cervical smears tests were performed as part of a “full gynaecological examination”.

The women were aware of the availability of free cervical screening in Latvia (87%, n=135) and their main source of information for this was the smear invitation letter (64%, n=87). Knowledge about the screening programme in Latvia was variable, the median age for commencement of screening, as part of the national cervical screening programme in Latvia, was correctly estimated to be 25 years. However there was a wide age range of answers, from young as 15years up to 50 years. In terms of smear frequency 59% (n=82) stated it was every three years and a third (33%, n=46) thought that they were performed on an annual basis. Comparing this to their actual screening behaviours the following was found, 87% (n=135) of the cohort had had a smear test in the past and the mean age at first smear test was 25 years (range 18-55 years), with the majority (83%, n=124) having been for a smear test in the last three years. Almost two thirds (61 %, n= 88) were compliant with screening, compared to 25% (n=37) who were not and 14% (20) who could not recall.

### **HPV and HPV vaccine knowledge (Table 4.3)**

Even though most women declared that they had heard of HPV (73%, n=115/157), they demonstrated limited knowledge of HPV. In those women who had either heard of HPV or were not sure if they had heard of it (10%, n=16), the median scores for the general HPV knowledge and HPV testing questions, were 7 out of 15 (range 0-15) and 4 out of 6 (range 0-6) respectively. For the general HPV knowledge category 12% (n=15) achieved a score of zero and only 2% (n=2) obtained the maximum score. Similarly for the HPV testing section, 31% (n=40) scored zero and 10% (13) achieved the highest score.

Fewer women responded to the questions about the HPV vaccine, 70% (n=90/129) had heard of the HPV vaccine and only 4 % (n=5) had received the HPV vaccine. When detailed HPV vaccine knowledge was assessed in those who had heard of HPV and the HPV vaccine (n=90), they achieved a median knowledge score of 4 out of 7 (range 0-7), 11% (n=10) scored zero and only one participant scored the maximum mark of seven.

### **Associations between socio-demographic factors and understanding of cervical cancer prevention methods**

Younger age showed a significant correlation with general HPV knowledge ( $p<0.01$ ) and HPV vaccine knowledge ( $p<0.01$ ) (Table 4.4). Higher educational attainment was conversely associated with a higher HPV testing knowledge score ( $p=0.02$ ). Neither marital nor employment status were found to show any significant correlations.

**Table 4.1 Socio-demographic characteristics**

<b>n=158</b>		
<b>Age (median/range)</b>		36 (21-71)
<b>Relationship status n(%)</b>	Married	78 (49)
	Widowed	4 (3)
	Divorced	11 (7)
	Separated	6 (4)
	In a civil partnership	17 (11)
	In a relationship	18 (11)
	Co-habiting	18 (11)
	Single	6 (4)
<b>Education n(%)</b>	No formal Qualifications	2 (1)
	Trade/technical /vocational	38 (24)
	GCSE's/O Levels or equivalent	29 (18)
	A Level or equivalent	7 (4)
	First degree	49 (31)
	Post Graduate degree	28 (18)
	Other	5 (3)
<b>Employment Status n(%)</b>	Employed full time	114 (72)
	Employed part time	13 (8)
	Unemployed	12 (8)
	Retired	5 (3)
	Housewife	14 (9)
<b>Ethnicity n(%)</b>	Latvian	151 (96)
	Russian	3 (2)
	Polish	2 (1)
	Other	2 (1)
<b>Country of Birth n(%)</b>	Latvia	154 (97)
	Russia	3 (2)
	Other	1 (1)

**Table 4.2 Cervical screening behaviours and knowledge**

			<b>n (%)</b>
<b>Why are cervical smears tests preformed?</b> (select all true options) (n= 157)	Diagnose pre-cancerous cervical cells	Correct	105 (67)
		Incorrect	52 (33)
	Diagnose cervical cancer	Correct	113 (72)
		Incorrect	44 (28)
	Pick up STD's	Correct	151 (96)
		Incorrect	6 (4)
	As part of a full gynaecological examination	Correct	121(77)
		Incorrect	36 (23)
<b>Aware of free cervical screening in Latvia</b> (n=155)	Yes		135 (87)
	No		20 (13)
<b>Source of information about smear tests</b> (n=135)	GP		26 (19)
	Friends		2 (1)
	Smear invitation letter		87 (64)
	Other		24 (18)
<b>Recommended screening commencement age in Latvia</b> (median/range) (n=117)			25 (15- 50)
<b>Recommended screen frequency in Latvia</b> (n=139)	Don't know		1 (1)
	Every 6 months		10 (7)
	Every year		46 (33)
	Every 3 years		82 (59)
<b>Have you ever had a smear test?</b> (n=155)	Yes		135 (87)
	No		16 (10)
	Not sure		4 (3)
<b>Age of first smear test (median/range)</b> (n=121)			25 (18-55)
<b>Country of first smear test (n=128)</b>	Latvia		122 (95)
	Other		3 (2)
	Not sure		3 (2)
<b>Timing of most recent smear test</b> (n=149)	Never had one		15 (10)
	0-3 years		124 (83)
	4-5 years		8 (5)
	More than 5 years		2 (1)
<b>Always attends for a smear test</b> (n=145)	Yes		88 (61)
	No		37 (25)
	Cannot remember		20 (14)



**Table 4.3 HPV and HPV vaccine knowledge**

	<b>Correct Response n (%)</b>	<b>Incorrect Response n (%)</b>
<b>General HPV knowledge questions (n=116)</b>		
<i>HPV is very rare</i>	110 (95)	6 (5)
<i>HPV always has visible signs or symptoms</i>	107 (92)	9 (8)
<i>HPV can cause cervical cancer</i>	88 (76)	28 (24)
<i>HPV can be passed on by genital skin-to-skin contact</i>	27 (23)	89 (77)
<i>There are many types of HPV</i>	54 (47)	62 (53)
<i>HPV can be passed on during sexual intercourse</i>	59 (51)	57 (49)
<i>HPV can cause genital warts</i>	26 (22)	90 (78)
<i>Men cannot get HPV</i>	107 (92)	9 (8)
<i>Using condoms reduces the risk of getting HPV</i>	47 (41)	69 (59)
<i>HPV can be cured with antibiotics</i>	105 (90)	11 (10)
<i>Having many sexual partners increases the risk of getting HPV</i>	55 (47)	61 (53)
<i>HPV usually doesn't need any treatment</i>	7 (6)	109 (93)
<i>Most sexually active people will get HPV at some point in their lives</i>	24 (21)	92 (79)
<i>A person could have HPV for many years without knowing it</i>	59 (51)	57 (49)
<i>Having sex at an early age increases the risk of getting HPV</i>	32 (28)	84 (72)
<b>HPV testing knowledge questions (n=91)</b>		
<i>An HPV test can tell how long you have had an HPV infection</i>	82 (90)	9 (10)
<i>If a woman tests positive for HPV she will definitely get cervical cancer</i>	85 (93)	6 (7)
<i>An HPV test can be done at the same time as a Smear test</i>	58 (64)	33 (36)
<i>HPV testing is used to indicate if the HPV vaccine is needed</i>	73 (79)	18 (20)
<i>When you have an HPV test, you get the results the</i>	80 (88)	11 (12)

<i>same day</i>		
<i>If an HPV test shows that a women does not have HPV her risk of cervical cancer is low</i>	41 (45)	50 (55)
<b>HPV vaccine knowledge questions (n=80)</b>		
<i>HPV vaccines require two doses</i>	35 (44)	45 (56)
<i>The HPV vaccines offer protection against all sexually transmitted infections</i>	78 (98)	2 (2)
<i>The HPV vaccines are most effective if given to people who have never had sex</i>	57 (71)	23 (29)
<i>Someone who has had HPV vaccine cannot develop cervical cancer</i>	70 (88)	10 (12)
<i>The HPV vaccines offer protection against most cervical cancers</i>	45 (56)	35 (44)
<i>One of the HPV vaccines offers protection against genital warts</i>	7 (9)	73 (91)
<i>Girls who have had the HPV vaccine do not need to have smear tests when they are older</i>	78 (98)	2 (2)

**Table 4.4 Associations between socio-demographic factors and knowledge of cervical cancer prevention**

	Purpose of cervical smears	General HPV knowledge	HPV testing knowledge	HPV vaccine knowledge
<b>Spearman's rho correlation coefficient (p value)</b>				
<b>Age</b>	-0.09 (0.28)	<b>-0.28 (&lt;0.01)</b>	-0.11 (0.18)	<b>- 0.21 (0.01)</b>
<b>Education level</b>	0.04 (0.65)	0.15 (0.06)	<b>0.19 (0.02)</b>	0.14 (0.08)
<b>Kruskal-Wallis Test P value</b>				
<b>Relationship status</b>	0.5	0.11	0.79	0.08
<b>Employment status</b>	0.88	0.37	0.59	0.62

### 4.3.2 Part 2 Interview Data

A total of 10 interviews were conducted, five women were from the primary care setting and five women were from secondary care. The median age of the women was 35 years (range 20-62 years) and 60% (n=6) of the women were married, 30% (n=3) were single and one participant was divorced but had recently been in a relationship (Table 4.5).

Eight theme categories and a total of forty-one codes were identified by inductive thematic analysis of the data set (Appendix IV). A description of the theme categories and the top-level codes within each group, along with the main findings are provided below. Details in parentheses following the quotes represent the participant's identification number (P) and age (in years).

\*= Quote via interpreter

#### 1. Perceptions of the healthcare system and healthcare providers in Latvia

##### *Access to healthcare, general health care behaviours and cost*

In the cohort of women interviewed there appeared to be a sense of superiority associated with private as apposed to state funded health care.

*“But if you wait like in these kinds of establishments it’s a bit harder”* (P1,20; in reference to the state hospital in which the interview was being conducted)

Several of the women admitted to either actually accessing or having a preference to private healthcare, however there was an appreciation of the cost implications and that might prevent the larger population having this choice.

*“I don’t think so, it’s too expensive”* (P1,20; in response to “do most people in Latvia use private healthcare?”)

The advantages of private healthcare included quicker access to specialist care, continuity of care offered by seeing the same doctor each time and the perception that the doctors were of superior quality. The consultation is not limited by time constraints,

therefore allowing all their concerns to be fully addressed. Whereas the experience in a state funded establishment can be more variable.

*“....my private all the time the same doctor” (P4,34)*

*“..there is more time for erm... the Doctor’s visit and then also she thinks that the Doctor’s attitude is different and there’s more time and so there is more chance to discuss things” but in the state system “Yeah and she has had both good, bad and medium. It varies” (P9,37)\**

Even within the state funded system there was an acute awareness of the cost repercussions relative to the low average salaries. There was the fear that attending for a test/investigation would result in a spiral of further investigations and the possible need for medications, increasing their financial burden.

*“...everybody is quite scared because they think that again they will discover something and I will need to buy some pills and the pills will cost a lot..” (P10,30)*

Disparities in the provision of healthcare in rural areas versus larger cities were also commented upon. Doctors who work in the larger cities were regarded as more specialised compared to those from the smaller villages. Difficulties with access to specialised care, such as cervical screening, which is based largely in the hospital setting, may inhibit women from more rural areas utilising it.

*“I changed the gynaecologist and mine now is in Riga but she’s very very good.... she’s was like oh you need to do this and you need to do that because like my home doctor never said that” (P10,30)*

Participant 10 had strong views about the healthcare system in Latvia. She represented the subset of the Latvian population who had migrated outside of Latvia for employment. However she returned to Latvia for all her healthcare, she quoted the reasons for this behaviour as *“there was no language barrier”* and that she felt *“safer”* in the event that anything were to *“happen”*, she had a family here *“who can take care*

of” of her. She also described that the doctors from outside of Latvia had a tendency to belittle her medical concerns and Latvian doctors would take her concerns more seriously.

*“And it’s like if I’m comparing my home doctor and Netherlands,..... then it’s a little bit different because like in Netherlands they almost have everything related to paracetamol and walks and just like...just sleep on it.” (P10,30)*

### **Doctor-patient relationship**

It was apparent that there was lot of trust vested in the opinions and recommendations of the doctors, their advice was not to be questioned nor was it felt necessary to conduct one’s own research. Furthermore the notion of having shared responsibility for decision-making was rejected.

*“So if the doctor says that you need to do this, she will do that. She is not one of those people who spend hours researching the internet, yes” (P8,43)\**

Most of the participants were willing to alter health behaviours (e.g. frequency of cervical screening) if advised to do so by the doctor, further exemplifying their level of trust in them. In saying this some questioned the doctors’ motives regarding certain recommendations, implying that personal financial gains of the doctor may have a greater influence than the actual health benefit for the patient.

*“She thinks that this examination, the gynaecologist would offer you this examination because of business and opportunity to do examination and earn some more money” (P6,35)\**

Exploring the personal characteristics of the healthcare professional, these did not appear to be as much of a concern as compared to the role of the healthcare professional performing the smear test. However participant 1 who was the youngest interviewee had a preference for younger age due to the fear that older physicians may cast judgements.

*“I think that for example girls my age and a bit older they would enjoy talking more with a younger woman not with an elderly woman who might judge her about her ways” (P1,20)*

The women indicated that they preferred healthcare professionals to have defined roles and skills. For example overall they would not feel comfortable to have their smear test taken by a GP or a nurse practitioner.

*“No, I think the gynae should do this, not the GP, as it is a private thing” (P2,26)*

*“I would like that this test would be made by a qualified doctor that has great experience in this area. Maybe in the U.K the nurses are different and more qualified” (P5,35)*

## 2. Annual gynaecological reviews

### *The rationale, experience and understanding of the popular practice of annual gynaecological reviews*

An emergent theme from the interviews was the practice of “annual gynaecological reviews”. This is started from young as 15 years of age and was usually carried out on an annual basis. This health behaviour appears to be something that has been passed down generations and is accepted as the norm.

*“...but I know from the childhood, from teenagers, that you have to go to gynaecologist at least every year to check everything” (P4,34)*

There was greater value placed on the reproductive organs, whereby they needed to be protected and hence the need for prophylactic screening.

*“....if she would have any lung problem, it's easier to treat it by antibiotics or medication, but if we speak reproductive organs, then she feels like it's more complicated and it causes more, like, pain or discomfort and so on. So it's better, like, see and understand that you have a problem earlier” (P6,35)\**

Participant 4 was particularly concerned about her reproductive organs, the following was the response to the question “do you have any gynaecological problems?” *“No I don't have, but I do it for myself, just to be sure that everything is fine”*. However when she was questioned about routine check ups for other organs, she responded with the following *“I think that I don't have any problems with the health things, that's why I don't go very often to the doctors”*.

Only a couple of women stated that they started to see the gynaecologist because they actually had gynaecological concerns, for example menstrual problems or “pregnancy”. It was surprising that despite their obvious concern regarding their reproductive organs the women had very little understanding of the examinations/investigations that were being performed during their review.



*“Yes, but to be honest I don’t quite remember the names of the procedures that they’ve done for me, but I’m fine, I’m fine” (P1,20)*

*“No not really, no they were just saying like I need to take this and this then I will call you if something pops up” (P10,30)*

It was clear that most of the women had some vague recollection of having a cervical smear test taken by the gynaecologist but they were uncertain of the details and in terms of the results they would normally only be told that the result is *“Yes, normal or not normal”* (P6,35). The gynaecologist was in charge of determining which tests were required at the annual review, *“she comes and the Gynaecologist does A, B and C”* (P9,37).

*“....takes some kind of, some kind of smears but she doesn’t know which ones” (P7,41)\**

Some women wanted more information about the investigations, which were being performed whereas others were content with the amount that they had been given.

*“Of course, I’m always like curious about what kind of tests, what they can conclude, what kind of facts, so what the results are...” (P10,30)*

*“Actually, to me it’s okay, if they say it’s okay, it’s normal” (P6,35).*

### 3. Cervical screening behaviours

#### *Existing cervical screening behaviours amongst the interviewed women and the barriers to screening that they face*

As mentioned before the women interviewed did appear to be participating with some form of cervical screening. However, not all the women were able to recall the age at which they commenced screening and in those who could it varied from 20-30 years old. The consensus view between all the women was that screening should be performed on an annual basis and the practice of annual smears was popular amongst the interviewed women.

A few were even going as frequently as every three to six months. They described a feeling of “fear” that something would be missed if they waited the recommended three years and that having annual smears made them feel “safe”. The reason for the national screening programme not recommending more frequent screening was believed to be due financial reasons rather than being evidence based.

*“I think it’s just connected with....With the money. With the Government money, but I think every woman should go at least one a year by her own means” (P5,35)*

The practice of annual smears/checks up appeared to be imbedded in their culture and the gynaecologist further reinforced it.

*“Mmm hmm yes it’s usually the Doctor who says “see you in a year” ” (P9,37; in response to the question “why is one year the magic interval?”)*

When women were questioned about the reason why they have smear tests done, their motives included the gynaecologist recommended it, *“just as usual” (P3,62)*, *“I think you have to do this”(P4,34)* and *“because I was pregnant and it’s normal to know about my health.” (P5,35)*. It wasn’t clear if they fully appreciated that cervical screening was separate to the annual gynaecological check up that they have.

## **Barriers**

The perceived barriers to participation with cervical screening fell into four broad categories, awareness, access, time and lack of symptoms. The women commented that cervical screening is not very popular in Latvia and therefore many women may not have heard of it or that they just ignore the invitation letters. Access was considered to be an issue, particularly for women who resided in smaller villages who would have to travel considerable distances. It was argued that work commitments for these women would be a priority. Time played a role in two ways, firstly the length of time that one would have to wait to get an appointment and secondly the women were generally too busy to make time. Lastly because they were asymptomatic it was not prioritised. One woman felt that if the smear test was offered at the GP surgery this might help overcome the access issue. However as previously mentioned many Latvian women may not feel comfortable either the GP or the practice nurse performing what is perceived as a “specialist test”.

*“I think in Latvia as well because a lot of people are like they’re so busy in this moment” (P10,30)*

#### **4. Knowledge and understanding of cervical screening, cervical cancer and HPV: Interviewee versus Population**

*The level of understanding and knowledge about the above topics of both the interviewee and their perception about population knowledge*

##### **Screening and colposcopy**

Many of the women were aware of the national cervical screening programme in Latvia, mainly as result of receiving the smear invitation letter. They also recognised that it was a free test and some women had utilised this by taking their invitation letter to the gynaecologist so that the cost of the test would be covered. They accepted the limitations of a screening test; in that it was not diagnostic and that the test itself could not actually stop the development of cervical cancer or abnormal cells, it would simply pick them up at an earlier stage.

*“Yeah she knows that, she knows that the government sends you a letter and then you can attend a Gynaecologist and have PAP smear for free and actually she uses those letters and always goes with this letter for screening” (P7,41)\**

*“if you’ve got it, you’ve got it already yes, but for sure you can prevent to grow and you have possibility to stop this cancer in... in the short time”. (P4,34)*

In comparison to this many believed that the awareness of the Latvian screening programme amongst the general population was low.

In relation to the smear test itself the women were able to provide an accurate description of what it involved and also comprehended that the purpose of the smear test was to screen for precancerous cervical cells or catch cervical cancer in the early stages. However a couple of women were not so sure and believed that it was testing for *“some kind of fungus or stuff like that” (P1,20).*

*“you put the plastic thing in and take a piece of your wall thing or like a smear of like, what’s the name...sample, sample” (P1,20)*

Knowledge regarding the management of an abnormal smear was poor, there was some idea that further examination was required but it was not known in what form this would be. None of the women could confidently recall or without prompts, knew what colposcopic examination involved. This is despite half of the participants being recruited from colposcopy clinic. This may reflect their own acceptance of not requiring detailed information on the procedures/investigations that were being performed by the doctor, as previously discussed. They conceptualised management in very simple terms, if there was an abnormality there then it needed to be removed. Furthermore there was a lack of awareness of the consequences of multiple treatments. However in contrast to this, one participant felt that the coincidental findings of minor abnormalities, which do not require treatment, that may occur as a result more frequent examinations would not cause increased anxiety.

*“...she was as well postponing me to for another six months and I was like no, I want to get rid of it as soon as possible and just like go on with my life” (P10,30)*

*“No she is not afraid of this because she has got a different experience that even if there are some minor changes usually the recommendations that she has received is to wait and then actually does, there is a risk of improvement”(P9,37)\**

### **Cervical cancer/ HPV and the HPV vaccine knowledge**

Overall the women were of the belief that cervical cancer did not affect many women. There was an underestimation of the scale of the disease burden in Latvia and a few who had done some reading prior to the interview were “shocked” to learn about the high incidence.

*“I was shocked, I was like mum did you know? .....I was like I was not aware of this, were you aware? And she was like no I have never heard, this is a very big number” (P10,30)*

The interviewees believed that the population on the whole were not fully exposed to the severity of the disease incidence in Latvia.

When asked about the age group of the women who are affected by cervical cancer, some of the participants thought that it affects both young and old women whilst others believed it affected older women only. However young was defined as 40-50years, and learning that women in their thirties or even twenties are affected was a surprise to them.

*“She thinks it’s more of a problem for older women” (P8,43)\**

Risk factors for developing cervical cancer were stated as multiple partners, hereditary, lifestyle, multiparity and it was also thought to be linked to uterine fibroids. The causal relationship between HPV and the development of cervical cancer was acknowledged by most but the strength/seriousness of the association was not.

*“.....like especially for these kind of like gynaecologist like issues, I was little bit surprised, because I thought that this is not that serious” (P10,30)*

Many of the participants had previously heard of HPV but detailed knowledge about it was variable. Similar to cervical cancer the prevalence of HPV amongst the population had been underestimated. There were mixed views about how HPV is transmitted, some women correctly fathomed that it was sexually transmitted and others did not know where it came from. It was evident that they were aware of the asymptomatic nature of the viral infection. Their view was that men were immune to HPV related pathology and seen merely as carriers.

*“I was reading about the virus and how and what type they are and then like that I was surprised that the percentage is so high” (P10,30)*

*“.....as far as she knows that boys only transfer the virus and they can infect the partner but they, there is no harm being done to them themselves so she thinks that the virus can not cause any harm in the male” (P9,37)\**

One interviewee commented on methods of protection against the virus and asked if condoms were protective. No one specifically mentioned the HPV vaccine but when

questioned as to whether they had heard of the HPV vaccine the majority of the women admitted that they had. However, interestingly one person commented, *“She does know that the vaccine is intended to prevent cervical cancer, but she does not know the connection between the vaccine and HPV”* (P8,43)\*. The women believed that the larger population would also be lacking knowledge regarding the details of HPV vaccination.

*“..a lot of people know that there is such a vaccine but the main problem is that they have heard about it but they don’t know what it means, what it does, how it works..”* (P7,41)

A few of the women were aware of when and in whom the vaccine was recommended, i.e. 12 year old girls prior to the commencement of sexual activity. The limitations of the vaccine with regards to the level of protection offered by it were correctly recognised, as was the need for continued screening in the future.

*“That this vaccine we usually start at 12 years, like a program and it’s better to do the vaccine before the sexual activities”* (P2,26)

*“vaccine does not necessarily protect you against all the types of the virus so even if you do get the vaccine, it doesn’t mean that you will be 100% protected”* (P9,37)

### **Sexually Transmitted Infections (STIs)**

The women felt more confident when talking about other STIs. The most commonly recalled ones were HIV, chlamydia, gonorrhoea and syphilis. One woman commented that a stigma was attached to talking about these but the same is not applicable to HPV, as HPV is not widely recognised an STI.

*“..this word she does not associate first of all with sexually transmitted infections,.....and that embarrassment is not really the term she would use to describe it, but she says that as opposed to gonorrhoea, for example, because of what that is for sure a sexually transmitted infection and it may be that that is something that she would not like to talk loudly about”* (P8,43; referring to HPV)\*.

## **5. Beliefs, perceptions and attitudes towards the Human Papilloma Virus**

### ***The views and attitudes about HPV, HPV testing and the HPV vaccine***

#### **HPV and HPV testing attitudes**

Participants described feelings of embarrassment when asked if they would feel comfortable talking about HPV with family and friends. One participant described how Latvia is a religious country and they would not like talking about it. This appeared to stem from the misconception that acquiring a HPV infection is synonymous with sexual promiscuity. Another woman, who had been found to have a HPV infection, became very emotional and tearful during the interview just talking about it. She feared judgement by those close to her, particularly as she was a divorcee.

*“Latvians are quite religious so they don’t like to talk about, especially like when the person is changing partners quite often, so they I think they won’t be so open to talk about it” (P10,30)*

Discussing the risks of HPV infection with their daughter and/or teenagers was more of a divided issue. Some of the women felt that at the right time they would be comfortable discussing this with their daughter whilst others perceived *“mums are actually embarrassed to talk to their children about this and there are many mums like that”* (P8,43). The other viewpoint was that the teenagers themselves might be “embarrassed” to talk about it and fail to acknowledge the seriousness of it. The prospect of primary HPV testing was described as “scary”.

#### **Attitudes towards the HPV vaccine**

Participant four had vocalised strong negative feelings towards the HPV vaccine. She had not consented for her daughter to receive the vaccine. She described that she was *“very suspicious”*, from her perspective there had not been much research done around it and adequate scientific information was not available. However at the same time she could not recall the information that she had been given because she had *“already decide for myself that I don’t want to do this”* (in reference to the HPV vaccine). Furthermore HPV was felt to be a relatively new concern, *“30 years ago we didn’t hear about this problem”*. Conversely when she was questioned how she would feel if there



was a vaccine against HIV/AIDs she described that *“it’s not something new, and everyone got information and many people are dying every day from this virus”* and therefore she would be more likely to accept it. This same participant was strongly in favour of the “annual gynaecological check ups” and it was evident that she failed to appreciate the difference between primary and secondary prevention, with a stronger emphasis being placed on the later.

Overall in the group of interviewed women there was sense of “fear” of the side effects of the vaccine and this was a major barrier in vaccine acceptance.

*“We have different problem in our country, there is an entire movement of parents that do not believe in vaccination, then they don’t vaccinate their children, for example, influenza because they hear about these negative examples”* (P8,43)

Those who were in favour of HPV vaccination did not seem to be concerned about the age of vaccination. They did not believe that 12 years old was too young as a *“girl at 12 can give birth to a child”* (P10,30) and that having the vaccine at this age would not encourage early sexual activity.

*“It would never occur to her that something like a vaccine would promote sexual activity”* (P8,43)

Male vaccination was perceived to be a good idea by most, they felt it would help reduce disease burden. Adolescent boys should be provided with more information so that they can make their choice about vaccination. Nevertheless it was thought that communicating about the HPV vaccine with boys would be more challenging but the reason for this was not specified.

*“This will be very good to vaccinate the boys but she thinks that it will be harder to talk them into doing this”* (P9,37)\*

## **6. Sources of knowledge and information**

### ***Their current sources of information and suggested avenues of dispersing information and knowledge***

#### **Cervical cancer and screening**

There was disagreement between the participants about the availability of information regarding cervical cancer and cervical screening. However they all seemed to agree that even if information was available accessing was not easy and that statistical data were difficult to obtain.

*“...there’s a lot of information but you need to search for it and not a lot of women know about this” (P10,30)*

The smear invitation letter was frequently cited; some felt that the information contained within this was adequate whilst other commented that it lacked factual information. In addition there was the suggestion that this might not be the best method of communication for young women, as many young women do not actually live at the address at which they are registered. The gynaecologist acted as source of knowledge for some and others utilised the internet. The limitations of the internet were that the data was perceived to be out-dated and that not much information was available in Latvian.

*“...she looked for it in Latvian which is actually another thing that there are a lot of information if you Google it in English” (P7,41)\**

Cervical cancer was not seen as a popular health problem and was not something that was very visually present, for example in magazines.

*“Yeah, it’s not that popular at least, and we don’t have that kind of things in magazines at least for women like we have here” (P1,20)*

#### **HPV and the HPV vaccine**

Generally the participants believed that there was a lack of HPV and HPV vaccine propaganda and awareness. Only one participant recalled the “HPV campaign” and a

few had seen TV adverts. Leaflets were available in GP and gynaecology surgeries but they were not eye catching and therefore could easily be missed.

*“I know that like there were some pamphlets as far as I can remember and at the home doctor and as well like in the gynaecologist office, but nothing very major that could catch my eye” (P10,30)*

The schools send out brochures about the HPV vaccine for the parents but no talks for the parents or the students took place, according to one of the participants who works as a teacher.

*“Just a letter gets sent. The school mainly gives an information to the parents and then the parents decide whether they want to or not.” (P3,62)*

### **Sexual health and sexually transmitted infections**

Sexual health education was provided at schools but one participant felt that teachers themselves were ashamed to talk about sex and the students behaved in an immature fashion during these discussions.

*...the teacher was ashamed to talk about that kind of stuff because you know children are mean, and the subject of sex is always a thing to laugh at, like if you talk about sex (P1,20).*

Leaflets found at youth centres contained a lot of information, which is presented in a “colourful and interesting” manner using lay language. Other sources of information included media. For example, one participant made a reference to an American drama (Sex and the City) and just “googling” for information.

### **Proposed information outlets**

The participants believed that awareness about cervical cancer, screening and HPV needed to be increased. The government were required to play a larger role in order to achieve this. There were various theories on how to encourage people to talk about the subject more; one such was that the focus should be on educating children. School

children would increase awareness by talking to their parents about what they have learnt. Many may have parents who do not visit the gynaecologist on a regular basis and therefore would otherwise be unaware of cervical screening and HPV/HPV vaccine. Although consideration would need to be given to the target age group at which to aim the education, one participant who was also a parent, felt that 12 year olds would not be interested in sexual relationships thus would not absorb this information and that 15 year olds might be a better target.

*“a normal 12 year old girl is not interested in these things, not so interested in boys or at least not, from the point of view of being sexually active, but for a 15 year old girl for example, this could be a mandatory subject during anatomy class or something like that and that you give this information to the girls and that later you test them to get the feedback what they have understood about it” (P8,43)*

Doctors (both GPs and gynaecologists) were considered to have a part in educating women and promoting screening. GPs in particular were thought to have easy access to a large group of women and were in a key position to guide women about the availability of smear tests locally.

*.... a lot of people are going to their home doctors .....they need to push the women to go there and to make sure and as well like its only not available in Riga but in smaller countries like in smaller cities (P10,30)*

However it was argued that younger women, who are generally healthy, may not visit their GP that often. Doctors may need to go out into the community at schools and universities to promote education and awareness.

*“...if doctors will come to the schools or universities and will talk with the children about it” (P4,34)*

Furthermore it was suggested that colourful and informative leaflets could be left in the waiting rooms of GP and gynaecology surgeries, although some participants had mentioned that this is already happening. It might be that they are not very prominently

placed and therefore do not attract much attention. Some stated that a scaremongering technique should be adopted in the leaflets, similar to that which is being used for cigarette smoking but it was acknowledged that this does not always work.

*“we should state in these materials.....that if you have this it might turn into this and so, kind of, a little bit maybe scare the people, even though she does understand on a packet of cigarettes we have these horrible pictures there of what is the effect, yet still, a smoker still buys a packet of cigarettes anyway” (P8,43)\**

Improvements with the smear invitation letter were recommended, such as more information should go out with them, in particular more statistical information. In addition it was proposed the smear invitation was sent in the form of an email rather than a letter and that this was backed with text message reminders.

*“like text message, check your email that you have that kind of thing that you have to go there and it’s like there. I think it would be more efficient” (P1,20)*

Utilising modern methods of communication, email, internet etc. was something that was a generational thing. As many of the younger participants suggested increasing the use of social media and pop-up ads on the internet, whilst the more older women appreciated its limitations in terms of access and ease of use.

*“...because internet it’s, it’s always information there but actually it’s hard accessible because not everybody reads the internet and again you can read different versions about it” (P7,41)*

Lastly there was an overwhelming feeling that the media in all its forms, TV, magazines and radio, needed to play a greater role in advertising the topic.

*“T.V., radio just to more often to speak about this” (P3,62)*

*“T.V programmes or information in magazines” (P5,35)*

*“information on television, social media, advertisements...” (P6,35)*

Many comparisons were made with the attention that breast cancer receives. There are big prominent breast cancer campaigns and many more women have heard of it. One of the participants who was a medical student commented that during her clinical rotations she had met many women who had been diagnosed with breast cancer but none who had been diagnosed with cervical cancer. Therefore she was unaware of how prevalent it was in Latvia.

*“..the campaign is great because is like if you ask any woman on the street about what kind of health campaigns have been there for women? Breast cancer” (P1,20)*

*“Well with the breast cancer, it’s loads of advertisement and a loads of things they tell at the G.P. surgeries, in the T.V. radio etc. than for the cervical cancer. It’s a big difference” (P3,62)*

*“I see the patients in the hospital, I have seen a lot of women with breast cancer, but there were no one... one woman who has this diagnosis..” (P5,35)*

## **7. Outside influences and personal emotions affecting cervical cancer prevention behaviours and choices**

*The affect of outside influences from family and friends on personal screening behaviours and choices. The emotions associated and/or affecting personal screening behaviours and choices*

### **Outside influences**

The two most commonly mentioned family members were “mum/mother” and “daughter”. Participants spoke about their daughters or the absence of a having daughter, in relation to their own HPV/HPV vaccine knowledge. Knowledge of the HPV vaccine had been gained through their daughters and those who did not have teenage daughters described themselves as being less knowledgeable. Most mothers expressed that they would feel comfortable talking about STIs in general and the sexually transmitted nature of HPV with their daughters.

*“In my generation speaks with their children quite openly about such problems, topics, you know” (P4,34)*

The perception that the interviewees’ held about teenagers overall in Latvia, was formulated from their perception/expectation of their own daughters particularly with regards to the age at which sexual activity is commenced.

*“No. I think that here in Latvia where we start sexual life not so early as in Great Britain and I hope that my daughter will not do this in the nearest time” (P5,35)*

The “mother” was spoken of in more of an advisory/ role model terms. The women described that it was their mothers who had advised them to go for these annual reviews and it was because their mothers had had gynaecological problems in the past, that they were more cautious about gynaecological related symptoms.

*“Yes, yes, since she was a teenager she got this problem. So I try to be very careful and go to the doctor all the time” (P4,34)*

Participant 10 made several references to her mother throughout the interview implying that they had mutually influential roles in each other's life. She described that when she received her first smear invitation letter her mother had explained that it was not important and therefore she ignored it and similarly her mother had negative views towards the HPV vaccine, which she also adopted.

*"I got the first one I was like 17 or 16 and I was always like I think asking her like what this is and she said like you don't need to worry about this, this is nothing that affects you .....my mum was very very negative about it and that time I was quite small and I was like okay, I will listen to mum, she understands, she knows what she's talking,"* (P10,30)

If she learnt something new she is likely to share this with her mother, whilst "preparing" for the interview she made reference to discussing the topic with her mother several times. Furthermore she commented on her parents as a unit; when she was growing up talking about sexual health was a "secret topic", and her health seeking behaviours have been learnt from her family.

*"the parents are very religious or very like don't talk about it, .....when I was growing up this was quite a secret topic, nobody discussed it"* (P10,30)

Sisters/sister in law were the other family members who were mentioned. Women referred to them with regards to sharing screening experiences, the extent to which they had an influential affect on their screening behaviours was not clear.

The decision to share their experiences with friends appeared to be dependent on several factors, how close they were to them, if they had family to talk to and their perception of their friends. Those who were close to their friends and/or were not able to talk to family would share experiences with friends.

Participant 1 had many friends who were medical students and therefore there was the sense that she perceived herself to have greater levels of knowledge compared to her peers. She believed that her circle of friends permitted her to speak freely about more personal matters. She described how she was "different" and perhaps "better" than



some of her friends, who did not have a gynaecologist or those who did have a gynaecologist but would lie to them about being sexually active.

*“..one friend of mine she went to gynaecologist and she asked about does she have a sexual partner at the moment she said no but she did have and she was ashamed to tell something like that, I just thought I think the doctor doesn't care” (P1,20)*

*“..she is a make-up artist. So kind of a ...downgrade in my opinion. But she's not stupid, she's not a stupid person but I don't know why she doesn't go to the gynaecologist” (P1,20)*

The participants made assumptions about the knowledge of their friends based on personal characteristics, for example age and marital status. One participant who was a medical student felt that HPV did not concern her friends as they were all married, possibly implying that HPV is thought of as an extra marital disease.

*“I don't know because all of my friends are in marriage ... No one wants to talk about sexual...that is not in marriage” (P5,35)*

Friends did not seem to affect actual screening behaviours or vaccine choices in the same manner as family did. Many described attending for annual gynaecological reviews and/or smears despite having friends who do not.

*“one friend, she completely against all vaccine and I'm not agree with it, yes, because when a child was born you need to do some basic vaccines” (P4,34)*

Overall the women felt that if they personally knew someone, a family member or a friend, who had been adversely affected by an illness this would influence their own behaviours. Some women explained that know anybody who had been affected by cervical cancer.

*“But I personally I don't know any person who died from this type of this in Latvia” (P5, 35 in reference to cervical cancer affecting young women)*

## Emotions

“Shame” and “Scared” were the two most frequently quoted emotions throughout the interviews. The interviewed women were “*scared of the unknown*” (P1,20), “*scared because they think that again they will discover something*”(P10,30) and “*afraid of cancer in case if it will develop within three years*”(P3,62). The participants were afraid that disease might be missed or of starting new relationships in the fear that they may contract the virus again.

*“she is afraid that she will start a new relationship and might end up with the same problem again” (P7,41)\**

Several women were afraid of receiving too much information prior to attending for an examination as this may cause undue stress whilst other suggested the use of scaremongering techniques as motive for participation.

*“sometimes you need to scare the people a little bit you know like you need to like be very straightforward with them because if you will not be very straightforward then you will not say how it will affect their life” (P10,30)*

The feeling of shame was used in reference to the potential of discussing sexual behaviours with parents or healthcare professionals.

One participant described feeling deeply ashamed that she had been diagnosed with HPV and became extremely distressed during the interview discussing it. She felt shameful about having a boyfriend rather than being married and it was the boyfriend who had given her the virus.

*“...she feels the shame about, at her boyfriend, I think that I got this from my boyfriend .....that’s why she cried. I think that it is some kind of emotional shame or something like that” (P7,41)\**

## **8. The impact of the interview**

*The impact of participation with this study, any changes in behaviour that might be instigated as a result and any knowledge gained*

The women commented that through the process of participating with the study they had gained knowledge of the topic. In addition the women described that they now had an increased desire to conduct research about cervical cancer in order to increase their understanding of it.

*“Yes, yes, of course. I want to know more, I want to know what we were talking about”*  
(P4,34)

There were suggestions that the interview may result in behavioural changes, for example being more inquisitive at the annual gynaecological reviews to have a better understanding of the tests that are being performed.

*“Yeah, I think that I would definitely pay more attention to it when I go to my gynaecologist again”* (P1,20)

The interviews highlighted the importance of cervical cancer prevention and therefore the women said that they would encourage friends and family members to participate with it.

*“I think that I will try at least to talk again with that girl that...I think that this really helped because I yeah, I didn’t have any kind of idea what it was so...”* (P1,20)

*“Definitely, like this is definitely...I already pushed my mum to make that appointment and as well for my sister in law”* (P10,30)

**Table 4.5 Interview participant characteristics**

<b>Participant ID</b>	<b>Age (Years)</b>	<b>Occupation</b>	<b>Relationship status</b>	<b>Setting</b>
<b>P1</b>	20	Employed	Single	Colposcopy clinic
<b>P2</b>	26	Employed	Married	Primary care
<b>P3</b>	62	Retired	Married	Primary care
<b>P4</b>	34	Unemployed	Married	Primary care
<b>P5</b>	35	Student	Married	Primary care
<b>P6</b>	35	Employed	Single	Primary care
<b>P7</b>	41	Employed	Divorced	Colposcopy clinic
<b>P8</b>	43	Employed	Married	Colposcopy clinic
<b>P9</b>	37	Employed	Married	Colposcopy clinic
<b>P10</b>	30	Employed	Single	Colposcopy clinic

#### 4.4 DISCUSSION

This mixed methods study highlights the complex interactions that exist between knowledge, self perceived health and importance of health, which govern not only cervical cancer prevention uptake but also general health behaviours in Latvian women.

##### *Access to Healthcare*

In this group there was a strong sense that private healthcare was superior for multiple reasons, which may represent the effects of healthcare reform that took place in Latvia in the post communist period(313, 319). The quality of provision of state healthcare has been shown to be poor; a population survey assessing user opinion found that 66% of Latvians rated the provision of healthcare as “bad”(320). The resultant effect of this is a greater preference for and the utilisation of private healthcare, in those who can afford it. Latvia has one of the highest rates of “out-of-pocket” payments in the European Union, despite having a funded National Health Service system(320). In the women interviewed for this study, although there was an appreciation of the cost implications for those who were less affluent than them, quality of care was deemed more important. This has also been shown in the Bulgarian population where quality related attributes were rated above financial implications when assessing healthcare consumer preferences(321). Furthermore there is a discrepancy in the provision and accessibility to healthcare between rural and urban areas, with more rural areas having limited choice of practitioners and with care mostly being provided by local internists or by feldshers (equivalent to a physician’s assistant)(322).

One participant described a behavioural pattern of returning to Latvia to access healthcare due to distrust of the country in which she was currently residing. Jackowska et al have noted similar findings in migrant EE women to the UK and the notion that doctors recommend paracetamol for all health concerns was also shared by them(150). One possible explanation for this pattern of behavior is that the move to another country is not a permanent one and therefore there is a hesitancy to fully adopt new health behaviours and a desire to maintain links with their home country. This can be further explained by the cross-cultural psychology theory, whereby it is thought that the way one adapts to a “new society” is a complex and continual process(323); perhaps suggesting that the length of time in the country of migration may have a part to play.

### ***Doctor-Patient Relationship***

The doctor was seen to have a strong influential role on health behaviours and the women described the paternalistic model of the doctor-patient relationship; whereby the doctor was knowledgeable and would advise on the tests/investigations that were required. In contrast to England where shared responsibility as part of the “patient centered medicine” approach(324) is more common, Latvian women rejected the idea of shared responsibility. A study in Romanian mothers, exploring their attitude towards the HPV vaccine, similarly found that the mothers did not want to take responsibility for the decision for or against vaccinating their daughters, they wanted the doctor to take the decision for them(325). It appears that this heightened trust in doctors, particularly in reference to women’s health, is common to EE. When the degree of trust in doctors was measured in Polish and Greek women, Polish women were more likely to completely trust the advice of their gynaecologist(326). The financial motives of the doctors did not go unnoticed by the patients but this did not prevent them from adhering to the advice of the doctors. In many Central and EE countries private practice helps to supplement the low doctor salaries but there is a danger that it can result in the recommendation of expensive and sometimes inappropriate investigations(319). Some may argue that this raises a conflict of interest and full disclosure should be advocated. In the United States where the patients may have to pay for services provided the doctor and there are high monetary incentives, it has been suggested that full transparency with the patient about financial benefits may result in enhanced patient trust(327). It is difficult to ascertain if the practice of annual gynaecological reviews, which was prevalent in this group is evidence based or financially driven. The participants were not clear as to what exactly these reviews consisted of but they were viewed as a form of “gynaecological screening”. This practice is shared in other EE countries(119, 123) and has previously been described to consist of a gynaecological (bimanual pelvic) examination including colposcopy and cytology(123).

### ***Annual Gynaecological Reviews***

Currently there is no evidence to support annual pelvic examinations in asymptomatic women(328). In the past this practice has been justified to screen for ovarian cancer, diagnose sexually transmitted infections and prior to prescribing contraception(329).

The use of bimanual examination to detect adnexal masses, even in ideal circumstances, has been found to be of limited value(330, 331). Pelvic examination is thought to be unnecessary prior to the prescription of contraceptives and of more importance is obtaining a comprehensive clinical history and monitoring the blood pressure(332). Pelvic examinations have been described by women as causing discomfort and embarrassment(333), and there is a risk that if they have had a bad experience with an unnecessary pelvic examination that it may prevent future participation with cervical screening(334). Conversely it may be argued that one of the benefits of the annual reviews is that it provides an opportunity for the clinician and the women to enquire about sexual health concerns that they would otherwise feel uncomfortable discussing(329). However, the women interviewed in this study placed a particular sense of importance on their reproductive organs compared to other parts of their body. It was felt that these were superior and required protection. Data regarding the uptake of the annual gynaecological reviews is not available as they are performed in the private sector. Similarly, Romanian mothers have been reported to fear that the HPV vaccine may cause loss of fertility and this was perceived to be worse than the potential risk of developing cervical cancer, as reproductive function was viewed to be synonymous with femininity(325). Nevertheless, realisation of the connection between the development of cervical cancer and the potential for subsequent loss of fertility was not apparent in the findings of the quoted Romanian study.

### ***Cervical Screening Behaviours***

Attendance for screening in this cohort was high at 87%, which is higher than the quoted national screening coverage of 59%(121). The high rate can be explained by the fact that the patients for the survey part of the study were largely recruited from colposcopy clinics. However it is of worry that 14 % (19/130) of the women recruited from colposcopy clinic claimed that they had not had a smear test in the past. When the women were questioned about their cervical screening behaviours it was not clear that they distinguished the difference between the annual gynaecological reviews and cervical screening. Furthermore, during discussions the two were often referred to as one. This resulted in them attending for annual smear tests outside of the national screening programme. A high prevalence of opportunistic screening has also been noted in other Central and EE countries(335). An Estonian study exploring reasons for non-

attendance to cervical screening found that a recent visit to the gynaecologist was the most commonly stated reason(336). The European guidelines for quality assurance in cervical screening do not recommend opportunistic screening(337). One of the pitfalls of opportunistic screening is the performance of unnecessary diagnostic procedures and treatments(338). The women interviewed in this study had little appreciation of this. Further it maybe argued that a form of organized screening is required to support opportunistic screening. Most of the women in this study stated that they had heard about screening as a result of receiving the smear invitation letter. In countries such as Bulgaria where there is only opportunistic screening, coverage is low and incidence of cervical cancer is high(339). A majority of the women were aware of the availability of a national screening programme in Latvia and more than half (69%) knew that screening was offered on a three yearly basis. This suggests that there was an issue with acceptability of the national programme and/or communication about the justification of the recommended practice was poor. This may also be true to an extent for healthcare professionals as some of the women commented that the reason they attended for annual smears was because they were advised to do so by their gynaecologist. It has been stipulated that one of the criteria for an effective screening programme is that the test should be acceptable(340), however to increase participation with an organized programme the programme itself must be acceptable too. Criticisms of the national screening programme can motivate participation with private opportunistic screening(341).

Barriers to screening attendance were similar to those, which have been identified in other population groups. Firstly there were the practical barriers such as access and lack of time(137, 342). Secondly there were the barriers related to the concept of perceived susceptibility and/or the value of screening to them(236, 343). The women interviewed in this study had poor knowledge of cervical cancer in terms of the high incidence in Latvia and the risk factors for developing it, resulting in a poor self-perceived susceptibility. A survey study amongst Czech and Slovak women showed that a small proportion of women believed that cervical cancer would have a clinical manifestation and the authors argue that this would result in non-compliance with screening in the absence of symptoms(168).



### ***Knowledge of the “Cervical Smear Test”***

Knowledge of the smear test itself in terms of the actual procedure was good, however there was confusion concerning the purpose of the test. Some women thought that the purpose was to pick up STIs or to diagnose fungal infections. Other groups have also misconstrued the purpose of the smear test; quoting that it is used to diagnose vaginal infection (yeast/gonorrhea)(344, 345), HIV/AIDs(344, 345) and even pregnancy(345). About a quarter of the participants considered smear tests to be part of a full gynaecological examination. In America where annual pelvic examinations are also prevalent, it has been found that 70% of women thought that PAP smears were synonymous with pelvic examinations(346). There is a danger that this erroneous belief can lead to missing screening invitations and a prolonged screen interval, in the belief that because they have had a pelvic examination they have also had a smear test. Lastly if it is believed that smears test are performed to diagnose developed cancer rather than as a preventative screening test, as was the view expressed by a percentage of the surveyed women in this study, then there is a risk of non-attendance in absence of symptoms(347). These findings indicate a need for increased education to avoid such misconceptions; the role of the clinician in this will be explored later. The role of colposcopy and the risk of multiple treatments were poorly understood. As a result of this the emotions of anxiety and fear, which can be associated with colposcopic examination(348), were absent in this group. Women in this study consisted of women who had never been to colposcopy, those who were awaiting colposcopy and those who had already attended.

### ***HPV/HPV Vaccine Knowledge and Attitudes***

The survey and the in depth interviews revealed that detailed HPV and HPV vaccine knowledge was poor amongst Latvian women. This is not entirely surprising as HPV testing is not routinely performed as part of the screening programme in Latvia(118), although the HPV vaccine has been available as part a state funded national vaccination programme since 2010(349). Studies from around the globe have consistently reported overall low levels of HPV related knowledge in different population groups(226, 350-352). Some have described a positive relationship between HPV knowledge and vaccine attitudes whereby increased knowledge levels results in positive vaccine attitudes(353). The correlation between knowledge and actual vaccine uptake is not very clear; Kessels

et al in a systematic review exploring factors associated with vaccine uptake in teenage girls found that higher vaccine knowledge was related to vaccine uptake(354). In comparison an earlier systematic review by Brewer et al showed that the correlation between vaccine knowledge and uptake might not be so clear(355). This was further explored in a prospective longitudinal cohort study amongst low-income, predominantly African Americans, in whom neither adolescent nor parental knowledge was related to actual vaccine uptake(356). Nevertheless in the current study group of women, their negative attitudes towards HPV and the HPV vaccine stemmed from lack of factual information and knowledge, implying that knowledge does have a role to play. In addition, having adequate knowledge is one of the key principles of informed decision-making(357), therefore even if it does not increase actual vaccine uptake it is an essential competent of obtaining informed consent. Doctor recommendation, although not specifically mentioned in this study, has been shown to be a strong predictor of vaccine uptake in other studies (355, 358, 359). In view of the doctor-patient relationship described by the women in this study, doctor recommendation is likely to carry similar importance for this group too. However the extent to which the doctor recommendation is accepted will depend on the perceived trust and legitimacy of the healthcare system and the doctor-patient relationship(360).

Comparing the vaccine attitudes discovered in this study to that of other EE countries, which also have low vaccine uptake rates, some similarities could be noted. Romanian mothers feared the potential side effects of the vaccine and it was described as a new “experimental vaccine” and hence there was a reluctance to accept the vaccine (325). A review assessing vaccine attitudes across Europe also found that vaccine hesitancy was largely related to fear of potential side effects and that some sort of post vaccination monitoring system may help reduce anxiety(360).

Romanian adolescents also had negative vaccine attitudes due to lack of information, parental vaccine concerns and fear of side effects(361). In contrast, among both the adult(85) and adolescent(86) Hungarian populations vaccine attitudes were positive although actual vaccine uptake remained suboptimal, which may be related to funding issues at the time of the studies. The adolescent vaccine concerns are mirroring those of the adult population showing that the two are closely related and that there is a reciprocal influential effect between the two groups.

In this current study it was evident that the “mother” and/or “daughter” played significant influential parts with regards to their screening behaviours, knowledge and vaccine attitudes. Mothers’ own positive screening behaviours and participation with preventative healthcare have been shown to be associated with enhanced engagement of their daughters with screening and vaccination(362).

Emotions towards HPV testing on learning that it were a STI, included embarrassment and shame. The women believed that testing positive for HPV would imply sexual promiscuity and feared that they would be judged. It is not clear if these emotions would deter women from participating with screening if primary HPV testing was introduced, because it has been reported that it is not necessarily HPV testing itself but rather getting a positive result which causes emotional distress(300). One of the interviewed women who had tested positive for HPV was extremely distressed and anxious about future relationships, fearing that she may contract the virus again. She was not so concerned about the cervical abnormalities that had been detected. Testing positive for HPV, irrespective of the cytology result, has been shown to be associated with increased psychological anxiety, particularly with regards to sexual relationships(303). The participants described Latvia as a religious country and they implied that STIs were an extra-marital problem. Religious and cultural beliefs, may further impact on the psychosocial consequences of a positive HPV test(363). The role of knowledge in relation to the level of anxiety is debatable, greater knowledge may result in increased anxiety levels (by being aware of the sexually transmitted nature of HPV and risk factors for acquiring it) or knowledge that most sexually active people will have had HPV infection at some point may help alleviate anxiety(364). Knowledge of the latter may help reduce the stigma attached with HPV infection.

### ***Cervical Cancer Awareness and Information Needs***

It was evident that, on the whole, publicity surrounding cervical cancer and its prevention was deficient. Having adequate access to information is essential as lack of knowledge and awareness has been described to be associated with poor screening attendance(161). Applying the principles of the health belief model, a lack of information may result in a falsely lower sense of perceived susceptibility. The smear invitation letter is an effective method of increasing screening awareness and

participation but the effect is felt to be greater with increasing age(365). However, one of the limitations of the smear invitation letter is that it is dependent on up-to-date population registries; figures as high as 30-60% of letters being sent to the wrong address have previously been quoted in England(366). The women in this study commented upon the geographical mobility of young women and this may provide an explanation as to why the smear invitation has been found to be more effective in older women. Some have attributed this to the more serious health attitudes of the older population(367).

Proposed information outlets included healthcare professionals, (GPs and gynaecologists), leaflets and all forms of the media. Does it really matter what the information outlet is and is there a difference between the various outlets? Waller et al concluded that the method of presentation of information is central to reducing the psychological impact of a positive test result and ensuring continued participation with screening(368). Latvian women invest a great degree of trust in doctors and therefore they were rated highly in terms of their preferred information source. This form of information sharing may be of particular relevance in the more rural and low socio-economic settings where poor health literacy may present as a barrier to accessing other forms of information(369). Patient information leaflets and brochures were believed to be good source of information but they needed to be more attractive and accessible. To be effective leaflets need to be noticed, readable and memorable(370). The content and the language of the information leaflets are also crucial, in terms of the emotional reactions that they may provoke(371). The use of the internet is debatable as it provides access to vast quantity of unfiltered information and therefore it is dependent on the users own knowledge base to interpret the data(372). Access and computer literacy can be other disadvantages for this form of information outlet. Many of the women remarked about the mass media campaigns for breast cancer that had taken place or were active in Latvia and they suggested that something similar for cervical cancer may help increase awareness. Mass media campaigns have been successful as influencing STI related health behaviours, with greater exposure resulting in greater behavioral change(373). Cancer prevention and screening information in the media is open to misunderstandings due to lack of/limited comprehension of the provided information(374). In addition the contents of the media campaigns need to be accurate. In Romania analyses of the mass media HPV campaigns showed that a much of the

information was inaccurate and key facts were omitted and therefore these were unsuccessful at increasing HPV vaccine uptake(83). However media exposure does raise overall awareness; this was seen in England as result of the media attention received by the reality TV celebrity Jade Godey(375). Whichever information outlet is utilized one needs to be mindful that the information needs of individuals vary and the “one size fits all approach” might not be appropriate.

### ***Migrant EE Women in England Versus Native Latvian Women***

Many similarities can be observed in the health behaviours of the migrant EE women (Chapter 3) and the native Latvian women from the current study. Overall private healthcare in EE was deemed to be superior by women from both groups. It is possible that the negative views held by the EE women about the English healthcare system relate to their experiences of an “on demand” private healthcare system in their country of birth and failure of such expectations to be fulfilled in England. One expectation that was described by women from both groups (migrant EE and native Latvian) is that of annual gynaecology reviews/cervical screening. Failure to meet expectations is also likely to explain the described differences in the doctor-patient relationships, in England compared to their countries of birth. The resultant effect of this can be a delay and/or reluctance to fully engage with healthcare services in England. A Norwegian study, similarly found that the migrant EE population in Norway had a higher rate of non-adherence with cervical screening compared to the native population and were less likely to be registered with a regular GP(376). In the Norwegian study the reasons for lack of engagement with primary care were not specifically explored but the authors speculated that this might be related to the migrant EE group travelling back to their home countries for healthcare. The findings of the studies from this thesis would suggest that this behaviour is related to the perceptions that the migrant EE group hold about the healthcare system/professionals of the host country.

The migrant EE group was a heterogeneous group and therefore a true comparison cannot be made with the native Latvian women. However, their shared beliefs would imply that there is little in change health behaviours on migration. This is discussed further in the Overall Discussion (Chapter 8).

### *LIMITATIONS*

There were some inherent limitations to this study. Firstly with regards to study design a convenience sampling approach was used and participants were selected from a single GP practice and single hospital institute. This can result in facility bias, whereby the individual institute's own practices and treatments may result in only certain types of patients being recruited (e.g. patients that are actively only seeking specific care or have a preference to a specific physician). A cohort sampled in such a manner, might not be representative of the general population. Secondly, for the survey component of the study participants from primary and secondary care were not equally represented and therefore were analysed together. It may be argued that those attending the colposcopy clinic are inherently more engaged with cervical screening services. However as mentioned previously, 14% of those from secondary care were not aware that they had a cervical smear test in the past. Is knowledge/awareness of screening important or is the fact that they have participated with screening enough? The survey results reported that overall knowledge levels were in fact low; therefore if the assumption is that the studied group is more knowledgeable than average Latvian women, then the knowledge in the general population must be lower. Similarly participants who had volunteered for the interview stage of the study are more likely to engage with screening services in the first instance. Therefore one may argue that this is not the target population, we should be targeting those who are not attending for screening. It is as equally valid to examine the motivations of women to do attend for screening, as it is to explore the barriers to screening in non-attenders(174).

The low recruitment rate from primary care might represent disengagement in this group of patients with healthcare services. Alternatively it may be that the physicians in primary care were less motivated to recruit than those from secondary care, as recruitment in secondary care was from colposcopy clinics. The physicians in secondary care are more likely to be aware of the relevance and importance of the research topic in Latvia and therefore have a greater sense of motivation for recruitment.

The study was conducted in the capital city of Latvia and more rural areas were not sampled. The populations in rural areas are likely to have different characteristics, motivators and accessibility issues with regards to cervical screening(121). Although

women from rural areas were not directly sampled, some of the women involved in this study had moved from a rural part of Latvia or had family who lived in rural areas. They were therefore able to provide an insight into the barriers faced by these women in accessing healthcare. Furthermore, accessibility issues are bidirectional: the women may have difficulties in accessing healthcare services such as cervical screening but similarly healthcare professionals and/or services may have difficulties in accessing them. Lack of access to this group of women in Latvia was the main reason for their exclusion from this study.

#### **4.5 CONCLUSIONS**

The current cervical screening behaviours in Latvian women appear to be governed by their lack of knowledge of the principles of screening and the natural history of the development of cervical cancer. Women fall in two categories: those who are over screened by participating in annual opportunistic screening and those who do not participate in any form of screening. Participation with organized cervical screening that has good quality assurance can be increased through greater patient engagement. To achieve this awareness about cervical cancer needs to be increased and the use of media outlets provides one possible method of accomplishing this. Further healthcare professionals have a vital role to play in patient education and in endorsing participation with the national cervical screening programme.

## **5 KNOWLEDGE, ATTITUDES AND AWARENESS OF THE HUMAN PAPILLOMAVIRUS AMONGST PRIMARY CARE PRACTICE NURSES: AN EVALUATION OF CURRENT TRAINING IN ENGLAND**

### **5.1 INTRODUCTION**

Cervical cancer prevention encompasses both primary and secondary prevention and knowledge/awareness of it is bidirectional, between those imparting the knowledge and those gaining it. Thus far in the thesis the focus has been on the knowledge and attitudes of the service user and how this may affect actual cervical cancer prevention health behaviours.

The integration of HPV into the CSP in England has posed many challenges for healthcare professionals. Firstly, there was a need to update the provision of training to ensure effective dissemination of the new protocol, in addition to providing HPV-related education. Previous studies have demonstrated that HPV knowledge amongst healthcare professionals is variable, even deficient in some cases (377-382). Secondly there is the challenge of communicating these substantial changes to patients in a clear and non-judgemental manner.

In England practise nurses (PN) perform the majority of the cervical smears and will often represent the first and only point of contact women have with the CSP. Consequently it is essential that PN are adequately informed about the new screening protocol and are able to convey information to women, regarding HPV, its role in cervical cancer aetiology and its natural history, without creating anxiety or confusion. With the introduction of HPV triage/TOC, the NHS CSP developed a HPV training package for all smear takers that was sent out to the GP surgeries included in this study in February 2012. HPV education was also incorporated into the 3 yearly updates, which are recommended by the NHS CSP for nurses, or a one off face-to-face HPV-specific training session. The aim of this study was to evaluate the effectiveness of current HPV training and to determine the level of HPV knowledge in PN cervical smear sample takers.



## **5.2 METHODS**

### **5.2.1 Sampling Frame**

The sampling frame was defined as all registered PN in Leicestershire and Rutland in England, with a valid smear sample taker number.

### **5.2.2 Data collection Methods**

An anonymous web based survey tool was used as direct access to the PN was not possible and the method of access was going to be through a mailing list held by the local Public Health England (PHE) screening team.

### **5.2.3 Questionnaire Development**

Following an extensive literature search and in collaboration with the local screening co-ordinator from PHE, the survey was developed. The PHE HPV training package was used as a guide from which to develop and set standards for the questions. Pre-existing validated HPV knowledge questions were incorporated into the survey where appropriate (227). This survey tool has been previously used to assess the level of HPV knowledge in the lay population and therefore it was felt that this is the minimum level of knowledge that healthcare professionals should have.

The survey was pre-tested on a convenience sample of 15 PN from outside the study area for content validity and relevance. It was estimated that the survey would take 10 minutes to complete.

The final 12-point survey explored four broad categories; demographics and level of experience, HPV knowledge (general HPV knowledge, HPV triage/TOC knowledge, HPV vaccine knowledge), attitudes towards the HPV vaccine and self-perceived adequacy of HPV knowledge. The knowledge questions were assessed using a “select all that apply” format and 5-point Likert scales were used to measure attitudes and perceptions. (Appendix V)

#### **5.2.4 Recruitment of Participants**

All registered PN cervical smear sample takers were recruited via a mailing list held by the local PHE screening team. The aim had been to sample as many PN in England as possible but due to governance and access issues this was not possible since the local screening team only held a mailing list for the PN in their area. As a result the sample was limited to the 147 GP surgeries in the Leicester, Leicestershire & Rutland area, England. Further, the “normal” method of sending communication to the PN was via the practice managers who would then cascade it to all registered PN cervical smear takers working within their surgery, therefore this method for communication was also adopted for this study. Although it is acknowledged that this method is not ideal due to the indirect nature of recruitment, however it was the only feasible option within the limited resources that were available.

Between May- July 2015 the anonymous cross sectional survey was conducted to evaluate the aims. Two reminder emails were sent during the study period and built in mechanism in the online survey tool “smart survey” prevented double entries.

#### **5.2.5 Data analysis**

The responses were numerically coded and the data were transferred into SPSS version 22. Descriptive statistics were generated for the responses and correlation co-efficients to describe relationships between two continuous variables. For independent samples the Chi square and Kruskal-Wallis test were used to compare categorical and continuous variables, as the data were non-normally distributed. All reported P-values were assessed using two-sided tests and statistical significance was taken as a cut-off of  $p < 0.05$ . Free text was analysed using Nvivo qualitative research software, examining for common themes.

This study was performed in accordance with the local clinical governance, audit and service evaluation guidelines.

### **5.3 RESULTS**

A total of 128 PN completed the online survey out of the 479 PN cervical smear takers registered for this area. Of these 94 were complete responses. Only the complete responses were used for data analysis. The age distribution of the respondents varied from 27-61 years (median 50 years) and all the PN in this cohort were females. The median number of years that the PN had been performing cervical smears was 10.5 years (range <1 -36 years). The majority of the PN (53.2%, n=50) last attended a HPV training session more than 12 months ago and 3.2% have never attended despite the fact they have been performing cervical smears for between 2 to 12 years (Table 5.1).

#### **General HPV knowledge**

Out of a maximum knowledge score of fifteen, the median score achieved by the participants was 13 (range 7-15). All of the PN answered more than 50% of the questions correctly and furthermore 83% (n=78) correctly answered 80% or more. Confusion existed regarding the need for treatment for HPV; with only 37.2% (n=35) correctly identifying that HPV does not require any treatment. More participants correctly identified the association between HPV and cervical cancer than that between HPV and genital warts ( $p=0.03$ ). However 9.6% (n=9) failed to recognise that HPV can cause cervical cancer and of these 3.2% (n=3) were not aware of either of the two associations. (Table 5.2)

#### **HPV triage and TOC knowledge**

Overall the PN had a thorough understanding of the HPV triage and TOC pathways, achieving a median score of 9 (range 5-10) out of a total of 10. Although in some there was uncertainty surrounding the timing of the HPV test and its interpretation; 17% (n=16) did not believe that the HPV test could be done at the same time as the smear test and 22.3% (n=21) failed to accept that if a woman does not have HPV then her risk of developing cervical cancer is low. Moreover the role of HPV testing post treatment (TOC) was misinterpreted, with only 66% (n=62) acknowledging that all normal, borderline nuclear and mild dyskaryotic samples are tested for hrHPV post treatment and 8.5% (n=8) believed that annual follow for ten years was still required despite a negative TOC result. (Table 5.3)

### **HPV vaccine knowledge**

This section was scored out of 7; the participants achieved a median score of 6 (range 4-7), with responses from three participants missing. Although the overall HPV vaccine knowledge score was good, detailed knowledge appeared to be lacking: 37.2% (n=35) were not aware that the vaccine protects against most cervical cancers and only 60.6% knew that one of the vaccines provides protection against genital warts. However, importantly all correctly acknowledged the need for continued cervical screening post vaccination. (Table 5.4)

### **Factors influencing of level of HPV knowledge**

PN age and the number of years of experience were not identified to correlate with HPV knowledge in any of the three tested knowledge categories (Table 5.5). Timing of the last HPV training session also did not have a significant influence on knowledge scores, and even those who had never attended a HPV training session achieved comparable knowledge scores. (Table 5.6)

### **Attitudes towards HPV vaccine**

Almost all the PN (98.9%, n= 93) either strongly agreed or agreed that they would recommend the HPV vaccine and 88% (n= 83) felt that the vaccine should be offered to boys as well. Those who were undecided or disagreed with boys being offered the HPV vaccine had a significantly lower overall general HPV knowledge scores compared to those who agreed or strongly agreed (p=0.02).

### **Self-perceived adequacy of HPV knowledge**

Only 68% (n=64) stated that they were adequately informed about HPV with the rest undecided, disagreeing or strongly disagreeing (19.1% (n=18), 10.6% (n=10), 2.1% (n=2)). In spite of this a greater proportion felt that they were confidently able to answer all questions asked by patients (77.7%, n= 73), with 16% (n= 15) undecided, 5.3% (n=5) disagreeing and 1.1% (n=1) strongly disagreeing. The HPV knowledge scores did not significantly vary between self-perceived awareness of HPV or ability to answer questions posed by patients. Moreover of the three PN who had never attended a HPV training session, 2 were undecided and 1 disagreed that they were adequately informed

about HPV, however one of them still agreed that she was able to confidently answer all HPV related questions.

### **Improving training**

Many of the PN expressed that the delivery of HPV training could be improved. The main themes that emerged from the free text were that there is requirement for continued HPV education and the provision of regular updates. Many PN suggested combining HPV training with the three yearly cervical smear updates, whilst others mentioned using emails or newsletters featuring salient HPV facts along with any other new developments. The most frequently mentioned proposal was to develop an online training programme, with an assessment component and commonly asked questions by patients. Several PN felt that online resources would be easier to access and therefore likely to increase participation. Key barriers to attending educational meetings were stated as travel distance and lack of time in which to attend.

## **5.4 DISCUSSION**

This study provides an objective measure of the effectiveness of current HPV training amongst PN and investigates possible methods of improvement.

The results of this study support that PN overall, have adequate levels of HPV knowledge. On average they correctly answered 86% of the knowledge-based questions across the three categories. It was however, evident that basic key facts were missed by some; 9.6% failed to identify that HPV can cause cervical cancer and over 30% did not recognise sexual intercourse at an early age as a risk factor or that most sexually active women will acquire HPV. It has been shown that simply informing women that HPV is common can help reassure them(383). Moreover, detailed awareness of HPV was also lacking: just over a fifth were unaware that HPV could be passed on by genital skin to skin contact or that it is responsible for genital warts. The most poorly answered question was regarding the treatment of HPV, a majority of 62.8% erroneously stated that HPV requires treatment.

A survey conducted using the same validated tool amongst lay women in the UK, showed that they also lacked awareness of these same facts (384). One may infer from

this that there is a correlation between the level of HPV knowledge in PN and that of women in the UK. Globally studies from countries with differing cervical screening programmes have shown that HPV knowledge levels in healthcare professionals are variable and may differ between specialities (385-389) and no one group of healthcare professionals/speciality has been consistently proven to be superior. In the England, PN have not previously been investigated but HPV knowledge in other groups of healthcare professionals (GPs, Paediatricians and Obstetricians and Gynaecologists) has been shown to be low(390). In New Zealand and Ireland where the majority of cervical smears are performed in primary care, studies exploring awareness of HPV in PN, have also found that detailed HPV knowledge was deficient(391, 392). PN and GPs were unclear on the role of HPV testing and how it is done(392). Level of HPV knowledge in school nurses, who are responsible for the administration of the HPV vaccine in many countries(393), is also variable(382, 394-396). HPV knowledge in nurses has been identified as an important precursor for a positive attitude towards the vaccine(394, 397).

The changes in the CSP, which resulted from the implementation of HPV triage and TOC, have had a significant psychological impact on women (302). The PN had a good appreciation of the HPV triage/TOC pathways, and this is likely to represent the availability of clear treatment pathway charts, which are easily accessible and often displayed in clinical settings (398). However, confusion existed regarding the role of TOC and the impact it has on follow-up post treatment. One possible explanation for this finding is that contrary to guidance, follow-up and often the initial TOC cervical smears have previously been conducted in the secondary care setting, although this situation has changed in many areas of England over the past few years. Therefore PN may lack exposure to this stage of management. Nevertheless compliance with national guidance requires TOC cervical smears to be performed in primary care and PN need to be familiar with the protocol.

Although most PN scored highly in the HPV vaccine knowledge category, it was apparent that some lacked up to date information about the HPV vaccination programme in England. In September 2012 there was a change from using the bivalent HPV vaccine to the using the quadrivalent vaccine, which provides additional

protection against genital warts (399). Over one third (35.1%) of PN were oblivious of this added benefit. In September 2014 the HPV vaccination schedule changed from a three dose regimen to a two dose one for adolescent girls under 15years old (400); 24.5% of PN did not appear to be informed of this change. Lack of awareness of recent changes to HPV vaccination is likely to be reflective of the fact that the majority of PN in the study cohort had not attended a HPV training session for over 12 months. Some may argue that as PN in England are not responsible for the delivery of HPV vaccination they should not be accountable for being up-to-date with vaccine related information. However, HPV vaccination is a major component of cervical cancer prevention and there should not be any segregation between the two forms of prevention, primary and secondary, rather the topic of cervical cancer prevention should be approached as a whole. Additionally, PN will be exposed to patients who have received the vaccine or those who have daughters who are eligible for the vaccine and therefore may be approached as a familiar and trusted source of information.

It is acknowledged that there are challenges of communicating HPV related information to women(401) and healthcare providers have self-reported feeling uncomfortable answering HPV-related questions(402). The exact reasons for this have not been established but one may argue that this is reflective of their own lack of HPV awareness, given the results of the previously mentioned HPV knowledge studies in this group. The provision of education to women has been shown to be key in increasing knowledge of HPV, cervical cancer and significantly decreasing concerns about receiving a positive HPV test result(403). In addition the value of participation with cervical cancer screening, in women, is positively associated with education(404).

The content and the quality of the information shared needs to be accurate and clear to avoid misunderstandings(300). Patients have erroneously believed that HPV testing is a test of fidelity(116), which is felt to have a dramatic impact on their personal relationships.

Clinical experience did not correlate with increased HPV knowledge, it may be inferred from this finding that clinical experience alone is not adequate to obtain sufficient awareness of HPV and that there is a requirement for formal HPV education. The

current training provided by PHE for PN consists of a new sample taker course followed by 3 yearly updates. Contemporary information on cervical screening in England, together with HPV education is incorporated into each session. However many of the PN expressed that there is a need to improve the provision of training, with 32% not satisfied that they are adequately informed about HPV. Furthermore a proportion of them stated that HPV education should be integrated into the 3 yearly cytology updates, it is of concern that they are not aware of the fact that this already takes place. The respondents felt that the delivery of training could be improved with the development of an online e-learning programme. The use of e-learning within medical education is increasing and it has been shown to be a useful adjunct to traditional teaching methods (405). Lack of time and travelling distance were identified as barriers to attending training sessions. One of the benefits of e-learning is that it permits learner centred education which transcends geographical boundaries(406) and therefore is likely to result in increased participation. Previous studies that have explored the role of web based continued medical education in the context of cervical cancer screening have shown favourable results, particularly in terms of increasing knowledge levels and enhancing the adoption of clinical guidelines (407).

### *LIMITATIONS*

The overall response rate was low (19.6% for complete responses), although it was difficult to accurately determine. The number of PN currently working in the region is thought to be below the 479 on the register, since the register does not account for nurses who have moved out of area or who are no longer practising. An up to date register is vital for ensuring that all PN are adequately trained and the lack of one may provide an explanation as to why three PN in this cohort had never attended a HPV training session.

Only one region within England was sampled, however PN of varying degrees of experience are represented and the guidance on training for cervical cancer screening is standardised across the country, although delivery may differ. Therefore this data may be indirectly applicable to other regions within England but to obtain truly representative data the survey would need to be rolled out nationally.



This study revealed that the PN scored highly on the HPV knowledge assessments; however there is some debate that the use of online survey tools compared to paper versions may result in falsely elevated knowledge scores. It has been argued that when using online surveys the participants have access to additional resources, for example the internet, which they may use to search for information(408). This could explain why, despite the PN achieving high knowledge scores, 32% felt inadequately informed about HPV and 22% felt that they could not confidently answer HPV-related questions posed by women.

## **5.5 CONCLUSIONS**

Women look to healthcare professionals for HPV related information (409) and therefore it is imperative that they are able to provide patients with clear, consistent and accurate information to help relieve their anxieties (300). The role of HPV in cervical cancer prevention is expanding and in the near future primary HPV testing will be the default methodology for cervical cancer screening (114, 410) The results of this study are concerning as PN perform the majority of the 3,500,000<sup>+</sup> cervical smears performed annually in England(411). PN are central to the CSP and are in a powerful position to impart knowledge to women. Consideration needs to be given to re-evaluating the delivery of HPV related health education to PN. Training needs to be provided in a more effective and efficient manner to ensure that professional understanding is not lagging behind scientific advancements.

**Table 5.1 Participant characteristics**

<b>Age (median/range)</b>	50 years (27 to 61years)
<b>Number of years performing cervical smears tests (median/range)</b>	10.5 years (<1 to 36 years)
<b>Timing of last HPV Training Session</b>	<b>n (%)</b>
In the last 3 months	4 (4.3)
In the last 6 months	11 (11.7)
In the last 12 months	26 (27.7)
More than 12 months ago	50 (53.2)
Never	3 (3.2)

**Table 5.2 General HPV knowledge questions (Questions used from validated HPV knowledge tool (227))**

	<b>Correct Responses n (%)</b>	<b>Incorrect Response n (%)</b>
<b>HPV is very rare</b>	94 (100)	0 (0)
<b>HPV always has visible signs or symptoms</b>	94 (100)	0(0)
<b>HPV can cause cervical cancer</b>	85 (90.4)	9 (9.6)
<b>HPV can be passed on by genital skin-to-skin contact</b>	73 (77.7)	21 (22.3)
<b>There are many types of HPV</b>	86 (91.5)	8 (8.5)
<b>HPV can be passed on during sexual intercourse</b>	89 (94.7)	5 (5.3)
<b>HPV can cause genital warts</b>	74 (78.7)	20 (21.3)
<b>Men cannot get HPV</b>	92 (97.9)	2 (2.1)
<b>Using condoms reduces the risk of getting HPV</b>	82 (87.2)	12 (12.8)
<b>HPV can be cured with antibiotics</b>	92 (97.9)	2 (2.1)
<b>Having many sexual partners increases the risk of getting HPV</b>	87 (92.6)	7 (7.4)
<b>HPV usually doesn't need any treatment</b>	35 (37.2)	59 (62.8)
<b>Most sexually active people will get HPV at some point in their lives</b>	62 (66)	32 (34)
<b>A person could have HPV for many years without knowing it</b>	89 (94.7)	5 (5.3)
<b>Having sex at an early age increases the risk of getting HPV</b>	64 (68.1)	30 (31.9)

**Table 5.3 HPV Triage and TOC knowledge questions (\*\* questions used from validated HPV knowledge tool(227))**

	<b>Correct Responses n (%)</b>	<b>Incorrect Responses n (%)</b>
<b>An HPV test can tell how long you have had an HPV infection**</b>	94 (100)	0 (0)
<b>If a woman tests positive for HPV she will definitely get cervical cancer**</b>	92 (97.9)	2 (2.1)
<b>An HPV test can be done at the same time as a Smear test**</b>	78 (83)	16 (17)
<b>HPV testing is used to indicate if the HPV vaccine is needed**</b>	93 (98.9)	1 (1.1)
<b>When you have an HPV test, you get the results the same day**</b>	94 (100)	0 (0)
<b>If an HPV test shows that a women does not have HPV her risk of cervical cancer is low**</b>	73 (77.7)	21 (22.3)
<b>All cervical samples showing borderline nuclear changes or mild dyskaryosis are tested for high-risk HPV.</b>	89 (94.7)	5 (5.3)
<b>All cervical samples showing normal, borderline nuclear changes or mild dyskaryosis 6 months post treatment are tested for high-risk HPV</b>	62 (66)	32 (34)
<b>If the post treatment high-risk HPV test is negative they will still require annual follow up for ten years</b>	86 (91.5)	8 (8.5)
<b>If post treatment both cytology and high risk HPV test are negative, they will need require a repeat smear in 3 years</b>	87 (92.6)	7 (7.4)

**Table 5.4 HPV vaccine knowledge questions (Questions used from validated HPV knowledge tool (227))**

<b>*</b>	<b>Correct Responses n (%)</b>	<b>Incorrect Responses n (%)</b>
<b>HPV vaccines require two doses</b>	68 (72.3)	23 (24.5)
<b>The HPV vaccines offer protection against all sexually transmitted infections</b>	90 (95.7)	1 (1.1)
<b>The HPV vaccines are most effective if given to people who have never had sex</b>	81 (86.2)	10 (10.6)
<b>Someone who has had HPV vaccine cannot develop cervical cancer</b>	90 (95.7)	1 (1.1)
<b>The HPV vaccines offer protection against most cervical cancers</b>	56 (59.6)	35 (37.2)
<b>One of the HPV vaccines offers protection against genital warts</b>	57 (60.6)	33 (35.1)
<b>Girls who have had the HPV vaccine do not need to have smear tests when they are older</b>	91 (96.8)	0 (0)

\* 3 responses missing from this whole section

**Table 5.5 HPV knowledge scores against practice nurse age and years of experience**

	<b>General HPV knowledge</b>	<b>HPV triage/TOC knowledge</b>	<b>HPV vaccine knowledge</b>
	<b>Spearman's rho correlation coefficient (p value)</b>		
<b>Age</b>	-0.150 (0.149)	-0.053 (0.610)	-0.126 (0.234)
<b>Number of years performing cervical smears</b>	0.096 (0.357)	0.009 (0.935)	0.127 (0.230)

**Table 5.6 HPV knowledge scores against length of time since last HPV training session**

	<b>Last 3 months</b>	<b>Last 6 months</b>	<b>Last 12 months</b>	<b>More than 12 months</b>	<b>Never</b>	<b>P value*</b>
<b>Mean Score (95% CI)</b>						
<b>General HPV Knowledge</b>	13.5 (10.74 - 16.26)	12.82 (11.45- 14.19)	12.85 (12.29- 13.40)	12.68 (12.17- 13.19)	12.00 (7.70- 16.30)	0.82
<b>HPV Triage/TOC Knowledge</b>	9.75 (8.95- 10.55)	9.18 (8.68- 9.69)	9.27 (8.98- 9.56)	8.88 (8.53- 9.23)	8.33(4.54- 12.13)	0.23
<b>HPV vaccine Knowledge</b>	6.25 (5.45- 7.05)	6.18 (5.59- 6.77)	5.96 (5.65- 6.27)	5.74 (5.50- 5.99)	5.33 (1.54- 9.13)	0.29

\* Kruskal-Wallis

## **6 KNOWLEDGE OF HUMAN PAPILLOMAVIRUS AND THE HUMAN PAPILLOMAVIRUS VACCINE IN EUROPEAN ADOLESCENTS: A SYSTEMATIC REVIEW**

### **6.1 INTRODUCTION**

HPV is the most common viral infection of the reproductive tract that most men and women who are sexually active will acquire at some point in their lives (41). The HPV vaccine is widely recommended in many European countries for female adolescents (aged 9-18years(84)), however independent of funding discrepancies, the uptake of the vaccine has been variable, ranging from <5%-86% (45, 412, 413). Reasons for vaccine uptake are multifactorial(414, 415), however knowledge of HPV and the HPV vaccine have been identified as key predictive factors in increasing uptake (354). To date studies have shown that awareness of HPV across all populations is poor(226, 416). It was hoped that the health promotion campaigns, which preceded vaccine introduction would result in heightened awareness of HPV, thus far the evidence for this is lacking and HPV knowledge remains suboptimal (417).

HPV vaccination is primarily aimed at adolescents and conveying HPV related health information to this group is arguably the greatest challenge for many healthcare professions (401). In spite of this, it is essential that adolescents fully understand, and are able critically appraise the information that they are provided, in order for them to participate in the decision making process and allow them to make informed choices (418). In addition, having a better understanding of HPV will have an impact on their decisions to partake in high-risk behaviours and cervical screening in the future.

The aim of this systematic review was to assess the level of HPV and HPV vaccine knowledge that exists amongst European adolescents. The concept for the study was developed following the initial pre-protocol PPI work that was conducted where women felt that it was important to explore the awareness of primary prevention of cervical cancer in the group who are eligible for it, the adolescents. Countries within the European Union have the right of free movement and therefore they are likely to have an impact on each other's health economy and contribute to their disease burden.



## **6.2 METHODS**

A mixed methods systematic review was conducted to assess our aim. The two main primary outcomes assessed were: “have you heard of HPV?” and “have you heard of the HPV vaccine?”

### **6.2.1 Search Strategy**

The PRISMA (preferred reporting items for systematic reviews and meta-analyses) guidelines for systematic reviews were adhered to. (419) Two electronic databases, Ovid Medline and PyscINFO were searched from 1946 and 1806 respectively to September 2014, for suitable papers. These databases were used without any limitations and they were deemed to be the most relevant databases for this research question. Searches were conducted using 11 combinations of the keywords, “HPV”, “Papillomavirus”, “Human papilloma virus”, “Health knowledge” “Attitudes”, “Practice”, “Patient education”, “Vaccine/vaccination” and “Primary prevention”. English language and human participant limits were applied to the search results. The titles and abstracts were screened to assess for eligibility of the study and the reference lists of all included studies were searched to identify any additional studies.

### **6.2.2 Inclusion and exclusion criteria**

All studies reporting data specifically on HPV and/or HPV vaccine knowledge in European adolescents were included. The upper age limit, for the purpose of this review was set at a mean of 20 years. This was because in some studies, which had been conducted in European secondary schools, the upper age limit reached 20 years (420-423). Only studies, which were conducted in a member country of the European Union, were included. Studies in which the main focus was vaccine uptake, acceptability or attitudes rather than knowledge were excluded. Studies providing insufficient information, for example letters and abstracts only, were also excluded.

### **6.2.3 Critical Appraisal**

Two researchers (HP, EM) independently reviewed the full texts for quality and suitability. The Critical Appraisal Skills Programme (CASP) tool was used to review the qualitative studies (424) and a quality checklist was developed, following the

principles identified by Pettigrew and Roberts (425) and using the Centre for Evidence-Based Management (CEBM) tool (426), for the quantitative survey studies. Any discrepancies between the two reviewers were discussed until a consensus was reached.

#### **6.2.4 Data Analysis**

Study features and outcomes were assembled in a tabular form, and formal meta-analysis was performed using RevMan (427). A random effect model (using a Mantel–Haenszel method) was used as the I<sup>2</sup> statistic showed heterogeneity of >50%. The effect estimate was expressed as a pooled odds ratio (OR) with 95% confidence interval (CI) and was represented graphically by forest plots. Statistical heterogeneity was examined using the  $\chi^2$  test and a P value of <0.05 was suggestive of heterogeneity. Clinical heterogeneity was examined by assessing the participants, intervention used, study quality and outcome measures. The meta-analysis was supplemented with meta-synthesis for the secondary outcome measures.

### **6.3 RESULTS**

#### **6.3.1 Study Characteristics**

The literature search revealed 905 suitable studies following the removal of duplicates (Figure 6.1). The full texts of 29 articles that met the initial inclusion criteria were reviewed. Following review of the full texts, 11 studies were excluded. Reasons for exclusion included, age of participants, studies not assessing HPV or HPV vaccine knowledge, study assessing the effect of intervention and adequate information not supplied. Where adequate information was not available we attempted to contact the author of the studies. Studies, which published results in more than one publication, were amalgamated resulting in four qualitative and fourteen quantitative studies to be included in the final review. Publication dates of the studies ranged from 2008-2013 and for some, the study date preceded introduction of the HPV vaccine in that country. Sample size ranged from 217-1769 for the quantitative and 10-87 for the qualitative studies. All of the included studies had been conducted in a Western European country (UK, Italy, Sweden, Netherlands, Portugal, Germany), with only one from Eastern Europe, from Hungary(428). Study characteristics are summarised in Tables 6.1 and 6.2.

### 6.3.2 Critical Appraisal

The four qualitative studies were considered to be of moderate to good quality (Table 6.3) Majority of the survey studies were thought to be of moderate or good quality. The response rate was greater than 70% in all but two studies (422, 429) (Table 6.4). However many of the studies predominately used convenience sampling and therefore the representativeness of the data may be questioned.

### 6.3.3 Primary Outcomes (Table 6.5)

#### Awareness of HPV

*“Have you heard of HPV?”*

Twelve of the quantitative studies specifically assessed for this outcome (420-423, 428, 430-436). The age of the participants involved in the studies ranged from 12-35 years (the mean age for each individual study did not exceed 20 years). Awareness of HPV varied significantly between the studies with the lowest level existing amongst a cohort of Swedish high school students aged 15-20 years (mean age 16 years), where only 5% had ever heard of HPV (420). The highest level of awareness of HPV was noted in Italian high school girls aged 13-23 years (mean age 16 years), where 92% had heard of HPV (423). Although only one study had been conducted in an Eastern European country (428), there was no Western/Eastern European divide noted. Awareness of HPV in Italian female adolescents has increased over time (421, 423, 431), a similar trend has been noted for both male and female adolescents in the Netherlands (434, 436) and Sweden (420, 433).

Factors found to be associated with greater HPV awareness included:

- 1) Vaccinated girls were more likely to have heard of HPV than unvaccinated girls(437) (77%,n=683 vs. 8.5%, n= 76; p= 0.017 (430))in two UK studies, however adolescent boys appeared to have an equal level of awareness as unvaccinated girls in a German study (429).
- 2) Higher education in general and in particular students studying a medical or health sciences related subject was found to correlate with greater awareness compared to non-health science subjects. (434-436).

3) Knowledge was found to positively increase with age (422) and in one Italian study, it was noted that each one year increment in age resulted in 14% increased knowledge (431). In addition, the Hungarian study demonstrated that high school students had better knowledge than those attending primary school (40%, n= 463 vs. 25%, n=152;  $p < 0.001$ ) (428). Again this is likely to represent the older age of the high school students.

4) Only one German study revealed a correlation with sexual experience, showing that students who had previous sexual experience had superior awareness of HPV than those who had never had sex (422).

5) Gender was found to be the greatest and most consistent predictive factor for having heard of HPV. Eight studies found that female adolescents were significantly more likely to have heard of HPV than male adolescents (421-423, 428, 433-436).

However in contrast, a detailed qualitative review by Racktoo et al (438) found that very few 12-13 year old girls, in a school where the HPV vaccine was available, had actually heard of HPV; 'What is HPV? Never heard of it', 'The V bit stands for vaccine.' 'Is it something ... protection vaccine?' (438). Williams et al also found that there was a poor understanding of HPV as the vaccine had been promoted as a "cancer vaccine" (437). Meta-analysis of the eight quantitative studies showed that adolescent females are significantly more likely to have heard of HPV compared to the boys, (OR 2.73, 95% CI 1.86-3.99) (Figure 6.2).

### **Awareness of the HPV vaccine**

*"Have you heard of the HPV vaccine?"*

Only five quantitative studies assessed for this specific outcome (420, 422, 423, 428, 433). Highest levels of vaccine awareness were again found in Italian teenagers, 94.5% and 71.3% of girls and boys respectively, in the group who heard of HPV had also heard of the HPV vaccine (423). This is a substantial improvement on the findings by Di Giuseppe et al who in 2007, found that in Italy only 42% of those that had heard of cervical cancer (n=706) knew that HPV vaccination was a preventative measure for cervical cancer and only a mere 15% knew that the vaccine was available in Italy (431). Knowledge of the HPV vaccine amongst Swedish adolescents was found to be extremely low, with awareness only reaching a maximum of 9.2% in girls in one study

(433) and in another the overall awareness was only 1.1% with no significant difference noted in gender (420). Furthermore in Germany only 9% of boys and 29% of girls had heard of the HPV vaccine (422). Lower levels of vaccine awareness corresponded to low awareness of HPV in these cohorts.

Female adolescents were again significantly more likely to have heard of the HPV vaccine (422, 423, 428, 433) and interestingly many adolescent boys felt that it did not even concern them (421). Meta-analysis of the four studies which compared awareness amongst girls verses boys found that girls were significantly more likely to have heard of the HPV vaccine (OR 5.64, 95% CI 2.43-13.07) (Figure 6.3).

#### **6.3.4 Secondary outcomes (Table 6.5)**

##### **Mode of transmission**

On the whole adolescents had a sound understanding of the fact that HPV is an STI (420, 421, 423, 428-431, 433, 434, 436, 439, 440). The study demonstrating the maximum level of knowledge regarding mode of transmission, was a study carried out amongst 1<sup>st</sup> year medical students, a group in which higher levels of knowledge would be expected (440) and the lowest levels were found amongst groups in which not many had heard of HPV in the first instance (420, 433). Very few participants recognised that HPV can be transmitted through genital skin-to-skin contact or non-penetrative intercourse (428, 430, 431). Other routes of transmission, which had been erroneously suggested included, air-borne where students, had applied the knowledge that they hold for other viruses such as the flu virus to HPV (438). In addition some mentioned blood transfusions (435), the use of public toilets and poor intimate hygiene (423).

Most correctly identified that condoms would reduce the risk of contracting HPV (423, 430, 431) but others falsely thought that condoms were fully protective (428, 434, 436). Some girls perceived their own risk of acquiring HPV as low, as they thought it was associated with girls that “sleep around” (439) or that they were protected because they used condoms (437). Furthermore there was confusion among some regarding the role of the oral contraceptive pill in protection against HPV (438, 439). A few groups

mentioned the HPV vaccine as a method of prophylaxis (439) and in Hungary more females than males identified this as preventative measure (428).

### **Link to cervical cancer and genital warts**

The correlation between hrHPV and cervical cancer was poorly understood, with a group of 12-13 year old girls in the UK believing that HPV and cervical cancer were the same (438). A better level of understanding was noted in those that had previously heard of HPV (423, 434, 435). However in two studies conducted in the UK, despite the majority of the participants having heard of HPV, only 50% or less were aware of its link to cervical cancer (430, 440) and interestingly one of these studies was conducted in a group of first year medical students pre and post the HPV public health campaign in the UK (440).

Compared to boys, girls in general (422, 423, 428, 433, 436) and vaccinated girls (429) were found to have significantly greater knowledge of the relationship between HPV and cervical cancer. Students of both genders, from a health sciences background had superior knowledge compared to non-health sciences students, although only 1.3%-24.4% from both groups recognized that HPV is associated with more than 90% of cervical cancers (435). Misconceptions existed regarding the hereditary nature of cervical cancer. One study showed that students of both gender from a non-health sciences and males from a health sciences background incorrectly stated hereditary cause as a risk factor for cervical cancer (435). Moreover 76% of medical faculty students also shared the same belief (434). Understanding of the association between HPV and genital warts was low (420, 423, 428, 430, 433), with the greatest levels existing in 15-19 year old Hungarian boys (428). Female gender was not found to be superior for this particular outcome. It is possible that the awareness of the association of HPV and genital warts is determined by the type of vaccine (bivalent/quadrivalent) that was available locally at the time of the study.

### **Level of protection offered by the vaccine**

Overall adolescents appreciated that the HPV vaccine protected against cervical cancer but uncertainty existed on the exact level of protection offered (430, 439, 440). Only a few knew that it was possible to still get cervical cancer after receiving the vaccine

(430) and that the vaccine only offers protection against some of the hrHPV subtypes (440). In contrast one group of girls thought that the vaccine would not stop them from getting cervical cancer but that it would stop them dying from it (439). There was disbelief that cervical cancer could be prevented with a vaccine (428). A minority mentioned that it might also protect against “STIs” (421) and genital warts (423). Others falsely believed that the HPV vaccine also protected against HIV/AIDs and viral hepatitis (423). The two Swedish studies revealed that adolescents felt their intention to use condoms would decrease after receiving the HPV vaccine and that other adolescents would feel the same (420, 433), however Italian teenagers acknowledged the need to use condoms during sexual activity following vaccination (423).

#### **Need for cervical screening in the future**

Four (430, 438, 439, 441) out of the five UK based studies found that the need for cervical screening following vaccination was not clear. Some thought that cervical screening was being provided as a “back up” for those who were still concerned after being vaccinated rather than it being mandatory for all (441). Vaccinated female medical students in the UK and Italian schoolgirls appeared to be more aware of the requirement for cervical screening (423, 440).

### **6.4 DISCUSSION**

This review has revealed that the level of HPV and HPV vaccine knowledge amongst European adolescents remains suboptimal. The results of this review are consistent with a previous review that explored the knowledge of all STIs in European adolescents, which found that of all the STIs the lowest level of awareness existed for HPV (442). Many studies have shown that increased HPV knowledge does result in increased vaccine uptake and acceptability (354, 416). When vaccine recipients and their parents are provided with balanced information, they have improved knowledge and risk perception, which results in increased vaccine uptake (443). There is a danger that unless all adolescents are fully able to grasp the information that they are provided, they will be inhibited from making an informed choice regarding HPV vaccination. In addition this will impact their judgment to partake in high-risk behaviours and decision to participate in cervical screening in the future.

This review attempted to identify factors, which may be associated with greater HPV knowledge. The following factors were explored looking for correlations.

### **Gender**

An emergent theme from our review was that female gender correlated with increased knowledge. Studies from all across Europe showed that female adolescents had significantly more knowledge than males, a trend which is also replicated in the adult population (226). This is likely to be reflective of the fact that HPV is primarily thought of as a women's health problem and that the majority of countries presently only recommend the HPV vaccine for females. However HPV is responsible for many cancers in men too, including cancers of the anus, penis, oral cavity and oropharynx (444). Furthermore men share an equal burden for HPV related genital warts (445) and it is anticipated that prophylactic vaccines targeting HPV 16 and 18 in men, could reduce the risk of penile squamous cell carcinoma by approximately one third (446). The UK's Joint Committee on Vaccination and Immunisation has recommended that men who have sex with men (MSM) (aged 16-40 years) should also be offered the HPV vaccine (80). The cost effectiveness of the vaccine has been debated as the rational against vaccinating adolescent boys (80). Moreover it has been argued that boys will receive a degree of protection from the herd immunity effect of vaccinated girls. However, for this theory to be true the vaccination uptake rates would need to be much greater. MSM would not be offered protection by the herd immunity effect as with heterosexual men and it is MSM who are at a higher risk of HPV related malignancies (447). For vaccination to be optimally effective it should be offered prior to sexual debut as it is in girls. The difficulty is identifying this sub-group prior to sexual debut, therefore it would seem reasonable to adopt a population-based approach for the vaccination of boys. Moreover HPV vaccination is only a part of the solution, abstaining from high-risk behaviour is equally important. Parents feel that by including boys in HPV education and in the vaccination campaign we can reinforce their responsibility in sexual health (448) and also avoid girls feeling stigmatised by being the sole target (449). The challenge will be developing educational materials, which are equally relevant to both genders.



## **Introduction of the HPV vaccine into national immunisation programmes and funding**

The timing of HPV vaccine introduction across Europe has varied and integration into national immunisation programmes and/or funding is not universal. The results of this systematic review do not consistently support the concept that the timing of vaccine introduction or the availability of a fully state funded HPV vaccine results in increased awareness of HPV. The highest level of HPV awareness was noted in Italian schools girls, in a study conducted in 2009, one-two years after the HPV vaccine was introduced into the Italian national vaccination schedule (450) and the lowest levels were seen in 2007 in Sweden. The Swedish study was conducted prior to implementation of the HPV vaccine in Sweden in 2010 (451). In contrast studies from both Hungary (428) and the Netherlands (434, 436) showed a greater level of HPV awareness than in Germany (422), despite the former studies being conducted prior to the implementation of a free HPV vaccination programme in their respective countries (84) and the German study taking place four years post “free of cost” vaccine introduction in Germany (452). However, a study assessing HPV knowledge in an older cohort of 18-25 year old students, a year earlier in Germany, did find a much a higher level of awareness (453). These findings imply that much more complex factors are involved in acquiring knowledge and that the timing of introduction of national HPV vaccination alone is not predictive.

## **Delivery of information**

Vaccine introduction in many European countries was preceded by health promotion campaigns, including school-based presentations (454, 455). The successfulness of these campaigns may be questioned, as overall HPV knowledge in this cohort remains insufficient. As previously discussed, this review showed that the evidence for the impact of vaccine introduction on knowledge is inconsistent. This raises the possibility that information may have been inappropriately targeted in some countries. McCusker et al, who specifically compared HPV knowledge, pre- and post- a HPV health promotion campaign in the UK, found that the campaign did not over time add much in terms of HPV knowledge (440).

Many studies have explored how to optimally deliver HPV related health information, by evaluating numerous different modalities of information sharing. Some have suggested supplementing HPV health information with numerical data to improve HPV related risk knowledge and perception (454), whilst others have looked at the role of using films for education (456, 457) and school based educational interventions (458). Adolescents in this review described their main sources of information as media (TV/Radio), schools (school nurse/ health education sessions) and the internet (428, 431, 433, 440). They felt that although written information was useful, it needed to be more user friendly and complemented with nurse led small group discussions (438). Some noted gender differences in preferred sources of information; girls were more likely to obtain HPV related information from their mothers (422), parents (428) or magazines (422, 428). Health sciences students were more inclined to seeking information from schools/teaching places and male non-health sciences students from the media (435). Currently a recommendation cannot be made on the most effective way of communicating HPV related information, as no one method has been found to be superior (459). However it is apparent from this review that adolescents are requesting more information than that which is presently available (428, 431, 433, 437, 439). The main challenge remains in maintaining knowledge over time (456). When delayed post education follow-up has been conducted, even after only one month, the initially noted benefit is diminished (460). This suggests that there is a need for continued educational reinforcement as opposed to a single intervention session. This is particularly important with regards to cervical screening post vaccination. This review revealed that despite information on the role of cervical screening post HPV vaccination being available on the information leaflets provided (461), it is not understood well by all and therefore regular reminders will need to be sent. The inability to retain knowledge over a prolonged period of time may also provide an explanation for the lower levels of knowledge noted in some of the studies in this review. Studies that were conducted a few years post vaccine introduction may have shown lower levels of HPV knowledge reflecting poor retention as a result of diminishing media hype for the vaccine over time.

### **Organisation of vaccination programme, school based verses primary care/private**

It has been proposed that countries, such as the England and Australia, which have school based vaccination programmes have achieved higher vaccination coverage rates (459). However the studies within our review showed that England, which operates a school based vaccination programme, has a vaccine coverage rate of 86% (413) but Portugal, where the HPV vaccine is administered in primary care and health centres (452), also had a comparable coverage rate of 84% (412). Additionally some GP's in England, have expressed concerns over of school nurses' ability to provide adequate information (401). The organization of HPV vaccine administration did not correlate with level of knowledge in this review, however knowledge was related to vaccine uptake: Italy, England and Portugal had the highest levels of vaccine uptake and also the greatest amount of knowledge.

### **Overall Findings**

The findings of this review suggest that there are substantial gaps in the basic HPV knowledge of European adolescents. This is concerning given the high prevalence of HPV (462) and the serious long term implications of persistent HPV infection. Having an adequate understanding of HPV will permit adolescents to make a balanced choice regarding HPV vaccination and will furthermore influence their participation with preventative health strategies in the future. HPV triage and "test of cure" were introduced in England, in 2011 (463) and they are also offered by many other European countries (121, 464). Women have met this new protocol with anxiety, confusion and embarrassment due to the stigmatism associated with HPV (300). It is likely that unless adolescents are adequately informed about HPV they will either fail to participate due to the false illusion that they are fully protected or have similar fears when they attend for cervical screening. HPV plays a pivotal role in the present and future of preventative cancer strategies for both genders therefore serious thought needs to be given on the innovation on newer methods of information sharing to increase HPV awareness.

## *LIMITATIONS*

There have been previous systematic reviews assessing HPV knowledge in various different populations (226, 416, 417, 465, 466) but this is the most up to date review that focuses on the primary target group for the HPV vaccine: adolescents.

This review was a comprehensive mixed methods review, using this approach provides more accurate data, which is likely to have a greater impact than qualitative or quantitative data alone (467). However the review was limited by the scope of the primary studies. Five of the survey studies had not validated their questionnaires and there were considerable variations in the way specific aspects of HPV knowledge were assessed, for example prompted versus open questions. In this review an upper age limit of 20 years was used, this was primarily because some of the European studies, which had been conducted in secondary schools, had students who were 20 years old. As a result of this we also included studies that had been conducted at university level and although the average age of these students did not exceed 20 years, this is a vastly different population and moreover in some studies there was quite an extensive age range (435). To account for the wide age ranges within studies we worked on the average age for data analysis purposes.

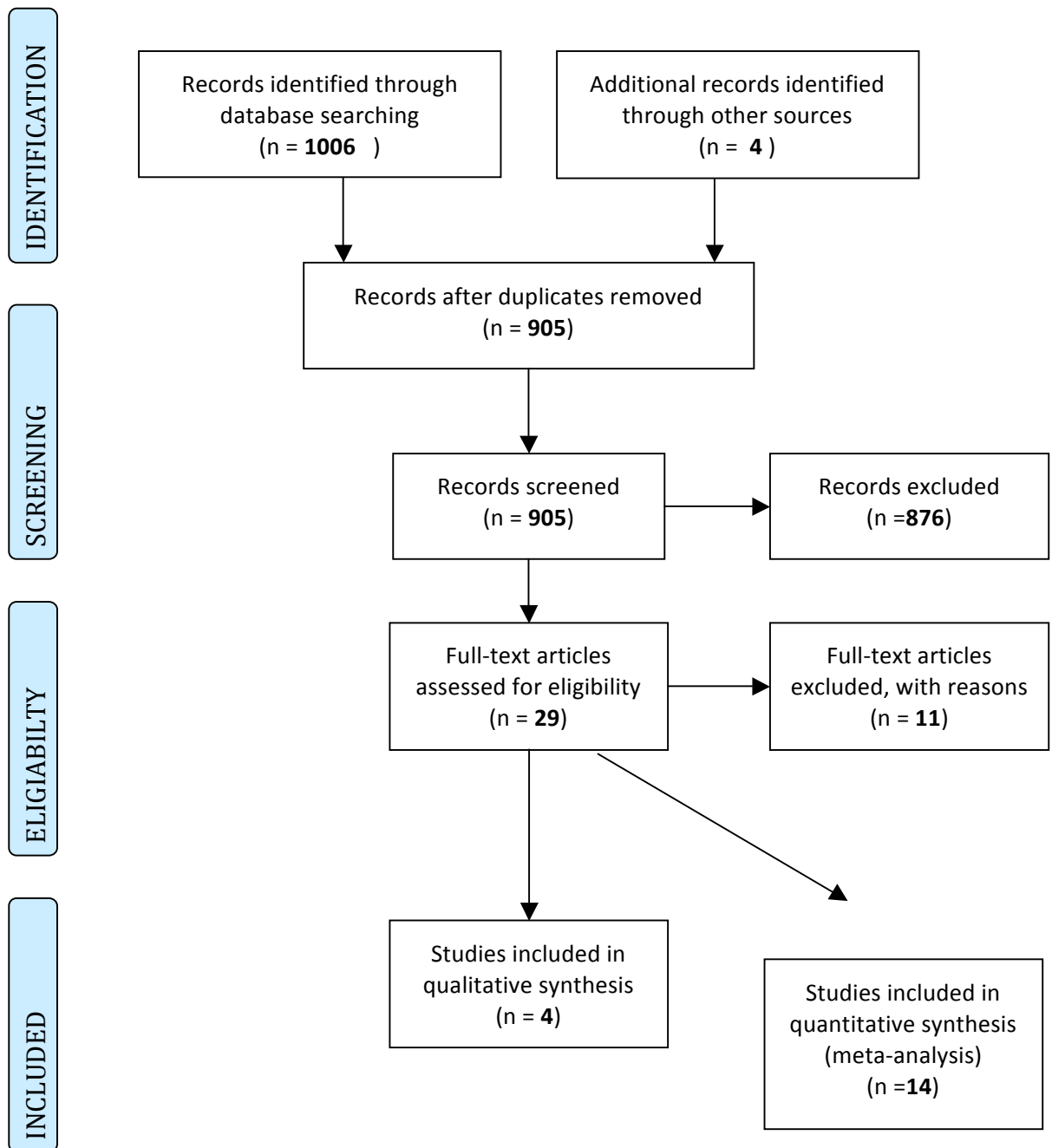
There was limited consideration given in many of the included studies to the role of social class or ethnicity on adolescent knowledge. This is an important determinant of cancer prevention so that cultural specific barriers are identified and resolved (465).

The majority of the studies employed a convenience sampling method, this resulted in samples that were not representative. The study populations were all heterogeneous and therefore difficult to truly compare. The most recent study included in this review was conducted in 2011 (422), which is three years from when the systematic review was performed. It is possible that since then that there have been further developments in the way in which HPV education is delivered and a more recent study is needed to provide an accurate assessment.

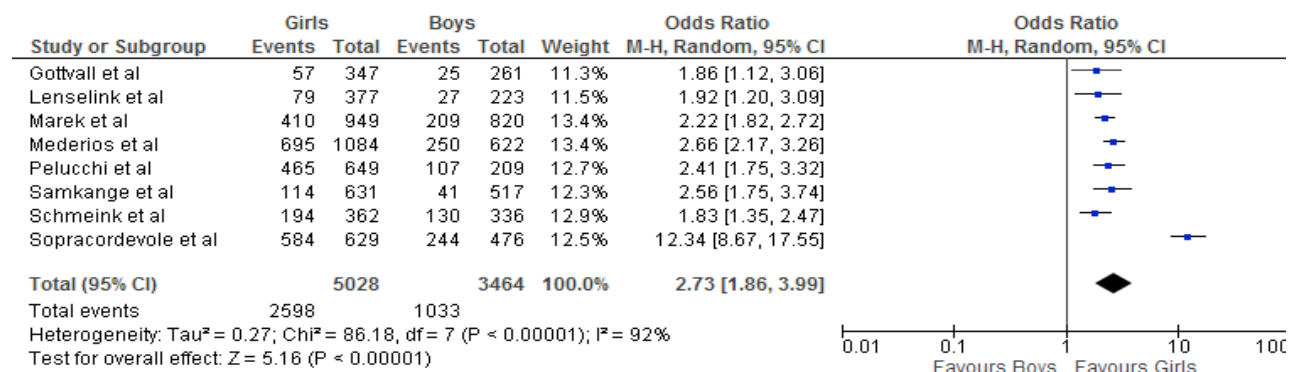
## **6.5 CONCLUSIONS**

Current evidence suggests that European adolescents have a limited understanding of basic factual HPV knowledge. Methods of delivering HPV information to this complex group need to be re-evaluated to promote increased awareness, as this will empower them to make informed choices regarding future preventative health behaviours.

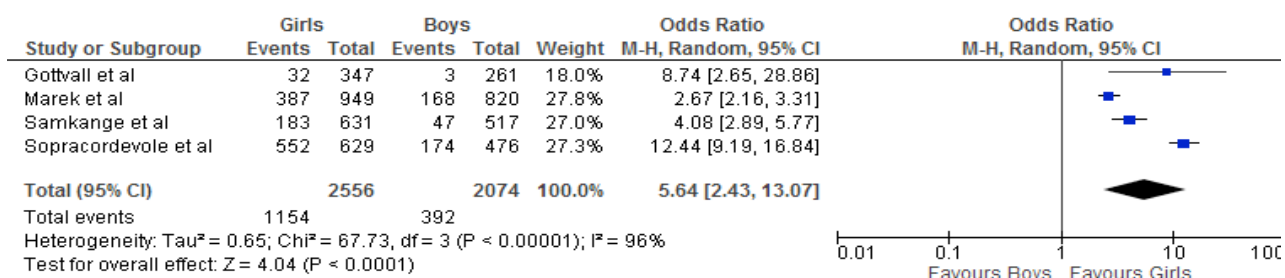
**Figure 6.1 PRISMA flow chart(419)**



**Figure 6.2** Meta-analysis results for the outcome *“Have you heard of HPV?”* A comparison between genders



**Figure 6.3 Meta-analysis results for the outcome “Have you heard of the HPV vaccine?” A comparison between genders**



**Table 6.1 Study Characteristics of qualitative studies**

Study/Country	Setting	Data Collection Method, Date	Participants	Method of Analysis	Key questions	Key Results
<b>Henderson et al 2011, 'A false sense of security'? Understanding the role of the HPV vaccine on future cervical screening behaviour: a qualitative study of UK parents and girls of vaccination age, UK</b>	39 schools and 4 General Practices, South-East England	Semi-structured interviews and small group discussion  Parents-July 2009- June 2010, Girls- Oct 2008-April 2010	37 parents  44 girls (14 unvaccinated, 30 vaccinated) Aged 12-13 years	Thematic combined with constant comparison of data	The level of protection offered by the HPV vaccine Decision-making in the context of awareness of the need for future cervical screening Information needs in relation to the HPV vaccine and future cervical screening	Uncertainty existed around the level of protection offered by the HPV vaccine. Girls were generally unclear of their need to attend screening in the future
<b>Hilton et al 2011, "I thought cancer was one of those random things. I didn't know cancer could be caught. . ." Adolescent girls' understandings and experiences of the HPV programme in the UK, UK</b>	Purposive recruitment, using adverts, leaflets, websites	18 focus groups (9 in Scotland, 9 in England) Dec 2009-May 2010	87 School girls Aged 12-18 years	Framework	Knowledge and understanding s about HPV infection and its link to cervical cancer Understanding s and concerns about HPV vaccination Vaccination experiences Understanding s of the importance of cervical cancer screening	Poor knowledge of HPV, only half were aware of the link to cervical cancer. HPV prevalence is underestimated and as a result girls assess their own likelihood of contracting HPV as low, believing that HPV infection is only common among people who have multiple sexual partners. Just over half were aware of the need for cervical screening in the future
<b>Racktoo et al 2009, 'HPV? Never heard of it' Students and the HPV vaccine, UK</b>	Northern city high school	4 focus groups, each with 5-6 students (Date of study not recorded)	21 girls Aged 12-13 years	Framework	Knowledge about HPV Concerns about the HPV vaccine Acceptability of the vaccination programme Information about HPV and the HPV vaccine	HPV and HPV vaccine knowledge is poor. Vaccine uptake is still high Better ways to deliver information are needed



<b>Williams et al 2011, Attitudes towards human papillomavirus vaccination: a qualitative study of vaccinated and unvaccinated girls aged 17–18 years, UK</b>	One state school and one state further education college	Face to face interviews March-May 2009	10 girls (5 vaccinated, 5 unvaccinated) Aged 17-18 years old	Framework	Knowledge of cervical cancer and HPV, their own and friends' experiences of and attitudes towards the HPV vaccine, and their decision to have it or not	Knowledge of HPV and the HPV vaccine was limited, some had not even heard of HPV Poor understanding of link to cervical cancer Misconceptions about HPV vaccine being for those that are sexually promiscuous
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**Table 6.2 Study characteristics for survey studies**

Study/Country	Setting	Data Collection Method, Date, Response Rate	Participants	Key questions	Key results
<b>Bowyer et al 2013,</b> Knowledge and awareness of HPV and the HPV vaccine among young women in the first routinely vaccinated cohort in England, <b>UK</b>	Thirteen state schools in London	September 2011 Self-completed questionnaire RR-98%	1047 participants Year 11 females Aged 15-16years old	Awareness and knowledge of HPV	80% were aware of HPV No difference were seen in ethnicity/religion/social class, however vaccinated participants were more likely to have heard of HPV Only three HPV knowledge items were answered correctly by over 60% of respondents; HPV can be passed on during sex (70.3%), having many sexual partners increases the risk of getting HPV (63.1%) and the vaccine requires three doses (69.8%)
<b>Di Giuseppe et al 2008,</b> Human papillomavirus and vaccination: knowledge, attitudes, and behavioural intention in adolescents and young women in Italy, <b>Italy</b>	Two Universities and six public secondary schools in Campania region, in the South of Italy	March-May 2007 Self-completed questionnaire RR- 99.5%	1341 participants in total No breakdown of school and university students Median age 19 years (range 14-24 years)	HPV knowledge Perceived risk of contracting HPV Sexual behaviour Sources of information	29.8 % reported that they have heard of HPV Only half had heard of cervical cancer 42% knew that the HPV vaccine was a preventative measure

<b>Forster et al 2012</b> , Interest in having HPV vaccination among adolescent boys in England, <b>UK</b>	College, South East England	March-September 2009 Self completed questionnaire RR- 89%	528 males, Aged 16-18 years	Knowledge of HPV (only have you heard of it) Intention to be vaccinated and reasons for and against	52% of boys had previously heard of HPV 41% said they intended to have HPV vaccination if it were available to them, 49% were unsure and 10% said they would not have it. None of the demographic factors were associated with increased awareness of HPV or intention to have the vaccine.
<b>Gottvall et al 2009</b> , High HPV vaccine acceptance despite low awareness among Swedish upper secondary school students. <b>Sweden</b>	24 classes, from one private and six public upper secondary schools, representing both vocational (31%) and theoretical (69%) educational programmes.	Autumn 2008 Self completed questionnaire RR- 86%	608 participates in total 347 females and 261 males Aged 15-16 years	General knowledge of sexually transmitted diseases Sources of information Knowledge of HPV and HPV vaccine.	88% answered questions regarding HPV knowledge with 'Don't know'. Only 13.5 % had heard of HPV and 5.8% of the HPV vaccine, girls are more likely to have heard of the vaccine Intention to use a condom decreased if the students themselves were to be vaccinated and they believed that other adolescents would share this view
<b>Hoglund et al 2009</b> , Knowledge of human papillomavirus and attitudes to vaccination among Swedish high school students. <b>Sweden</b>	Five High Schools in Sweden	2007 Self-completed questionnaire RR- 80%	459 students 250 females and 209 males Aged 15-20 years Mean age 16.2 years	Knowledge of sexually transmitted diseases Knowledge of HPV Sexual behaviours Attitudes towards HPV vaccination	More than half of the students had had sexual intercourse. HIV was noted as the most common STI, one person mentioned of HPV. Only 5% have ever heard of HPV. No difference in knowledge between boys and girls. They would be less interested in using condoms if vaccinated against HPV

<b>Lenselink et al 2008</b> , Young adults and acceptance of the human papillomavirus vaccine, <b>Netherlands</b>	2 university's and 1 non-university technical college	August-September 2005, Self-completed questionnaire RR- 91%	600 students 377 females and 223 males Aged 19-25 years Mean age 19.8 years	Knowledge of HPV, cervical carcinoma, Pap smears, and acceptance of HPV vaccination	17.7% in total had heard of HPV Medical students had more knowledge than other students Misconception existed regarding role of family history as risk factor for cervical cancer Only lower age and female gender were associated with vaccine acceptance Education and knowledge were not associated with acceptance
<b>Marek et al 2011</b> , Adolescents' awareness of HPV infections and attitudes towards HPV vaccination 3 years following the introduction of the HPV vaccine in Hungary, <b>Hungary</b>	Public primary and secondary schools from 16 Hungarian cities and towns, covering each of the 7 administrative regions of Hungary	January and May 2009 Self-completed questionnaire RR > 90%	1769 school students 596 were students of primary school Aged 12–14 years 1173 attended secondary school Aged 15–19 years	HPV/Cervical cancer knowledge Routes of transmission /prevention of sexually transmitted diseases Information sources Attitudes about screening/HPV vaccination	20% of male and 30% of female primary school students had previously heard of HPV 30% of male and 50% of female secondary school students had heard of HPV. Half of the participants thought that 'vaginal intercourse' was the only way of spreading HPV
<b>McCusker et al 2013</b> , Gaps in detailed knowledge of human papillomavirus (HPV) and the HPV vaccine among medical students in Scotland <b>UK</b>	University of Glasgow	Nov 2008 & Nov 2009 Self-completed questionnaire RR- 100% & 98.2%	2008- 150, 2009-217 1st year medical students Aged 17-20 years	Level of HPV knowledge The effect of HPV public information campaign on knowledge If men and women acquire similar level of knowledge from the same sources	96% & 92% (2008 & 2009) of females and 100% & 86 % of males were aware that HPV is sexually transmitted. 44% and 39% of females thought that 80-100% of cervical cancer is associated with HPV. (Male 46% & 35%). 50% & 73% females thought the vaccine covers 0-5 HPV types (52% & 51% males)

<b>Medeiros et al 2010,</b> Knowledge differences between male and female university students about human papillomavirus (HPV) and cervical cancer: Implications for health strategies and vaccination, <b>Portugal</b>	University of Porto, Six faculties split into health sciences and non-health sciences schools. One higher education nursing school	June 2007- June 2008 Self-completed questionnaire RR- 83% (calculated)	1706 university students 1084 females and 622 males From these 1113 were health sciences students (802 females and 311 males) and 593 were non-health sciences students (282 females and 311 males). Aged 17-35years Median and mean age 20 years	Knowledge about cervical cancer Knowledge about HPV Knowledge about the relationship between HPV and cervical cancer Attitudes and beliefs about HPV vaccination Attitudes and beliefs about sexual education.	55.4% (n = 945) of students had already heard of HPV, significant associations found between area of subject and awareness of HPV (health sciences Vs non health sciences) Knowledge of HPV, out of 32 the mean score was 15.56 (SD = 4.91). No statistical differences were found regarding gender, only with area of subject. Knowledge & beliefs about the relation between HPV & cervical cancer, statistical differences were found between the two groups by subject studied
<b>Pelucchi et al 2010,</b> Knowledge of human papillomavirus infection and its prevention among adolescents and parents in the greater Milan area, Northern Italy, <b>Italy</b>	Two middle schools in Milan (one private and one state run), Five high schools specialising in classical, linguistic or scientific studies (two private and three state run) in the greater Milan area and Varese, One state-run technical school in Milan.	May-June 2008 Self-completed questionnaires RR- 77% for parents RR - 79% for children	2,331 parents 863 children 649 females and 209 males 209 (5 students did not respond to gender question) Aged 14-20 years Mean age 16 years	Student questionnaire: HPV infection & vaccination Willingness to be vaccinated Sexual activity	Female and male students were 75% and 63% (p = 0.008) aware that the HPV vaccine is aimed at preventing cervical cancer Students- 68% of females and 40% of males said they would undergo HPV vaccination (p < 0.001). Female students who had a boyfriend or had engaged in sexual activity were less likely to be in favour of the vaccine 45% of the female teenagers perceived themselves at risk of HPV infection.

<b>Samkange-Zeeb et al 2013,</b> Awareness and knowledge of sexually transmitted diseases among secondary school students in two German cities, <b>Germany</b>	8 Secondary schools in Bremen and Bremerhaven in Northern Germany	Oct-Dec 2011 Self-completed questionnaire RR- 28%	1148 school children 632 females and 516 males Aged 12-20 years old Median age 15 years	Sexual Activity and information about sex. Awareness of STDs Knowledge of STDs, Awareness of HPV	13 % had heard of HPV. Significantly more females than males had heard of HPV (18 vs. 8 %), only 6% responded positively to all 3 HPV questions. 26 % were aware that HPV can cause cervical cancer (36 % of the girls and 15 % of the boys) and 20 % that it is possible to be vaccinated against HPV (29% of the girls and 9 % of the boys), With multivariate analysis; age, gender and having ever had sex remained the significant predictors of awareness of HPV.
<b>Schmeink et al 2011,</b> Young adults awareness of HPV and vaccine acceptance after introduction of the HPV vaccine in the Dutch national vaccination program, <b>Netherlands</b>	University students from Nijmegen, Netherlands	June-Dec 2009 Self-completed questionnaire RR- 96%	698 students 362 females and 336 males Aged 18-25 years Mean age 20.5	Sexual behaviour, vaccine acceptance, knowledge of HPV, cervical cancer and national cervical screening programme	46.4% were aware of HPV. Of these 87% knew that it was sexually transmitted, 79.6% thought that condom use is fully protective. 47.5% knew that the lifetime risk of acquiring HPV is >50%. 4.4% aware that it is asymptomatic. 83.4 % of all participants had heard of warts, but only 32% knew they were caused by HPV. Females had greater awareness than males and medical students had overall more knowledge.

**Table 6.3 Quality appraisal of qualitative studies**

	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between the researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Overall study quality
<b>Henderson et al 2011</b>	Yes	Yes	Yes	Yes	Yes	Not clear	Yes	Yes	Yes	Yes	M
<b>Hilton et al 2011</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	G
<b>Racktoo et al 2009</b>	Yes	Yes	Yes	Yes	Yes	Not clear	Yes	Yes	Yes	Yes	M
<b>Williams et al 2011</b>	Yes	Yes	Yes	Yes	Yes	Not clear	Yes	Yes	Yes	Yes	M

M= moderate quality

G= good quality

**Table 6.4 Quality appraisal of survey studies**

	Did the study address a clearly focused question / issue?	Is the research method (study design) appropriate for answering the research question?	Is the method of selection of the subjects clearly described?	Could the way the sample was obtained introduce selection bias?	Was the sample of subjects representative with regard to the population to which the findings will be referred?	Was the sample size based on pre-study considerations of statistical power?	Was a satisfactory response rate achieved?	Are the measurements (questionnaires) likely to be valid and reliable?	Was the statistical significance assessed?	Could there be confounding factors that haven't been accounted for?	Overall study quality
<b>Bowyer et al 2013</b>	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	M
<b>Di Giuseppe et al 2008</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	M
<b>Forster et al 2012</b>	Yes	Yes	Yes	Yes	No	No	Yes	Can't tell	Yes	No	M
<b>Gottvall et al 2009</b>	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	M
<b>Hoglund et al 2009</b>	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	G
<b>Lenselink et al 2008</b>	Yes	Yes	Yes	No	No	No	Yes	Can't tell	Yes	No	M
<b>Marek et al 2011</b>	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	No	M
<b>McCusker et al 2013</b>	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	No	M
<b>Medeiros et al 2010</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	G



<b>Pelucchi et al 2010</b>	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No	M
<b>Samkange-Zeeb et al 2013</b>	Yes	Yes	Yes	No	Yes	No	No	Can't tell	Yes	No	P
<b>Schmeink et al 2011</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	No	M
<b>Sopracordevole et al 2012</b>	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No	M
<b>Stöcker et al 2013</b>	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	M

M= moderate quality

G= good quality

**Table 6.5 Assessment of HPV knowledge by study**

Study	Heard/ Aware of HPV	MOT/ Protection	Link with cervical cancer & genital warts	Heard/ Aware of HPV vaccine	Level of protection offered by HPV vaccine	Need for cervical screening in the future
<b>Henderson et al 2011</b>	NA	NA	NA	NA	Understood that the vaccine offered high but not complete protection against CC	Uncertainty regarding the need for cervical smears in the future
<b>Hilton et al 2011</b>	NA	<ul style="list-style-type: none"> <li>• Little known about MOT but those that were aware of ST nature, perceived their own risk of contracting HPV as low, it was thought to be associated with “girls that sleep around”</li> <li>• Condoms and avoidance of sexual intercourse stated as protective factors</li> </ul>	About half were aware of the link to CC	NA	<ul style="list-style-type: none"> <li>• Referred to as the “cancer jab”, unable to provide details on the level of protection</li> <li>• Some believed that the vaccine protects against all high risk HPV types, others knew it protects only against some</li> </ul>	Only half of vaccinated girls were aware of the need for cervical smears in the future
<b>Racktoo et al 2009</b>	Only a few had heard of HPV	<ul style="list-style-type: none"> <li>• Misconceptions about MOT, spread in the same way as an air-borne virus-flu virus</li> <li>• Few identified MOT as ST</li> </ul>	Confusion about the link with CC, generally unaware	NA	Aware that the vaccine would not protect against all types of CC	Not well informed about the cervical screening programme
<b>Williams et al 2011</b>	Poor knowledge promoted as “cancer vaccine”	Misconceptions about the level of protection offered by condoms	Poor understanding of link with CC	NA	Aware it protects against CC	NA
<b>Bowyer et al 2013</b>	80% girls only	<ul style="list-style-type: none"> <li>• 70% ST<sup>a</sup></li> <li>• 55.4% Genital skin contact<sup>a</sup></li> <li>• 57.6% condoms protective<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>• 53.1% link with CC<sup>a</sup></li> <li>• 23.2% link with GW<sup>a</sup></li> </ul>	NA	<ul style="list-style-type: none"> <li>• 46.9% know that it protects against most CC<sup>a</sup></li> <li>• 35.7% knew that you can</li> </ul>	52.7% <sup>a</sup>

					still get CC even after vaccination	
<b>Di Giuseppe et al 2008</b>	29.8% girls only	<ul style="list-style-type: none"> <li>• 75.2% penetrative ST</li> <li>• 29.1%, non-penetrative ST</li> <li>• 34.8% condoms</li> </ul>	NA	NA	42.1% knew it reduces risk of CC	NA
<b>Forster et al 2012</b>	52% boys only	NA	NA	NA	NA	NA
<b>Gottvall et al 2009</b>	<ul style="list-style-type: none"> <li>• 16.4% girls,</li> <li>• 9.6% boys (p=0.017)</li> </ul>	ST <ul style="list-style-type: none"> <li>• 12.1% girls</li> <li>• 5.4% boys</li> </ul>	CC <ul style="list-style-type: none"> <li>• 11.8% girls</li> <li>• 3.1 % boys (p= &lt;0.001)</li> </ul> GW <ul style="list-style-type: none"> <li>• 2.9 girls</li> <li>• 3.8% boys</li> </ul>	<ul style="list-style-type: none"> <li>• 9.2% girls</li> <li>• 1.1% boys (p= &lt;0.001)</li> </ul>	NA	NA
<b>Hoglund et al 2009</b>	5% <sup>b</sup>	2.9% ST <sup>b</sup>	1.2% link to CC <sup>b</sup> 1.4 % link to GW <sup>b</sup>	1.1% <sup>b</sup>	NA	NA
<b>Lenselink et al 2008</b>	<ul style="list-style-type: none"> <li>• 21% girls,</li> <li>• 12.1% boys (p=&lt;0.01)</li> </ul>	<ul style="list-style-type: none"> <li>• 84% ST<sup>a,b</sup></li> <li>• 16% condom not fully protective<sup>a,b</sup></li> </ul>	81% link to CC <sup>a,b</sup>	NA	NA	NA
<b>Marek et al 2011</b>	12-14yrs <ul style="list-style-type: none"> <li>• 31.2% girls,</li> <li>• 19.3% boys (p=0.002)</li> </ul> 15-19yrs <ul style="list-style-type: none"> <li>• 49.1% girls,</li> <li>• 28.8% boys (p=0.000)</li> </ul>	ST (vaginal) <ul style="list-style-type: none"> <li>12-14 yrs               <ul style="list-style-type: none"> <li>• 40.1% girls</li> <li>• 43.2% boys</li> </ul> </li> <li>15-19yrs               <ul style="list-style-type: none"> <li>• 50.7% girls</li> <li>• 47.1% boys</li> </ul> </li> </ul> ST (any form) <ul style="list-style-type: none"> <li>12-14yrs               <ul style="list-style-type: none"> <li>• 53.7% girls</li> <li>• 48.3% boys</li> </ul> </li> <li>15-19yrs               <ul style="list-style-type: none"> <li>• 44.5% girls</li> <li>• 47.7% boys</li> </ul> </li> </ul> Skin to skin <ul style="list-style-type: none"> <li>12-14 yrs               <ul style="list-style-type: none"> <li>• 6.6% girls,</li> <li>5.5% boys</li> </ul> </li> <li>15-19yrs               <ul style="list-style-type: none"> <li>• 3.3% girls,</li> <li>5.7% boys</li> </ul> </li> </ul> Condoms fully protective <ul style="list-style-type: none"> <li>12-14yrs               <ul style="list-style-type: none"> <li>• 18% girls,</li> <li>30.2% boys (p=0.002)</li> </ul> </li> <li>15-19yrs               <ul style="list-style-type: none"> <li>• 24% girls,</li> </ul> </li> </ul>	CC <ul style="list-style-type: none"> <li>12-14<sup>a</sup> <ul style="list-style-type: none"> <li>• 43% girls</li> <li>• 45.5% boys</li> </ul> </li> <li>15-19<sup>a</sup> <ul style="list-style-type: none"> <li>• 54% girls</li> <li>• 48.7 boys (p=0.037)</li> </ul> </li> </ul> GW <ul style="list-style-type: none"> <li>12-14<sup>a</sup> <ul style="list-style-type: none"> <li>• 16.5% girls</li> <li>• 27.3% boys</li> </ul> </li> <li>15-19<sup>a</sup> <ul style="list-style-type: none"> <li>• 28.4% girls</li> <li>• 33.8% boys</li> </ul> </li> </ul>	12-14 years <ul style="list-style-type: none"> <li>• 29.3% of girls</li> <li>• 13.7% of boys (p=0.000)</li> </ul> 15-19yrs <ul style="list-style-type: none"> <li>• 46.4% girls</li> <li>• 24.1 boys (p=0.000)</li> </ul>	NA	NA

29.3% boys						
<b>McCusker et al 2013</b>	NA	ST <ul style="list-style-type: none"> <li>• 96% &amp; 92% girls (2008/2009)</li> <li>• 100% &amp; 86% boys (2008/2009)</li> </ul>	CC <ul style="list-style-type: none"> <li>• 44% &amp; 39% girls (2008/2009)</li> <li>• 46% &amp; 35% boys (2008/2009)</li> </ul>	NA	HPV vaccine protects against 0-5 types of HPV <ul style="list-style-type: none"> <li>• 50% &amp; 73% girls (2008/2009)</li> <li>• 52% 51% boys (2008/2009)</li> </ul>	94% of fully vaccinated girls would attend for cervical smears in the future (2009)
<b>Medeiros et al 2010</b>	<ul style="list-style-type: none"> <li>• 64.1% girls</li> <li>• 40.2% boys</li> </ul>	Health sciences students (boys and girls) more likely to say vaginal ST and skin contact than non-health science students. (figures not provided)	CC <ul style="list-style-type: none"> <li>• 70.7-91.2% girls<sup>a</sup></li> <li>• 63.6-89.3% boys<sup>a</sup></li> </ul>	NA	NA	NA
<b>Pelucchi et al 2010</b>	<ul style="list-style-type: none"> <li>• 72% girls,</li> <li>• 51% boys</li> </ul> <p>(p&lt;0.001)</p>	ST <ul style="list-style-type: none"> <li>• 90.5% girls,</li> <li>• 92.5% boys</li> </ul>	90.5% of girls, 89.7% boys perceive HPV as “dangerous”	NA	To prevent CC <ul style="list-style-type: none"> <li>• 75.3% girls</li> <li>• 62.6% boys</li> </ul> To prevent a STD <ul style="list-style-type: none"> <li>• 12% girls</li> <li>• 14% boys</li> </ul>	NA
<b>Samkange-Zeeb et al 2013</b>	<ul style="list-style-type: none"> <li>• 18% girls</li> <li>• 8% boys</li> </ul> <p>(p&lt;0.001)</p>	NA	CC <ul style="list-style-type: none"> <li>• 36% girls</li> <li>• 15% boys</li> </ul>	<ul style="list-style-type: none"> <li>• 29% girls,</li> <li>• 9% boys</li> </ul>	NA	NA
<b>Schmeink et al 2011</b>	<ul style="list-style-type: none"> <li>• 53.6 % girls</li> <li>• 38.7% boys</li> </ul> <p>(p&lt;0.01)</p>	<ul style="list-style-type: none"> <li>• 87.6% ST<sup>a,b</sup></li> <li>• 79.6% condom fully protective<sup>a,b</sup></li> </ul>	CC <ul style="list-style-type: none"> <li>• 55.5% girls</li> <li>• 45.9% boys (p=0.01)</li> <li>• 32% GW<sup>b,c</sup></li> </ul>	NA	NA	NA

<b>Sopracordevole et al 2012</b>	<ul style="list-style-type: none"> <li>• 92.8% girls</li> <li>• 51.3% boys</li> </ul>	ST <ul style="list-style-type: none"> <li>• 74.7% girls<sup>a</sup></li> <li>• 60.7% boys<sup>a</sup> (p&lt;0.001)</li> </ul> Condoms protective <ul style="list-style-type: none"> <li>• 72.6% girls<sup>a</sup></li> <li>• 61.5% boys<sup>a</sup> (p=0.002)</li> </ul>	CC <ul style="list-style-type: none"> <li>• 93.8% girls<sup>a</sup></li> <li>• 72.5% boys<sup>a</sup> (p&lt;0.0001)</li> </ul> GW <ul style="list-style-type: none"> <li>• 17.3% girls<sup>a</sup></li> <li>• 18.4% boys<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>• 94.5% of girls<sup>a</sup></li> <li>• 71.3% boys<sup>a</sup> (p&lt;0.001)</li> </ul>	Protects against CC <sup>d</sup> <ul style="list-style-type: none"> <li>• 97.1% of girls</li> <li>• 77% of boys (p&lt;0.001)</li> </ul> Protects against GW <sup>d</sup> <ul style="list-style-type: none"> <li>• 13% girls</li> <li>• 13.2% boys</li> </ul> Protects against HIV/AIDS <sup>d</sup> <ul style="list-style-type: none"> <li>• 7.6% of female, 21.3% of boys (p&lt;0.001)</li> </ul>	Smear after vaccination <ul style="list-style-type: none"> <li>• 93.3% girls, 81.6% boys (p&lt;0.001)</li> </ul> Use of condoms after vaccination <ul style="list-style-type: none"> <li>• 75.5% of girls 51.7% of boys (p&lt;0.001)</li> </ul>
<b>Stöcker et al 2013</b>	NA	ST <ul style="list-style-type: none"> <li>• 73.1% girls,</li> <li>• 52.5% boys ST (p&lt;0.001)</li> </ul>	CC <ul style="list-style-type: none"> <li>• 50.8-64% girls<sup>e</sup></li> <li>• 43.9% boys</li> </ul>	NA	NA	NA

- a = assessed only in those that had heard of HPV
- b = no breakdown between sexes given but reported that no significant difference was noted
- c= assessed only in those that had heard of GW
- d= assessed in those that had heard of both HPV and HPV vaccine
- e= unvaccinated/ vaccinated girls
- MOT- mode of transmission
- ST- sexually transmitted
- CC- cervical cancer
- GW – genital warts
- NA- not assessed

## **7 ADOLESCENTS' AWARENESS OF HPV INFECTION AND ATTITUDES TOWARDS HPV VACCINATION 5 YEARS FOLLOWING THE INTRODUCTION OF THE HPV VACCINE IN LATVIA**

### **7.1 INTRODUCTION**

The systematic review conducted to assess the level of HPV and HPV vaccine knowledge in European adolescents (Chapter 6) revealed a paucity of data in this group from EE countries. In order to address this knowledge deficit, a study was conducted in Latvian adolescents, due to the previously mentioned established research relationships with collaborators in Riga, Latvia. Furthermore it allowed a direct comparison of two populations, adult and adolescent, from the same EE country. Thereby enabling exploration of service user perspective and knowledge of cervical cancer prevention as a whole.

The most recent figures show that the incidence rates, of cervical cancer in Latvia, have increased from 8.9/100,000 in 1989 to 23.4/100,000 in 2011(313). Despite a total population of than less 2 million(468), there were 284 new diagnoses of cervical cancer in 2012 and it is the second most common cancer affecting young women (15-44 years old) in Latvia(349).

HPV is one of the most common sexually transmitted infections(41) and it is highly prevalent in the young sexually active population(469). HPV prevalence in EE has been estimated to be high as 21.4% compared to a global prevalence of 11.7%(298). Data on HPV prevalence in Latvia is scarce and out-dated, however the most recent estimates show an overall prevalence of 26.2%(470). HPV vaccination was introduced as part of a state funded national programme in 2010(471). In Latvia, all adolescent girls aged 12 are eligible for fully state funded HPV vaccination(452). Delivery of the vaccine has been through a combination of schools and primary care health centres(349). Data on vaccine coverage shows that uptake was only approximately 60% in 2011(339) and 53.4% in 2012(82). More recent coverage data are not yet available.

The aim of this study was to explore the level of HPV and HPV vaccine knowledge in Latvian adolescents 5 years after the introduction of the HPV vaccine.

## **7.2 METHODS**

### **7.2.1 Sampling Frame**

The sampling frame was defined as all Latvian adolescents attending secondary education, in Riga. No age criteria were set as the aim was to sample as large a sample as achievable and to cover a wide age range if possible.

### **7.2.2 Data Collection Methods**

An anonymous paper based survey tool was used. In view of the time constraints in which the study needed to be conducted and the resource limitations, using a paper-based survey was thought to be the best option. Paper-based surveys result in marginally higher response rates and are less resource intensive(472).

### **7.2.3 Questionnaire Development**

The survey was developed following an extensive literature search of published survey studies on HPV/vaccination knowledge in this population group(351). Further appropriate questions were selected from a validated HPV knowledge tool(227) and adapted for the Latvian population. The survey was developed in English and then translated into Latvian by our Latvian collaborators. The final survey consisted of 6 sections (socio-demographics, smoking status and sexual behaviours, smear history, STI knowledge, HPV and HPV vaccine knowledge and sources of information) and 30 question items. The majority of the questions were closed questions and with either a multiple choice answer format or true/false/don't know format for the knowledge questions (Appendix VI). Using the closed question format has been shown to reduce the amount of missing data compared to open-ended questions and increase the response rate(473).

### **7.2.4 Recruitment of Participants**

A convenience sample of students attending a state funded secondary school Riga, were recruited. Recruiting from a state funded school ensured an equal representation of students from varying social backgrounds and Riga is home to one third of Latvia's

total population(474). Selection of the school was based on established relationships with the head teacher of the school, resulting in ease of access.

In September 2015 the paper-based survey was administered to grade 10, 11 and 12 students during a sexual health teaching session since it was felt that this was the most appropriate time. . Ethical matters that required consideration included the age at which it would be appropriate to distribute the questionnaire. The questionnaire was largely regarding a STI and contained questions pertaining to sexual behaviours. Consideration needed to be given to what was both ethically and culturally acceptable. It was therefore decided that by administering the questionnaire during a sexual health class, cultural and ethical acceptability could be assumed. During this class discussions of a similar nature were already taking place and by default our sample was limited to those adolescents who were old enough to be receiving sexual health education. The survey was distributed at the beginning of the teaching session and the students were given 20 minutes to complete the anonymous survey. By providing the students with a specific time and place in which to complete the survey it has was hoped that this would result in a greater response rate because in effect a “captive audience” had been created.

#### **7.2.5 Data Analysis**

The data were transferred into the SPSS, version 22 and the responses were numerically coded. Descriptive statistics were generated for the responses and Chi square test or Fisher exact test as appropriate were used for univariate analysis. All reported P-values were assessed using two-sided tests and statistical significance was taken as a cut-off of  $p < 0.05$ . Each question was analysed individually to account for missing responses.

Ethical approval for the study was obtained from the University of Latvia ethics commission board (13/08/2015).

### **7.3 RESULTS**

In each grade there were three classes consisting of 30 students each, resulting in a total sample size of 270. A total of 121 surveys were completed giving a response rate of 45%. Male and female students were equally represented, 51% (n=62) and 49% (n=59)



respectively. The median age of the students was 18 years (range 16-21 years) and most of the participants were of white Latvian ethnicity (n=119, 98.3%) (Table 7.1).

Only 15% (n=18) of the students were smokers but 58% (n=70) were sexually active, with no difference in gender noted for either of the two outcomes (Table 7.2). When the results were analysed by age it was noted that all 5 students aged 19 years and above and 74% (n=45) of 18 year olds were sexually active compared to only 36% (n=20) of 16-17 year olds ( $p<0.001$ ). In the 19 years and above age group 40% of them had had 3 or more sexual partners.

Condoms were stated as the most popular form of contraception (86%, n=60) amongst both male and female students. Even though only 6% (n=4) stated that they did not use any contraception, 39% (n=26) disclosed that they did not always use contraception.

### ***Cervical Screening***

Eight (13%) girls stated that they had previously had a cervical cytology test and a further 12 (20%) were not sure if they had one or not. The age of first smear test ranged from 14 to 18 years, median age 17 years.

### ***Knowledge of Sexually Transmitted Infections***

Just 21% (n=25) of the students were able to name three sexually transmitted infections (STIs), and 12% (n= 15) were not even able to name one. One third (33%) of the students aged 16 were not able to name any STIs compared to 17% and 7% of 17 and 18 year olds respectively ( $p=0.04$ ). All respondents above 19 years could recall at least one STI, but overall there was no significant gender difference in their ability to recall STIs (Table 7.3). HIV/AIDS were the most commonly named STI by all students, followed by syphilis, gonorrhoea and herpes.

### ***Knowledge of HPV***

Only 26 respondents (21%) said that they had heard of HPV (Table 7.3). Female students had greater awareness of HPV than male students (36% compared to 8%,  $p<0.001$ ). In those who had heard of HPV, 69% (n=18) correctly identified sexual and genital skin-to-skin contact (27%, n=7) as modes of transmission (Table 7.4). Some

respondents erroneously stated that HPV transmission occurs through blood transfusions and the use of public toilets. The use of condoms (81%, n=21), the HPV vaccine (50%, n=13) and good personal hygiene (35%, n=9) were thought to confer protection against HPV. When the students were asked about conditions that are caused by HPV infection, 73% (n=19) knew of the association with cervical cancer, with female students having a greater level awareness (86% versus 20%, p=0.01). Only 27% (n=7) were aware of the association of HPV with genital warts and none identified its link to penile cancer. Of concern is that 19% of respondents (n=5) thought that HPV was causative of HIV/AIDS. No association was found between HPV awareness and the other socio-demographic factors (Table 7.5).

### ***Knowledge of the HPV vaccine***

Overall knowledge of the HPV vaccine was very poor, only 10% (n=12) had heard of the vaccine and more females than males had heard of the HPV vaccine (19% versus 2%, p= 0.007) (Table 7.6). Only four (7%) female students reported having had the vaccine. The respondents believed that the age of vaccination in Latvia ranged from 11 to 18 years. Assessment of detailed HPV knowledge in those who had heard of the HPV vaccine showed that six out of the eleven female students had left the questions unanswered and the only male student who had heard of the HPV vaccine had selected the "not sure" option for all of the questions. In those females who had attempted to answer the questions, four out of five were aware of the three-dose vaccine schedule and appreciated the level of protection offered by the vaccine; three out of five correctly identified the need for cervical screening and the risk of development of cervical cancer following vaccination. Four of the female students understood that the vaccine does not provide protection against all STIs.

### ***Sources of information***

Only 4% of the students (n=5) felt adequately informed about HPV in contrast to 66% (n=80) who strongly disagreed/disagreed that they were adequately informed. The most popular sources of information were the Internet, school and doctors. There was no significant difference in gender noted with regards to sources of information (Table 7.7).

## 7.4 DISCUSSION

This study demonstrates that awareness about HPV and the HPV vaccine amongst Latvian adolescents is poor. These findings are consistent with that of the systematic review, described in Chapter 6, which explores all European studies that have been conducted in this group(351). HPV knowledge in adolescents from other EE countries has been shown to be variable, only 22% of Romanian adolescents aged 16-18(361) had heard of HPV compared to 40% of Hungarian adolescents aged 15-19 years(428). There was a lack of appreciation of detailed HPV and HPV vaccine knowledge, however it was difficult to draw any firm conclusions as so few had heard of HPV or the HPV vaccine in the first instance. The mixed methods study conducted amongst the adult female population in Latvia (Chapter 4) similarly revealed poor awareness of HPV. In view of this one may question the effectiveness of any HPV awareness campaigns that may have taken place during the introduction of the HPV vaccine, in Latvia. Further the method of information sharing or obtaining informed consent for HPV vaccination may require exploration and modification. Although HPV vaccine attitudes were not specifically explored in this study, in the adult study it was clear that negative vaccine attitudes had been developed due to vaccine misconceptions.

Most of the respondents correctly identified mode of viral transmission as sexual but recognition of the role of genital skin-to-skin contact was under valued. Other researchers have noted similar misconceptions regarding mode of HPV transmission, whereby adolescents have believed that transmission occurs through an air-borne route(438), through blood transfusions(435) and the use of public toilets(423). Most of the students were knowledgeable about the causative relationship between HPV and cervical cancer but not of that between HPV and genital warts or HPV and penile cancer. One possible explanation for this is that when the HPV vaccine was introduced the emphasis may have been on its role in the prevention of cervical cancer rather than any other association. Also, it may stem from the belief that by minimizing the connection of HPV with genital warts the stigma associated with it as an STI could be reduced and hence vaccine acceptance would be greater(475). Acknowledgement of HPV as a STI was met with shame and embarrassment in the adult Latvian population.

Female gender was the only factor found to correlate with increased awareness of HPV and the HPV vaccine. This has also consistently been reported upon in other studies both in the adolescent(351) and adult populations(226). Thus far the main focus for prevention of HPV infection and/or resultant conditions has been on females. However, there is now an increased appreciation of the equal burden of HPV infection in males(445) and the possible serious long term sequel of HPV infection with regards to the risk of malignancies of the anus, penis, oral cavity and oropharynx(444). The vaccine is not currently recommended for adolescent boys in Latvia.

Furthermore, general awareness of STIs was deficient, with some students unable to recall even one STI. This was surprising, as the survey had been administered during a sexual health class. Low levels of knowledge and awareness of STIs have also been reported on in other European countries(442). HIV/AIDS were by far the most commonly mentioned STIs, it likely that is reflective of the extensive global awareness campaigns for HIV/AIDS which have taken place since the 1980's(442). Education of HIV/AIDS appears to have eclipsed that of other STIs, even though the prevalence of HPV in adolescents is dramatically higher(476). In contrast to HPV awareness, no gender divide was found with regards to awareness of STIs in general. This further emphasises that the transmission of HPV infection is not thought of as a shared responsibility between males and females in the same manner as other STI's.

It was evident that Latvian adolescents participated in high-risk behaviours, more than half had been sexually active and almost 40% had already had more than three sexually partners. Multiple sexual partners has been identified as risk factor for both acquisition and persistence of high-risk HPV infection(477, 478). This finding has also been noted in heterosexual males with regards to penile infection with high-risk HPV types(479). The majority of the respondents stated that they used contraception; although it was of concern that almost 40% of these admitted that this was not always the case. Condoms were the most commonly used form of contraception. It has been suggested that condoms may not prevent infection with HPV, as infection may occur and/or be transmitted from an epithelial surface that is not covered, however it may still provide protection against the development of HPV related conditions(480).

Half of the respondents mentioned that the HPV vaccine was a method of reducing the risk of acquiring the virus, although in our cohort only 7% of the females had received the HPV vaccine. This is despite the fact that it has been offered free of cost to all females aged 12 years since 2010(349), therefore most of the females in this cohort would have been eligible for free vaccination. Some researchers have identified greater vaccine knowledge to positively correlate with vaccine uptake(354). In addition, HPV vaccine attitudes and perceptions of the parents(481, 482) and the school nurses(483, 484) are believed to play a part. Latvian mothers have been found to have poor HPV vaccine related attitudes and similarly uptake of cervical cancer screening is also suboptimal(121). Maternal screening behaviours have equally been shown to be linked to HPV vaccine initiation(485).

Despite the recommended age for commencement of cervical cancer screening in Latvia being 25 years, 13% of the female adolescents in our study had already had a cervical smear test performed although none these students, had received the HPV vaccine. It may be inferred from this that these female adolescents, either they themselves or through the beliefs of their parents, appreciated the need for prevention of cervical cancer but believed that secondary prevention is superior to primary prevention. The other argument is that they (the mothers or the daughters) are not specifically concerned about the prevention of cervical cancer but that the smear tests were performed, as part of the “annual gynaecological review” which we have discovered is prevalent amongst Latvian women. The implication being that there is a need to “protect” the reproductive organs as a whole rather than to prevent the development of cervical cancer. Hence, explaining the difference in uptake of primary and secondary prevention.

The majority of students themselves felt inadequately informed about HPV and most of their knowledge was acquired from the Internet, school and doctors. Communicating HPV related knowledge to this group is a challenge and thus far the most optimal method for doing this has not been identified(459). Physicians find it challenging to talk about the HPV vaccine and are less likely to endorse it compared to other childhood vaccinations(486), this itself can result in a lower intention to be vaccinated. Physician recommendation is particularly relevant to this group as it was noted in the adult study that the Latvian population invest a lot of trust in their doctors.

### *LIMITATIONS*

There were limitations to this study. The sample size is relatively small and therefore the representativeness of these data may be questioned however, these data provide a glimpse into the understandings of this previously unstudied group. Ideally sampling more than one school and a random selection of schools would have resulted in more representable data and would have been the preferred option. Sampling schools from more rural areas would have again resulted in more representable data but also in addition highlighted issues concerning access to and availability of healthcare, which may differ from that in a major city. However due to clinical governance limitations and access issues to these other educational institutions this was not possible and presents a flaw in the methodology.

It may be argued that by administering the survey during a sexual health class an element of bias was introduced, conversely the findings of this study showed that despite this “advantage” the students did not perform very well. In addition the low response rate may indicate disengagement of the students with the topic of sexual health, as despite been given allocated time during the class to complete the survey more than half opted not to do so. Interpretation of the detailed HPV knowledge questions was limited as so few of the students had heard of HPV/HPV vaccine and even in those who had many did not attempt to answer these questions, although this finding in itself can be perceived as lack of knowledge.

### **7.5 CONCLUSIONS**

Cervical cancer is a major health burden for Latvian women. HPV vaccination appears to be the best available method of prevention however, uptake rates need to be much higher for there to be a substantial impact on the existing high prevalence of HPV in Latvia. Through increased awareness and education on HPV and STIs, vaccine acceptance might be enhanced and participation in high-risk behaviours may be reduced.

**Table 7.1 Socio-demographic characteristics**

		<b>Total (n=121)</b>	<b>Male (n=62)</b>	<b>Female (n=59)</b>
<b>Age* (median/range)</b>		18 (16-21)		
<b>Ethnicity* n(%)</b>	White Latvian	119 (99)	61 (100)	58 (98)
	Asian	1(1)	0	1 (2)
<b>Religion ** n(%)</b>	Roman Catholic	22 (19)	14 (24)	8 (14)
	Lutheran	37 (31)	15 (25)	22 (37)
	Christian Other	5 (4)	4 (7)	1 (2)
	Jewish	2 (2)	0	2 (3)
	Hindu	2 (2)	1 (2)	1 (2)
	Buddhist	3 (3)	0	3 (5)
	Prefer not to say	10 (8)	5 (8)	5 (8)
	Atheist	17 (14)	11 (19)	6 (10)
	Other (not specified)	20 (17)	9 (15)	11(19)

\* 1 response missing

\*\* 3 responses missing

**Table 7.2 Smoking status and sexual behaviours**

		Total n (%)	Male (n=62) n (%)	Female (n=59) n (%)	$\chi^2$ P value
<i>Do you smoke?</i>	Yes	18 (15)	9 (15)	9 (15)	0.91
	No	103 (85)	53 (85)	50 (85)	
<i>Have you been sexually active?*</i>	Yes	70 (58)	39 (63)	31 (53)	0.25
	No	51 (42)	23 (37)	28 (47)	
<b>In those who were sexually active: Male, n= 39, Female, n=31</b>					
<b>Total number of sexual partners</b>	1	27 (39)	14 (36)	13 (42)	0.44
	2	17 (24)	8 (21)	9 (29)	
	3 or more	26 (37)	17 (44)	9 (29)	
<b>Contraception used</b>	Condoms	60 (86)	38 (97)	22 (71)	<b>0.004</b>
	Contraceptive pill	5 (7)	0	5 (16)	n/a
	No contraception	4 (6)	1 (3)	3 (10)	0.31
	Other	1 (1)	0	1 (3)	n/a
<b>Always uses contraception (in those who use contraception: Male, n= 38, Female, n=28)</b>	Yes	40 (61)	22 (58)	18 (64)	0.6
	No	26 (39)	16 (42)	10 (36)	

\* Fisher exact test due to small sample size



**Table 7.3 Knowledge of STIs and HPV**

<i>Can you name three STIs?</i>		<b>Total n=121 n (%)</b>	<b>Male n=62 n (%)</b>	<b>Female n= 59 n (%)</b>	<b><math>\chi^2</math> P value</b>
<b>Number of STI's named</b>	0	15 (12)	4 (6)	11 (19)	0.24
	1	42 (35)	20 (32)	22 (37)	
	2	39 (32)	27 (44)	12 (20)	
	3	25 (21)	11 (18)	14 (24)	
<b>Most commonly named STI's (Of those that named at least one, Total n=106; male, n=58, female, n=48)</b>	HIV/AIDs	96 (91)	51 (88)	45 (94)	0.31
	Syphilis	33 (31)	24 (41)	9 (19)	<b>0.012</b>
	Gonorrhoea	24 (22)	15 (26)	9 (19)	0.38
	Herpes	22 (21)	13 (22)	9 (19)	0.64
	HPV	8 (8)	2 (3)	6 (13)	0.14*
	Hepatitis	7 (7)	3 (5)	4 (8)	0.7*
	Chlamydia	7 (7)	3 (5)	4 (8)	0.7*
<b><i>Have you heard of HPV?</i></b>	Yes	26 (21)	5 (8)	21 (36)	<b>&lt; 0.001</b>
	No	81 (67)	51 (82)	30 (51)	
	Not sure	14 (12)	6 (10)	8 (14)	

\* Fisher exact test due to small sample size

**Table 7.4 Detailed HPV knowledge in those who had heard of HPV**

		<b>Total n=26 n (%)</b>	<b>Male n=5 n (%)</b>	<b>Female n= 21 n (%)</b>	<b>Fisher exact P value</b>
<b><i>How is HPV transmitted (select all true options)?</i></b>	Sexual	18 (69)	3 (60)	15 (71)	0.63
	Blood transfusion	3 (12)	1 (20)	2 (10)	0.49
	Genital skin to skin contact	7 (27)	2 (40)	5 (24)	0.59
	Using public toilets	1 (4)	1 (20)	0	0.19
		6 (23)	1 (20)	5 (24)	1
	Not Sure				
<b><i>How can you reduce your risk of getting HPV (select all true options)?</i></b>	Condoms	21 (81)	3 (60)	18 (86)	0.23
	OCP	0	0	0	
	HPV vaccine	13 (50)	2 (40)	11 (52)	1
	Personal Hygiene	9 (35)	2 (40)	7 (33)	1
	Antibiotics	0	0	0	
	Don't Know	3 (12)	1 (20)	2 (10)	0.49
<b><i>Which conditions are caused by HPV(select all true options)?</i></b>	Cervical Cancer	19 (73)	1 (20)	18 (86)	<b>0.01</b>
	Genital Warts	7 (27)	3 (60)	4 (19)	0.10
	HIV/AIDs	5 (19)	1 (20)	4 (19)	1
	Hepatitis	2 (8)	1 (20)	1 (5)	0.35
	Infertility	4 (15)	0	4 (19)	0.56
	Penile Cancer	0	0	0	
	None of the above	0	0	0	

**Table 7.5 Associations between socio-demographic factors and awareness of HPV**

		<b>Have you heard of HPV?</b>		$\chi^2$ P value
		<b>Yes n (%)</b>	<b>No n (%)</b>	
<b>Age</b>	≤ 17 years	10 (18)	45 (82)	0.39
	≥ 18 years	16 (25)	49 (75)	
<b>Religion</b>	Roman Catholic	2 (9)	20 (91)	0.48
	Lutheran	10 (27)	27 (73)	
	Other	6 (19)	26 (81)	
	Prefer not to say	2 (20)	8 (80)	
	Atheist	5 (29)	12 (71)	
<b>Smoking status</b>	Non-smoker	22 (21)	81 (79)	1*
	Smoker	4 (22)	14 (78)	
<b>Number of sexual partners</b>	0	9 (18)	42 (82)	0.98
	1	3 (12)	23 (86)	
	2	7 (41)	10 (59)	
	3 or more	7 (27)	19 (73)	

Outcomes for variables have been aggregated to form larger groups, to account for outliers

\* Fisher exact test due to small sample size

**Table 7.6 Knowledge of the HPV vaccine**

		<b>Total n=121 n (%)</b>	<b>Male n=62 n (%)</b>	<b>Female n= 59 n (%)</b>	<b>Fisher exact P value</b>
<b><i>Have you heard of the HPV vaccine?</i></b>	Yes	12 (10)	1 (2)	11 (19)	<b>0.007</b>
	No	84 (69)	47 (76)	37 (63)	
	Not Sure	25 (21)	14 (23)	11 (19)	
<b><i>Have you had the HPV vaccine?</i></b>	Yes	4 (3)	0	4 (7)	0.08
	No	72 (60)	36 (58)	36 (61)	
	Not Sure	45 (37)	26 (42)	19 (32)	
<b><i>Can boys have the HPV vaccine?</i></b>	Yes	6 (5)	3 (5)	3 (5)	0.56
	No	4 (3)	1 (1)	3 (5)	
	Not Sure	111 (92)	58 (94)	53 (90)	

**Table 7.7 Sources of HPV related information**

	<b>Total n=69 n (%)</b>	<b>Male n=29 n (%)</b>	<b>Female n= 40 n (%)</b>	<b><math>\chi^2</math> P value</b>
<b>Parents</b>	4 (6)	0	4 (10)	0.13*
<b>School</b>	24 (35)	10 (34)	14 (35)	0.97
<b>Doctors</b>	17 (25)	6 (21)	11 (28)	0.52
<b>TV</b>	8 (12)	5 (17)	3 (8)	0.27*
<b>Radio</b>	1 (1)	1 (3)	0	0.42*
<b>Magazines/ Newspapers</b>	3 (4)	1 (3)	2 (5)	1*
<b>Internet</b>	26 (38)	9 (31)	17 (43)	0.33

\* Fisher exact test due to small sample size

## 8 OVERALL DISCUSSION

This thesis explored knowledge, attitudes and behaviours of cervical cancer prevention methods in the migrant EE population to England. Comparison of the two mixed methods studies in England and Latvia (Chapters 3 & 4) showed that the screening behaviours of EE women both prior to and after migration appear to be largely influenced by their perception of healthcare in general. The English arm of the study showed that many of the migrant EE women held negative attitudes towards the English healthcare system and thus were not accepting of it. Similarly, the screening practices of the Latvian women were chiefly determined by their perception of state-funded healthcare and doctor recommendation. It is acknowledged that the migrant EE group is a heterogeneous group and that direct comparisons cannot be made between the English and Latvian studies. The uptake and provision of cervical screening and HPV vaccination in these Eastern European countries also varies significantly (See Chapter 1), further questioning the legitimacy of comparing the Latvian data with that from the English study. However, the English study did reveal that there were common health behaviours and beliefs shared amongst the migrant EE women included in the study, i.e. the practice of annual gynaecological reviews and their level of trust in the English healthcare system. Further the Eastern European countries included in this study historically shared similar healthcare systems, having been part of or dominated by the Soviet Union. The data from the study conducted in Latvia together with the descriptions provided by the migrant EE women in English study, support that there are minimal changes made to the cervical screening behaviours and attitudes on migration. In addition, cervical cancer knowledge levels were found to be poor in both the studies, suggesting that these too are sustained on migration.

It has been proposed the process of acculturation follows a linear path that is determined by the length residence in the migrating country(487). In this thesis, the impact of length of residence in England on cervical screening behaviours was not clear. The studies conducted only included first generation EE women; to further assess the process of acculturation a study exploring the cervical screening behaviour in second or subsequent generations would be required. However “the context of reception” is also believed to influence the process of acculturation(488). This refers to the behaviours

and attitudes of the receiving society; the data from this thesis would suggest that this is where changes can be made to improve participation with cervical screening in the migrant EE group. Healthcare professionals in England (the receiving society) have a vital role to play; they need to understand the context in which the health beliefs of the migrant EE women are formed, i.e. the set up/provision of healthcare in their country of origin. Individualised education on the natural history of cervical cancer and cervical screening will need to be provided in order to justify the differences (from their country of origin) in the provision of cervical screening services in England. Collaborating with colleagues who are responsible for the implementation of cervical cancer prevention strategies in EE would be beneficial for both parties. It would help the English service providers to have a better understanding of the differing healthcare systems in EE and vice versa. This would assist to minimize the provision of conflicting advice and therefore increase trust from the women. It is appreciated that in reality this might not be achievable due to the scale of the task and the resource implications. Nevertheless, the collaborative work that was conducted in Latvia (Chapters 4 & 7) provided information regarding the rationale and the context behind certain behaviours that were noted in the migrant EE group.

Outreach community work and opportunistic promotion of cervical cancer prevention strategies are required, when the women first make contact with healthcare services in England (primary or emergency care). The main limiting factors of adopting this strategy are those of resource and time, in an already overstretched NHS service. However, it might be argued that the resource/cost implication of treating a patient with cervical cancer is significantly greater. In addition, there is the question of whose responsibility it is to provide this education, the PN, the GP or the emergency care team? Chapter 5 of this thesis showed that even PN nurses who perform the majority of cervical smears in England are not fully knowledgeable about cervical screening protocols or HPV vaccination. Providing inaccurate/conflicting information is likely to further perpetuate the negative attitudes that the migrant EE women hold about the English healthcare system. These findings indicate that before patients can be educated the focus needs to be on ensuring that healthcare professionals themselves are adequately informed.

Chapters 6 & 7 of this thesis explored knowledge and attitudes of primary prevention of cervical cancer. It was evident from these studies that overall knowledge levels regarding HPV vaccination are low amongst European adolescents in general and specifically in Latvian adolescents. In Latvia the HPV vaccine uptake rate was suboptimal, and this might be linked to low knowledge levels. The studies conducted in the adult EE populations revealed that many of the EE women held negative vaccine attitudes. The implications of these findings are that there will be a negative impact on the herd immunity effect of HPV vaccination in England. This will either be as a result of influx of potentially unvaccinated EE women to England and/or low uptake of the vaccine by EE girls already residing in England. Increasing the uptake of cervical screening in this ethnic group has been proposed as a method to balance this effect(489).

The incidence of cervical cancer has been predicted to rise by 43%(182) in the UK between 2014 and 2035; from the findings of this thesis one may speculate that the migrant EE population will be in part responsible for this rise. The views and attitudes expressed by the EE women in this study suggest that they are not fully compliant with cervical screening in England. Further the uptake of cervical screening in their home countries is suboptimal (Chapter 1) and therefore there is the potential that many of the migrant EE women will not have been screened prior to migration. The largest Eastern European population in England is from Poland(178), however the uptake of cervical screening in Poland is only 25% (Table 1.2, Chapter 1). The migrant EE women (Chapter 3) described that many of the migrant EE women prioritise employment, accommodation and schooling for their children, therefore might not engage in cervical screening. The findings of this thesis suggest that there are two groups of migrant EE women who are not compliant with cervical screening in England; those who have some knowledge about screening but do not trust the English healthcare system fully and those who have no awareness of screening either in England or their country of birth. Targeted education to increase awareness of cervical screening in both these groups is imperative but the difficulty will be in identify the later group as they might not present to healthcare services in England.



The focus of this thesis was primarily on the prevention of cervical cancer in the migrant EE group, however the most significant finding of this thesis relates to the general principles of access to healthcare services in England. These findings have a direct implication on cervical cancer prevention but also on all aspects of preventative healthcare for the migrant EE population in England.

## **8.1 KEY RECOMMENDATIONS**

- Adequate training and education of healthcare professionals on:
  - Cervical cancer prevention methods
  - Cultural context of healthcare related beliefs, attitudes and behaviours of the migrant EE population
- Provision of education about cervical cancer prevention to migrant EE women
  - Opportunistic, when presenting to emergency care services
  - At the time of registration with the GP
  - Outreach community workshops

## **8.2 FUTURE RESEARCH PROPOSALS**

To further assess the process of acculturation, the cervical cancer prevention attitudes and behaviours of second-generation migrant EE women would need to be explored. Additionally, this would provide useful information on the processes that do or do not result in changed in behaviours/attitudes and allow an assessment of the successfulness of any interventions. The challenge of conducting such a study would be that of identifying this cohort. This thesis identified that the migrant EE population are a “hard to reach group”. However, it is possible that second generation migrant EE women might integrate with society to a greater extent. The second generation are unlikely to experience the same language barriers as the first generation, especially if they have been educated in England. The findings of this thesis suggested that the health behaviours of the first generation migrant EE women in England are determined by their experiences of healthcare in their country of birth prior to migration. The proposed study will help identify the extent to which these experiences are passed down to subsequent generations. This information is essential to develop strategies to promote the uptake of cervical cancer prevention methods in this high-risk ethnic group.

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## APPENDIX

### Appendix I Study Questionnaire: *“Behaviours, attitudes and knowledge of cervical cancer prevention strategies in migrant Eastern European women to England”*

*\* Questions adapted/questions added or removed for Chapter 4 study “Cervical cancer prevention; A mixed methods study evaluating the knowledge, behaviours and attitudes of Latvian women”*

#### **A study exploring the cervical screening behaviours and knowledge of cervical cancer amongst different population groups**

1. What is your date of birth? (DD/MM/YY) \_\_\_\_/\_\_\_\_/\_\_\_\_

2. What is your gender?

☐ Female

☐ Male

3. Which of the following best describes your current relationship status?

☐ Married

☐ Separated

☐ Co-habiting

☐ Widowed

☐ In a civil partnership

☐ Single

☐ Divorced

☐ In a relationship

4. What is the highest level of qualification that you have received from school, college or since leaving school?

☐ Postgraduate degree

☐ First degree

☐ A-levels or equivalent

☐ GCSE's/O-levels or equivalent

☐ Trade/technical/vocational

☐ No formal qualifications

☐ Other qualification, please specify .....

## 5. What is your current employment status?

- ☐ Employed full time  
☐ Employed part time  
☐ Unemployed  
☐ Retired  
☐ Housewife

## 6. What is your ethnicity?

<b>White</b>  <input type="checkbox"/> English/Welsh/Scottish/ Northern Irish/British  <input type="checkbox"/> Irish  <input type="checkbox"/> Gypsy or Irish Traveller	<b>White Eastern European</b> <input type="checkbox"/> Bulgarian <input type="checkbox"/> Hungarian <input type="checkbox"/> Polish  <input type="checkbox"/> Czech <input type="checkbox"/> Latvian <input type="checkbox"/> Romanian  <input type="checkbox"/> Estonian <input type="checkbox"/> Lithuanian <input type="checkbox"/> Slovakian  <input type="checkbox"/> Slovenian  <input type="checkbox"/> Other please state	<b>Asian/Asian British</b> <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Chinese <input type="checkbox"/> Any other Asian background – please state.....
<b>Black/ African/ Caribbean/Black British</b>  <input type="checkbox"/> African  <input type="checkbox"/> Caribbean  <input type="checkbox"/> Any other Black/ African/Caribbean background- please state.....	<b>Mixed/ Multiple ethnic groups</b>  <input type="checkbox"/> White and Black Caribbean  <input type="checkbox"/> White and Black African  <input type="checkbox"/> White and Asian  <input type="checkbox"/> Any other mixed/multiple ethnic backgrounds- please state.....	<b>Any other ethnic group, please state.....</b>

7. In which country were you born?.....

If you were not born in the UK;\* (*question removed*)

a. How many years have you lived in the UK for? .....

b. How often do you visit your home country?

- ☐ Once a month 1  
☐ 2-3 times per year  
☐ Less than once a year

8. Is English your first language?

- ☐ Yes (Go to question 10) ☐ No

9. If English is not your first language;

a. Do you speak/understand English?

- ☐ Yes ☐ No ☐ Not very well

b. Can you read English?

- ☐ Yes ☐ No ☐ Not very well

c. Which language do you mainly speak at home?.....

*Questions 8 and 9 adapted as below*

**8. In the last 5 years have you lived outside of Latvia?**

- ☐ Yes ☐ No (go to question 10)

If yes how long for

- ☐ Less than 6 months  
☐ Up to 12 months  
☐ More than 1 year  
☐ 2-3 years  
☐ More than 3 years

**9. In which country did you live in when you were staying outside of Latvia? .....**

## Health Behaviours

### 10. Are you registered with a GP in the UK/ **Latvia**?

- ☐ Yes ☐ No (Go to question 11)

If yes;

a. How long have you been with this GP? .....

b. If you were not born in the UK, how soon after arrival to the UK, did you register with the GP? \* *(question removed)*

- ☐ 0- 3 months  
☐ 3-6 months  
☐ 6-12 months  
☐ More than 1 year

### 11. If you have not registered with a GP in the UK/ **Latvia**, what is the reason for this? (tick all that apply)\

- ☐ I did not know how to register with the GP  
☐ I was not aware of the need to register with a GP  
☐ I did not have the necessary documents (i.e. utility bill) required to register with a GP  
☐ I felt that my English was not good enough to communicate with the staff at the GP surgery \* *(question removed)*  
☐ I have no health problems and therefore did not feel there was a need to register with the GP  
☐ I thought that I would have to pay to see the GP/ It is not free  
☐ Other, please state.....

## Cervical Smear Questions

**12. Why do you think cervical smear tests are performed? (tick all that you think are correct)**

- ☐ To diagnose pre-cancerous cells
- ☐ To diagnose cervical cancer
- ☐ To pick up STI's (sexually transmitted infections)
- ☐ To have a full gynaecological check up

**13. Are you aware of the availability of free routine cervical screening in the UK/ Latvia (smear tests)?**

- ☐ Yes
- ☐ No (go to question 16)

If yes;

How did you hear about routine cervical screening?

- ☐ From the GP/practice nurse
- ☐ From a friend
- ☐ Received smear invitation letter
- ☐ Other please state.....

**14. At what age are women first invited for cervical cancer screening (smear test) in England/Latvia?**

.....

**15. How often is a smear test repeated in England/Latvia?**

- ☐ Every 6 months
- ☐ Every year
- ☐ Every 3 years

**16. Have you ever had a smear test?**

- ☐ Yes
- ☐ No
- ☐ Not sure (If No/Not sure go to the next page)

**17. How old were you when you had your first smear test? .....**

**18. Where did you have your first smear test (in which country)?.....**

**19. How long ago was your most recent smear test?**

☐ I have never had one

☐ 0-3 years

☐ 4-5 years

☐ More than 5 years

**20. In which country did you have your most recent smear test? .....**

**21. Do you always attend for smear tests when invited?**

☐ Yes

☐ No, If not why not?.....

☐ Cannot remember



## HPV (Human Papilloma Virus) Questions

### 22. Have you heard of HPV (Human Papilloma Virus)?

☐ Yes ☐ No ☐ Not sure

### 23. Which of the following regarding HPV are true (tick all that apply);

- ☐ HPV is very rare
- ☐ HPV always has visible signs or symptoms
- ☐ HPV can cause cervical cancer
- ☐ HPV can be passed on by genital skin-to-skin contact
- ☐ There are many types of HPV
- ☐ HPV can be passed on during sexual intercourse
- ☐ HPV can cause genital warts
- ☐ Men cannot get HPV
- ☐ Using condoms reduces the risk of getting HPV
- ☐ HPV can be cured with antibiotics
- ☐ Having many sexual partners increases the risk of getting HPV
- ☐ HPV usually doesn't need any treatment
- ☐ Most sexually active people will get HPV at some point in their lives
- ☐ A person could have HPV for many years without knowing it
- ☐ Having sex at an early age increases the risk of getting HPV

### 24. Have you heard of the HPV vaccine?

☐ Yes ☐ No

### 25. Have you had the HPV vaccine?

☐ Yes ☐ No ☐ Not sure

**26. Which of the following regarding the HPV vaccine are true (tick all that you think apply);**

- ☐ HPV vaccines require two doses
- ☐ The HPV vaccines offer protection against all sexually transmitted infections
- ☐ The HPV vaccines are most effective if given to people who have never had sex ☐
- Someone who has had HPV vaccine cannot develop cervical cancer
- ☐ The HPV vaccines offer protection against most cervical cancers
- ☐ One of the HPV vaccines offers protection against genital warts
- ☐ Girls who have had the HPV vaccine do not need to have smear tests when they are older

**27. Do you know that HPV maybe tested for when you have a smear test?**

- ☐ Yes ☐ No

**28. Which of the following regarding HPV testing are true (tick all that apply);**

- ☐ An HPV test can tell how long you have had an HPV infection
- ☐ If a woman tests positive for HPV she will definitely get cervical cancer
- ☐ An HPV test can be done at the same time as a [Pap test/Smear test/Pap smear test]
- ☐ HPV testing is used to indicate if the HPV vaccine is needed
- ☐ When you have an HPV test, you get the results the same day
- ☐ If an HPV test shows that a woman does not have HPV her risk of cervical cancer is low

**Only answer the following questions if you were born in a country outside the UK; \* *(all the questions from this section were removed)***

**29. Is there a screening programme available in your home country?**

☐ Yes ☐ No ☐ Not sure

**30. Which of these cervical screening behaviours best describes you?**

- ☐ I attend for cervical smears **only in my home country**
- ☐ I attend for cervical smears **only in the UK**
- ☐ I attend for cervical smears in **both my home country and in the UK**

**31. If you attend for smears in your home country;**

**a. What is the reason for this? (please tick all that apply)**

- ☐ It is more convenient to go back home
- ☐ I can have smear tests performed more often there
- ☐ The smear tests are performed by a doctor/gynaecologist there
- ☐ I can have a full gynaecological check up at the same time
- ☐ I do not trust the system here
- ☐ Other reason, please state.....

**b. How often would you go home for a smear test?**

- ☐ Every two-three years
- ☐ Every year
- ☐ More than once a year
- ☐ Other.....

**32. Is the HPV vaccine available in your home country?**

☐ Yes ☐ No ☐ Not Sure

**33. Is the HPV vaccine available for free (part of a vaccination programme)?**

☐ Yes ☐ No ☐ Not Sure

**Do you have any suggestions on how we can encourage more people to attend for cervical smears?**

--

***We are very interested in people's views about cervical screening, if you would be interested in discussing your views further in a short one-to-one interview with the researcher, please provide your contact details below;***

**Name:**

**Address:**

**Contact telephone number:**

**Appendix II Interview Topic Guide: “Behaviours, attitudes and knowledge of cervical cancer prevention strategies in migrant Eastern European women to England”**

**\* Questions adapted for Chapter 4 study “Cervical cancer prevention; A mixed methods study evaluating the knowledge, behaviours and attitudes of Latvian women”**

**Interview topic guide for semi-structured interviews**

Introductions

Explanation of project aims

Complete consent form and answer any questions, ensure that they have read and understand the participant information sheet

House keeping

**1) Cervical screening behaviours**

- What are their screening behaviours and what influences them?
- What do their friends and family do?
- Do they find that they can easily access screening services in the UK/Latvia?
- How much do they know/understand about the NHSCSP/ **National Latvian screening programme?**
- What arrangements for cervical screening exist in their country of origin (for the nEE group only)?
- How does the NHSCSP compare to screening in their home country (for the nEE group only)?
- How can we increase the uptake of cervical screening in the migrant population/ **Latvian population?**

**2) HPV**

- How much do they know about HPV, prior to reading the questionnaire had they heard of HPV?
- Have they heard of the vaccine?
- Do they know anything about the link between HPV and cervical cancer
- Is the vaccine available in their home country, is it free
- How can we improve HPV knowledge?
- HPV and its association with promiscuous sexual activity

**3) Themes that have emerged from the survey will be further explored, for example access to health care on immigration, particular patterns of screening behaviour etc**

**Appendix III Thematic Analysis Categories and Codes: “Behaviours, attitudes and knowledge of cervical cancer prevention strategies in migrant Eastern European women to England”**

***Perceptions of the healthcare system and healthcare providers in England versus their country of origin***

- Registration with the GP
  - Information provided at the time of registration with GP
- Access to health care in England
- Trust in the English healthcare system
  - Attitudes towards the differences in two healthcare systems
- Access to healthcare in their country of birth
- General health behaviour’s prior to migration
- Doctor-patient relationship

***The social interactions of the migrant Eastern European population***

- Access to the migrant population
- Integration of the migrant group with society, barriers and facilitators
  - Lifestyle
  - Isolation
  - Social interaction
  - Stigma felt as a migrant
- Employment

***Knowledge, awareness and understanding of cervical cancer and the cervical cancer screening programme***

- Cervical cancer
  - Awareness/Knowledge
    - Breast Cancer
- Cervical cancer screening
  - Awareness of cervical cancer screening
  - Knowledge of the programme
  - Knowledge of the test
- Information provided at the time of the smear test

***Access to information about cervical cancer and screening and the adequacy of currently available knowledge***

- Sources of information about cervical cancer and screening
- Need for more information

***Knowledge, awareness and understanding of cervical cancer and the cervical cancer screening programme in their country of birth prior to migration***

- Cervical cancer
- Cervical cancer screening
- Information provided

### ***Cervical cancer screening; from the invitation to the smear test***

- The smear invitation letter
  - The reminder letter
  - The information leaflet
- Access to cervical screening services
- Cervical screening behaviours
  - Age of first smear test
  - Views on starting age of smear test
  - Influences
  - Barriers
  - Motivation
  - Priority
  - Screening frequency
  - Attitudes towards screening frequency
- The smear experience
  - Quality
  - Emotions
  - The person performing the smear test
    - Role
    - Gender

### **An “Abnormal Result” Receiving an abnormal smear result**

- Abnormal results
- Colposcopy

### ***Human Papillomavirus- Awareness and attitudes towards HPV***

- Awareness and knowledge of HPV
- Sources of HPV related information
- Attitudes and emotions
- Sexually transmitted disease

### ***Human Papillomavirus Vaccine***

- Awareness and knowledge of the HPV vaccine
- Vaccination status
- Attitudes towards HPV vaccination

### ***Human Papillomavirus Testing***

- Awareness and attitudes towards current HPV testing
- Views, attitudes and perceptions about primary HPV testing

### ***Cervical cancer prevention in their country of birth for the nEE group***

- Cervical cancer screening
- HPV vaccination

***The affect of influences imposed by family and friends on cervical prevention behaviours***

- Mother/daughter/sister
- Other family
- Friends

***Discussing cervical cancer prevention***

- Discussing the smear test
- Discussing HPV testing and treatment
- Forums in which discussion about cervical cancer may occur

***The views and perceptions of the participants on how the uptake of cervical cancer prevention methods might be increased***

- Media, leaflets and social media outlets
- The importance of the content of promoting screening uptake
- Increasing uptake for EE born women
- Education



**Appendix IV Thematic Analysis Categories and Codes: “*Cervical cancer prevention; A mixed methods study evaluating the knowledge, behaviours and attitudes of Latvian women*”**

**Perceptions of the healthcare system and healthcare providers in Latvia**

- Access to healthcare
- Cost
- General health behaviours
- Doctor-patient relationship
  - Age
  - Gender
  - Role of healthcare professional performing smear test

**Annual gynaecological reviews**

- Experience
- Frequency
- Reason for going
- Understanding

**Cervical cancer screening behaviours**

- Screening behaviours
- Frequency
- Reason for attending
- Barriers to participation with cervical cancer screening
  - Access
  - Awareness
  - No symptoms
  - Time

**Knowledge and understanding of cervical cancer screening, cervical cancer and HPV: Interviewee versus Population**

- Screening and colposcopy
  - Smear test
- Cervical cancer
- HPV and the HPV vaccine
- Other STIs
- Population Knowledge

**Beliefs, perceptions and attitudes towards the Human Papilloma Virus**

- HPV and HPV testing attitudes
- Attitudes towards the HPV vaccine

**Sources of knowledge and information**

- Cervical cancer and screening
- HPV and the HPV vaccine
- Sexual health and other STIs
- Proposed information outlets
  - Breast cancer

**Outside influences and personal emotions affecting cervical cancer prevention behaviours and choices**

- Outside influences
  - Daughter
  - Mum
  - Other family
  - Friend
  - Other
- Emotions
  - Fear
  - Shame

**Impact of the interview**

**Appendix V Study Questionnaire: “*Knowledge, attitudes and awareness of the human papillomavirus amongst primary care practice nurses: An evaluation of current training in England*”**

**Practice Nurse HPV knowledge Survey**

1. How old are you?.....
2. What is your gender?
  - ☐ Female
  - ☐ Male
3. How many years have you been performing cervical smears?.....
4. How long ago did you attend a training session on HPV testing (triage) and test of cure?
  - ☐ Never
  - ☐ In the last 3 months
  - ☐ In the last 6 months
  - ☐ In the last 12 months
  - ☐ More than 12 months ago

## HPV (Human Papilloma Virus) Questions

**5. Which of the following regarding HPV are true (select all that apply);**

- ☐ HPV is very rare
- ☐ HPV always has visible signs or symptoms
- ☐ HPV can cause cervical cancer
- ☐ HPV can be passed on by genital skin-to-skin contact
- ☐ There are many types of HPV
- ☐ HPV can be passed on during sexual intercourse
- ☐ HPV can cause genital warts
- ☐ Men cannot get HPV
- ☐ Using condoms reduces the risk of getting HPV
- ☐ HPV can be cured with antibiotics
- ☐ Having many sexual partners increases the risk of getting HPV
- ☐ HPV usually doesn't need any treatment
- ☐ Most sexually active people will get HPV at some point in their lives
- ☐ A person could have HPV for many years without knowing it
- ☐ Having sex at an early age increases the risk of getting HPV

**6. Which of the following regarding HPV testing, HPV triage and test of cure, are true (tick all that apply);**

- ☐ An HPV test can tell how long you have had an HPV infection
- ☐ If a woman tests positive for HPV she will definitely get cervical cancer
- ☐ An HPV test can be done at the same time as a Smear test
- ☐ HPV testing is used to indicate if the HPV vaccine is needed
- ☐ When you have an HPV test, you get the results the same day
- ☐ If an HPV test shows that a woman does not have HPV her risk of cervical cancer is low
- ☐ All cervical samples showing borderline nuclear changes or mild dyskaryosis are tested for high-risk HPV.
- ☐ All cervical samples showing normal, borderline nuclear changes or mild dyskaryosis 6 months post treatment are tested for high-risk HPV
- ☐ If the post treatment high-risk HPV test is negative they will still require annual follow up for ten years
- ☐ If post treatment both cytology and high risk HPV test are negative, they will need require a repeat smear in 3 years

**7. Which of the following regarding the HPV vaccine are true (tick all that you think apply);**

- ☐ HPV vaccines require two doses
- ☐ The HPV vaccines offer protection against all sexually transmitted infections
- ☐ The HPV vaccines are most effective if given to people who have never had sex
- ☐ Someone who has had HPV vaccine cannot develop cervical cancer
- ☐ The HPV vaccines offer protection against most cervical cancers
- ☐ One of the HPV vaccines offers protection against genital warts
- ☐ Girls who have had the HPV vaccine do not need to have smear tests when they are older

**8. Would you recommend the HPV vaccine?**

- ☐ Strongly Agree
- ☐ Agree
- ☐ Undecided
- ☐ Disagree
- ☐ Strongly disagree

**9. Do you think that the vaccine should be offered to men/boys as well?**

- ☐ Strongly Agree
- ☐ Agree
- ☐ Undecided
- ☐ Disagree
- ☐ Strongly disagree

**10. Do you feel adequately informed about HPV?**

- ☐ Strongly Agree
- ☐ Agree
- ☐ Undecided
- ☐ Disagree
- ☐ Strongly disagree

**11. Are you able to confidently answer HPV related questions asked by the patients?**

- ☐ Strongly Agree
- ☐ Agree
- ☐ Undecided
- ☐ Disagree
- ☐ Strongly disagree

**12. Do you have any suggestions on how we may improve the delivery of training on HPV for practice nurses?**

**Appendix VI Study Questionnaire: “Adolescents’ awareness of HPV infection and attitudes towards HPV vaccination 5 years following the introduction of the HPV vaccine in Latvia”**

**A study exploring the awareness of HPV in Latvian adolescents**

**1. How old are you?**

**2. What is your gender?**

☐ Female

☐ Male

**3. What is your ethnicity?**

☐ White Latvian

☐ White Russian

☐ White other

☐ Asian

☐ Black

☐ Other (please specify).....

**4. What is your religious preference?**

☐ Roman Catholic

☐ Church of England

☐ Christian other

☐ Jewish

☐ Muslim

☐ Hindu

☐ Atheist

☐ Other (please specify).....

**5. Do you smoke?**

☐ Yes

☐ No

**6. How you ever had sexual intercourse?**

- ☐ Yes      ☐ No (go to question 10)

**7. How many sexual partners have you had?**

- ☐ 1  
☐ 2  
☐ 3 or more

**8. What do you use for contraception?**

- ☐ Condoms  
☐ Contraceptive pill  
☐ Contraceptive Implant  
☐ Contraceptive coil  
☐ No contraception used

**9. Do you always use contraception?**

- ☐ Yes      ☐ No

**10. Have you ever had a cervical smear test (pap smear test)?**

- ☐ Yes      ☐ No      ☐ Not sure

**11. How old were you when you had a cervical smear test (pap smear test)?.....**



## HPV (Human paillomavirus)

### 12. Have you heard of HPV?

- ☐ Yes      ☐ No      ☐ Not sure

### 13. How can you get HPV? (select all true options)

- ☐ Through sexual intercourse  
☐ From blood transfusions  
☐ Genital skin-to-skin contact  
☐ From using public toilets

### 14. Which of the following reduce your risk of getting HPV (select all true options)

- ☐ Condoms  
☐ Contraceptive pill  
☐ Vaccination  
☐ Good personal hygiene  
☐ Antibiotics

### 15. Which of the following conditions are caused by HPV? (select all true options)

- ☐ Cervical cancer  
☐ Genital warts  
☐ HIV/AIDS  
☐ Hepatitis  
☐ Infertility  
☐ Penile cancer

### 16. Have you heard of the HPV vaccine?

- ☐ Yes      ☐ No      ☐ Not sure

### 17. Have you had the HPV vaccine?

- ☐ Yes      ☐ No      ☐ Not sure

**18. At what age is the HPV vaccine given?.....**

**19. Can boys have the HPV vaccine?**

☐ Yes      ☐ No      ☐ Not sure

**20. Which of the following regarding the HPV vaccine are true (tick all that you think apply);**

☐ HPV vaccines require three doses

☐ The HPV vaccines offer protection against all sexually transmitted infections

☐ The HPV vaccines are most effective if given to people who have never had sex ☐  
Someone who has had HPV vaccine cannot develop cervical cancer

☐ The HPV vaccines offer protection against most cervical cancers

☐ One of the HPV vaccines offers protection against genital warts

☐ Girls who have had the HPV vaccine do not need to have smear tests when they are older

**21. Do you feel you have been given enough information about HPV?**

☐ Strongly Agree

☐ Agree

☐ Neutral

☐ Disagree

☐ Strongly disagree

**22. Where have you got most of your information about HPV?**

☐ Parents

☐ School (nurses/teachers)

☐ Doctor (GP)

☐ TV

☐ Radio

☐ Internet