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**CERVICAL SCREENING IN YOUNG  
WOMEN: AN EXPLORATION OF  
ISSUES ASSOCIATED WITH  
PARTICIPATION AND NON-  
PARTICIPATION USING A  
GROUNDED THEORY**

**MABEL OSEBHAJIMENDE OKOEKI**

**PhD**

**2016**

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GROUNDED THEORY**

**MABEL OSEBHAJIMENDE OKOEKI**

A thesis submitted in partial fulfilment  
of the requirements of the  
University of Northumbria at Newcastle  
for the degree of  
Doctor of Philosophy

Research undertaken in the  
Faculty of Health and Life Sciences

October 2016

## **Abstract**

### **Introduction**

Cervical cancer is 11<sup>th</sup> most common cancer among young women in the UK. Early detection through screening is thought to have resulted in a 75% decrease in cervical cancer and saves over 4,500 lives each year. However, recent years have seen a continuous decline in screening uptake, especially among young women. Scientific literature reviews show little research in this area. There is therefore a need for a qualitative exploration into the reasons and motives for low uptake of cervical cancer screening from service users' viewpoints in England. This study explores factors that influence the participation and non-participation of young women aged 25-34 in the NHS cervical cancer screening programme in the Northeast. Findings are expected to inform age-specific interventions aimed at increasing participation.

### **Methodology**

Employing the qualitative approach of grounded theory (GT) enabled the development of an understanding of participants' behaviours and factors affecting participation, including health beliefs and other associations that influence the decision to attend screening. Twenty-four research participants were recruited purposively and theoretically from universities in the Northeast and a community centre in Newcastle, as well as through the Northeast Call and Recall Centre in accordance with ethical approval. Data was collected through semi-structured face-to-face interviews and a focus group session. The analysis was done using the GT techniques of the constant comparative method and theoretical sampling, aided by individual sorting and use of Mind Genius software.

### **Findings**

Awareness of cervical cancer prior to receiving a screening invitation was found to be relatively low and there was an overall lack of understanding of what the screening entails. There was no direct correlation between health beliefs and participation, however, health beliefs were influenced by cultural, environmental and social factors. The findings from both the interviews and the focus group led to the creation of three contextual categories, which are: health views relative to self; knowledge/awareness; and health service influences and practicalities associated with participation in cervical cancer screening. The three main categories and their subcategories were further conceptualized to create a core category, 'sexual association', made up of four elements: awareness, human issues, emotional attribution, and acceptability. Decisions to participate in the cervical cancer screening were largely influenced by the elements within 'sexual association', showing the psychosocial or cognitive impact of the association between sex and the cervical cancer screening

procedure. Sexual association seemed to be a key influence in participation, with factors from the three main categories feeding into it.

## **Discussion**

All participants, particularly in relation to health protection, viewed the screening positively. Within the sexual association and practicality issues, there are facilitators and potential barriers. The psychosocial impact (fear, embarrassment, intrusiveness and taboos) of sex being associated with cervical screening, as well as practical issues, tends to dissuade people from participating in the screening. An explanatory model was developed to understand the factors influencing participation and non-participation and this has commonalities with the health belief model and social cognitive theory, which are typically used to explain health behaviours. This is one of the few studies investigating factors that affect the uptake of cervical cancer in the Northeast of England. The results obtained in this study are likely to have high importance to policy and practice, as they represent user-focused perspectives. Recommendations and implications for further research, policy, practice and education are provided.

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Above all my profound gratitude goes to the Almighty God who gave me the good health and resilience to undertake this research despite all the challenges encountered during this study.

## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the School Research Ethics Committee and NHS research Ethic committee East of England-Norfolk on (3/06/2014)

**I declare that the word count for this Thesis is**

Name: Mabel Osebhajimende Okoeki

Signature:

Date: 3<sup>rd</sup> of November 2017

Word count:

## **CHAPTER 1: Introduction**

### **1.1 Chapter overview**

The first chapter of this thesis commences with a summary of the purpose of this doctoral study, outlines the rationale and general aims that motivated this study, and concludes with a synopsis of the entire thesis.

### **1.2 Brief Description of the Researcher's background**

The academic convention of the third person, which is commonly used in research projects, is not employed here; rather the first person will be used as it makes it a more personal reflection of my views and who I am as a researcher. I have always had a background in healthcare with my first degree being in human physiology. My interest in public health and health promotion in the healthcare system began during my undergraduate days, during seminars focusing on unavoidable deaths due to ignorance or poor healthcare utilisation. The experiences I gained while volunteering for several health promotion projects further fuelled my passion for general health promotion, especially how practice and public policy could benefit from field evidence and help facilitate increased disease prevention and health protection.

The quest to deepen my understanding of public health practices and issues informed my decision to do a master's degree in public health. During the master's study, I was exposed among other things to public health policies and interventions, epidemiology and health protection, health promotion, global health and research methods.

After my Master's degree, I took a job with a sexual health charity, which not only provided me with the opportunity to apply my knowledge and skills in public health, but also the opportunity to work directly with the people dealing with public health issues. A major career turning point for me occurred during a one-to-one session with some women (from various ethnic backgrounds) to whom I was providing evidence-based support, as they were living with life changing health issues. After undertaking an educational course on the importance of screening for women, most of them expressed concerns about screening attendance with half of them failing to attend screening for either breast or cervical cancer. Being from an African country with a poorly structured health service, where, unlike in the UK, routine screening is not made available for free, I could relate with their concerns. These concerns and my personal screening experience prompted my interest in evidence-based research to unpick issues around screening.

Despite my personal experience, my appreciation of screening primarily draws from a professional perspective, viewing screening as a valuable public health intervention. Identifying with this research topic is evocative of both my professional experience and personal interest (Strauss & Corbin, 1990).

Undertaking this study was influenced and motivated by personal and anecdotal issues raised about screening. My interests in the topic area made the research process easier. This stance and background may have possibly influenced data collection and analysis. However, to minimise this, I drew on appropriate techniques derived from grounded theory, which enabled me to stay as true as possible to the data.

It is noteworthy that the National Health Service Cervical Cancer Screening Programme (NHSCSP) is solely based on autonomy (informed choice), with decision-making centred on information provision (invitation letters and leaflets). With my wealth of knowledge and professional stance, it can be difficult not to be viewed as an advocate of the programme. This was minimised by reiterating my position as a researcher concerned with exploring views and experiences of cervical cancer screening only. There exists literature where researchers were perceived as advocates thereby influencing responses and views of participants (Bloomberg et al., 2007). To avoid this in my study, I chose the semi-structured interview to enable adequate expression of views with little personal influence.

### **1.3 Purpose of study**

This PhD thesis, in keeping with the principles of grounded theory, explored factors influencing participation in the NHSCSP in the Northeast of England. The study attempted to understand the expressed opinions of young service users with a view to better understand the motivating factors that influence their decisions to either take part or refuse to engage in cervical screening. In addition, one of the most important objectives of the inquiry was to gain insights and/or perspectives that could aid a deeper understanding of these motivating factors and based on that, suggest measures that could increase screening uptake to ultimately improve the general health and wellbeing of women.

### **1.4 Background to the National Health Service Cervical Cancer Screening Programme (NHSCSP)**

In any health intervention, it is important to understand the need, which in this case is prevention of cervical cancer.

#### **Cervical cancer as a public health issue.**

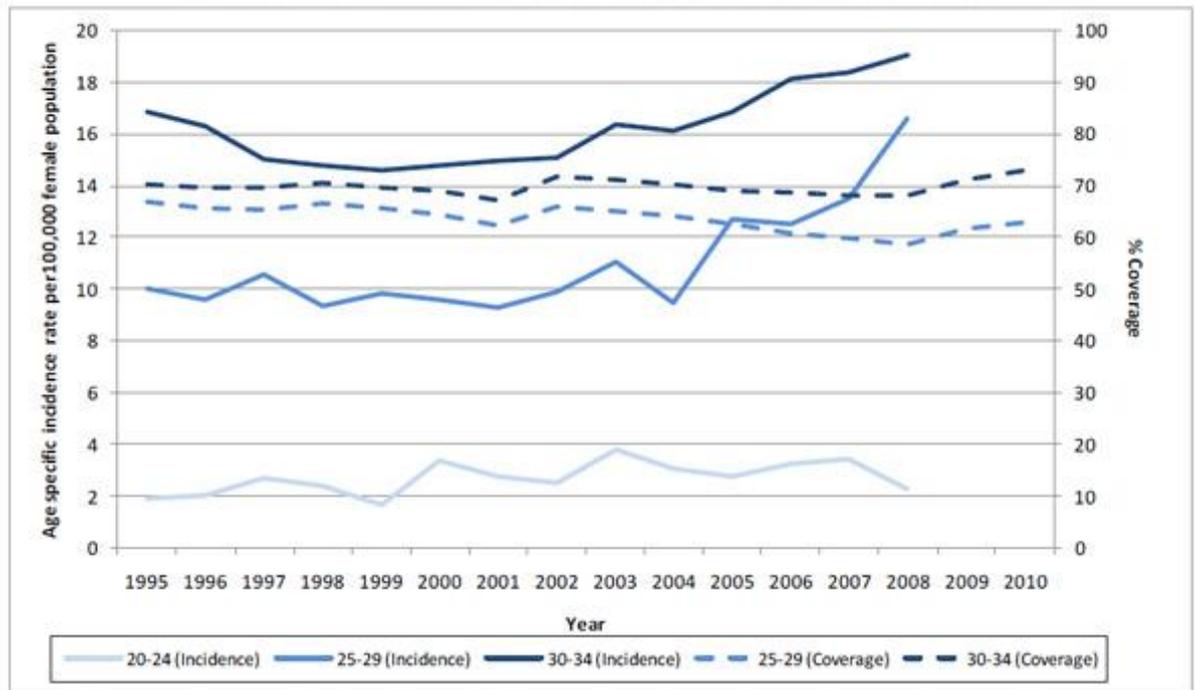
Cervical cancer remains a public health issue worldwide, with increasing incident rates in developing countries according to the World Health Organisation (WHO, 2008). Cervical cancer develops in the epithelial cells of a woman's uterine cervix (the entrance of the womb) (Cancer Research UK, 2013). It is quite possible for women of all ages to develop cervical cancer at some stage in their lifetime (WHO, 2013). However, women in their late 30s and 40s tend to record higher incidences of the

disease (Taylor et al., 2004). Some presumed factors in this changing pattern of incidence are discussed in section 3

According to the NHSCSP (2012) report, about 3,400 women are diagnosed with cervical cancer in the UK each year, even as cervical cancer is considered the most common type of cancer in women under 35 years. About 78% of 25-64-year-old women were diagnosed with cervical cancer between 2009 and 2011, while 11% of women aged 75 and over were diagnosed with the disease within the same period (NHSCSP, 2012; Cancer Research UK, 2012).

With the commencement of the cervical cancer screening programme from the mid-1980s, the incidence rate for the disease has decreased (Trent Cancer Registry, 2012). The largest decrease of 63% and 66% between 1980-1987 and 2009-2011 respectively was in women aged 50 and above. In the case of the younger women (25-35), incidence rates initially decreased by 34% between 1985-1987 and 2000-2003, but there has been a significant increase of 54% since then (Trent Cancer Registry, 2012; NHSCSP, 2012). This increased rate is thought to be related to, and reflective of, the increase in HPV infection and smoking prevalence in this age group (Trent Cancer Registry, 2012). Further increase in the incidence rate in recent years has also been attributed to the diagnosis and subsequent death of the celebrity, Jade Goody, from cervical cancer in 2009, leading to increased cervical cancer screening uptake (Lancucki et al., 2012; NHSCSP, 2012; National Cancer Intelligence Network, 2010). The death of Jade Goody, aged 27, was highly publicised, thereby raising awareness of how fatal late diagnosis of cervical cancer could be, considering her relatively young age. Moreover, as shown in the graph below, this high-profile death led to an increase in uptake amongst those aged 20-34 between 2009-2010 (National Cancer Intelligence Network, 2010).

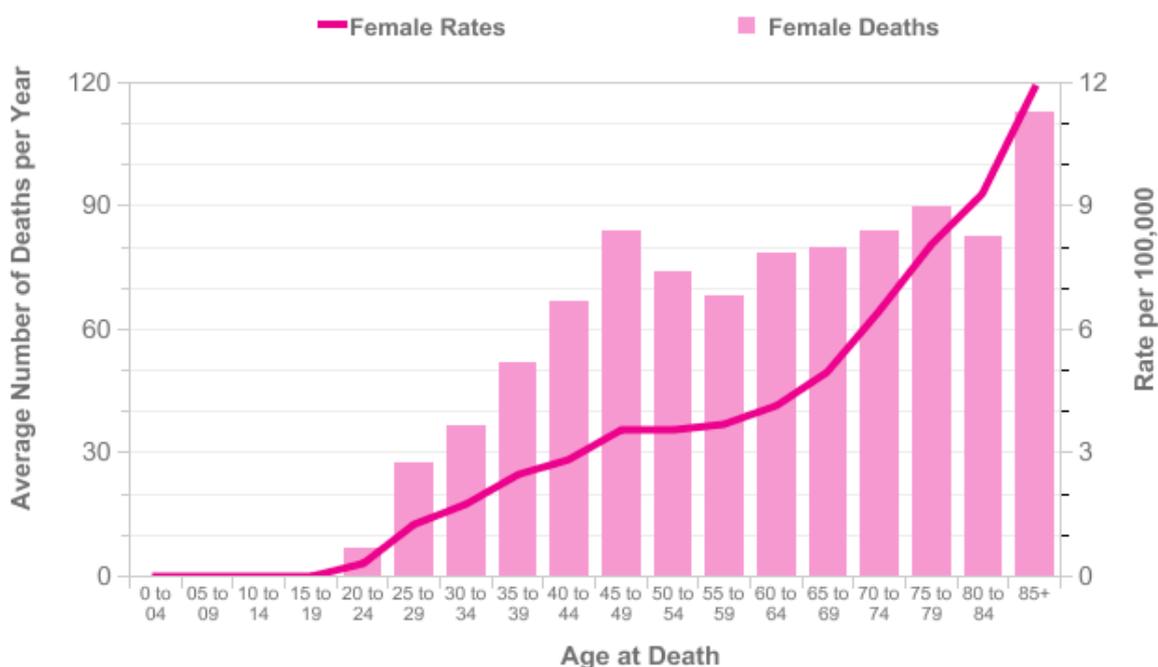
**Figure 1. Recent trends in cervical cancer incidence in women aged 20-34 (1995-2008) and coverage of screening of women aged 25-34 (1995-2010) in England.**



Source: National cancer Intelligence Network, 2010

Recent records revealed that in England, about 759 women were killed by cervical cancer in 2008 alone (NHSCSP, 2012; Waller et al., 2009). Mortality is higher in parts of the north and lowest in parts of the south. Similarly, across various ages in the UK, 31% of cervical cancer deaths were in women aged 75-79 and 7% in those under 35 (NHSCSP, 2012). A review of the recent records between 2005 and 2009 revealed that over 65% of women diagnosed with cervical cancer remained alive 5 years later. (Cancer Research UK, 2013). The chart below shows the age-specific mortality rate per 100,000 in the UK (Cancer Research UK, 2013).

**Cervical cancer (C54) average number of deaths per year and age-specific mortality rates, UK 2009-2011.**



Source: Cancer Research UK, 2013

**Causes/risk factors in cervical cancer**

The precise cause of cervical cancer is not yet known. However, certain associative factors have been suggested and debated over the years (Waller et al., 2004; Cancer Research UK, 2013; Parkin, Boyd & Walker, 2011; International Agency for Research on Cancer, 2014). In the UK, causes have been linked to lifestyle and other factors (Parkin, Boyd & Walker, 2011). The physical indications of cervical cancer are mostly not discernible; they could remain unnoticed until a later stage. Vaginal bleeding is considered the most discernible physical indication of cervical cancer. Several risk factors are associated with cervical cancer, with Human Papilloma Virus (HPV) identified as the most common (WHO, 2013; Walboomer et al., 1999). A brief summary of some of the risk factors of cervical cancer is presented below (see chapter 2 for in-depth review).

## **Human Papilloma Virus (HPV)**

Available medical evidence considers Human Papilloma Virus (HPV) the most common precursor to cervical cancer (WHO, 2013; Cancer Research UK, 2013), mostly because virtually all incidences of cervical cancer occur in the presence of persistent HPV, although not all HPV leads to cervical cancer. Hence, HPV is regarded as a ‘necessary cause’ of cervical cancer (Cancer Research UK, 2010; Waller et al., 2004; Parkin, Boyd & Walker, 2011; Bosch et al., 2002). HPV infection is estimated to be the most common sexually transmitted infection, with about 40 types passed on through sexual contact (Cooper, 2011; Cancer Research UK, 2014). Of the 15 types of HPV associated with cervical cancer, only types 16 and 18 are attributed to 70% of diagnosed cases (NHSCSP, 2009; Cancer Research UK, 2014; Goldsmith et al., 2007). HPV is rarely detected in women who have never been sexually active. Risk factors for HPV infection therefore include number of sexual partners and non-use of condoms. However, condoms offer limited protection from transmission of HPV (NHSCSP, 2013; Cancer Research UK, 2014). Furthermore, Deacon et al. (2000) discovered that for women with HPV, first intercourse at an early age was a main risk that could cause severe abnormalities. Therefore, it is suggested that length of time being sexually active, and number of sexual partners affect duration of exposure, which increases the likelihood of developing abnormalities. One interesting find from the study was that the danger of multiple sexual partners is only limited to increasing the chances of an initial infection, since further re-infection does not increase the severity of the disease. However, the mechanisms through which HPV causes cervical cancer are not fully understood (Deacon et al., 2000; Bosch et al., 2002).

**Other suggested risks factors** include smoking, HIV, long-term use of oral contraceptive, parity and socio-economic status (Cancer Research UK, 2014; International Agency for Research on Cancer, 2014; Parkin, Boyd & Walker, 2011; International Collaboration of Epidemiological Studies of Cervical Cancer (ICESCC), 2006).

### **Parity**

It is also suggested that the number of pregnancies (parity) and age of first pregnancy and birth in women make them more susceptible to cervical cancer. Women who had their first full term pregnancy at a later age are more likely to develop cervical cancer than those who had their first full term pregnancy at a younger age, establishing that risk increases with age (NHSCSP, 2013; Cancer Research UK, 2014; Smith et al., 2003; Winer, Lee & Hughes, 2003; Woodman et al., 2009).

Cervical cancer risk increases with each full-term pregnancy (International Collaboration of Epidemiological Studies of Cervical Cancer (ICESCC), 2006). As reported by Cancer Research UK,

(2014), a pooled analysis reported by ICESCC showed that the association with parity is limited to squamous cell carcinoma, with no association for adenocarcinoma (ICESCC, 2006). The reasons for these associations is unknown.

### **Socio-economic status**

A link has also been made between socioeconomic status, incidence, and mortality from cervical cancer (Cancer Research UK, 2014). One of the factors identified for cervical cancer is low economic and social status of women, which gives rise to a higher prevalence of poverty and increased likelihood of ignorance about health issues and preventive behaviours (Dos Santos and Beral, 1997). These factors increase women's vulnerability to illness and preventable diseases such as cervical cancer (Dos Santos & Beral, 1997; Tadesse, 2015; Moore & Driver, 2014).

Parikh et al. (2003) highlights the link between rates of cervical cancer and particular social strata. This link suggests that lifestyle factors are evidently one of the principal factors responsible for the observed disparity. Furthermore, the study suggested that in the more affluent countries in Western Europe, lifestyle factors constitute one of the main reasons for differences in class, while for women in less affluent countries in Asia and Africa, access to screening was the critical factor behind the disparity (Parikh et al., 2003).

In the UK, screening attendance is patterned demographically, with women from ethnic minorities, lower educational attainment and lower socioeconomic status (SES) being less likely to attend screening (Sutton & Rutherford, 2005; Moser et al., 2009; Webb et al., 2004). However, the overall biggest risk factor or determinant of cervical cancer in England is non-attendance of screening (NHSCSP, 2013). (More details in chapter 2).

### **The NHS Cervical Screening Programme (NHSCSP)**

Cervical screening is a nationwide population screening service. It begun in the UK in the mid-1960s, although the national programme was not established until 1988. Preceding 1988, screening was opportunistic and was only offered during hospital visits (Armstrong, 2015; McGregor et al., 1986). However, there were concerns that those at greatest risk were not being screened, and that those who had positive test results were not being followed up and treated (NHSCSP, 2014).

A formalised national screening programme was established in 1988 for women aged 20-65, with the Department of Health instructing all Health Authorities to introduce computerised call-recall systems to meet certain quality standards (Patnick, 2000).

Screening seeks to find the presence of a disease (in asymptomatic people) at a stage when it can be easily treated. The aim of the NHSCSP is the reduction of death from invasive cervical cancer

through early detection, with the hope of providing effective treatment at an earlier stage of diagnosis (NHSCSP, 2013; Cancer Research UK, 2014).

Cervical cancer is detected using a Liquid-Based Cytology (LBC) system. This is not a diagnostic test, but a preventive method used to detect early abnormalities, which, if left untreated, could lead to the development of cancer in a woman's cervix (NICE, 2003; Cancer Research UK, 2014; Public Health England, 2016). The LBC system involves taking sample cells from the cervix for analysis using a speculum to open the woman's vagina and a small soft brush to sweep around the cervix to collect cells for analysis (Cancer Research UK, 2014). Slight discomfort with the procedure has been reported by women who have been screened (Cancer Research UK, 2014; Waller et al., 2009; Teng et al., 2014). If an abnormality is detected, a diagnostic test called a colposcopy will be performed (Public Health England, 2015).

However, prior to 2008, detection of abnormal cells was done using a Pap smear, until the introduction of LBC. The Pap smear is similar to the LBC in many respects, the main difference being that a wooden spatula was used to take the cells from the cervix before being placed inside a glass slide. The LBC was adopted because it preserves cells better and makes it easier for scientists to view cells for longer, thereby making it a more reliable method (NICE, 2003; Cancer Research UK, 2014).

Cervical screening is delivered locally through general practices (GPs) and community clinics (NHS England, 2016). Before the NHS restructuring in 2013, it was delivered through the Primary Care Trusts (PCT, now dissolved) and General practices (GPs) (NHSCSP, 2009). Invitation to attend screening is done by the NHS call and recall database, often referred to as the Exeter system, which invites women registered with a GP. It also tracks any follow-up investigation and recalls women for screening every 3 or 5 years if there is no abnormality (Health and Social Care Information Centre, 2015).

Within the NHSCSP, women receive their first invitation for routine screening at age 25. In England, preceding 2003, the age of first invitation was 20, which was subsequently raised to 25 after changes in national policy (Cancer Research UK, 2013; NHSCSP, 2009; 2012). This was because cervical cancer risk is very low for women under 25, with an additional high probability of false positive outcomes and the attendant unnecessary treatment (Health and Social Care Information Centre, 2013). However, Scotland and Wales retained the starting age of 20. This study is focused on young women aged 25 to 34, with 25 being the age of first invitation. The screening intervals are: first invitation (age 25), then every three years between 25-49 and every five years between 50-65. Women aged 65+ years are removed from the call and recall (invitation) system, unless they need ongoing surveillance and follow up. They are also only invited for screening if they have not been

screened since age 50 or have had a recent abnormal test (Health and Social Care Information Centre, 2015).

### **Human Papilloma Virus (HPV) vaccination in the UK**

HPV is the most common risk factor for cervical cancer before non-attendance (WHO, 2013; NHSCSP, 2013). Cervical cancer prevention through screening is now being complimented by HPV vaccination (women aged 12-18). Furthermore, a self-test for HPV is currently offered to women thought to be at risk of cervical cancer (NHSCSP, 2009; Cancer Research UK, 2012). All girls aged 12-18 in the UK are offered HPV vaccination through the national HPV immunisation programme, which aims to protect girls against infection with the HPV 16 and 18 (Health Protection Agency, 2013). The HPV vaccination programme was introduced in September 2008 and offers free vaccines to all 12-13-year-old and 17-18 year-old girls. It takes about 10 to 20 years after HPV infection for cervical cancer to develop. Hence, women are advised to continue accepting their invitations for cervical screening as the HPV vaccination will not prevent all types of cervical cancers (NHSCSP, 2013).

### **1.5 Rationale for the study/ the problem**

This research contributes to existing body of knowledge by exploring the reasons why young women, especially in Northeast England, fail to take up cervical screening. This research will focus on young people within the ages of 25-34 who have never been screened and those who have attended their initial invitation but have not gone for a rescreen.

There is limited research on this age group. Willoughby (2006) recommended that further research that focuses on this age group should be carried out. Literature that focuses on factors influencing uptake of the cervical screening has been done in other countries such as the US (Head & Cohen, 2011; Maosavel & El-Shaarawi, 2007), Canada (Cerigo et al., 2013), Sweden (Oscarsson et al., 2008; Blomberg et al., 2008) and various regions in the UK, with emphasis mainly on ethnic minority groups (Abdullahi et al., 2009; Chiu, 2004) and much older women. These factors will be explored in depth in chapter 2 alongside other studies. Moreover, research that has taken place in other regions of the UK, which focused on general age groups and various ethnicities will be reviewed, as well as their various methodologies and approaches. Some of these are quantitative and focus on epidemiological evidence relating to coverage and incidence of cervical cancer, whilst others were mainly surveys (Olesen et al., 2012; Behbakht et al., 2005; Waller et al., 2009). Those that used qualitative methodologies were often guided by a specific behavioural framework such as the 'health

belief model'. This could hinder identifying or exploring other issues that might arise in the course of the study (Waller et al., 2012).

There are not enough studies focused on the aforementioned age group within the UK and most especially the Northeast England. A study conducted by the NHS focused more on proposed interventions within this age group rather than giving in depth attention to participants' views regarding uptake/screening attendance (NHS Yorkshire and Humber, 2010). Notwithstanding, there are still significantly low uptake levels for cervical screening in the Northeast (NHSCSP, 2013; Public Health England, 2015). In addition, connection of low uptake within minority ethnic groups can be equated to that of the Northeast as the level of ethnic minorities' population in this area is increasing, even though there is no standard measure for uptake by ethnic minorities within the cervical screening programme (ONS, 2012; NHSCSP, 2013). Therefore, there is a need for a bottom-up approach to examining the factors that influence participation in cervical cancer screening from service users' viewpoints, particularly in the Northeast. An in-depth understanding of these factors is likely to hold the key to devising age appropriate strategies for increasing uptake and will also add a unique perspective to the limited existing body of knowledge in England around cervical screening participation.

This study will focus on understanding factors that influence young women's decisions in whether or not to participate in the cervical screening programme. This is worth investigating, as this age group is prone to HPV and is deemed high risk due to concerns around being sexually active, having more than one sexual partner, or of being likely to have engaged in high-risk sexual activities (O'Connell et al., 2009). In addition, there is evidence of low uptake in the Northeast; an area associated with high incidence of cervical cancer and cancer deaths (Patel, et al., 2012; Cancer Research UK, 2012; ONS, 2012). The aforementioned concerns set a premise for this research study, with the Northeast, Yorkshire and the Humber Quality Assurance Reference Centre (QARC) also showing interest through their advice and financial support. They also advised on the need for the study to be Northeast focused due to the statistical evidence of low uptake stated above.

## **1.6 Research aim and Objectives**

### **Aim**

This study aims to develop an understanding of factors that influence participation and non-participation among young women aged 25-34 living in Northeast England, in the national cervical screening programme.

### **Project Objectives:**

- To identify factors that influence participation in cervical screening by young women
- To identify factors that influence non-participation in cervical screening by young women
- To consider the views and beliefs of young women in relation to cervical cancer prevention and screening
- To obtain insights from young women that could inform recommendations for an appropriate intervention to encourage young women to go for a smear test

**Research Questions:** What factors influence young women's decisions to participate or not to participate in the national cervical cancer screening programme?

## 1.7 Organisation of the thesis

**Chapter 1:** provides some relevant background information about the current policies and recent changes within the national screening programme in the UK.

**Chapter 2 (literature review)** explores and reviews a wide range of literature encompassing historical, policy and theoretical aspects. Some of the themes considered include the polarising arguments about grounded theory and what side of the argument this thesis would take, as well as a summary review of public health policies with respect to cervical cancer. A review of historical and theoretical literature appraises the most relevant contexts that underpin this thesis, followed by the evolution of appropriate strategies for screening uptake. Other themes explored include an overview of factors that influence cervical cancer screening participation as indicated by previous studies and theories about health behaviours, especially decision-making.

**Chapter 3 (Philosophical and methodological stance)** presents the philosophical approach that not only underpins this thesis, but also informs the methodology and its justifications. To effectively explore the lived experiences of this study's participants to better appreciate their decision-making process towards participating in cervical cancer screening, grounded theory (GT) was chosen as the methodology. GT encapsulates aspects of relativism, social interactionism and constructivism. This chapter gives a brief history of GT, with a focus on its strengths, limitations and relevance to the study topic.

**Chapter 4 (Research design and method)** encompasses a detailed account of all relevant activities carried out to produce primary data in line with GT principles, including the tools used to collect and analyse data, and the measures deployed to ensure validity of the data and its analysis. The use of Mind Genius to organise and schedule the analysis process, and theoretical sampling and constant comparative analysis were chosen to generate the requisite rigour to carry out this study.

**Chapters 5, 6 and 7:** Findings of this study are presented across chapters 5 to 7 and organised around the three-major emergent conceptual categories generated from the data. Chapter 5 will show the findings from the interviews. Chapter 6 shows representations from findings from the focus group. Chapter 7 shows findings from the integration of both the focus groups and the interviews. This shows the final arrangement and contextualisation of the model/framework derived.

**Chapter 8 (Discussion)** explores the key findings using the explanatory model derived as a guide whilst reflecting how the findings differ or correlates with existing literature. As this study is aimed at changing behaviours, the relationship and contribution of this current study to existing behavioural theories, some of which were discussed in chapter 2, will be explored. Reflections on the sampling procedures, data collection and analysis and ethical issues are also presented for reflexivity, as advocated by Charmaz (2014).

**Chapter 9 (Contribution to knowledge, study implications and conclusions):** presents strong justifications for the contribution to knowledge this study sought to achieve, while making cogent applicable recommendations and suggestions, even as it outlines the limitations of the study.

## CHAPTER 2: Literature Overview

In grounded theory, the place of a literature review has been highly debated (Charmaz, 2014; Giles et al, 2013). A literature review constitutes the premise for the study and enables the researcher to identify current findings, issues and theories around the proposed study (Bowling, 2000). Thus, a general literature overview is carried out in this chapter.

To undertake a review of relevant literature made available in the last decade, the Northumbria University search engine (NORA) was used to search sources like PubMed, Science Direct, CINAHL, Google Scholar and the Cochrane Database among others. In addition to the digital search, a hand search of relevant grey literature and government publications was also carried out. At the commencement of this research in March 2013, an initial review of literature established the contextual background for this thesis. However, it is noteworthy that attempts were made to keep up to date with evolving research in relation to the field of study. These were not discussed in this chapter but rather are explored in the discussion (chapter 8) in relation to their relevance to the findings.

Various studies on cervical cancer uptake have been conducted both nationally and internationally. Many studies in the UK take a specific focus e.g. on particular locations or ethnicities. Others focus on areas such as breast cancer screening, which has more entrenched screening programmes in place already. The few studies based in the UK were conducted in the southern part of the country with a focus on ethnicity and included women of all eligible screening ages. No studies were conducted in the Northeast. Although a few studies have explored a similar age group to the present study, or closed age groups, these were located elsewhere in the UK or abroad (Bloomberg, 2007; Waller et al., 2011; Webb et al., 2004; Logan & Mcilpatrick, 2011; Waller et al., 2004; Olesen et al., 2012, Brown et al., 2011; Mosavel & El-Shaarawi, 2007). The scarcity of age-specific studies and the increasing decline in participation especially within the Northeast highlighted the need for this study. This influenced the choice of a qualitative methodology and informs the basis for the choosing the constructivist grounded theory, which will be discussed in the next chapter.

This chapter outlines the theoretical contexts and historical perspectives on which this study is predicated. More so, it evaluates the public health promotion policies and practices in the UK, especially as they relate to cervical cancer screening. Crucially, relevant health behaviour theories will be examined in the context of their influence on decision-making about screening participation. A further exploration within this section will assess the factors influencing participation in the cervical screening programme and how the decision-making process works. This will be followed by a review of existing health behaviour theories/models within public health as a way of evaluating its impact and importance to the attendance for cervical screening and the NHSCSP in general. It is

necessary to give some thought to the critiques of screening that exist, both in the case of cervical screening in particular and in the wider context.

## **2.1 The place of literature in grounded theory (GT) studies**

The place of literature in grounded theory has long been disputed and remains contentious (Charmaz, 2006; 2014). The classic grounded theorists (Glaser & Strauss, 1967; Glaser, 1978) advocated for a delay in the literature review until after analysis has been completed with their rationale based on avoiding the viewing of data through a lens of earlier ideas (Charmaz, 2014). Glaser and Strauss (1967) pointed out that this may cause themes to be spawned from the literature rather than being allowed to emerge from primary data. To avoid this possibility, Glaser (1992) advises that literature should be considered after the analysis of primary data to prevent the researcher from interfering with the inductive emergence of data. A further argument is that prior knowledge could influence the way data is interpreted and advocates open-mindedness (entering the research with no preconceived idea) (Dey, 1999; Calman, 2006). Strauss and Corbin (1998:48) clarified their position on this by alluding to the difficulties of distancing ourselves from existing literatures or ideas, as we bring a considerable wealth of knowledge from our professional and disciplinary background to the inquiry. Charmaz, (2006) argued that there is a relative ambiguity with the position maintained by Glaser (Glaser, 1992; 1998), about grounded theorists remaining uncontaminated by the extant literature (Charmaz, 2006).

Charmaz and other grounded theorists (Charmaz, 2006; 2014; Dunne, 2011; Giles et al., 2013, Strauss and Corbin, 1990) support the prior use of literature, arguing that it is untenable to distance ourselves from the literature, as it helps the researcher in the selection of an appropriate methodology for their study. However, they advise that caution must be taken not to be too engrossed in the literature to avoid too much influence. Instead, they suggest that the researcher remains open-minded and takes precautions against allowing previous knowledge to influence their current research. Giles et al. (2013) suggested that instead of seeking to avoid preconceptions, these ideas should rather be grounded in evidence, with the researcher carrying out further investigation to justify the need for their research. They further reiterated that the initial literature review through reflexivity could enhance grounded theory research. Similar to the suggestion by Giles et al. (2013), Thornberg (2011) called for “informed grounded theory”, advising that researchers can use extant literature as a possible source of inspiration, ideas, experience, creative or critical reflection, which is in line with the logic of abduction and rejects the notion of pure induction. Therefore, the literature review could help in the identification of areas of criticism or debates within the research area often referred to as “leads”, rather than allowing the literature to lead the research (Morse, 1994; Holton, 2008).

Alternatively, Charmaz explains 'informed GT' as applying pre-existing theories and research findings in the substantive field in a cautious, sensitive, creative and flexible way, instead of seeing them as a barrier or obstacle (Charmaz, 2006). Informed GT has its roots in Charmaz's constructivist GT and the rational idea of abduction. She further advocated that delaying the literature review should not encourage the writing of a scanty review of the literature or instigating a careless attitude to earlier works. A literature review should not only strengthen the argument and credibility of the research study (Thornberg, 2011; Charmaz, 2006; 2014), but also provide a platform to set the stage for what will be done in subsequent chapters (Charmaz, 2014).

This study draws on Charmaz's constructivist and Straussian GT assumptions on the role of the literature review (Charmaz, 2006; Strauss and Corbin, 1998). However, attempts have been made to remain alert to what extent the literature influences the findings and ideas from my research. In addition, the review will aim to relate and focus on the importance and relevance of this research (Turners & Karsten, 2012).

In addition to the methodological arguments stated above, institutional pressure around the provision of a literature review greatly influenced the researcher's decision to include a literature review. The ethical committees (within and outside the university) expect that research proposals, along with other supporting documents be submitted for approval. This involves demonstrating any gaps in literature (providing justification for the study and choice of methodology) as well as indicating that the research will provide a unique contribution to knowledge. Lastly, failing to provide a review of relevant literature at an early stage can leave the researcher open to criticism, especially during project and ethical approval (Dunne, 2011). These justifications need to be provided partly to demonstrate that the study is ethical, i.e. that participant's time is used correctly (discussion on ethical consideration is included in chapter 3) before approvals are granted. This acted as a premise for conducting a literature review before data collection in this current study.

A narrow preliminary overview of literature was conducted early in this research to assess and identify some of the likely concepts, opinions and questions as well as gathering other relevant information about the factors affecting the participation of women to cervical cancer screening. This initial review helped to prevent the study from duplicating existing knowledge in the field and provided the rationale for embarking on the proposed research.

Furthermore, with respect to specific emerging findings from the primary data, the option to use literature to appraise such particular findings was suggested by Strauss and Corbin (1998). This approach was implemented in the discussion chapter as more recent literature, published after the start of the study (March 2013), was highlighted in relation to the findings. This helped to put the study findings into perspective relative to existing knowledge and to see how the concrete elements

of the theory evolved outside existing knowledge (Charmaz, 2006; 2014; Strauss & Corbin 1998). This was done through constant comparative analysis.

Having defined the reasons for engaging in a literature review in spite of the argument against this in some GT literature, I felt it was important to undergo a review to get a better understanding of certain terms in this field of the study i.e. Public Health and Health Promotion. It is also important to undertake the reviewing and identification of gaps in existing studies/literature, whilst considering available behavioural health theories relevant to this study.

## **2.2 What is Public Health (PH) and Health Promotion?**

Public Health has a plethora of terms and definitions. The World Health Organisation (WHO) refers to it as measures designed to achieve the prevention of disease, promotion of the health for the majority of the population (WHO, 2013). The UK Faculty of Public Health defines it as "the science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of the society" (Macdowall et al., 2006, pg. 9; UK Faculty of Public Health, 2010). These are the most used of all the definitions. Both definitions highlight public health as being concerned with the total system, not just the eradication of a particular disease. The three main public health functions are:

- *The assessment and monitoring of the health of communities and populations at risk to identify health problems and priorities*
- *The formulation of public policies designed to solve identified local and national health problems and priorities*
- *To assure that all populations have access to appropriate and cost-effective care, including health promotion and disease prevention services (UK Faculty of Public Health, 2010).*

The domains of Public Health in the UK are provided in the table below.

Table 1 Domains of Public health

| Health improvement  | Improving services  | Health protection   |
|---|---|---|
| <ul style="list-style-type: none"> <li>• Inequalities</li> <li>• Education</li> <li>• Housing</li> <li>• Employment</li> <li>• Family/community</li> <li>• Lifestyles</li> <li>• Surveillance and monitoring of specific diseases and risk factors</li> </ul> | <ul style="list-style-type: none"> <li>• Clinical effectiveness</li> <li>• Efficiency</li> <li>• Service planning</li> <li>• Audit and evaluation</li> <li>• Clinical governance</li> <li>• Equity</li> </ul> | <ul style="list-style-type: none"> <li>• Infectious diseases</li> <li>• Chemicals and poisons</li> <li>• Radiation</li> <li>• Emergency response</li> <li>• Environmental health hazards</li> </ul> |

Source: UK Faculty of Public Health, 2010

The domains listed above provide a framework for the organisation and delivery of public health interventions, which adopts multi-sectorial and multidisciplinary workings, (Griffiths et al., 2005). Interventions can cut across the three domains. Health promotion is a pivotal part of public health, which focuses on intervention such as screening to prevent diseases.

Health Promotion as a discipline does not yield itself to easy interpretations and definitions, although it is seen as one of the models/concepts of the ‘new public health’ (Naidoo and Wills, 2009). However, it has been generally argued to be a multi-dimensional process that involves both individuals and governments at various levels, and uses tools such as education, empowerment and the implementations of healthy policies (Scrivens & Garman, 2005; 2007). These activities are aimed at preventing ill health and promoting the health and the wellbeing of the population. The Ottawa Charter for Health Promotion Redefined Health Promotion as “the process of enabling people to increase control over their health and its determinants, and thereby improve their health” (WHO, 1986). This became the accepted definition (Scrivens & Garman, 2005; 2007; Naidoo & Wills, 2009), offering recognition of the fact that preventing illness and promoting health can be influenced by factors outside the control of individuals and includes socio-economic status, poverty, health literacy, demographic backgrounds, political and environmental conditions (Ewles & Simnett, 2005). Consequently, the WHO (2012) suggested that in addition to education and prevention of ill-health, health promotion activity should be directed towards developing policies that act on the determinants of health to ensure that the environment in which people live is conducive to health. Health promotion also includes strengthening community action and reorienting health services to promote maximum public

participation (WHO, 1998; 2012). There are various schools of thought and many critiques on what health promotion may mean (Ewles & Simnett, 2003). Despite the multidisciplinary nature of health promotion and the various approaches to its delivery, from simple lifestyle and behavioural approaches (Naidoo & Wills, 2009), to tackling broader complex structural determinants (Scrivens & Garman, 2007), all health promotion activities share one common goal; improving the health of populations (McDonald and Bunton, 2002). To reflect the changing trends in public health, Scrivens and Garman (2005) point to the shift from the term 'health promotion' to the more recent 'health improvement.' This shift goes beyond the substitution of one phrase for another, but in effect, the idea behind the term reflects contemporary thinking in public health promotion. For example, while the focus of health promotion tends to be on individual health education, health improvement presents a broader reach that incorporates the three main domains of the new public health model prescribed by the UK Faculty of Public Health (Griffiths et al., 2005; UK Faculty of Public Health, 2010).

### **2.3 Screening as a public health initiative/intervention**

Evaluating a real world public health intervention's effectiveness is complex, as can be seen in the cases of cancer and other diseases (Goldie, 2006). Screening is an important public health intervention, as it is a first line approach to reducing the incidence of most disease and improving health (Gray, 1996; Public Health England, 2013; Lewis et al., 2008; PHAST, 2011). The WHO defines screening as:

*...a public health service in which members of a defined population, who do not necessarily perceive that they are at risk of, or are already affected by, a disease or its complications are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of disease or its complications (Wilson & Jungner, 1968; WHO, 2013).*

The basic idea behind screening is that early detection of risk factors or disease would deliver benefits to the individual concerned and the public in general (Department of Health, 2012). Screening programmes vary across countries. In the United States, the screening committee or commission is more concerned with tests rather than the whole programme, while the UK definition of screening focuses on the programme as a whole (Ruffle & Gray, 2007).

The UK national screening committee defines screening as:

*...a public health service in which members of a defined population who do not necessarily perceive they are at risk of or already affected by a disease or complication are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or*

*treatments to reduce the risk of a disease or its complication.* (UK national screening committee, 2014)

The key importance of screening is the reduction of risks and/or complications typically among asymptomatic individuals by early detection, treatment and prevention of further spread of a disease (Gray, 1996, Public Health England, 2013).

### **2.3.1 Principles/Criteria's of screening**

Wilson and Jungner for the WHO provided the first criteria for evaluating the practicality, efficacy and relevance of a screening programme. These criteria are still in use today and explore and take into consideration the 4 stages below (see also accompanying table).

- Knowledge of disease
- Knowledge of test
- Treatment for disease
- Cost considerations (Wilson & Jungner, 1968)

Table 2. Wilson and Jungner's principles of screening

| <b>PRINCIPLES</b> |  |
|-------------------|--|
| <b>1</b>          | The condition should be an important health problem        |
| <b>2</b>          | There should be a treatment for the condition              |
| <b>3</b>          | Facilities for diagnosis and treatment should be available |
| <b>4</b>          | There should be a latent stage of the disease              |
| <b>5</b>          | There should be a test or examination for the condition    |

|           |  |
|-----------|--|
| <b>6</b>  | The test should be acceptable to the population  |
| <b>7</b>  | The natural history of the disease should be adequately understood   |
| <b>8</b>  | There should be an agreed policy on whom to treat as patients  |
| <b>9</b>  | The total cost of finding a case should be economically balanced in relation to medical expenditure as a whole |
| <b>10</b> | Case finding should be a continuous process, not just a “once and for all” project                             |

In the UK, the National Screening Committee’s current criteria for screening are based on those original ten principles (Public Health England, 2013b) as summarised below:

- The condition - this should be identified as a health problem, well understood, cost of intervention already implemented and should be practical. In addition, the history of the people diagnosed should be well understood.
- The test - this should be as simple as possible and well validated. Acceptability of the test by the population should be achieved and policy set in place for continuous investigation and best practice.
- The treatment - An effective treatment/intervention should be in place, as evidence has shown better outcomes through early intervention. In addition, policies provided should be evident and aimed at putting the best interest of the individuals at heart. All healthcare providers should have in place clinical management teams for the condition/illness prior to screening participation.
- The screening programme – evidence-based studies/trials showing the effectiveness of the programme in reducing morbidity and mortality should be presented. The programme should be proven to be clinically, socially and ethically acceptable by health professionals and the public. Its benefit should outweigh its harm, and its cost-effectiveness must be well explored.

All issues and recommendations stated in condition, test and treatment above should be considered before rolling out the screening programme (Public Health England, 2013b; UK National Screening Committee, 2003).

Cervical cancer screening, one of the numerous screening programmes organised in the UK, is an invasive test because of the location of the cervix. The test is called the Papanicolaou smear also known as Pap smear or test (Cancer Research UK, 2012) and involves taking a sample of cells from

the cervix with a small brush. The cells are then sent to be tested for abnormalities. If borderline or mild changes are found, the sample will also be tested for high-risk Human Papilloma Virus (HPV) strains. If extensive changes are found, these will be treated. Detecting and treating abnormal cells through screening can help prevent cervical cancer. Outside prevention, the screening can aid in early detection of cervical cancer, where a successful treatment is most likely. To encourage more attendance, efforts are being made to find an alternative, less invasive screening process (Cancer Research UK, 2012). The screening is presently offered to women between the ages of 25-64 in the UK. However, women under 25 or above 65 must request screening at their GP practices. The cervical screening is not a diagnostic test, but rather a preventive test to detect the presence of changes in the cell structure within the cervix (Cancer Research UK, 2012).

### **2.3.2 Strengths and limitations of screening**

As discussed, screening programmes are aimed mainly at saving lives through early detection, diagnosis and where necessary, treatment (Public Health England, 2013a; PHAST, 2011). Cancer instances can be potentially decreased as a result of screening at the interim with a long-term projection (Raffle & Gray, 2007; Raffle et al., 2003). For example, in the UK, cervical cancer death is reduced by almost 5,000 yearly, in addition to a 75% and 50% prevention among older and young women respectively (Cancer Research UK, 2012; NHSCSP, 2010). In the same way, the rates for both breast and bowel cancer have reduced significantly with about 2 million women and men screened yearly leading to about 1,300 diagnoses (for breast cancer) and up to 2,000 lives saved yearly by 2025 (for bowel cancer) (Cancer Research UK, 2014; 2015). However, the cervical screening programme is still recording decreasing uptake especially among young women. Hence the need for this study, to explore those factors that influence screening uptake, to gain insights into how to increase screening participation to meet targets.

It is important to note that not everyone benefits from screening. Some might even be harmed by their participation (Raftery & Chorozoglou, 2011). Screening procedures or programmes are not 100% perfect and there is a possibility of over-diagnosis (i.e. false positive results for those who do not have the disease). Furthermore, one in five tests will miss something (Cancer Research UK, 2012). Inconclusive results can lead to unnecessary treatment (Waller et al., 2009; Cancer Research UK, 2012). Such cases could result in undue anxiety, stress, further investigations and even treatments that are not only unnecessary and avoidable but also expensive to patients and the health service.

Conversely, instances of false negative screening outcomes portend far graver consequences for the individual concerned, who gains a false sense of security while the disease progresses. Nonetheless, the potential advantages of screening still significantly outweigh the possible mishaps that could arise from unwarranted treatment (Public Health England, 2015; Cancer Research UK, 2014).

Despite the strong advantages of screening, there may also be ethical implications (Wilson & Jungner, 1968). Through screening, the health service stimulates seemingly healthy people to make better-informed choices about their health. In spite of associated risks (e.g. false negatives and positives), it is important that people understand that screening is not a fool proof process, and have realistic expectations of what the screening can deliver (Lewis et al., 2008; PHAST, 2011). The elucidation of the principles and challenges of screening discussed above could help reduce the impact of ethical issues and limitations associated with screening (Wilson & Jungner, 1968). This is evident in the success of the Screening programmes in the UK (e.g. cervical, breast and bowel cancer) as adopted by the UK Screening Programme Committee (Public Health England, 2013b; PHAST, 2011; NHSBCSP, 2006; Cancer Research UK, 2013).

#### **2.4 Development of Cancer Reduction Strategies**

As the cause of 84 million potential deaths in 2015 (WHO, 2013), cancer remains one of the foremost causes of death. With such an alarming projection, various strategies and policies have been produced around screening, which are proven to prevent cancer deaths (WHO, 2013; NHS cervical cancer screening, 2011). A cancer prevention plan drawn up in 1948 by the WHO showed that cancer could be reduced through 3 levels. These include the primary, secondary and tertiary prevention level. Both the primary and tertiary levels involve encouraging behavioural and lifestyle changes, and improving treatment and conditions respectively. The secondary prevention level includes screening, to aid early detection and treatment of cancer (WHO, 2002a; 2002b). Secondary prevention has the potential to minimise the period that the disease affects an individual, or its spread in the community by fending off and/or putting off the negative impacts of the disease as it progresses (WHO, 2007). A comprehensive cervical cancer control guide has since been published (WHO, 2014) to help in the control and further reduction of death from cervical cancer through prevention and treatment.

Most developed countries with effective health systems have been able to roll out cancer prevention programmes e.g. the NHSCSP and the bowel cancer screening programme (NHSBCSP) in the UK (Cancer Research UK, 2013; NHSCSP, 2013; <http://www.cancerscreening.nhs.uk/>). However, many other countries lack effective health systems and adequate financial resources compared with developed countries, to tackle problems associated with cancer. Indeed, more than 70% of all cancer deaths occur in low- and middle-income countries, with limited resources (WHO, 2007; 2014).

In 2007, the World Health Assembly adopted a resolution committing the WHO and its Member States to the process of gender mainstreaming. The implication being to improve the understanding of the role of gender in the allocation of health services, and reduction of inequality in health service provision, thereby prioritising the delivery of services such as cervical cancer screening in areas with a high prevalence for cervical cancer (WHO, 2014). In addition, they vowed to actively help

strengthen health systems in general and to develop, test and implement appropriate technologies to make comprehensive cancer care feasible and affordable in low- and middle-income countries.

#### **2.4.1 Development of the NHS Cervical Screening Programme (NHSCSP)**

Cervical screening has been in use in the UK since the mid-1960s, although the national programme was not established until 1988 (NHSCSP, 2004). The formal national screening programme, established in 1988, was designed for women aged 20-65 and all health authorities were instructed to adopt the computer based call-recall system to attain agreed standards (Patnick, 2000).

Within the NHSCSP, women receive their first invitation for routine screening at 25 years. In England prior to 2003, the year of first invitation was 20, which was subsequently raised to 25 after changes in national policy (Cancer Research UK, 2013). However, Scotland and Wales still retain the starting age of 20.

Until 2003, the UK-wide guidance required that all women should be screened at least every 5 years, although in fact, over half of the Health Authorities in England sent out invitations every 3 years (HSCIC, 2015; Patnick, 2000). However, following the recent changes, the qualifying ages for invitations and the screening interval have been altered.

The change in screening age has resulted in many debates with people calling for it to be reduced due to increased cancer instances in younger women (NHSCSP, 2014). In June 2009, the policy changes to cervical screening of 2004 (ACCS, 2009) was upheld by an independent advisory committee for cancer screening in England after being reviewed. Furthermore, after extensive analyses of available data in 2009, it was discovered that screening women aged 20-24 had little or no effect on the incidence of cervical cancer in women under 30 (Sasieni et al., 2009). Therefore, it was concluded that the move to reduce the age bracket for those entitled to free cervical screening on economic grounds is likely to encounter public resistance. The two-pronged changes of screening age and the intervening period between screenings could potentially elicit some interesting reactions, which could throw some light onto how women perceive cancer individually and collectively as women in within a defined society.

#### **What the screening entails**

The screening involved detecting cervical cancer using the Liquid-Based Cytology (LBC). This is not a diagnostic test for cancer, but a preventive method used to detect early abnormalities, which, if left untreated, could lead to cancer in a woman's cervix (Cancer Research UK, 2014; Public Health England, 2015). The LBC involves the use of speculum to open a woman's vagina, and a small soft brush to sweep around the cervix, to gather the sample cells from the cervix. The brush is then rinsed

in a pot of liquid, and taken to the laboratory for analysis. (Cancer Research UK, 2014). Prior to 2008, the detection of abnormal cells was done using a Pap smear. The LBC is considered more reliable, and was adopted because it preserves cells better and makes it easier for scientists to view cells (Department of Health, 2013).

### **Organisation of cervical cancer screening programme before the NHS restructuring in 2013**

Prior to the NHS restructuring in 2013, cervical screening was organised and delivered locally through PCTs and General Practices. The programme required all PCTs to have a nominated individual responsible for screening and implementing national guidelines. Established in 1994, it had two main priorities:

- Develop systems and guidelines, which will assure a high quality of cervical screening throughout the country
- Identify important policy issues and help resolve them, as well as improve communications within the programme and to women (NHSCSP, 2004).

Invitation to attend screening was sent out by the NHS call and recall system, also known as the Open Exeter system, to all qualifying women registered with a GP. Women not registered with a GP could also access screening by visiting NHS community clinics if they fell within the screening age (NHSCSP, 2013; HSCIC, 2014). The call and recall system also keep track of any follow up investigation and recalls women for screening in 3 or 5 years' time if there is no abnormality. It is possible for women who do not wish to attend to have themselves removed from these lists through negotiation with a practice nurse or GP.

Reduction of healthcare costs is one of the priorities for the NHS in the UK, in the light of recent tight government budgets. Approximately half of the costs of the cervical cancer-screening programme took the form of target payments to GPs for smear taking, i.e. GPs were presented with financial incentives to reach the national target (Patnick, 2000). These payments were introduced in 1990 to encourage GPs to ensure their female patients participated in the programme. No payment was made for coverage below 50%, a low payment is received for between 50-79% and a higher payment for 80%+ (Ellis & Chisholm, 1997; Armstrong, 2005).

### **Key changes in the structure of the programmes as a result of NHS reorganisation**

Public Health England (PHE) now leads the NHSCSP and other cancer and non-cancer screening programmes. The national office of the NHSCSP within PHE delivers systems and guidelines to assure safe and effective cervical cancer screening, and resolution of important policy issues in addition to improving the programme through the Screening Quality Assurance Service (SQAS).

Nationally, there are 4 regional quality assurance coordinating groups in the 4 main areas of activity of the cervical cancer screening programme. The regional SQAS include London, Midlands and East, North, and South (Public Health England, 2015; HSCIC, 2014).

Currently, NHS England plays a role in the cervical screening programme (HSCIC, 2014). This involves commissioning of cervical screening through the NHS Commissioning Boards (NHSCBs) at the four main areas of cervical screening, whilst adhering to the national standards of PHE. The four main areas of cervical screening are: Call/recall, cervical cytology services (including HPV testing), cervical histology services and colposcopy services. This specification operates up to the point of diagnosis of cervical cancer; subsequent management and treatment is outside its scope (NHS England, 2016; NHS Screening Programme, 2015).

Invitation is still through the regional call and recall centres/systems. Screenings are delivered at local GPs and NHS Community Clinics by trained professionals. The samples are then sent to designated laboratories or colposcopy clinics (NHS England, 2016).

### **Uptake of the NHS cervical Screening Programme**

Successful and effective screening is largely dependent on participation, with non-participation hindering success and potentially leading to a waste of public health funds. However, several studies have reported low uptake of screening tests for cervical cancer and other cancers (Lancuski et al., 2010; Labeit et al., 2013; Ekechi et al., 2014; Weller et al., 2007; Waller et al., 2009;). As stated earlier, coverage from the inception of the screening process has been around 80% but in recent years, there has been a continuous decline in uptake (NHSCSP, 2012; Waller et al., 2009).

Variations in uptake have been reported in women in terms of age, socio-economic status/ social deprivation, ethnicity and location.

**Age** - There has been noticeable variation around uptake across age groups (NHSCSP, 2009). Figures show a continuous decline among all women aged 25-29, showing the lowest coverage/uptake rate at about 10% lower than 30-34 year-olds and 20% lower than 50-54 year-olds (NHSCSP, 2012). Young women aged 25-34 have shown the highest decline, with only two thirds screened within the last 5 years, down from 75% in 2001 (Health and Social Care Information Centre, 2010). This trend is not peculiar to UK; similar trends have been noted in other countries such as Australia, Canada, Sweden, France and Italy (Lancuski et al., 2010).

This fall in uptake in younger women is of particular concern, as the benefit of cervical cancer is more effective in women screened at a young age. Nonattendance or delay in going for screening has a potential to lead to diagnosis at later stage of cancer (The Guardian, 2014; Cancer Research UK,

2011; Peto et al., 2004). Although the underlying reasons for this decline are unknown, some studies and reports have attributed this falling participation to an increased understanding of the link between HPV and cervical cancer, and other factors, e.g. embarrassment (Albrow et al., 2014; Zur Hausen, 2002; Waller et al., 2009; 2011). Concern around HPV vaccinated women not seeing the need to go for cervical cancer screening has led to a continuous emphasis on the need to educate women on the importance of cervical screening, since HPV vaccination only protects against HPV types 16 and 18 (Lynge et al., 2009; Cervical Cancer Screening Programme, 2009).

The UK-based qualitative study by Henderson et al. (2011), which sought to understand how HPV vaccination in young women affects future cervical screening uptake, showed a lack of understanding of the importance of cervical cancer screening irrespective of vaccination status amongst the female teenage participants and their parents. However, this study was limited in that it only included women aged 12-13 and their parents, and was conducted in a PCT in Southeast London. It is unknown if the views will differ in much older women in the 16-20 age group and in a different setting. However, they suggested that information obtained should include a distinction between the benefits of the vaccination and those of cervical cancer screening (Henderson et al., 2011).

Part of the Cancer Reform Strategy (DH, 2007) included proposals to address the falling participation rate in young women, as well as reducing variation in coverage across regions. Numerous calls from both screening providers and health practitioners on the long-term implication of the continuous decline in young women attending screening act as a premise to undertake this study.

**Socio-economic status (SES) and social deprivation** - The relationship between SES and cervical screening uptake has been examined at 3 different levels: health district (Baker & Middleton, 2003), general practice (Ibbotson et al., 1996) and individual level (Sutton & Rutherford, 2005). This association at different levels has been explored using variable indicators. Using the health belief model to examine this association, Sutton and Rutherford found that age, marital status, education, ownership of a car and property affected uptake. Married women showed a higher uptake. This could be associated with other factors such as gynaecological examinations and awareness levels due to frequent hospital visits, since it is established that sexual behaviour is a risk factor of cervical cancer (Cancer Research UK, 2013). The reason for uptake among married women was not well defined. It was also not known how and why these social demographic factors were chosen. Although many variables were included in SES studies, there are still numerous debates around accepting such findings and care should be taken in making interventions solely based on study results, considering that social-economic indicators are not standardised. The association between age and uptake was not correlated nor deemed significant in this study. It would have been useful to know the uptake of cervical cancer among women of various ages within a SES context.

According to some reports, SES is used interchangeably alongside social deprivation (Logan and Mcilpatrick, 2011). Deprivation has been linked to increase risk of cervical cancer. Women living in the most deprived areas of England are twice as likely to be diagnosed with cervical cancer (Cancer Research UK, 2008). A (2008) study conducted by the National Cancer Intelligence Network (NCIN) reported that deprivation was probably responsible for poor uptake of cervical cancer screening in these areas. According to analysis carried out between 2000 and 2004, women from more deprived areas showed a positive diagnosis of about 12 per 100,000 compared to 6 per 100,000 in more affluent areas. This increase is attributed to lifestyle choices such as higher rates of smoking and earlier onset of sexual activity. They recommended that more work is needed to tackle cancer in low-income communities (Health and Social Care Information Centre, 2011).

Evidence suggests that uptake for women from socially deprived areas still remains low with limited knowledge of cervical cancer (Dos Santos & Beral, 1997; Logan and Mcilpatrick, 2011). This finding is concerning as there is a positive correlation between knowledge of cervical cancer and screening attendance (Arevian et al., 2006; Logan & Mcilpatrick, 2011). It was also evident from this study that women had negative perceptions of screening due to negative anticipated feelings and past experiences. The author presumed these perceptions are also shaped by social-cultural beliefs. A major strength of the study was in the recruitment of participants and choice of locations, and the detailed description of participants' characteristics and study sites. One limitation of the study was its small sample size and lack of age distinction in reporting findings. The study findings however, could offer some insight about the reasons for the decline in uptake of cervical screening in some socially deprived regions in the UK such as the Northeast (Willoughby et al., 2006; ONS, 2012; Health and Information Centre, 2011).

**Location/ region** - Screening coverage/uptake shows geographical variation across the UK. The Northeast, Yorkshire and The Humber areas show coverage below the national average (Willoughby et al., 2006; National Cervical Cancer Screening, 2012). Cervical cancer incidence rates tend to be lower in the South and East of England but higher in the North and the Midlands (HSCIC, 2011; Newcastle NHS Foundation Trust, 2012). The highest incidence rates are in parts of Scotland, Northern Ireland and the North of England, and the lowest rates are in the South and East of England (Cancer Research UK, 2013). The five Strategic Health Authorities (SHAs) with the highest rates (Yorkshire and The Humber, East Midlands, Northeast, North West and West Midlands) had incidence ranges from 6.8 to 11.3 per 100,000 females (Quinn et al., 2005; Patel et al., 2011; Trent Cancer Registry, 2012).

Willoughby et al. (2006), in their descriptive study, which examined the increase in cervical cancer between 1995-2005 in the Northeast, Yorkshire and The Humber, reported an increased incidence rate and decline in coverage predominantly amongst two key groups of women: younger women;

and those from black and minority ethnic groups (Chiu, 2004). Recent statistics released by the HSCIC (2013) support these findings, which show that young women aged 25-34 indicate continuous decline in uptake, especially those aged 25-29. As stated above, this high incident in the Northeast might be relative to low uptake within the age group in this region (Fozzard & Greenwood, 2012; HSCIC, 2011; 2013).

A health profile analysis by the Office of National Statistics (ONS) in 2010 shows the Northeast of England as having a deprivation level higher than the England average with various degrees of health inequalities. Although the death rate from cancer in the Northeast is levelling, it still falls above the national average (DOH, 2010). This correlates with the statistics above, showing high incident rates and low uptake, which has the potential to lead to a diagnosis of cancer at a later stage and lead to poorer outcomes (Smith et al., 2003). Reports and studies have shown that cervical cancer is more common in less affluent areas, and that uptake is greater amongst more educated women (Patel, et al., 2011; Cancer Research UK, 2013). A few years ago, cervical cancer coverage in the 12 Local Authorities in the Northeast revealed that 6 PCTs have fallen below the regional and national average. Middlesbrough, the most deprived area of the Northeast (Newcastle NHS foundation Trust, 2012), Newcastle and Hartlepool showed the lowest uptake in 2010/2011 (Fozzard & Greenwood, 2012; Chiu, 2004; NHSCSP; Newcastle NHS Foundation Trust, 2012).

**Ethnicity** - Although the coverage/uptake of cervical screening by ethnicity is not officially recorded in the cervical screening register, the impact of uptake among women from this group cannot be over emphasized. Overall, ethnicity is poorly recorded in the UK, especially in primary care (Pringle & Rothera, 1996; Kumarapeli et al., 2006; Baker et al., 2007). However, according to some studies, ethnicity is a major predictor of non-attendance (Marlow et al., 2015; Ogedegbe et al., 2005; Behbakht et al., 2004). Uptake of cervical screening in black and ethnic minority communities continues to be a concern in many areas of England (NHS Cervical CSP, 2012). A follow-on research to the populus survey (NHSCSP, 2009), carried out by Szczepura in 2008, looked into bowel and breast cancer screening uptake rates among members of the South Asian ethnic community. Women from this community were only half as likely to attend bowel cancer screening and 15 times less likely to attend breast cancer screening than members of the non-South Asian community. Lack of knowledge and the ethnicity of the GP were the main reason for non-uptake reported in this study. Even though the study cannot be generalised to all ethnicities, it provided a premise for further studies to understand uptake in women from ethnic minorities. Other studies that have explored reasons for nonattendance without exploring uptake rates across varying ethnic groups, have identified similar barriers. (Abdullahi et al., 2009; Marlow et al., 2015; Ogedegbe et al., 2005; Behbakht et al., 2004). These and other existing studies will be discussed in depth when exploring reasons/factors associated with some of the aforementioned differences later in the chapter.

## **Exploration of decision-making and participation in Public Health initiatives**

To explore the factors affecting uptake in terms of participation and non-participation as reviewed in the existing literature, it is important to understand what decision-making and participation means, and how this is reflected in the way people respond to health initiatives/intervention such as the cervical cancer screening.

**Decision-making** is a process that involves movement through a series of phases (Rosenstock, 2005). According to Rosenstock, the movement entails the interaction of the individual with events and people, which directly or indirectly influence the individual's decision and subsequent behaviour. Decision-making is a complex phenomenon, which could be influenced by myriad factors such as race, age, gender, occupation, environment or socialisation (Galdas, Cheater & Marshall, 2005; 2007). Decision-making can involve many deliberations on options and their consequences, although Doya and Shadlen (2012) propose that decision-making is a cognitive function and that many decisions are reactive and automatic.

Decision-making models observed in health services show that this process could be paternalistic, a shared decision-making (SDM) or informed decision-making (IDM) (Rimer et al., 2004; Wackerbarth et al., 2007). SDM and IDM are encouraged in health services, which advocate that the decision-making process should be shared by the health professional and the individual. Such decisions should reflect and be consistent with the preferences at the service user's desired level (Sheridan et al., 2004). However, due to limited resources IDM is not always fully implemented.

There have been debates around full use of IDM channelled towards informed choice in decision-making. Recent UK policy advocates for participation/decision-making to reflect, "informed choice" (Marteau et al., 2001; 2010). It has been argued that this policy possibly leads to non-participation among those from socially deprived areas with varied individual values that are sometimes culturally influenced (Raffle, 2001; Crockett et al., 2009; Orbell & Hagger, 2006). However, it is noteworthy that most health-related decisions are influenced by symptoms and this might be more challenging for asymptomatic conditions and their interventions, such as cervical cancer and screening respectively. People may perhaps find it unnecessary to undertake screening in the absence of symptoms.

Decisions to participate in public health interventions are not only influenced by provision or promotion of the health problem (e.g. cervical cancer and screening), but also by the individual, based on whether their decision need has been met (Rimer et al., 2004; Jackson et al., 2008). Decision-making cannot be discussed without also talking about participation, as the former leads to the latter.

**Participation** on the other hand, is a very broad term and a concept used in many ways. It could simply mean involvement. However, this may range from active involvement too little or no involvement (Labahn, 1995). Participation has been cited as among the most misunderstood ideas that have emerged from human relations studies. It entails the creation of opportunities under suitable conditions for people to make decisions on issues affecting them (Pateman, 1970). Participation also involves sensitizing people in their local environment to increase their receptivity and ability to respond to development programmes, as well as to encourage local initiatives (Oakley, 1989). Participation is important in healthcare because the success of any healthcare intervention is primarily predicated on getting as many people as possible to take part (Rifkin, 1990). This thinking ensures that resources are used in a way that brings the greatest possible benefit to the highest possible number of people. The WHO advocates active involvement of individuals in assessment, planning, implementation and evaluation of healthcare services (McHunu, 2009). This should translate to partnership working arrangements among significant stakeholders from the community and healthcare providers. However, it has been noted that certain partnership arrangements that are expected to work in principle may not actually work in practice (Mchunu, 2009). It has also been reported that the development of healthcare interventions hardly ever involves active participation of the people except in passively partaking in the end product (Brown et al., 2005).

Communities and individuals may be involved in health interventions or services at different levels (McHunu, 2009). Involvement could be exercising full citizenship power in terms of assessment, planning, implementation, monitoring and evaluating of the programmes (McHunu, 2009). It could also involve a platform where views can be aired, though whether this is considered during policymaking is a matter for debate (Moote et al., 1997). The last level involves access to health services provided by agencies such as Health Improvement Programmes, immunisations and screening programmes (Rifkin, 1990; Brown et al., 2005; McHunu, 2009). Service involvement with these is passive rather than active, which seems to be the case in most community-oriented health programmes where people are expected to accept what is being offered.

Participation in the cervical screening programme is generated through invitation letters to take a smear test. The present study could help explore a better understanding of the reasons for participation in the screening programme. It could potentially improve participation at policy level, since effectiveness of any public health intervention (e.g. screening) depends hugely on the participation of those most at risk of the public health problem (Rose et al., 2001).

## **2.5 Reviews of Existing literature on factors influencing participation in cervical cancer screening**

Factors influencing uptake or participation in screening services have been explored in studies of various cancer screening programmes (Thomas et al., 2005; Szczepura et al., 2003; Jepson et al., 2007; Taskila et al., 2009; O’Neil et al., 2009; Weller & Campbell, 2009). In addition to the differences in factors related to uptake discussed earlier such as age, SES/social deprivation, ethnicity and location, some studies have also explored other related factors/links. These may act either as barriers preventing people from taking part or as facilitators/motivators in people’s choices and decisions to take part in screening.

A lot of reasons have been attributed to the underutilization of screening, including fear, denial, embarrassment, pain, and inconvenience (Logan & Mcilpatrick, 2011; Oscarsson et al., 2011; Waller et al., 2009). Some of these reasons have been linked with demographic, SES, psychological and cultural factors (Oscarsson et al., 2011; Behbakht, 2004). Inaccuracies in patients’ addresses and medical records, and inconvenient appointment times have also been suggested as possible factors in non-participation (Waller et al., 2009; Bang et al., 2012). In addition, the inconvenience women have to go through during the smear test and the information on the risk and nature of cervical cancer itself can provoke unpleasant emotions, so the individual may not find the screening process very pleasant (Oscarsson, Wilma & Benzein, 2011; Waller et al., 2009; Bang, 2012). Studies looking at predictors of uptake for cervical cancer screening have identified the nature of the test (sometimes painful and uncomfortable) as one reason for not going for a re-screen (Waller et al., 2009; Labeit et al., 2013). Whereas, in other studies, non-attenders opted out of the screening due to negative stories from friends or family members (Abdullahi et al., 2009; Logan & Mcilpatrick, 2011; Cooper, 2011).

These barriers vary across various age groups, ethnicity, country and regions in the UK (Waller et al., 2011; Abdullahi et al., 2007; Logan & Mcilpatrick, 2011; Ogedegbe et al., 2005; Olesen et al., 2012). Some of the barriers mentioned in some of the studies conducted with young women include (but are not limited to) issues around competing time demands, insufficient knowledge of cervical cancer and its prevention, frequent changes of address, fear of pain, procrastination and embarrassment. (Waller et al., 2009 ; Mosavel & El-Sharaavi, 2007 ; Black et al., 2011 ; Waller et al., 2011; Kahn et al., 1999). Some of these areas will now be considered in more depth.

### **Knowledge, perceptions and attitudes towards cervical cancer and its screening**

Studies have consistently shown misinformation and a lack of knowledge regarding cervical cancer and preventative screening to be major barriers to screening adherence (Logan & Mcilfalick, 2011; Redwood-Campbell et al., 2011; Black et al., 2011; Thomas et al., 2005; Ogedegbe et al., 2005; Al

Sairafi & Mohammed, 2009). Inadequate knowledge (Al Sairafi & Mohamed, 2009) and lack of awareness can become a barrier to cervical cancer prevention. Redwood-Campbell et al. (2011), in their Canadian study exploring barriers to attendance of cervical cancer screening, used a case study-based qualitative approach involving 2 focus groups with women from various ethnic backgrounds aged 35-69. Most participants admitted to having a poor understanding of cervical cancer itself and a lack of knowledge of the screening procedures. This was reflected in participants' misconception about the causes of cervical cancer, with some citing birth control pills, diets and weight as probable causes. Perceptions of low-risk could readily discourage participation because the women involved are ignorant of the dangers of non-participation as well as the benefits of participation. Overall, the participants exhibited a positive attitude towards their health and cervical cancer screening. However, barriers such as language, clinician's gender, embarrassment, modesty (which are often culture-specific feelings) were reported as reasons for non-attendance. This study was based on the health belief model, which could have led to the exclusion of important findings that may have reflected the barriers to screening. Another limitation of the study was that opinions about knowledge were culturally limited in terms of language barriers, i.e. understanding the available information on cervical cancer and its procedure.

Similarly, Brown et al. (2011), who explored knowledge, attitudes, beliefs and practices in a US focus group, found that limited knowledge and confusion about cervical cancer across ethnicities constituted barriers to screening uptake. In this study, the majority of participants (79%) were aged 40 years and above, and acknowledged that they were not only quite unaware of the causes, symptoms and modes of contracting cervical cancer, but also had limited knowledge of the screening procedure, despite admitting to having heard about cervical cancer and that it was preventable. Concerns about loss of virginity for younger women if they undertook the cervical screening test were also raised. This may relate in part to a lack of knowledge regarding the Pap smear screening process and the socio-economic background of the family. There was also a lack of knowledge of the anatomical position of the cervix, with much confusion and uncertainty regarding the causes and risk factors of cervical cancer. This is particularly worrying, given that cervical cancer has different risk factors, as explained above (Cancer Research UK, 2013). Awareness of these can better inform women to not only make the correct informed decision, but also play a greater role in the prevention or reduction of the incidences of cervical cancer. Knowledge of HPV, one of the major risk factors of cervical cancer was also limited, with half of the participants reporting not knowing about it. In terms of attitude and perception towards screening, responses varied, with half of the participants attending a smear test in the past year. Even though most of the women reported being unaware of the screening guidelines for cervical cancer, they were aware of the Pap smear. Furthermore, participants in this study who had not been for screening cited factors such as lack of knowledge of

cervical cancer and screening, a busy schedule, and fear of the unknown. This set of motivating factors was also identified in other studies (Thomas et al., 2005; Ogedegbe et al., 2005).

The study by Brown et al. (2011) was similar to the one by Redwood-Campbell et al. (2011), in that it was limited in size and in age of participants. The fact that over 75% of participants were aged 40 and above had implications for the awareness level of the participants. This assertion was corroborated by reports from a contrast study by Black et al. (2011), which used 10 focus groups to explore barriers to cervical screening in young women aged 20-29. The participants happened to be well educated; hence, there was an adequate knowledge about the Pap smear by participants, who understood that the test is essential for women who are sexually active. However, there remained some confusion about Pap tests and STI screening, with many young women mistakenly assuming that they were being tested for all STIs when they participated in cervical cancer screening (Black et al., 2011). Knowledge of cervical cancer and the screening procedure and guidelines acted as an actual facilitator to screening attendance in this study. Although the study tried to be diverse in terms of ethnicity, SES (exploring various educational and employment backgrounds) and location (living in both rural and urban areas), 66% were white Caucasians. This could have positively influenced their knowledge level of cervical cancer and screening. As suggested earlier, ethnicity is/ a predictor of low uptake (HSCIC, 2013). Like most qualitative research inquiries, the study was limited in size. Moreover, the fact that more than half of the study participants were students in higher education could also have influenced their knowledge levels and under-representing women who were less highly educated.

Perception of cervical cancer screening among adolescents has also been explored. Mosavel and El-Shaaravi (2007), in their US study of 12-17 year old girls from ethnic minority backgrounds and low-income urban neighbourhoods, showed a variation in the knowledge of cervical cancer and screening. Knowledge, although limited, reflects a representation of the assemblage of information from different sources. Negative perceptions of cervical screening were also reported to emanate from personal stories and social networking interactions nurturing and amplifying feelings such as fear, uncertainty and anxiety in the same study. It has been suggested that the ways information is communicated can have both negative and positive effect on people's perceptions or attitude towards the message contained in the information (Anderson & Martin, 2003). In spite of its insight about the intention to screen, as well as knowledge and perception of cervical cancer, Mosavel and El-Shaaravi's study was limited because it was a part of a larger study that was focused on cervical cancer, health promotion and the mother-daughter relationship. In addition, it was also geared towards much younger women (aged 12-17), as part of evaluating opinions around the implementation of HPV vaccination, not the cervical cancer Pap smear.

Studies have also looked at perceptions and attitudes towards cervical cancer screening. Lyon et al. (2009) undertook a study involving young women aged 25-34 as a part of a larger project to improve uptake in cervical cancer screening in the Blackpool area. Women from socially deprived areas were identified as non-attendees. Their views were acquired using a focus group method. Perceptions of screening were positive, although attitudes towards attending for screening varied among participants. Attitudes toward non-participation were centred on a lack of knowledge about what it feels like to have a cervical smear, lack of knowledge about cervical cancer and its treatment, low awareness levels of the benefits of cervical screening and lack of understanding about why there is an age limit. Although these barriers were not mutually exclusive, they were influenced by other factors such as fear and embarrassment, which will be discussed later in this study.

Although the study above provided age-specific perceptions and attitudes towards cervical cancer screening, it focused only on women living in a deprived area in a small city in the UK, thus generalisation from the study is limited. Another limitation was that the research questions and study objectives were tailored towards improving uptake with little attention paid to the reasons for participation and non-participation. Nonetheless, the study provided the premise for further study within the age group to explore diversity among participants, such as ethnicity and education levels (Lyon et al., 2009). A similar study conducted by Logan and Mcilfattrick (2011) involving women aged 35-55, who were living in socially deprived areas of Northern Ireland, reported similar findings of inadequate knowledge acting as a barrier, although the knowledge level varied across participants.

As deduced from the reviews of studies above, perceptions and attitudes to cervical cancer screening are largely influenced by knowledge and awareness levels. The decision to attend screening is essentially multifactorial.

### **Embarrassment/pain and fear**

There are abundant opinions about the effect of emotions on the decision-making process. However, recent studies have sought to provide more concrete insights (Ackerson & Preston, 2009). Applied to cervical cancer screening, negative emotions such as fear of pain and embarrassment, which are highly associated with uncertainty, adaptively elicit a risk aversion response in some individuals, leading to delay or non-participation in most cases. This can be alluded to its negative psychological impact on decision making process (Bloomberg et al., 2009; Waller et al., 2009; Logan & Mcilfattrick, 2011).

A population-based study carried out as part of the data for the ONS opinion poll 2008-2009 by Waller et al. (2009), analysed the views of 580 women aged 26-64, on barriers to screening attendance with a comparison to non-attendance. The main barriers reported include embarrassment,

fear of pain, procrastination and fear of the outcome of the test. Screening status was independently associated with appointment difficulty, sexual inactivity, lack of trust in the test and procrastination. However, some of the responses and correlations from this study were made from the barrier statements provided, which have implications for bias in the responses, as some women might have had other views but not had the opportunity to express these. The views provided in this study might not reflect participants' entire thoughts about the subject. The use of interviews in qualitative studies may be appropriate in further exploring the opinions of participants with a view to clarifying misunderstood opinions (Creswell, 2008; Bowling, 2008).

Moreover, it could be argued that some misconceptions and misunderstanding of cervical cancer may also have positively influenced decisions for participation, which may not have been reflected in the screening uptake (Waller, et al., 2009), as the uptake for younger women has remained relatively low (NHSCSP, 2013). Waller et al. (2009) also failed to report on the correlation between age and barriers. This is relevant because certain barriers assume greater significance at different ages. In addition, relationship status and childbirth could also play a part in acceptance of screening. Women who are married and within the reproductive age, and those with children are more likely to go for screening as they relate the screening to part of a gynaecological check-up (Thomas, 2005; Olesen et al., 2012). A survey by Olesen et al. (2012) found a strong correlation between having children and participation. However, the study did not provide the context to this association because it is a survey study where views cannot be expatiated. The association could be the fact that women who have undergone childbirth are desensitised to the feeling of embarrassment and pain associated with screening (Olesen et al., 2012). Furthermore, women who are married were found to be more concerned about childbirth and, as such, more likely to undergo gynaecological checks. Also, in a cultural context, married women are less stigmatised when it comes to screening attendance (Redwood-Campbell et al., 2011).

Barriers similar to those recorded by Waller et al. (2009), such as embarrassment, fear of pain and procrastination were also reported by Adolfsson et al. (2012). This Swedish study, which involved women aged 23-60, differs from the previous study in that an interview method was used to collect the views of the 14 participants, while the data was analysed using Graneheim and Lundman's method of content analysis. Although the study was supposed to explore views of non-attendees who have received invitation letters, it mainly centred on past experiences and their impact on the general decision-making process. In addition to the barriers stated above, the women in the study emphasized the importance of the health professional's attitudes in terms of respect, and a more sympathetic care, not only in terms of screening but also throughout the healthcare system. Another Swedish study, which employed similar methodology (content analysis), was undertaken by Oscarsson et al. (2007). In this study, embarrassment was associated with body image and low self-esteem. Another

distinction between this study and the previous Swedish study is that it explored barriers beyond past experiences, with additional focus on the cost effectiveness of cervical cancer promotion among non-attendees.

Unlike embarrassment, the context of fear and its influences on participation have been explicit in past studies. Fear in the context of cancer death can act either as barrier or a motivator to screening attendance, whilst fear associated with the screening procedure, such as pain (due to lack of knowledge of what to expect and the nature of the screening procedure) often act as barrier to screening (Waller et al., 2009; 2012). Fear of pain was found to be the second most common barrier after embarrassment. This finding was made using an omnibus survey, but no context was provided. Nonetheless, Marlow et al. (2015) made this more explicit in their study, which explored self-perceived barriers to cervical screening in ethnic minority women aged 25-64 living in London. Fear of pain and fear of cancer were some of the emotional barriers reported by participants as influencing participation. The association of cervical cancer with pain came from personal experiences and anecdotal information from those who had previously attended screening. This was cited as a reason for delay in attendance and in some cases, non-attendance. This opinion was highest among first time attendees and can be associated with misconception and a lack of understanding/information of the screening procedure. Fear of cancer was relative to the outcome of result and the fear of death. This causes anxiety amongst the women concerned, leading to avoidance. In contrast, fear of death also acted as a motivating factor, as some participants attended screening to get some peace of mind and to ease the anxiety arising from the fear of death. Overall, the study was limited, as most participants had been screened, so views from non-attendees were limited. A similar study conducted in London on Somalian women (Abdullahi et al., 2009) reported similar findings. However, these were limited to a specific ethnic minority group. In this context therefore, one strength of Marlow et al. (2015) was its ethnic diversity.

Emotional barriers such as fear, embarrassment and pain have potential to influence screening behaviour. However, the context of embarrassment varies across studies and remains understudied. Although emotional barriers influence uptake of cervical cancer screening, practical barriers are more predictive and will be discussed in the section below.

### **Practical barriers**

Practical barriers were more predictive of uptake than emotional barriers such as fear and embarrassment (Waller et al., 2009; Marlow et al., 2015). Practical barriers have been reported in the majority of studies as reasons for non-participation (Waller et al., 2009; Marlow et al., 2015, Abdullahi et al., 2009; Brown et al., 2011). Cost of the screening (Brown et al., 2011) busy schedule, low prioritization of the screening, appointment difficulties and surgery opening times among other

factors were stated as reason for non-participation (Waller et al., 2009; Marlow et al., 2012; Abdullahi et al., 2009; Brown et al., 2011). Waller et al. (2009) suggested that practical barriers are more modifiable than emotional barriers and it is therefore easier to create interventions to meet such barriers and subsequently change behaviours.

However, creating interventions to change behaviours relative to the practical barriers above may not influence the uptake of cervical cancer, as individuals' non-participation could be indicative of more than one factor, including awareness, emotional or practical barriers. Moreover, these factors may just be opinions voiced to justify the behaviour of non-attendance, which could indicate a deeper issue (Waller et al., 2009). It is a long-established view by psychologists that in general, many people may not always have the ability to reflect their true motives for behaviours (Nisbett & DeCamp Wilson, 1977).

### **Summary of the literature review section**

The barriers identified from the reviewed studies showed similar trends and included practical, emotional religious/cultural or personal barriers. However, these studies have a range of limitations regarding samples, methodologies and location.

Although most studies reviewed here focused on barriers to participation, only a few focused on motivation to participation. To engage in any kind of screening, available literature reveals that participants are motivated by some anticipated benefits, such as peace of mind following a negative result in early stage diagnosis, and eventual treatment and decreased risk of mortality (Brown et al., 2011; Marlow, 2015).

Although a few studies focus on reasons for participation in the screening programs, the major motivating factors are: fear of the disease itself, education, knowledge and benefit of the screening, as well as the pain and fear of leaving their loved ones and children without the care of a mother (NHS, Yorkshire and Humber, 2013; Redwood-Campbell et al., 2011). Ogedegbe et al., (2005) identified that most people who attended a previous screening opted for it based on factors identified in three categories: attitudes and beliefs (personal health/cancer history, recommendation from friends, routine nature of the test and wanting to care for oneself); social network experience (advice from families and friends, information from the media, knowing someone with cancer and medical recommendation); and accessibility (convenient location of screening services). This study however looked at three types of cancer screening; colorectal, cervical and breast, which might have influenced the participants' responses (Ogedegbe et al, 2005). These studies have been conducted mainly among older women and specific ethnic minority women, but little attention has been given to screening practices or the educational needs of younger women concerning cervical cancer. As

explained earlier, the influence of health professionals has also acted as a major facilitator especially among ethnic minority woman, with advocacy on improvement centred around health professionals' training and involvement in screening awareness (Adolfsson, et al., 2012; O'Connor et al., 2013).

Most of the studies explored above utilised the health belief model - one of the behavioural change theories/models (Thomas et al., 2005; Redwood-Campbell, 2005; Waller et al., 2011) – to explore why people do or do not participate in screening. The behavioural change theories are explored below to give an insight into factors or influences that affect the decision-making process towards behavioural change interventions such as cervical cancer screening.

### **Behavioural Change Theories/models (BCTs)**

The most successful public health programs and initiatives are based on an understanding of health behaviours and the context in which they occur (Glanz & Bishop, 2010). Behavioural Change Theories (BCTs) support the development, implementation and evaluation of public health and health promotion interventions (Glanz et al., 2002). Behaviour theories, modules and frameworks have been known to help understand and in some cases, predict how humans behave (Glanz et al., 2002). BCTs helps in understanding the factors that influence decision-making and choices that people make. There are many psychological and behavioural models, (Green, 2000; Nutbeam & Harris, 2004).

BCTs can either be explanatory or change model/theories and in some instances, both. For example, the Health Belief Model (HBM) was developed as an exploratory model (Glanz et al., 2002), while the trans-theoretical model, due to its stages of change construct, was developed to help in planned change effort (Harris, 2004). Some BCTs were used to explore factors influencing attendance or accepting cervical screening as evident in some of the studies described above (Thomas et al., 2005; Redwood-Campbell et al., 2004; Waller et al., 2011).

Many health behaviour models have been used by researchers and authors in understanding, predicting and changing behaviours depending on the subject area been studied or change sought (Glanz & Wilson, 2010). However only a few have been widely adopted or referenced by researchers. These are:

- The Health Belief Model (HBM)
- The Trans-Theoretical Model/stage of change (TTM)
- Social Cognitive Model (Glanz et al., 2002).

## **Health Belief Model.**

The HBM is one of the most widely used conceptual models in the prediction and understanding of behaviour (Sutton, 2002). Its prominence in public health and health promotion is highly documented (Glanz et al, 2002). It can therefore be utilised or described as a structure or platform that is often used to harmonise a person's health behaviour and the probable outcome. In this sense, HBM helps healthcare or public health institutions to better understand influences that motivate behaviour and how they mediate these motivations.

In this study, HBM, which is based on a psychosocial approach to explaining health-related behaviour, may find some use in assessing women's knowledge about cervical cancer and screening, as well as the possible motives for behaviour to either participate or not in screening programmes. Certain studies (Waller et al., 2011; Redwood-Campbell et al., 2011) utilised or drew on the construct of the HBM in their studies in attempting to explain factors affecting the decisions to attend the screening programme.

HBM operates within four constructs (See Fig 2 Below) and is made up of the following key variables:

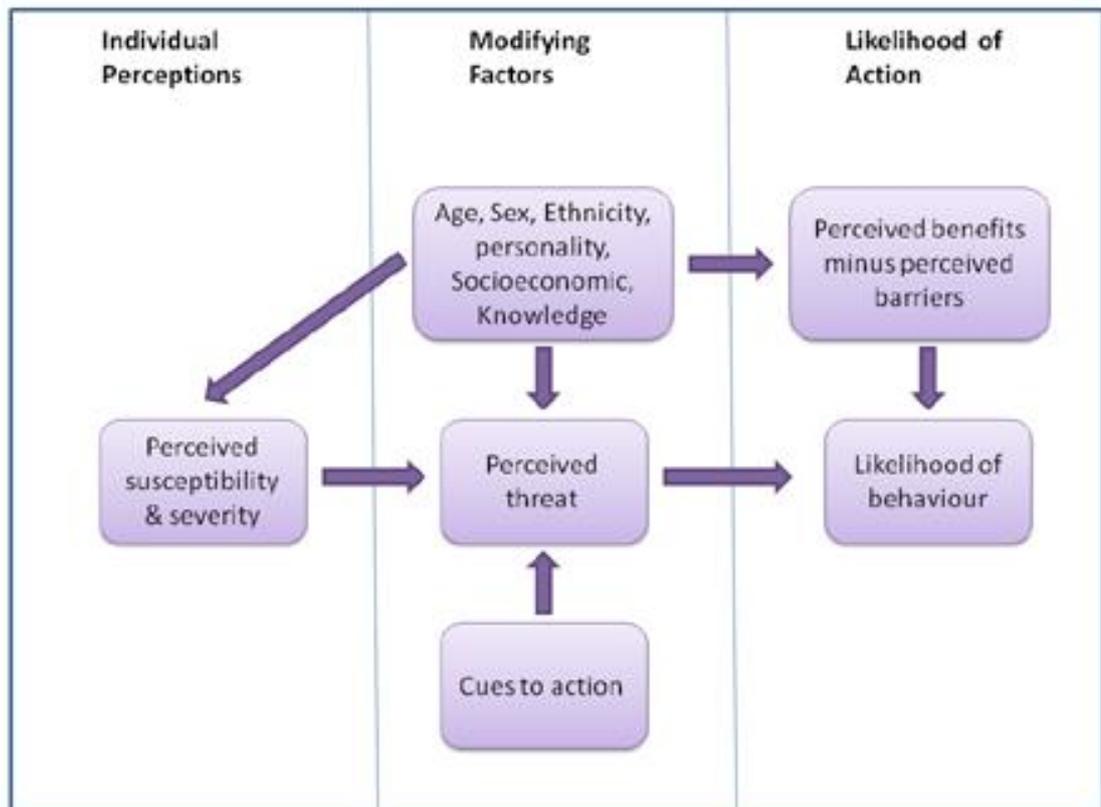
- Perceived threat: Consists of two parts: perceived susceptibility indicating the subjective perception of the risk of contracting the disease or problem; and perceived severity of a health condition, based on feelings surrounding the seriousness of contracting the disease and leaving it untreated.
- Perceived benefit: The believed effectiveness of strategies designed to reduce the threat of illness.
- Perceived barriers: The potential negative consequences that may result from taking particular health actions, including physical, psychological and financial demands.
- Cues to action: Events, either bodily, e.g. physical symptoms or environmental that motivate people to take action. The "Jade Goody effect" (Lancucki et al., 2012) is a good example of a cue to action. Other variables include socio-economic segmentation or geography that affects perceptions and influences health behaviour.
- Self-efficacy: The belief in being able to successfully undertake the behaviour, in this case attending a smear test appointment. The HBM can be used to understand and explain why some women do and others do not attend a smear test when invited.

However, the HBM has been criticised because it fails to explore social norms, which are thought to be important in determining behaviour. Also, its abstract nature and emphasis on the rationality of

peoples' behaviour probably makes it more useful as a framework rather than a true model (Gillam, 1991).

The challenge sometimes posed to its utilization is how women perceive their risk of cervical cancer infection and/or understand the fact that early detection may not necessarily equate to death. Hence, Kacroo and Etzel (2009) highlighted the critical role health literacy plays in combating the adverse impacts of poverty and ignorance, even as it facilitates increased screening participation. Although it is normally difficult to alter health behaviour, the establishment of appropriate health policies and interventions working alongside cultural and social factors, provides the opportunity for health providers to use HBM to exert some influence on the beliefs and attitudes towards cervical cancer screening knowledge and uptake.

Figure 2 Health Belief Model.



Source: Shaw, 2012.

### Trans-Theoretical Model or Stages of Change Theory

The TTM proposes that an individual does not automatically accept or adopt a new behaviour, but rather take their time through it. They go through various stages of psychological or emotional adjustment, which in this case happen to be in five processes (explained below). The stages were originally considered to be linear, but are now thought to be more cyclical, with people moving around the cycle several times before sustainable behaviour change is achieved (DiClement & Prochaska, 1998). Interventions needs to be introduced gradually if sustained behaviour change is to be achieved (Andreasen, 1995).

- Pre-contemplation stage: Engagement with the screening programme is or might be non-existent for young women. They also do or might not intend to change their non-attendance behaviour. Use of incentives or informative material at this stage could have a positive effect on behaviour, because awareness could act as a push or trigger to move to the stage of contemplation.

- Contemplation stage: Consideration around going for screening is made by the individual. There is an acknowledgement of the need to change behaviour. A little push, such as confirmation by health professionals or even the receipt of an invitation letter for cervical cancer screening might increase the potential to attend screening.
- Preparation stage: This is the stage when an individual is confident that they can change their behaviour. In the case of cervical cancer screening, the individual is at the stage where they are trying to schedule an appointment. However, this stage is critical, as any negative incident or report could trigger the individual back to the pre-contemplation stage.
- Action stage: Behaviour change is attained at this level, i.e. participation in the cervical screening. Continuous positive influence could encourage consistency in this new attained behaviour.
- Confirmation or the maintenance stage: Behaviour is constant in this stage with an intention to remain so. The possibility of relapse at this stage is almost non-existent, irrespective of negative experiences. However, continuous encouragement is needed by the individual for confirmation of their success in attaining and maintaining the behaviour (DiClement & Prochaska, 1998; Hasting, 2007; Lyon et al., 2009).

A major hindrance for this theory is that it needs to be validated with a questionnaire. This does not allow other sociocultural factors, reasons for behaviour and how individuals could be supported, to be accounted for (Andrea, 2005). A major criticism of this theory is that it focuses too much on the individual without assessing the important role of external environmental influences (Basler, 1995; Prochaska et al., 1992; Lyon et al., 2009). It is however, argued that the stages should not or cannot be followed religiously but rather act as a guide on how people's thoughts change towards a particular behaviour (DiClement, 2005; Hasting, 2007). Incorporating different types or exploring multiple behaviour change theories could increase understanding of why people act the way they do and why these changes vary among individuals (Buxton et al., 1996).

### **The Social Cognitive Theory (SCT)**

SCT not only explains how behaviour is understood, it also has relevance in health education (university of Twente). The focus of SCT goes beyond behaviour change modalities to include psychological aspects such as emotions and cognition (Glanz et al., 2002). It is argued that once behaviour is achieved, there is a possibility of its retention. The process between getting and retaining behaviour is made explicit by SCT. Bandura (1986) defined the process as 'triadic reciprocal determinism', which could be influenced by 2 factors: environmental and interpersonal, which also influence each other. The interpersonal factor is explained in the context of self-efficacy. Self-efficacy is defined as "the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1997; Glanz et al., 2002), that is, an

individual's confidence in themselves to carry out and subsequently succeed in that task. In the context of cervical cancer screening, it can be suggested as a person's belief that they can go for screening and maintain continuous participation in the future, irrespective of an unforeseen negative experience.

The environmental factors may be associated with available resources and the state of the economy of the individual or the community. The influence of the environment could be dependent on 2 factors; the relationship or association of the individual with their immediate family, friends, colleagues or church members, or a general social context such as societal values/norms or socio-economic conditions. It is noteworthy that the individual and the environment influence each other interchangeably. Interventions that take into consideration these variables (individual and the environment) could help in effecting behavioural change. This is suggested because, in agreement with Maibach & Cotton's argument, the environment forms the characteristics and behaviour of a person and that these acquired behaviours consequently shape their immediate social domain (Maibach & Cotton, 1995).

SCT proposes that since behaviour is socially constructed, to get people to change their behaviours, making popular behaviours accepted (new norm) and removing some acceptable behaviours (old norm) from the society could lead to behaviour change with the new norm now referred to as the 'new normal' (May et al., 2007). That is, people will adopt behaviours if they observe it to be common and acceptable in their immediate and wider environment. Four processes can be utilised to realise or achieve this behavioural change. As stated above, self-efficacy is one of the processes. The other processes are self-observation, self-evaluation, and self-reaction. There is an interrelationship between these processes, thereby having an effect on motivation to change behaviour as well as meeting the goal of attaining/retaining such behaviour (Redmond, 2010; 2016). SCT has been criticised for certain limitations in its assumptions and that it has failed to recognise that knowledge is not the only precondition to behaviour change as suggested by certain studies (MacKinnon et al., 1991; Donaldson et al., 1994). Other factors may play a factor in behaviour change, for example, health reason or self-esteem. SCT has been unsuccessful in predicting how many people might be motivated on to the next step of behaviour change, (Hasting, 2007) while comparatively acknowledging advantage of implementing new behaviour that could cause sustainability.

The list of BCTs is inexhaustible and adoption of the theories is encouraged depending on the subject or topic areas. Three theories have been discussed in this section, as they are the most commonly used theories when creating intervention or trying to predict behaviours, in this case, cervical cancer screening.

## **2.6 Rationale for this study and contribution to knowledge**

Cervical cancer is still very much a global public health problem and early detection could lead to a reduction in incidents and possibly impact on treatment (Cancer Research UK, 2010). Studies have shown a continuous decline in uptake of cervical screening in all women, with those aged 25-34 showing the highest decline (NHS information Bulletin, 2008; NHS Information Centre, 2009; Patel et al., 2012; Cancer Research UK, 2013). Some of the factors that might affect participation and uptake are explored in the studies above. These include knowledge, attitude, perceptions, ethnicity, socio-cultural and socioeconomic status/deprivation and age. Gaps have been identified in the research literature around age, location, methodology, social deprivation/socio economic status.

Most of the studies reviewed above were conducted among women of various ages. Most were conducted among older women (Logan and Mcilpatrick et al., 2011; Ogedegbe et al., 2005; Abdullahi et al., 2009; Mosavel and Elsharaavi, 2007; Brown et al., 2011; O'Connor et al., 2013; Thomas, 2005; Adolfsson et al., 2012). Only a few studies have been conducted in the age group of women showing low uptake (Black et al., 2011; Waller et al., 2011; NHS Information Centre, 2009), with one making a comparison with the older women (Waller et al., 2011). There is no published research on Northeast England that identifies influences or reasons for screening attendance and avoidance. The Northeast has shown a continuous decline in uptake in young women aged 25-34 (Patel et al., 2012; NHS Information Centre, 2009; NHS cervical cancer screening, 2012).

Qualitative studies were conducted mostly outside the UK, e.g. in Canada, the US and Sweden (Black et al., 2011; Redwood-Campbell, 2011; Brown et al., 2011; Ogedegbe et al., 2005; Adolfsson et al., 2012; Oscarsson et al., 2007) or in other locations in the UK (Webb et al., 2004; Waller et al., 2009; 2011; Logan and Mcilpatrick, 2011; Thomas et al., 2011). Also, the generalisability of existing studies (McCaffery et al., 2001; Wardle et al., 2005; Szczepura et al., 2003; Alexander et al., 2003) that explored the factors or influences affecting uptake of other established screening (e.g. colorectal and breast cancer) is debatable compared to factors influencing cervical cancer screening attendance.

Methodologically, most of the studies exploring factors influencing uptake were surveys/questionnaires (Waller et al., 2009; Behbakht et al., 2004), while the qualitative studies employed focus group methods (Logan and Mcilpatrick, 2011; Brown, et al., 2011; Waller et al., 2011; Thomas et al., 2005). It can be argued that although focus groups are useful in nurturing interactions within a group dynamic, and in the gathering of broad and in-depth information within a relatively short time, this could hinder the nature of information collected as a result of issues around confidentiality and trust (Kruger, 1997; Oliveira, 2011). This is compounded if the topic being explored is regarded as sensitive (e.g. cervical cancer screening), thereby leading to emotional and psychological barriers such as embarrassment or anxiety. Adopting either a one-to-one interview or multiple data collection

method (both interview and focus group), as employed within this current study, compensates for the limitations associated with adopting only one means of data collection. People who may feel embarrassed in a group setting might be more comfortable in a one to one interview.

Most studies employed content analysis (Logan and Mcilpatrick, 2011; Oscarsson et al., 2007; Waller et al., 2011; Adolfsson et al., 2012), whilst others were guided using the HBM, although there are arguments that vital information regarding influencing factors might be missed if only a single behavioural model is used (Waller et al., 2011; Redwood-Campbell et al., 2011).

The current study therefore employs both interviews and focus groups to address the gap described above. A major advantage of using both data collection methods is that it fosters collection of wide range of rich information from a group interaction in a short space of time (Krueger, 1997), while also helping clarify or validate immediately from the group. In addition, in-depth interviews give an opportunity to get in-depth information from individuals without the possible embarrassment of sharing in a group (Creswell, 2008).

The methodology chosen for this study was the Grounded Theory (Charmaz, 2006), where information is extracted from the data and with opportunities to create a theory. This gives the researcher in the context of public health the possibility of adopting various aspects of the different behavioural theories depending on emerging themes from my data rather than adopting a single behavioural theory/model. Thus, the data drives the theory development not the imposed Behaviour Change Model.

Most of the available studies were conducted with women from ethnic minority groups of all ages (Redwood-Campbell et al., 2011; Thomas et al., 2005; Abdullahi et al., 2009; Brown et al., 2011). Most of the factors from these studies were socio-cultural, emotional and in many cases practical (e.g. busy schedule and appointment difficulties). There is a need to include young women irrespective of their ethnicity in this study, as it has been argued that behaviours can be acquired and adopted. The possibility of young women from a range of groups including BME, irrespective of their education or exposure could hold beliefs and unpleasant stories about the screening, thereby leading to negative perceptions and subsequent delay in screening (Brown et al., 2011; Mosavel and El-Shaaravi, 2007).

Social deprivation and SES were not evidently explored in most studies, but most of the ethnicity studies highlighted possible links between SES and ethnicity (Brown et al., 2011; Abdullahi et al., 2001). Only two studies linked to social deprivation by choosing an area of low deprivation (Logan and Mcilpatrick, 2011; Abdullahi et al., 2009). Most studies were conducted in urban areas (Waller

et al., 2011; Black et al., 2011). This implies a need for further research to explore factors in suburban or rural areas.

This study was conducted in Northeast England, one of the most deprived areas in the UK, with low uptake in cervical cancer screening (Willoughby et al., 2006). One of such area in is Middlesbrough, which have the highest rates of screening decline (Public Health England, 2013; Patel, 2012) and with known level of deprivation (ONS, 2012). Blacks et al. (2011) suggest that an association between deprivation and incidence of cervical cancer may be underestimated by the inclusion of low risk, high ethnic mix, and high deprivation level as evident in Middlesbrough. Cancer is one of the most common causes of premature deaths in Middlesbrough before heart, lung and liver diseases (Director of Public Health report, 2013).

The studies in this review explored and provided insight into factors affecting uptake. These factors were dependent on the age and characteristics of the women in these studies (i.e. older women and women from a defined ethnic group within the same country), which cannot be generalizable to younger women as age differences and social context affects behaviour (Waller et al., 2012; Lancucki et al., 2010).

This doctoral research contributes to the limited body of knowledge in exploring the reasons why young women are failing in taking up cervical screening especially within Northeast England. The issue of declining coverage rates is complex and multi-factorial. The complexity of both the decline and how a woman chooses to participate in the cervical screening programme means that this subject remains an area of ongoing research. The findings of this research will inform practice and service provision, and hopefully provide a springboard for developing age appropriate interventions/recommendations capable of increasing the awareness and subsequent uptake of cervical screening. This project will provide evidence that is likely to underpin practice, as it was conducted with support from Northeast, Yorkshire and the Humber Quality Assurance Reference Centre (QARC).

### **Aims**

This study aims to develop an understanding of factors that influence participation and non-participation among young women aged 25-34 living in the Northeast of England in the national cervical screening programme.

### **Project Objectives:**

- To identify factors that influence participation in cervical screening by young women
- To identify factors that influence non-participation in cervical screening by young women

- To consider the views and beliefs of young women in relation to cervical cancer prevention and screening
- To obtain understandings from young women that could inform recommendations for an appropriate intervention to encourage young women to go for a smear test

**RESEARCH QUESTION:** What factors influence young women's decisions to participate or not in the national cervical cancer screening programme?

The next chapter will explore the theoretical foundation for this study, choice of the methodology and justification of its adoption. The historical context of the chosen methodology and arguments regarding its use will also be provided. Also outlined within the chapter are the ethical implications for undertaking this type of research.

## **CHAPTER 3: Philosophical and methodological approaches**

This chapter outlines the philosophical and methodological foundation guiding the study. The rationale for the chosen methodology, which includes the ontological and epistemological assumption underpinning it are presented. Crotty (1998) stated the justification for carrying out research in a particular way is based on the foundation of the chosen philosophical stance within the chosen method. Guba and Lincoln (1999) emphasised on the importance of explicating the guiding philosophical assumptions that will inform the enquiry process. Symbolic Interactionism (SI) theoretically informed this study and is associated with the Grounded Theory (GT) methodology. In essence, GT was adopted for this study and SI aligned my philosophical assumptions with this methodology. I have also described the diverse range of GT approaches available to justify the basis for the approach taken here. My positioning, viewpoint, sensitivity and ethical consideration are also discussed.

### **3.1 Philosophical perspectives**

Based on the study rationale provided in section 2.6, a qualitative approach seemed an appropriate paradigm because it permits the investigation of certain situations and events by adopting a depictive, rational and unstructured method (Bryman, 1988). The viewpoint or set beliefs of an individual regarding a particular subject can be explored or extracted through the adoption of different methodologies with the hope of making sense of the emerging issues or in-depth information, which is grounded in the individual's viewpoint. Unlike the qualitative approaches, quantitative approaches are more objective, i.e. they emphasise extrapolative capability as well as the generalisation of information collected (Myer 2000; Lincoln & Guba, 2003). In order to better understand my philosophical point of view, understanding the meanings associated with paradigms is imperative.

In a research context, Weaver and Olson (2006) defined 'paradigm' as a revelation of how research is guided by describing processes through which an inquiry is accomplished. How a researcher sees the world is shaped by paradigm, which is predisposed by our social construction such as family, religion, experiences, education, community and society at large (Flay et al., 2009; Sengstock, 2009). According to Denzin & Lincoln (2005), as an early career researcher, it has been advised that from the beginning of research project, I must state clearly the paradigm into which the research fits so as to inform the knowledge or allow identification of roles generated by the process of enquiry. This paradigmatic position is seen in how the research is conducted from data collection through to presentation, showing how it varies from other research in that field.

Research paradigms in health research are either positivist/objectivist (quantitative) or naturalist/interpretivist (qualitative) in nature (Guba & Lincoln, 1994; Weaver & Olson, 2006). Within an interpretive research paradigm, it can be argued that the researcher and the participants

co-construct meanings of the issues instead of trying to objectively verify an existing hypothesis (Charmaz, 2006; Mills, Bonner & Francis, 2006).

Based on the argument above, this study is positioned within Guba and Lincoln's (1994; 2005) paradigm. The main purpose of undergoing a research study according to Lincoln and Guba (1994) is to understand "where the whole is greater than the sum of the parts and where the accumulation of the parts does not entirely capture the whole" (Sengstock, 2009; Guba & Lincoln, 1994; 2005). As a result, ontologically, the aim of this study is achieved by getting the views of those who lived (attendees) or expected to live (non-attendees) the cervical screening experience. A better understanding of influences on the decision-making process or intention to attend cervical screening can only be provided by the target population (in the context of this study of young women).

Additionally, relativist ontology and a subjective or transactional epistemological approach are incorporated within this paradigm (Guba & Lincoln, 2005). In other words, I chose a relativist ontological stance and both social interactionism and social constructivist epistemological stances as my worldview within the study.

Methodologically, how participants construct their reality and the meaning of the data collected by the researcher is co-constructed by the researcher and the researched (Guba & Lincoln 1990:26; 2005:196). In this study, the research question "What influences young women's decisions regarding participation in the cervical cancer screening programmes?" was asked in order to gather information to attain the aim of the research. Consistent with a qualitative inquiry, such a broad approach places the researcher in a position of discovering deep-rooted concerns, ideas or views in the phenomenon under study. Furthermore, a comprehensive research question lessens possibilities of confining such research to a narrow focus to the degree that it reduces understanding (Calman, 2006; Dey, 1999; Strauss & Corbin, 1998).

Based on its reputation in understanding human social interaction, GT can provide deeper comprehensive details on complicated situations and associated complexities (Dey, 1999; Glaser, 1992). One of the reasons for using GT is its ability to consider external influences of structure and procedure. These influences affect how the study is conducted and subsequently the derived results (Annells, 1996; Calman, 2006). SI and GT are jointly influenced by how humans construct meaning out of the happenings around them through interactive processes or social interaction within or between contextual structures and their environment or other people (Blumer, 1969). GT is therefore appropriate for exploring the understanding of young women's health beliefs with respect to cervical cancer and how this affects participation in the screening process.

### **3.1.1 Symbolic Interactionism: The theoretical perspective**

SI, developed by Blumer in 1969, can be seen as a way of exploring how people form meanings or understand their world through their environment. Blumer further argued that SI is a way individuals find solutions through social involvement in situations that cannot be resolved in isolation. This implies that for in-depth meaning or sense-making to occur regarding a particular subject or area of interest (in this case, low uptake of cervical cancer screening in young women) a form of interactive relationship has to be built between the individual providing the meanings, understanding and insights, and the researcher to discover contextual influences. Interpretation of the information collected, and insights provided is therefore presented in a way that will help provide solutions that could alter preconceived meanings and present participants with a modified meaning that could increase uptake.

The theoretical perspective of SI is based on the following three assumptions: (1) Individuals act or respond to phenomena based on the meaning or importance placed on them; (2) These meanings are influenced through interactive processes or social interaction between them and their environment (people inclusive); (3) An individual's preconceived meanings are modified through social interaction, i.e. meanings are continuously created and recreated through interpreting processes through social interactions (Blumer, 1969; Carter & Fuller, 2015).

In summary, in order to understand the behaviour of an individual or group dynamics, investigating the hidden meanings behind their behaviour is imperative and highly recommended. This is because these preconceived meanings were borne using reflective abilities through social interaction, which were adopted from their social environment symbolically like using object, equipment, and language or even eating habits and other available entities within their environment. (Blumer, 1969; Annells, 1996). SI, as proposed by Charon (1989), focused on the relationships and interrelationships between individuals and their immediate environment or society they live in. Adding to this, Flick (1998) argued that the depiction of the subjective meanings and interactive series of actions are the bedrock of any research based on their chosen viewpoints. Charmaz (2014) agrees with this notion by stating that the use of SI acts as an inspiration for researchers undergoing theory given research leading to theoretical implication based on the chosen theoretical perspective. Therefore, individual human beings are viewed as active rather than passive agents (or predetermined organisms) in the SI perspective (Charon, 1989).

It has also been shown that individuals, when faced with similar situations, exhibit a patterned behaviour, which Blumer (1986) refers to as joint-action. These patterns of behaviour come into play because of structural rules and processes and in some cases physical resources connected to class, gender and community (Denzin, 2004). "Joint action" considered in this study because young women may display shared behaviours consistent within their sociocultural environment/background. Based

on Blumer's observation, it is imperative that the researcher should be cognisant of the implication of the individual's formed behaviour and actions because of their interaction with their social environment in the course of the research journey. When individuals within a group exhibit actions that are linked or similar, this patterned behaviour can be attributed to a shared group norm (or conformity) (Denzin, 2004; Shah, 2016).

The assumptions of SI are further based on the fact that actions are well thought out by individuals within their social world before an impulsive reaction is made (Charmaz, 2014). Utilisation of SI gives the researcher an edge, as it enables the recognition of patterned behaviour of the individual without eliminating their viewpoint (Morse, 2001). Recognition of SI in GT helps in the specification of variables and prediction of outcomes as a result of its content acting as an abstract theoretical framework of premises and concepts for which social realities are viewed in the research (Charmaz, 2006; 2014). Milliken & Schreiber (2001) therefore advocated that the role of SI in the research is felt from the beginning (epistemological decision-making) to the end (analysis of information collected and subsequent theory development).

In agreement with the constructivist paradigm (Charmaz, 2006), I believe that while acknowledging the presence of multiple realities, individuals create their own version of reality which is presented differently. Through interaction, the researcher and participants work collaboratively to understand the individual's representation of reality (meaning), which is constructed at a time under particular circumstances. In addition, I also agree with Cutcliffe & McKenna (1999), who claim that GT is an interactive process involving the researcher and researched. This is based on Charmaz's stance that the research process, which involves communication and interrelationship between the researcher and the researched, leads to the creation of the theory (not "discovery") (Charmaz, 2006; 2014). Based on the data collected, the researcher constructs a theory, which could be influenced by the researcher's preconceived views, due to his/her social interaction (family, religion, peers etc.) (Charmaz, 2006). The researcher cannot wholly separate themselves from the research and, as such, could fundamentally influence the research as a result of their own social interaction/interpretations. Charles Cooley refers to this as the "looking glass self" or "reflective appraisal" (Boundless, 2014). SI provided the theoretical foundation needed to explore and understand the factors influencing young women's participation in the screening programme.

### **3.2 Grounded Theory as a Methodology**

The methodology reports the processes required by the researcher to address the issue or phenomenon under study (Guba & Lincoln, 1994). The methodology for this study was based on the study aims and objectives. Despite following the advice by Denzin and Lincoln (2005) regarding having a theoretical foundation in choosing the appropriate methodology, methodological

determination could become a problem. The research questions/aims are consistently shown to be a major determinant in directing the chosen methodological approach of a piece of research (Creswell, 2007; Bryman, 1988; Calman, 2006). Bryman (1988) asserts that choosing a research methodology should be based on how well it can answer the research question. As stated earlier, the theoretical perspective or foundation of this study assumed that the social world is viewed from the reflective personal appraisal of the environment by both the individual providing the information and the person seeking the information. This therefore guides how the research topic or phenomenon will be investigated.

This study drew on the principles of grounded theory, which leads to the creation of a theory that is “grounded” in information made available by the researched (Charmaz, 2006; Holloway & Wheeler, 2010; Dunne, 2011). This is a distinctive feature of GT. The researcher approaches the research open-minded to generate the theory solely from the data collected, unlike quantitative approaches, where an existing hypothesis is chosen to guide the research process (Creswell, 2007; Charmaz, 2006; Mills et al., 2006). Besides theory generation, whilst also contributing to the reliability of the study, GT proffers an advantage through early analysis of the data through “constant comparative data analysis” (Myers, 2008).

GT was developed in the School of Nursing, University of California San Francisco, by two sociologists, Glaser and Strauss in the mid-1960s (“Awareness of Dying”) (Calman, 2006). It is influenced by and theoretically rooted in SI, and the methods of conducting GT research (Milliken & Schreiber, 2001; Charmaz, 2014; Calman, 2006; Blumer, 1969:2).

### **3.2.1 Distinction between the various schools of Grounded theory**

Different types of GT are available according to Dey (2002). The earlier or ‘classical’ GT was created by Glaser and Strauss in 1967, due to their dissatisfaction with available theories and their dominance in sociological research. Their argument was that existing theories hindered the development of new theories arising from data or information collected in new research (Glaser & Strauss 1967, Dey 1999). However, there soon followed a divergence in their original viewpoints, assumptions and statements. This led to Glaser moving ahead to develop his school of thought popularly known as the Glaserian GT (containing original work and subsequent writing). Strauss (collaborating with Corbin) developed Straussian GT (Heath & Cowley, 2003; Charmaz, 2014; McCallin, 2003; Benoliel, 1996). However, the arguments surrounding these schools of thought have moved researchers away from the positivism associated with both Glaserian and Straussian GT, leading to a third approach (Seale, 1999; Charmaz, 2000; 2005; Bryant, 2002; 2003; Clarke, 2003; 2005). It is however, necessary to anticipate issues that could arise during the research design with respect to methodology. The adoption of a particular approach should be based on various purposes and the topic to be

studied. As Bryant and Charmaz (2007) stated, there are similarities between the various schools of thoughts of GT, with difference in their application in comparison to the original methodology by Glaser. After an extensive review of literature around GT methodology, I was able to understand the differences across the three schools of thought, which were evident in the methodological approach and centred on their varying theoretical perspective/assumptions leading to methodological variance. Without acknowledging the dominance of one method over the other, a constructivist approach was taken for this study, drawing on some aspects of Straussian GT due to its interpretive approach.

Ontologically, Glaserian GT is based on the assumption that we function separately from the meaning we place on a reality. In that context, the researcher is seen as separate from the research (Annells, 1996). This assumption was termed “critical realism” which also allows flexibility in data collection (Kempster and Parry, 2011). Breckenridge et al. (2012) stated that Glaser advocated that GT aims to provide a practical explanation of how to resolve concerns that may be seen as a bother instead of telling the participant’s story (Glaser, 2002). In other words, the findings of GT are not focused on the people but rather on the patterns of behaviours in which people engage (Breckenridge et al., 2012). This implies that the views/concerns in the data may not have been voiced directly but rather abstracted from the context in which they arose (Glaser, 1998). The Glaserian version contrasts with the Straussian and constructivist version in that the latter 2 versions follow the relativist assumption which argues that reality is an interpretation of multiple realities that are interrelated and as such, the researcher is part of the research and cannot be independent and objective in the method (Strauss & Corbin, 1998; Charmaz, 1990; 2003; Charmaz & Mitchell, 2001). In other words, the participant is given a voice (Breckenridge et al., 2012). This is achieved by incorporating the multiple voices, views and visions of participants in rendering their lived experiences (Charmaz, 2006). The slight distinction however, is the reflective nature of the constructivist GT, which pays close attention to empirical realities and people’s collected renderings and location of themselves within those realities (Breckenridge et al., 2012; Charmaz, 2005).

In summary, Glaser defined grounded theory as “a method of ‘discovery’; where categories emerge from the data, the method depends on pragmatism with analysis of basic social process often direct and narrow” (Sengstock, 2008; Charmaz, 2006). The Straussian version focused on the use of new technical procedures rather than emphasizing comparative methods. Arguments around the various schools of thought suggest that Glaser’s version is a more relaxed approach that focuses on theory emergence from the data, while the Straussian version was described as too procedural, thereby forcing data into preconceived categories (Charmaz, 2006; Cooney, 2010).

Although the constructivist GT adopts the original assumptions/guidelines, it does not follow religiously the “positivist” assumptions suggested by classical GT (Charmaz, 2014). It rather assumes, emphasises and acknowledges that the information, analysis process and emergent theory

are “socially constructed” during the research process by both the researcher and the researched (Charmaz, 2000; 2003; 2014; Charmaz & Mitchell, 2001). This is achieved by assuming a reflective and flexible approach, in agreement with the original Glaser and Strauss approach, which advocated for the use of flexible strategies in adopting GT in one’s own research. This research uses a GT process provided by Charmaz (2005; 2006) whilst acknowledging the theoretical and methodological advances over the years.

### **Between the Straussian and constructivist grounded theory**

Having distinguished between the various GT approaches available, my assumptions and stance were closely related to both the Straussian and constructivist approaches. Although the constructivist approach was more appealing in comparison to the Straussian (due to the interpretivist orientation), I decided to draw on both approaches during the research design (chapter 4). The prescriptive and complex nature of the Straussian approach, due its very rigorous and systematic approach in comparison to other qualitative approaches, has been highly criticised (Goulding, 2005). Constructivist grounded theory on the other hand, employs a more flexible approach that is less rigid (Charmaz, 2006). Charmaz (2006), Bryant (2002) and Clarke (2003; 2005) further argue that “it is possible to use the original guidelines of grounded theory developed almost four decades ago and combine them with the post-modern methodological assumptions and approaches”.

Based on the above, I decided to use constructivist GT whilst also acknowledging some of the principles of Straussian GT. The utilisation and adoption of both approaches would help maintain flexibility (Constructivist) and structural guidance (Straussian) in the research process. This is because in line with modern thought, Corbin acknowledges that new information or insight is not acquired only by building or creating a model (theory). However, the adoption of any other recognised and significant approach or outcome presentation (including storytelling, in-depth data description or case analysis) is acceptable but must be made explicit from the outset of the study. As stated earlier, adopting both approaches (Corbin and Strauss, and Charmaz) allowed for flexibility and creativity whilst putting on the Charmaz’s reflexive approach and mind-set guided the emergent explanatory model (Charmaz, 2006; Corbin and Strauss, 1998).

Consideration of these theoretical assumptions led to the resolution that in order to understand the factors influencing young women’s participation and non-participation in the cervical cancer-screening programme, drawing on the constructivist approach would be appropriate.

### **3.5 Developing grounded theory**

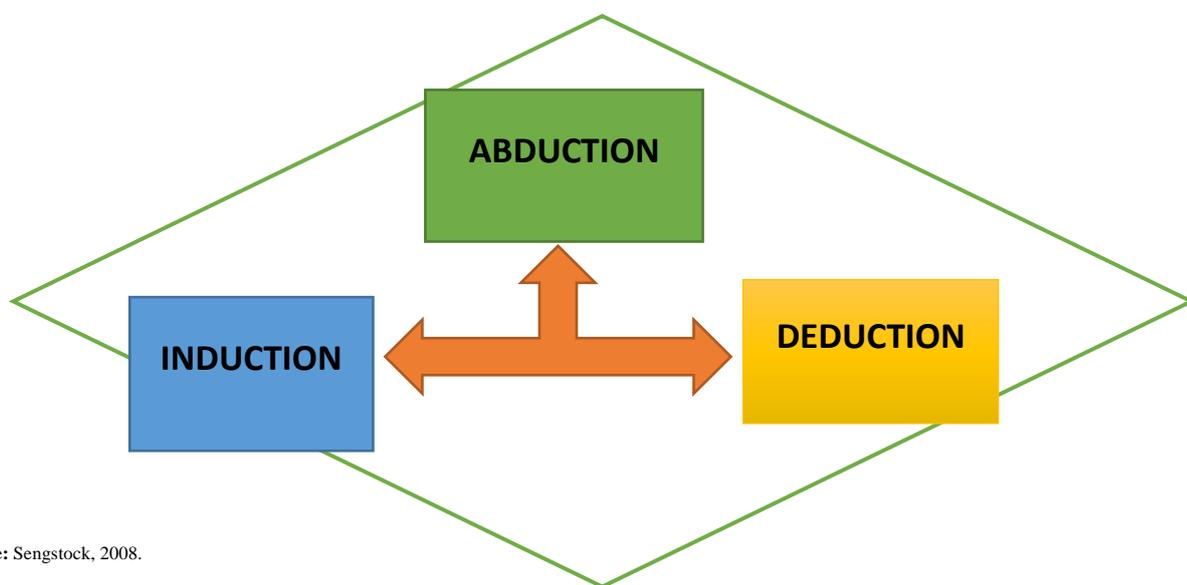
GT could be referred to as the pioneer amongst a set of freshly discovered methodologies, which use conceptualisation to capture and present the deep-rooted problems or insights of a phenomenon

instead of simply providing a descriptive account (Charmaz, 2014; Mills et al., 2006). In GT, theory development is an inductive process that requires the interpretation of the information collected, which is then reflected in the generated theory (Calman, 2006). Charmaz's constructive theory agrees with this viewpoint as she advocated that the researched and the researcher co-construct meanings during data collection and subsequent analysis (Charmaz, 2014; 2006; Sengstock, 2008). She further postulated in *Constructing Grounded Theory* (2006 edition) that "the positive approach to grounded theory lends itself to the positivist and deterministic approach to research where it considers the existence of a singular interpretation to reality" (p.131), whilst also avoiding preconception and reformulation of existing hypothesis (Charmaz, 2006).

The subsequent theory created is usually substantive (based on its significance to the subject of exploration). A substantive theory, which helps in explaining, predicting and interpreting a chosen phenomenon, can be adopted and modified in comparison to other theories that have wider application due to their broad nature (Strauss & Corbin, 1998; Young & Ward, 1998:548). Conceptualisation is hoped to aid in the generation of some sets of categories in an inductive manner, which could in turn lead to the creation of a theory aimed at answering the research question and meeting the objectives in this study (GetanehAlemu, 2015).

Figure 3. shows the relationship that leads to generation of a theory involves the researcher moving between categories of data (induction) and how these categories fit with other subsequently collected data (deduction) (Reichertz, 2007). The role of all 3 has been discussed in detail (Reichertz, 2007; Charmaz, 2006; 2014; Strauss and Corbin, 1998), with more emphasis on both induction and deduction. However, Reichertz (2010) argued that abduction tends to guide the discovery of new knowledge with popularity or increased interest in its use leading to the creation of the term 'the abductive turn'. On the other hand, Charmaz (2014) reflected on the abductive influence whilst explaining theoretical sampling. She describes it "as a means of considering all plausible theoretical explanations for the surprising data, forming a hypothesis for each explanation and checking these hypotheses empirically by examining the data to arrive at the most plausible explanation". Furthermore, Ezzy (2002:13) explained abduction as the theoretical foundation that informs theory generation, showing the approach followed from data collection to the development of emergent theory. Contrasting 'induction' with 'abduction', Ezzy "makes imaginative leaps... to generate theory without revealing all the required steps followed to reach the theory development stage" (Ezzy, 2002:14). In essence, abduction depends on both inductive and deductive testing.

Figure 3 Relationship between abduction, induction and deduction in grounded theory



Source: Sengstock, 2008.

The processes in Figure 3 are organized through the core elements of the GT method. In GT, the core characteristics are described as ‘coding’, ‘memoing’, ‘constant comparative method of analysis’, ‘theoretical sampling’ and ‘theoretical sensitivity’ (Charmaz, 2006; 2008; Strauss & Corbin, 1998). Other characteristics according to Strauss and Corbin (1998) are ‘critical analysis’, ‘conceptual abstraction’ and ‘openness to emerging data’ (p.7). A detailed discussion of these core elements is carried out in chapter four.

### **3.6 A perspective on maintaining influence during the GT process**

Before a researcher begins a GT study, it is imperative to identify their philosophical stance, which reflects how they view reality and how this reality would affect how they carry out an unbiased research. The relationship between the researcher and the participants in GT help to reduce such bias, as the research is shaped by both individuals (Charmaz, 2006; De Chesnay, 2014; Strauss & Corbin, 1998). “The grounded theory researcher becomes immersed in the data and plays an integral role in every aspect of the research. Therefore, this raised the issue of maintaining a balance between neutrality and sensitivity during this shaping process” (Charmaz, 2014; Calman 2006). As a way of maintaining balance and reducing bias or attaining the essential neutrality in the research, an explanation of how the researcher achieved this is expected, despite their preconceived assumptions (open-mindedness).

The researcher's nationality, education, professional background and personal experience of the phenomena being studied provided an insight on relativeness of the researcher to the participants. This commonality with the study participants could positively influence the generation of in-depth information. The common experience of accessing the cervical screening programme, although with different experiences and perceptions of the programme and the health service in general, assisted in the analytical process through an increased sensitivity to the data. Acknowledging that my knowledge level and experiences could act as a barrier to objective and inductive data analysis (Strauss & Corbin, 1998), I took extra care and paid more attention throughout the research process. It is therefore my responsibility as the researcher to decide, through reflexivity, what is included as data and to how this reflects the views of the participants.

Strauss and Corbin (1998) maintain that neutrality is essential to attain an unbiased and precise understanding of the data. Perceptions of the delicate distinctions and meanings in the data are achieved through sensitivity (Strauss & Corbin, 1998:42). Identification and connection with the concepts coming from the data was possible due to the researcher's ability to differentiate between these understated and sometimes unrecognisable distinctions. The researcher, through 'open-mindedness', provided a voice to the participants, thereby maintaining neutrality and eliminating/limiting bias (Strauss & Corbin, 1998). Constant comparison of the data, adopting different data collection methods, diversifying the research participants and regular supervisory meetings help maintain a good level of objectivity and bias reduction.

Charmaz (2014), and Strauss and Corbin (1998) acknowledged the difficulties and sometimes impossibilities associated with removing oneself from the research and blocking out prior knowledge, experiences which could potentially influence how data are interpreted. In other words, theory "construction is influenced by our past and present interactions with people, perspectives and research practices" (Charmaz 2006:10). As a result, I ensured that my perceptions, attitude and experiences as a cervical cancer screening service user had little impact on the research journey and understanding of the participants' views. The researcher also reflects on her viewpoints and perspectives (Mills et al., 2006, p.12) through conversations and academic discussions. As well as allowing the voices of the participants, it is only natural that the interviewer voices her viewpoints without overshadowing the participant's opinion.

### **3.7 Rigour and Quality**

Rigour is the process of sustaining and ensuring quality of the research and its results (Ezzy, 2002). The most acceptable way for evaluating GT studies is still being argued, as more researchers are adopting the methodology (Charmaz, 2014; Glaser & Strauss, 1998; 2008; Guba & Lincoln, 2005). Fit, workability, relevance and modifiability were measures used by the Glaserian GT to assess rigour

(Glaser and Strauss, 1967; Holton, 2008). Providing cogent explanations of how the study meets the required standards will advance social justice inquiry and reduce unmerited dismissals of the findings/research, if it was used to create an argument (Charmaz 2005: p 527) for the researchers. Rigour in this study drew on Charmaz's constructivist criteria (credibility, originality, resonance and usefulness) and some of Strauss and Corbin's criteria (reliability and trustworthiness), to meet "interpretive sufficiency" (Charmaz 2005: p 528; Holton, 2008; Chiovitti & Piran, 2003). All processes in this research are described in Chapter 4. "Memo writing, constant comparative analysis, and theoretical sampling, data collection and analysis, identification of a core category and development of a theory" were elements of GT used in this study (Strauss & Corbin 1998).

Validation through constant comparative method helped in the emergence of concept as embedded within GT as an in-built verification and validation. The coding of data enhanced internal validity (see chapter 4) as well as in theory development. This was made possible by reporting the findings in the participants' own words and conceptualisation of concepts interpreted by the researcher being grounded in the data (Backman & Kyngas, 1999).

The theory made available was relevant to the population, as it offers direct insights and enhanced understanding of participants' views/perspectives and reveals the action of the phenomena under study (Chesnay, 2014; Calman, 2006; Charmaz, 2005; 2014). Strauss and Corbin (1998) assert that the developed theory should be evaluated based on its depth, instructive and predictive ability rather than its generalizability. In agreement with Strauss and Corbin's (1998) recommendation, this research suggests that the explanatory or substantive theories should be explored in similar contexts or areas.

### **3.8 Ethical considerations**

Several ethical issues needed consideration in order to achieve a feasible and well carried out research project. This was done by submission of a research proposal and 'supporting documents' for reviewed by Northumbria University. Approaching and negotiation of research sites and potential participants was an area where ethical consideration was critically reviewed, with areas considered a problem being addressed as the research progressed. One such anticipated issue was in the area of the topic itself, cervical cancer, which is considered "sensitive", with a tendency to cause emotional distress. This was put into consideration and anticipated by the research process. Furthermore, University approval was granted after necessary adjustments were made based on recommendations provided by the approval committee. The university ethics process was lengthy due to circumstances beyond my control and approval was gained after 6 months. Regardless of the time and hurdles undertaken, I found the ethics processes very helpful and could understand that the committee had

my best interests at heart, since the research was human-based, and they wanted any harm to either participants or myself to be minimised (Corden & Millar, 2007).

Constructive feedback and suggestions provided by the review board helped hasten and buttress submission for the NHS research ethics approval. Before the University ethical approval, a series of amendments were suggested. For instance, clarification of different research strategies and other appropriate approvals (R and D) were suggested. These were to avoid delays during the data collection stage. It was further advised that the information sheets, invitation letters and all supporting documents for participants be made readable and written in plain and simple English. Ethical issues were raised in relation to the safety of both the researcher and the potential participants. In the case of the researcher, safety around lone working was raised, as some of the interviews would be conducted in people's homes. It was suggested that the researcher adhere to both the NHS and university lone worker protocol, and that the supervisory team be informed of a scheduled interview before and after the interview. Any incident involving the researcher, or the participants should be reported to the supervisory team. With respect to participant safety, the researcher developed a protocol to reduce risk and harm. As the research topic is a sensitive one, the researcher was advised to take with her some leaflets and contact details of support organisations to give to participants when necessary and in cases where it is felt that the participant may be at risk. This was to be discussed with the supervisory team immediately after the data collection episode.

Ethical issues around confidentiality, informed consent, avoiding coercion, distress and data protection were also considered. An informed consent form was provided, making certain that the necessary information needed to make decisions around participating was available. Participants were aware of their right to opt out of the research at any time during the data collection phase (interviews/focus group). Leaflets with details of community support groups as well as contact details of the supervisory team were made available as a reference for further advice and clarification when needed. No personal details appeared on the consent form or on other supporting documents. This was in line with the Data Protection Act (1998). Lofland et al. (2006) stated that "it is an obligation as well as respect for researchers to ensure confidentiality of research participants' details". Consequently, all names were replaced with pseudonyms to protect anonymity.

Health research and interventions advocate the need for sensitivity (benevolence) as many topics are sensitive. This ensures harm reduction in the course of the research (Robson, 2002). As the subject area was quite sensitive, potential participants were given the autonomy to opt out or excuse themselves from the research at any time if they have privacy or confidentiality concerns. These options were applicable to participants in the interviews and focus group session. Also, permission was sought for both sessions to be audio taped. Consent (see Appendix 6) was guaranteed by asking all participants in both the interviews and the focus group to sign a form prior to all sessions. Ethical

issues affecting the focus group discussion are the issues of anonymization and confidentiality. This is because the way the discussion operates, and the nature of the data collection process make it infeasible to pledge complete privacy (Kitzinger, 1994; Smith, 1995). This could discourage potential participants from opting into the session due to lack of trust regarding sensitive personal information. Effort was made to create a level of confidentiality guarantee or ‘assurance’, whilst acknowledging that information shared within the group could potentially be voiced or mentioned outside the group based on the social group (ethnic minority young women). This was carried out through pre-session debriefing and reiteration of the importance placed on issues of confidentiality and data protection by the university (Stewart & Shamdasani, 1992). Participants in the focus group were persuaded to keep confidential all information or issues discussed within the group.

All resources connected to this study were treated as confidential and kept secure at all times in compliance with the Data Protection Act (1998), either in a locked cabinet at Northumbria University or in a database on a password-protected computer. Where direct quotations from study participants are used, these are identified by pseudonym only to preserve the anonymity and privacy of the individuals

Following review of possible ethical issues and receipt of the University ethical approval, the NHS research ethics application was made. The NHS review process can be carried out in different ways depending on the nature of the study, using either a proportionate review process or a review panel meeting. The latter process takes longer and fortunately, my research protocol met the proportionate review process. After calling the proportionate review helpline and making a booking, I was booked to the Norfolk REC, and a date was set for me to submit my documents, after which I waited for their suggestions and most especially for their approval.

A favourable NHS REC approval was granted within 3 weeks of submission. The quick response was due to the fact that the form and supporting document has addressed all ethical concerns and issues, after it had been critically and thoroughly scrutinised by the university ethics subcommittee.

It is worth reiterating that the ethical approval process served as a control mechanism or approach for the identification, evaluation and resolution of potential issues or problems that could arise in the course of the research. However, it is important to note that the ethical issues discussed above can be categorised into two dimensions: procedural ethics and ethics in practice, which are both distinct (Guillemin & Gillam, 2004). Procedural ethics as a process of getting relevant permission to carry out research involving humans. Ethics in practice, also known as ‘everyday ethical issues’ include all issues that arose during the conduct of the study. It is worth noting that not all practical ethical issue can be predicted, but other research and ethical dilemmas within those studies acted as a guide for their identification.

## **Conclusion**

This chapter describes the theoretical perspective of the researcher and the reasons behind adopting the methodology. Symbolic Interactionism (SI) was chosen as the guide for both the ontological and epistemological viewpoint of the chosen methodology. In addition, SI also influenced the overall research process. Furthermore, a justification of the chosen methodology (Grounded Theory) was provided by reflecting on the available schools of thought as well as their distinctiveness and their best fit concerning how they answer the phenomenon under study. The chapter ended with the provision of the debates around sensitivity, study validity and potentially anticipated ethical issues and possible ways of addressing such issues. The next chapter focuses on the research design, including a discussion around data collection through to analysis.

## **CHAPTER 4: Research Design and Method**

This chapter describes the procedure applied in the research design, also known as the research method. It begins with recruitment process for study participants, detailing how the research sites were approached and negotiation was conducted, followed by the various sampling strategies. Theoretical sampling, one of the important strategies for use with the GT methodology, was not used due to challenges encountered during the recruitment stage. Instead, multiple variation purposive sampling was utilised. However, attempts were made, and a few participants were theoretically sampled based on themes that were emerging from the data already collected. The demographic makeup of both interview and focus group participants is also provided. The process of data collection and analysis occurred concurrently but are described under different headings in this chapter. Following the GT tenet (Charmaz, 2014), analysis began promptly once the focus group was conducted and some interviews had been done. This process of analysis continued until saturation was reached and theory generation achieved.

### **4.1 Approaching research sites/negotiating access**

Approaching research sites and negotiating access is an important aspect of any research, as it informs the entire structuring and implementation of the research, from the proposal through to data collection. This section will highlight the recruitment strategies adopted, challenges faced and justification for the chosen methods. The initial plan was to recruit participants through the cervical cancer call and recall office (Area Teams), which is responsible for sending out screening invitation letters to women who fall within the screening age. There are 2 Area Teams (offices) running the open Exeter system in the Northeast; one in Gosforth and the other in Darlington. Unlike other screening programmes (e.g. bowel and breast cancer), which are run/regulated through a national screening service/body, the cervical screening programme is regulated regionally and coordinated through area teams. Cervical screening is carried out in GP surgeries, while other screening programmes are done at the hub. Some limitations were identified around using GP surgeries. Outside the ethical issues, the major hurdle was that practices are very busy and even if they decide to participate, may require payment to help in recruitment.

The call and recall centre utilise an IT system that follows a recurrent sequence and an alert system known as call/recall to invite women who are considered vulnerable to cervical cancer and fall within an age group to participate in the screening programme. Based on the regional policy and age of the women, letters are received on either three- or five-year intervals. GPs collate the details of those who qualify for screening and send these to the call and recall team for onward invitation of the women to the screening programme. This method of allowing review of eligible patients was deemed effective in including many women into the programme. This process is termed a “failsafe mechanism”. Another reason for using the GP was also to keep track of women who have relocated

from an area and have been allocated or registered to another practice, thereby keeping them on the system and preventing invitations being set to the wrong home address (NHS Digital, 2015).

The aim of selecting the centre as a collaborator to help recruitment was because firstly, based on confidentiality and the Data Protection Act, direct contact with NHS service users is restricted or sometimes completely prohibited. When access is permitted, service user consent is required by the researcher. Second and most importantly, as they are responsible for identifying eligible women and posting screening invitation letters (they have the complete information for both attendees and non-attendees), it was decided to employ their services. This was to ensure that the researcher had no direct access to patient data in respect of data protection and the confidentiality clause (Hegney & Chan, 2010).

However, the anticipated recruitment through the call and recall centre came with many hurdles based on practical and approval issues. This project was carried out at a time when the NHS and the centre were going through major structural changes (HSCIC, 2013) and contacting staff to undertake certain approvals proved difficult. No one within the call and recall area team or QARC seemed to know who did what (assigned responsibility) within the NHS. Coupled with the elimination of PCTs, most of the roles were allocated to Public Health England. This led to delays in terms of what Research and Development (R&D) groups are responsible for this project (Public Health England has no R&D department). Many enquiries were made, and I was sent to various organisations and individuals, none of whom seemed clear about what approvals were needed (e.g. Caldecott) or who had the authority or responsibility to give or undertake them.

A flowchart of challenges encountered in finalising recruitment strategies and how these led to delays in both university and the NHS REC approval process is included below. These challenges led to consideration of alternative recruitment strategies as advised by the review panels during the University ethics approval process.

Figure 4 Challenges faced approaching the initial recruitment sites (Before R& D approval)

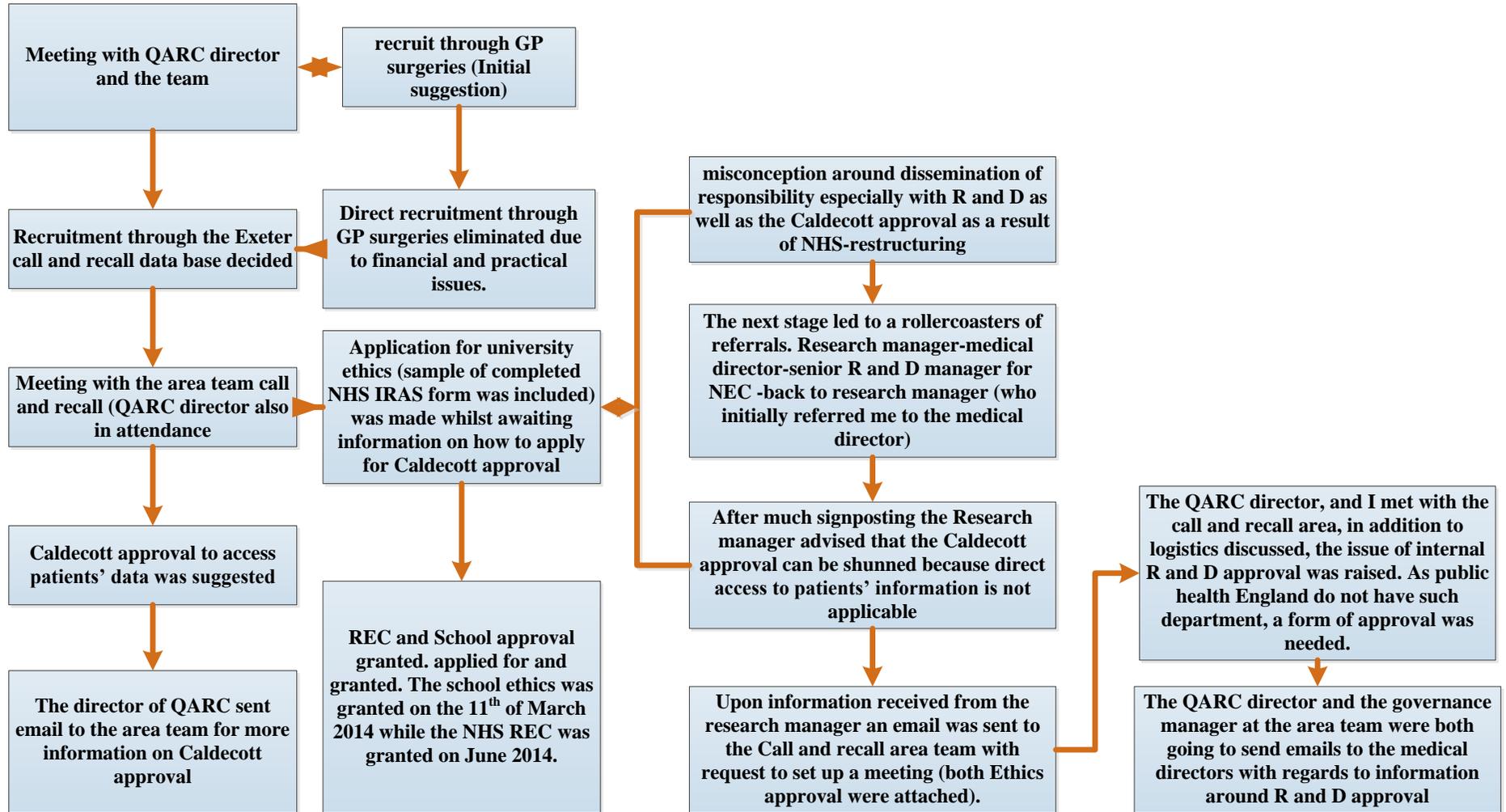
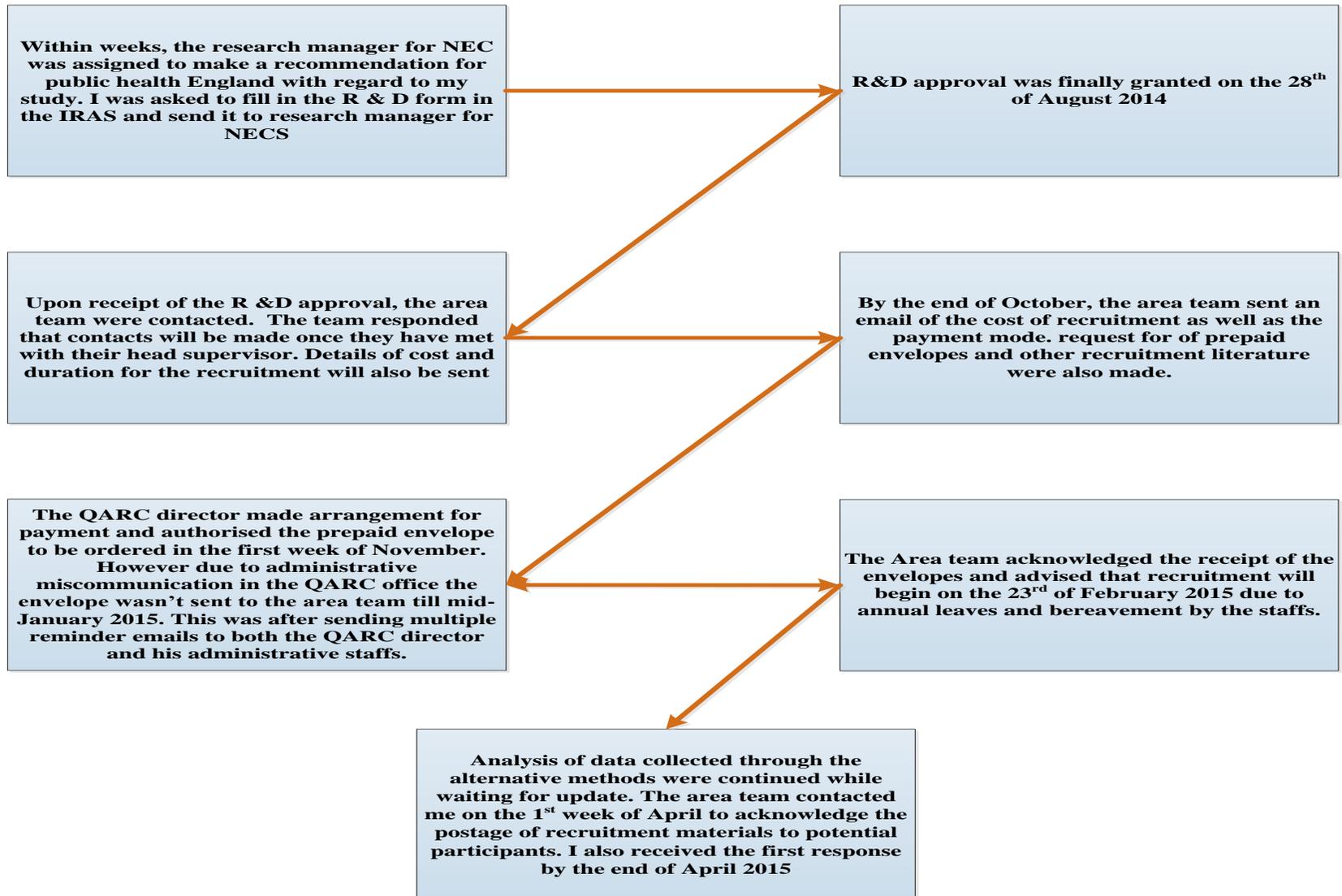


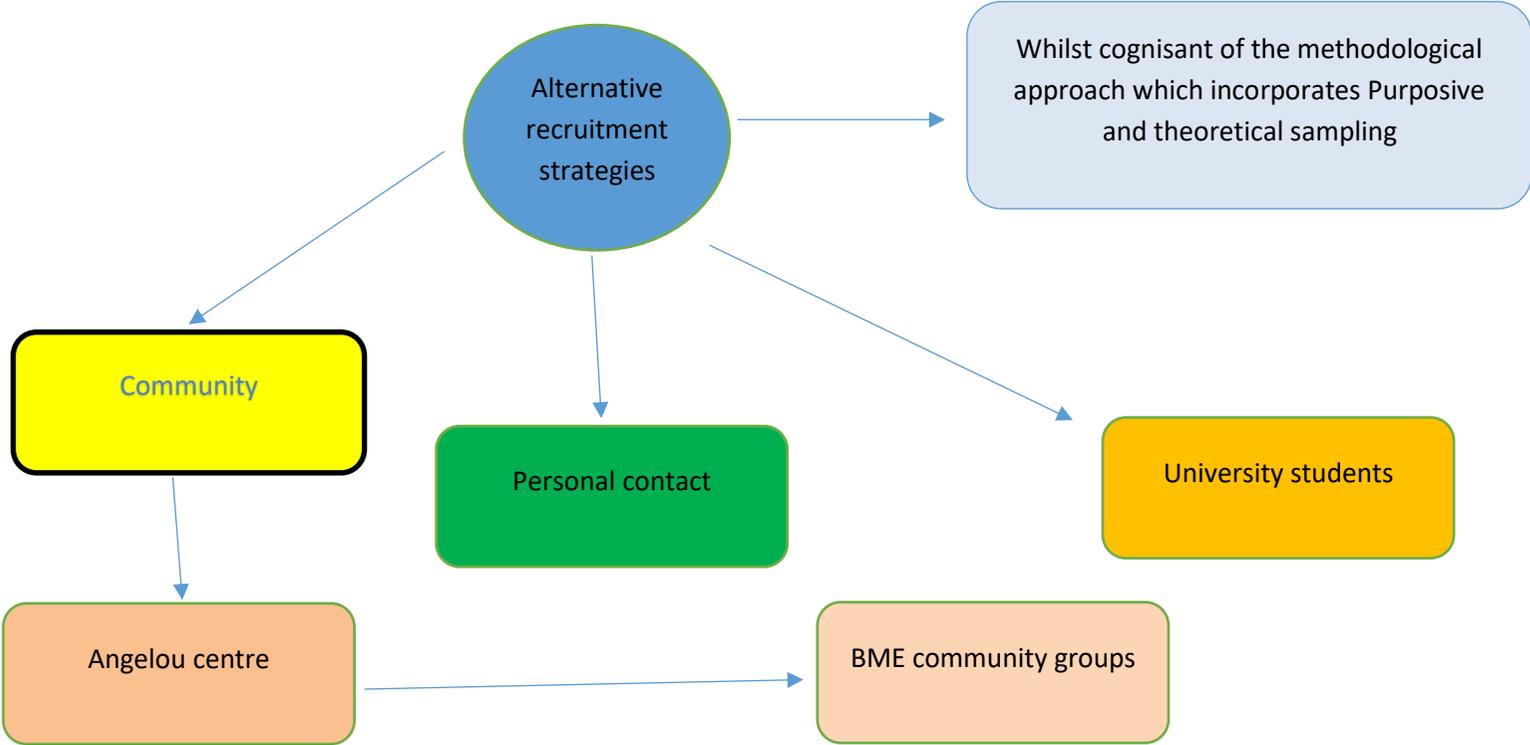
Figure 5 Challenges faced during recruitment (R&D approval until data collection)



Figures 4 and 5 present all the difficulties encountered during the recruitment stages and how the time-bound nature of the study led to the alternative methods employed. The difficulty in recruitment resulting from the restructuring of the NHS and changes to the NHS screening programme (see chapter 2) has implications and act as a premise for further exploration for future studies.

The figure below presents the alternative recruitment sites and how they were negotiated.

Figure 6. Alternative recruitment sites/strategies



## Community

Recruitment was carried out through local community groups or centres, such as religious groups (churches, mosque), ethnic groups or nurseries. The Angelou Centre Newcastle was approached, and they were keen to help in recruitment. The centre has a diverse service user base in terms of ethnicity, religion and SES. In addition to the centre, recruitment was also carried out in a 20s to 30s group in a local church. This was done using snowball sampling by word of mouth and through emails sent by the group coordinator to those eligible for the study (see table below).

Table 3. Inclusion and Exclusion criteria

| Inclusion Criteria   | Exclusion Criteria   |
|--|--|
| Women aged 25 to 34  | Lack capacity to consent   |
| Women who haven't attended for any smear test even though they have been invited | Do not speak English (will be included if an interpreter is available) |
| Women who attended their first smear test and haven't attended any more          | Do not reside in the Northeast of England                              |
| Women who are up to date with their smear test                                   | Are not aged between 25 and 34   |
| Resident in the Northeast of England   | Women who are not able to consent (those with learning disabilities)   |

## University students

A group known to have low uptake rates were people living in postcode areas close to the universities. Most students also fell within the age group under study. Recruitment was carried out in 3 of the major university in the Northeast; Northumbria, Teesside and Newcastle University. Northumbria University recruitment was carried out through emails from the university portal for postgraduate students and through the university student's union. In addition, some snowball sampling was also carried out through word of mouth. A similar process was carried out at Newcastle University and Teesside University.

## Personal contacts

As the study commenced, it was observed that to acquire a reasonable sample size, snowball sampling seemed necessary. Snowball sampling involves personal face to face contact or through word-of mouth to recruit participants who otherwise would have been difficult to recruit using the initial recruitment strategy (Bonevski et al., 2014). Recommendations were made to include women from variable but similar social communities who met the inclusion criteria and were keen to take

part (Calvo, 2005). Some participants also recommended other young women who they felt met the inclusion criteria.

#### **4.1.1 Recruitment of participants**

As stated above, recruitment was carried out from various sites. These include the call and recall centre, universities in the Northeast and the community (ethnic minority community Centre and church). The call and recall used data from the Middleborough and Newcastle sites. In all, 500 invitations were sent out, 282 letters for those who have never been screened and 218 for those who have been for testing just once and at non-respondent stage. 15 responses were received, with 10 returned due to change of address and 1 from a parent whose daughter couldn't consent due to disability. Of the remaining four, three were willing to be interviewed, however only two finally took part in the study. It is noteworthy that recruitment and data collection was stopped due to time constraint. There was a possibility of more responses from respondents from the call and recall recruitment route, however this was halted as the study was time-bound as this route took a long time.

14 of the 16 participants who were interviewed were recruited through the universities, Northumbria (6), Newcastle (1) and Teesside (3), while the other 4 were theoretically sampled. Emails were sent through the Northumbria University postgraduate student mailing list and only 3 people replied expressing an interest in participating. The remaining 3 and the student from Newcastle University were purposively sampled through word of mouth. The Teesside University recruitment was conducted by sending an email to a mutual colleague, who in turn distributed the message to potential participants who fitted the inclusion criteria. Of the 8 emails sent, 3 students responded to take part in the study and were later interviewed.

Participants recruited from the Angelou Centre were from a group in the centre with 8 participants, while 1 was theoretically sampled from a local church in Newcastle. Overall, 24 participants took part in the study. 10 women were recruited from the Angelou Centre but only 8 took part in the focus group discussion. The participants' characteristics for both the interview and focus group are presented in chapters 5 and 6 respectively.

The maximum variation sampling approach was employed for recruiting participants, although this was not the scheduled sampling method. It was initially hoped that a maximum number of 60 participants would be included in the interviews, who were from parts of the region with minimum cervical cancer uptake rate. This was assumed to achieve saturation. The point at which enough quality information has been collected to support the study is known as 'saturation' (Charmaz, 2014; Creswell, 2007; Goulding, 1999). This means that no fresh ideas are being received from subsequent

data collection and analysis. In GT terms, theoretical saturation is considered achieved if a theory has been developed or is emerging (Corbin & Strauss, 2008). Arguments abound around the number of interviews needed to attain saturation. Suggestions were placed between 20-60 (Creswell, 2007; Charmaz, 2014). I decided to conduct 20-60 interviews and a focus group session, in anticipation to retain as many participants as possible in case some potential participants decide to withdraw from the study. The quality of a study and the subsequent theory could be threatened if saturation is affected by participant's availability, accessibility and time (Corbin & Strauss, 2008).

Women living in wealthier postcodes in comparison to those who did not (likely low social standing) responded highly to cervical cancer invitation based on data presented by mappings from practices. However, an effort was made to have an even distribution of participants from areas of low uptake and varied social economic status during recruitments from the alternative centres (universities, church and the Angelou Centre) as a result of recruitment difficulties (see Figure 4) encountered from the call and recall centre. Variation in sample distribution can influence the theoretical power and credibility of research findings (Charmaz, 1990; 2000).

The overall number of participants interviewed was 16, while 8 took part in the focus group session (i.e. 24 participants overall). All individuals who responded to the study invitation were interviewed including instances when it was felt that no new knowledge was emerging. Individuals with low perceived susceptibility to cervical cancer may opt out of the screening programme and likewise low enthusiasm for research involving cervical cancer as well. Personal perceptions led to the assumption that the lack of uptake might be relative to negative perceptions of cervical screening and difficulties in identifying and reaching them. To avoid exclusion of individuals with limited communication ability (e.g. non-English speakers), I used interpreters in the focus group and its recruitment.

Nonetheless, in order to avoid forcing individuals to participate in the research study, the removal of the researcher's preconceived ideas and expectation is advised to add credibility to the study (Hegney & Chan, 2010). The reason for adopting the GT methodology was to collect data rich in depth and based solely on the participants' point of view. Drawing on this principle will enable me to interpret the acquired information (participant's viewpoint) to a more conceptual level (Charmaz, 2014, Mills et al., 2006).

#### **4.1.2 Sampling approach**

This section shows how the sampling and recruitment of participants was carried out. The way the GT tenet of 'theoretical sampling' was attempted and employed in the study is also discussed under separate headings.

Sampling can be defined as the process of choosing people from a population of interest for a study. Data collected from these people can be generalised or show a level of representativeness of the population from which they were chosen (Bowling, 2008). However, sampling may also be considered in relation to the challenges presented by the process. The first challenge with sampling in qualitative research deals with identifying and negotiating access to sites and individuals in order for a research project to take place. Devers and Frankel (2000a) note that the researcher is the research instrument and most studies using qualitative research techniques necessitate the development, sustenance and subsequent ending of relationships with research participants and sites. The development and sustenance of cordial relationships is vital for operationalization and quality of sampling and for the credibility or reliability of findings and conclusions. A researcher who is unable to solicit and obtain subjects' participation cannot proceed with sampling or the research. On a related issue, Groger and Mayberry (1999) suggest negotiation processes and protocols involved in obtaining access to target subjects come at a cost of delays. In a typical research environment and limited timeframe for a study, this would suggest that sampling decisions are often moderated by the reality and practicality of administering one sampling technique or another. Access to a facility or respondents may be refused, thereby creating problem in the process of data collection, depending on the stage of the data collection process. This was evident in this study, as negotiation of sites and the actual sampling process were delayed due to the ethical approval process and internal protocols, which eventually led to sampling of participants from alternative sites.

Tuckett and Stewart (2004) note that one way of tackling the problem of accessing sampling sites and sample selection would be to be open-minded in regard to alternative sampling methods and to also apply different data collection techniques. As Greene and McClintock (1985) suggest, the use of different data collection methods provides the researcher the opportunity to account for similarity or otherwise of information collected.

### **Selective or purposive sampling**

Selective or purposive sampling are non-random techniques, which do not require exact numbers of participants. The research aims, or questions orientate the researcher to what needs to be known or what data needs to be collected. The researcher then sets out to find people who can, and are willing, to provide the information by virtue of knowledge or experience. This involves identification and selection of individuals or groups who are proficient and well-informed with a phenomenon of interest (Creswell and Clark, 2011). Schatzman & Strauss (1973) suggest that after several observation visits to the sites, the researcher will know who to sample for the purpose of the study. While not all researchers will be able to 'visit sites', some (like myself) may have other opportunities to engage with relevant stakeholders and literature in order to gain a picture of who it would be useful or important to sample. Schatzman & Strauss (1973) discuss sampling of time,

locations, events and people. In their discussion of sampling people, they state that the researcher selects people according to the aims of the research. Categories such as age, gender, status, role or function in organization, stated philosophy or ideology may serve as starting points. In the present study, issues such as attendance and non-attendance for screening were important initial categories for consideration and the original plan was to sample these groups via the call and recall centre which organises screening. However, due to unforeseen changes in service organization and stakeholder roles, this was not possible (see section 4.1).

The description of purposive sampling given by Schatzman & Strauss (1973) seems similar to Patton's (1990), who suggests the "logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling" (p. 169). Unlike random studies, which deliberately include a diverse cross section of ages, backgrounds and cultures, the idea behind purposive sampling is to concentrate on people with particular characteristics who will be better able to assist with the relevant research (Ilker et al., 2016). However, it is suggested that as a study progresses, and categories are identified, these new categories may lead or propel the researcher to other sets of sampling based on issues within the said categories (Charmaz, 2006; Glaser, 1998). Although this sampling is similar to theoretical sampling, there have been arguments around its authenticity. Glaser (1978) vehemently stated that this purposive sampling according to Schatzman and Strauss (1973) is very different from theoretical sampling, because unlike theoretical sampling, purposive sampling is a "calculated decision to sample a specific area according to a set of preconceived but reasonable initial sets of dimensions which are worked out in advance for a study" (Coyne, 1997). However, clarification of the difference between the later part of selective sampling and theoretical sampling has been debated (Coyne, 1997). It could be argued that there are similarities between the two, especially given that the subsequent sets of sampling may not be 'preconceived', but emerge from the data analysis and, as in this study, some sampling was carried out based on the information emerging from the data. One such instance was the sampling of participants who haven't been sexually active, to understand their perceptions around acceptance of the screening programme and of future screening attendance.

### **Maximum variation sampling**

A maximum variation sample is a special kind of purposive sample. Although purposive sampling is not representative, maximum variation sampling attempts to include as wide a variety of participants as possible. This type of purposive sampling attempts to look at a research topic from a variety of angles to achieve a greater understanding. Also known as 'Heterogeneous Sampling', it involves selecting participants across a broad spectrum relating to the topic of study. For example, if one was researching an education program, one may include students who hated the

program, students classed as ‘typical’ and students who excelled. In the present study, even though there were difficulties in accessing participants via the screening organisers, attempts were made to access as wide a range of participants as possible (see tables 8 and 9). Maximum variation purposive sampling (Creswell, 2007; Teddlie and Yu, 2007) was utilized in this study to overcome the difficulties in the recruitment process. The purposive sampling approach was utilised by including individuals who have either attended screening or those who have not attended but with an idea or experience of the phenomena being studied. Purposive sample sizes are usually considered using theoretical saturation. Purposive sampling in grounded theory study is deemed successful when data collection and analysis occur concurrently (Denzin and Lincoln, 2001; Charmaz, 2014; Goulding, 1999). Concurrent data collection and analysis was carried out during the initial part of the data collection within the study. In instances where it was not possible, comparison was made to ensure the emerging themes corresponded with the already coded data.

### **Convenience sampling**

Convenience, nonprobability or non-random sampling involves the inclusion and selection of participants into a study with certain practical criteria, such as easy accessibility, geographical proximity, availability at a given time or the willingness to participate (Ilker et al., 2016). Leiner (2014) suggests “captive participants such as students in the researcher’s own institution are main examples of convenience”.

The main objective of convenience sampling is to collect information from participants who are easily accessible to the researcher. Although commonly used, it is not usually purposeful or strategic (Palinkas et al., 2013). Unless otherwise stated by the researcher, an assumption associated with convenience sampling is that the members of the target population are homogeneous. That is, that there would be no difference in the research results obtained from a random sample, a nearby sample, a co-operative sample, or a sample gathered in some inaccessible part of the population (Ilker et al., 2016). This type of sampling is often criticised as being unrepresentative of the sampled research population.

Miles and Huberman (1994) suggest purposive sampling methods place primary emphasis on saturation (i.e. obtaining a comprehensive understanding by continuing to sample until no new substantive information is acquired), while convenience sampling methods place primary emphasis on generalizability (i.e. ensuring that the knowledge gained is representative of the population from which the sample was drawn) (Palinkas et al., 2013). This description of purposive sampling is very like theoretical saturation in GT and therefore indicates the appropriateness of purposive sampling in a GT study. In this doctoral study, an element of

convenience sampling was used to access participants in and around the educational institution and church attended by the researcher.

### **Theoretical sampling**

Purposive and theoretical sampling have been used simultaneously or interchangeably by some researchers. However, there are still some distinctions between both. As in purposive sampling, Glaser (1978) acknowledged that theoretical sampling involves researchers at the beginning of their research identifying a group that will provide the best data for their questions and lead to more questions being identified and answered. He further stated that the researcher identifies where to sample from but not necessarily what to sample for or where the sampling might lead (Coyne, 1998; Glaser, 1978). According to Charmaz (2014), “it simply means gathering more suitable and relevant data to fill out and elaborate your emerging categories as well as bringing unambiguous organized checks and improvement into the analysis process”. This implies that the researcher starts the study with a sample where the phenomenon occurs, and the next stage of data collection is when theoretical sampling begins. This is supported by Chenitz and Swanson (1986) (in Coyne, 1998), who state that in theoretical sampling, the sample is not selected from the population based on certain variables prior to the study, but rather the initial sample is determined to examine the phenomenon where it exists. The resulting data is then guided by a sampling strategy called theoretical sampling.

Theoretical sampling involves the researcher collecting, coding and analysing data to decide which data to collect next or for further data collection to fit into emerging information (Coyne, 1998). Deciding where to sample next according to the emerging codes and categories is theoretical sampling. Theoretical sampling on any categories is stopped once elaboration and saturation are attained (Glaser, 1992). Thus, theoretical sampling is not so much led by the sample, but more by the emergent data and codes. Further sampling through constant comparative analysis of the information from the already collected data to expatiate or build on the codes identified is called theoretical sampling (Charmaz, 2006; Strauss and Corbin, 1990). In the present study, theoretical sampling was data-driven rather than participant-orientated in that the data analysed from initial participants indicated further areas for questioning in subsequent data collection. This orientation was partly driven by the difficulties encountered in accessing participants (section 4.1), but was felt to be in keeping with GT.

Theoretical sampling is peculiar and pivotal to GT and any GT study or researcher should be able to differentiate it from other sampling methods. It is also important to note that theoretical sampling is an ongoing process of data collection that cannot be predetermined (Becker 1993; Coyne, 1997) and can be used to verify and validate categories. Therefore, questions asked throughout a study could be altered based on already collected data. Glaser (1967; 1978; 1992) defined theoretical sampling

in GT as a “process by which data collection is continually guided” and can therefore be referred to as ‘analysis driven purposive sampling’ or ‘analysis governed purposive sampling’.

In a separate argument on theoretical sampling, Sandelowski et al. (1992) stated that the researcher projects a sampling frame at the beginning of the study (purposive sampling), which permits the researcher to develop the conceptual lines that will ultimately drive theoretical sampling. However, Glaser (1978) argued against Sandelowski, stating that the “initial decisions for theoretical collection of data are based only on a general sociological perspective on a general subject or problem area... not on a preconceived theoretical framework” (p. 45). Although theoretical sampling and purposive sampling might be similar, Coyne (1997) concluded that theoretical sampling has an element of purposive sampling, but not all purposive samples are theoretical.

In this present study, theoretical sampling alone was not possible because of the challenges encountered during recruitment (see section 4.1). However, purposive sampling (including the attempt to have a maximum variation) was utilised and, as described above, data driven theoretical sampling using questions and emerging themes was also employed to strengthen the research and maintain consistency with GT principles. Comparative analysis of data collected as well as theoretically sampling the questions was an attempted means to follow this principle when collecting both the focus group and interview data. Themes emerging in the initial interviews prompted the active recruitment of 2 other participants. One example of this ‘theoretical sampling’ of the 2 other participants was when participants in the focus group and interview (discussed below) identified “sexual inactivity” as a reason for non-attendance for screening. I decided to explore this topic more and this influenced the recruitment of the 2 further participants. In a random conversation about my study, one of the women I spoke to, mentioned her screening status and highlighted that she was not sexually active. As this was a common theme emerging from the data analysis, I decided that if the woman was willing, and she met the inclusion criteria, I would invite her to be a participant and she agreed. Thus, theoretical sampling was undertaken in this instance.

The other 2 participants were theoretically recruited from the researcher’s place of worship through word of mouth. It can be argued that researchers may encounter difficulties while trying to distinguish between the emerging concepts and as such, are sometimes unsure and may be steered towards using what is within reach (convenience) (Goulding, 1999; Creswell, 2007).

Outside issues around recruitment difficulty, the use of purposive sampling alongside theoretical sampling was also based on Patton’s (1990) suggestion that purposive sampling can be used to collect or initiate a sampling process, but as the study “progresses and categories identified, these new categories led or propel another set of sampling based on issues within the said categories”. This notion was also supported by Sandelowski et al. (1992), who stated that within a GT study, the

researcher is allowed to project a sampling frame at the beginning of the study (purposive sampling), which then leads to the possible development of conceptual lines that will ultimately drive theoretical sampling. Although grounded theorists like Glaser have vehemently opposed the authenticity and classification as a GT study using Patton's approach, they later acknowledged theoretical sampling as an 'analysis driven purposive sampling', because data collection is guided continuously. These arguments help justify the sampling method utilised in this study and situations where unforeseen difficulty arises. Purposive sampling was deemed appropriate, as the study involved a predetermined group (young women aged 25-34 living Northeast England), although multiple variables were also factored in the group. Some participants were also convenience sampled within the educational institution (universities) and local church to include diversity within young women in the study age group.

## **4.2 Data collection**

Data collection methods require consideration while undertaking this GT inquiry. Grounded theorists using a flexible approach improved their data collection technique (Charmaz 2006). The direction of the research was guided by the data collected. This is achievable using several data collection strategies, due to the flexible nature of GT (Charmaz, 2006). To effectively provide the best answer to a research question, the method chosen is very important (Charmaz 2006). The data collection method also affects which phenomena the researcher will see; how, when and where they will be viewed; and what sense the researcher will make of them (De Chesnay, 2014; Charmaz, 2006). A range of possible data collection approaches were available, including survey, observation, focus group discussions and interview (Creswell, 1994).

Data were acquired using focus group discussions and individual interviews. Triangulation was used to understand and acquire multiple insights of the topic and this was made possible by adopting various data collection approaches (Charmaz, 2014, Graham and Thomas, 2008). A semi-structured approach to the interviews and focus group was adopted which used unstructured questions (Minichiello et al., 2004). This helped reduce any potential prejudice and the researcher's influence, thereby assuring credibility, as pre-decided questions might contain preconceived notions (Charmaz, 2006).

### **4.2.1 Interviews**

One-to-one semi-structured interview was one of the methods employed in this study to get an overview and insights into experiences of the participants. The same opening question was used in both the individual interviews and the focus group. This approach allowed generation of rapport with participants, gaining data related to the participant's health views and health beliefs, and helped clarify misconceptions. Using semi-structured interviews afforded me the opportunity to listen

attentively, pause and, when possible, enquire further about a point that was not clear (Newton, 2010). Having prior knowledge of the phenomena under study due to the flexibility of the GT methodology is an added advantage in the interview process when exploring views with participants (Fielding, 1994). Due to the willingness of participants to provide their views during data collection, employing a non-structured format of interviewing (despite it been a structured interview) led to generation of rich data (Charmaz, 2006; Guba & Lincoln, 1981). Care was taken not to provide leading questions to avoid influencing the participants' viewpoint with my preconceived ideas. This was achieved by allowing the participants to air their views without interruption (Glaser & Strauss, 1967; 1996; Newton, 2010). One of the cautions taken during the interview was to not overcompensate or lead them with the type of questions asked. E.g. Avoiding direct questions like "did the screening make you feel embarrassed?" This kind of question can be leading, and participants may be obliged to answer to the affirmative, so no deeper understanding would be gained beyond 'feeling embarrassed'. Based on that, and to encourage freedom and comfort, I started most interviews by asking questions around their views on health and access to services, followed by specific questions regarding cervical cancer and the screening programme, whilst questions regarding experiences came later on in the interview.

Overall, 16 interviews were conducted in various settings (homes, library and offices) that were convenient for the participants. Interviews were audio recorded and transcribed. All participants gave their consent to be audio recorded. Nevertheless, important points were jotted down during interview, including comments made after the audio recorder has been switched off. I also developed a checklist to remind me of practical things I need to do before, during and after the interviews. For example, prior to any interview, I had to make sure that the recorder is switched on, the battery has sufficient life, and a new file has been selected for the fresh interview. The interview schedule acted as a guide for the interview questions. However, questions were constantly rephrased to enable the participants to understand what was being asked. Participants were also offered opportunities to raise issues of importance to them that are not covered in the interview guide. The interviews were conducted over 10 months between August 2014 and May 2015.

#### **4.2.2 Focus groups**

Information was collected from a focus group (FG) discussion conducted at the Angelou centre. Only one focus group was conducted due to time and logistical constraints. Recruitment for focus groups is more cumbersome due to issues around contacts and trust between the researcher and potential participants. A focus group is a method of data collection using moderate discussion based on participants' perception and experience of a topic being explored by a researcher (Kruger and Casey, 2009; Kitzinger, 1995). Information difficult to obtain in individual interviews can be collected using

focus groups as the synergy and dynamism generated within homogenous collectives often reveals unarticulated norms and normative assumptions (Kamberelis & Dimitriadis, 2005:903).

Using an informative approach, focus groups supersede the boundary of individual memory; this is because as one individual raises a point of view, this stimulates the memories of others with similar experiences, thereby providing an avenue for others to share their own perspective of the “raised point” (Kamberelis & Dimitriadis, 2005:903). Through focus groups, varieties of information from different standpoints or viewpoints are collected from individuals with similar interests or from similar backgrounds (Beya & Nicoll 2000; Minichiolo, et al., 2004). Through the ‘group dynamic’, in-depth and rich information was collected from the focus group discussion (Kamberelis & Dimitriadis, 2005). According to Kamberelis & Dimitriadis (2005) (in Sengstock, 2008), focus groups are likened to a “magnifying glass, inducing social interaction analogous to those that occur in everyday life but with greater clarity”.

A focus group session explored the views of women from an ethnic minority group to understand their reasons for participation and non-participation in terms of variation in social dynamics and SES. It also aids in getting a ‘social dynamics’ of the sensitive issue of sex, a topic saddled with stigma in some cultures. Participants provided their insights about health, cancer, cervical cancer, attendance history; factors that affected their decision to screen or not to screen, ways the screening process can be improved, as well as exploring emerging themes from the interview sections. Women who participated in the focus group discussions were between 25-34; the average marital status was married; the average educational attainment was not discussed, and most were migrants and can be classified as being of low or middle SES. The focus group session was facilitated by the researcher, who took notes. One participant volunteered to interpret.

The focus group guide was similar to those of the semi-structured interviews, with distinction in the emerging concepts (derived from interview analysis), which were further explored in the focus group session (Minichiolo et al., 1995). The ideal number of participants to be included in a focus group has been a topic of contention within existing literature. The number with the highest consensus is between 4-12 in a single section (Creswell, 1994; Denzin & Lincoln, 2000; Tang and Davis, 1995). Tang and Davis (1995) however stated that care should be taken in choosing a sample size, as the number in a group could potentially affect the dynamics of the discussion. In this study, the focus group had 8 participants. This small number was to provide an equal opportunity for all participants to contribute and it was a manageable number for the researcher to control (Jamieson & Williams, 2003; Stewart & Shamdasani, 1990).

The focus group session was tape-recorded, and notes were taken with the consent of the participants. The focus group session lasted 1<sup>1/2</sup> hours while an extra 30 min was used to educate the women of

cervical cancer, its screening and associated issues. Unstructured questions were utilised in exploring and understanding women's health beliefs of cervical cancer and how this affects their attitude towards participation in screening. An unrelated question to the study topic was used as an icebreaker to get full attention and to gradually draw the participants into the group discussion. The unstructured interviews also guided the group session to prevent the loss of any important aspect of the research questions (Minichiello et al., 2004; St John, 2004).

### **Research settings**

In addition to the geographical location of the study (see Table 3), the interview and focus group location was also considered. Before commencing both the interview and focus group sections, I explored various things that could act as a potential delay or influence in the overall output of information collected for the study. This is because cervical cancer and the screening procedures are seen as a sensitive subject due to their association with the genitalia. Consideration of issues that could potentially arouse psychological and negative emotions amongst the study participants was anticipated. I therefore decided that the chosen setting for both the interviews and focus group would be comfortable and free from interruptions, to put the participants at ease and gain their full trust in the process. Conducting the interviews in a place of comfort, such as the home was chosen for some participants whilst other preferred their offices and a few were unbothered about the location. The group session took place at the Angelou centre, a place where the participants were comfortable and had access to interpreters when needed. The university library or personal office were also deemed comfortable by participants from the university.

Based on the settings chosen above, issues of travel and discomfort were dealt with. As a result of the autonomy placed on them to pick their own research setting, participants were more open and trusting about personal issues, thereby adding to the credibility of the information collected. However only a few interviews were conducted in participants' homes due to potential ethical dilemmas affecting both the researcher and the participant. In spite of these observed setbacks, such as inability to control the interview because of unanticipated distractions like uninvited guests, doorbell or phones ringing, there are also a few advantages. One advantage is that the home is seen as a place of control as participants consider it as their 'safe haven'; a place they are in their comfortable space. On my part, I encountered some personal dilemmas, e.g. when I interviewed a nursing mother with 2 toddlers. She chose the sitting room with the TV volume to a distracting level because of the children. Although I protested; to remain true and professional, I allowed it as the TV was a way of the participant keeping control of her children. The presence of the children and the TV led to constant distractions during the interview, making continuity and recording difficult. It also led to difficulties in the subsequent transcription. This incident led to the reconsideration of the research setting, and the minimisation of the use of home settings, compared to less distracting convenient

venues (Yew and Andrew, 2006). Control and autonomy was regained by the researcher whilst building and creating a good rapport and relationship with the participants.

### **The research relationship**

Generally, in qualitative research, the researchers often find it difficult to place themselves within the research, as they do not want to over-influence the research (Charmaz, 2014; Strauss and Corbin, 1998). However, for research to be effective there needs to exist a level of relationship between the researcher and the researched (Charmaz, 2014). Qualitative research is a social event involving an interplay between both the researcher and the researched leading to the creation of a close personal connection to ensure the success of the research. This is needed to enhance smooth, unhindered communication between the researcher and the researched during either the focus group or interview sessions (Lincoln & Denzin, 2000; Hammersley & Atkinson, 1995; Eide & Kahn, 2008).

In the current research, I had this challenge with regard to my place as a researcher. This was due to me being an outsider, a woman and an NHS service user (Blackwood, 1995). During the course of relationship building, the issue of the researcher's identity always comes to mind and how it influences the research. For me, my identity within the research centred on my ethnicity, being a service user and being a professional (i.e. researcher). There were instances where I was asked personal questions which were outside the scope of the research. I politely declined, as I did not want to reveal too much information about myself. This is to reduce misunderstanding, as personal bonding could hinder the data collection process (Crozier, 2003). This was not an easy task, as some participants felt I was not forthcoming, I however provided an explanation citing the potential of my personal bias as I have already undergone the cervical screening process I did not want my view to influence theirs. They were understanding, and I created the bond by cracking unrelated jokes and where possible engaged in small talk (Vincent & Warren, 2001). My being from an ethnic minority community and gender was used to instil self-assurance, confidence and to build rapport with the participants from the university as well as those from minority backgrounds, as their views were relatable.

As stated earlier, to get the most out of a research study and create good relationships, there must be a connection between the participant and the researcher, although there have been instances where this relationship was unbalanced to some extent (Berg, 2001). For instance, the participants might exaggerate the knowledge and insights of the researcher. This was evident among the focus group participants, who wanted to be lectured on cervical cancer and its issues and a lot of personal questions meant for health professionals were also presented. It was difficult to convince them on my professional limitations while trying to maintain their trust and interest. To avoid cases like this,

researchers are encouraged to focus on the way they present themselves to their participants to avoid negatively influencing or hindering an acceptable relationship (Gerson & Horowitz, 2002).

Another measure for building rapport was contacting potential interview participants through emails, while good relationship was created with the staff of the centre, as most of the participants in the focus group have great trust and respect for the staff, and take them seriously. Interviews and focus group sessions were conducted at a timely manner, although this took a longer than anticipated time due to issues identified during recruitment. After each interview and the focus group session, participants were thanked and the staff at the Angelou centre were sent thank you emails and text messages.

Ethically, I tried to keep participants out of harm's way. Although I had a few challenges on the level of empathy to proffer to the participants, as there is no standard to the level of distance a researcher must create between themselves and the researched. For instance, based on my personality and the participants' assumed exaggerated views regarding my knowledge of cervical cancer or issues around health in general, there were expectations that all their questions regarding cervical cancer and the screening would be answered. Most of the participants requested a full lecture on risk factors of cervical cancer and in-depth information on the screening process from expectations to how to eliminate anxiety associated with screening. As a researcher, I was tempted to give a lecture at the end of the group session, however I spoke to a member of staff to request a visit from a health professional to give in-depth information at one of their drop-in sessions to answer personal questions only a professional can provide. Eide and Kahn's (2008) advice is that one of the requirements for a researcher is the ability to acquire and be knowledgeable about their research area i.e. from having an in-depth knowledge of issues and current literature to having the necessary resources and connections, which could aid or assist participants when needed.

In addition, there may be instances where communication could hinder a good connection between the researcher and the researched during an interview or focus group (Eide & Kahn, 2008). In this study, some of the participants have only basic English language skills and as such, communication was difficult. Fortunately, one participant offered to interpret, and this altered the structure of the focus group session. The participants were understanding and supportive of their fellow participant, although the session took longer, it was successful, as everyone felt comfortable and included in the group conversation.

According to GT scholars and researchers, it is imperative that the researcher always remembers their place and position during the period of data collection (Charmaz, 2006; 2014, Strauss and Corbin, 1999). This was put into consideration while collecting data to minimise my influence, bearing in mind my ethnicity, gender and being a user of the service explored in this study. This is

because the data collection process is an active process, which may not only evoke memories and reflections but could also bring about unsettling issues and life changes for both the researcher and the researched. It has been acknowledged that the researchers bring in a personal and social ‘self’ to the research process, whilst guarding against sharing beliefs/values or forming an emotional attachment with the participants. In order to achieve a good relationship and better explore both the research and social process of the phenomena under study, Letherby (2000) recommended that the researcher should make an effort to identify and understand the participant’s experiences and direction of the viewpoints. While some researchers have a better understanding of the ‘separation of self’ within a qualitative study, all researchers must strive to have a level of expertise that aid in the presentation of data to be understood and accepted by a broader audience either through publication or through oral presentation.

Based on my knowledge, role as a researcher and experiences using the service, it was ensured that participants were allowed to express their views and opinions uninterrupted and without coercion. This enabled ‘distance creation’, as I could relate on a personal level to some of the emerging issues and views from the information collected. In cases where an incident was encountered as part of ‘good practice’, I conveyed this in my notes during data analysis for maintaining credibility.

### **4.3 Data analysis**

Data Analysis (DA) is a vigorous procedure of thinking that involves the inspection, experimenting with various ideas or views and development of categories within the data collected until arriving at a logical conclusion that aids in theory development in the context of the GT approach. It is an iterative continuous process of sorting out data (Charmaz, 2006) that involves continuous reflection about the data, and keeping memos throughout the research process (Charmaz, 2014; Creswell, 2009). In any research, DA involves a process of continual contemplation regarding the information collected. It is carried out alongside data collection, interpretations and report creation depending on the methodology adopted (Creswell, 2009).

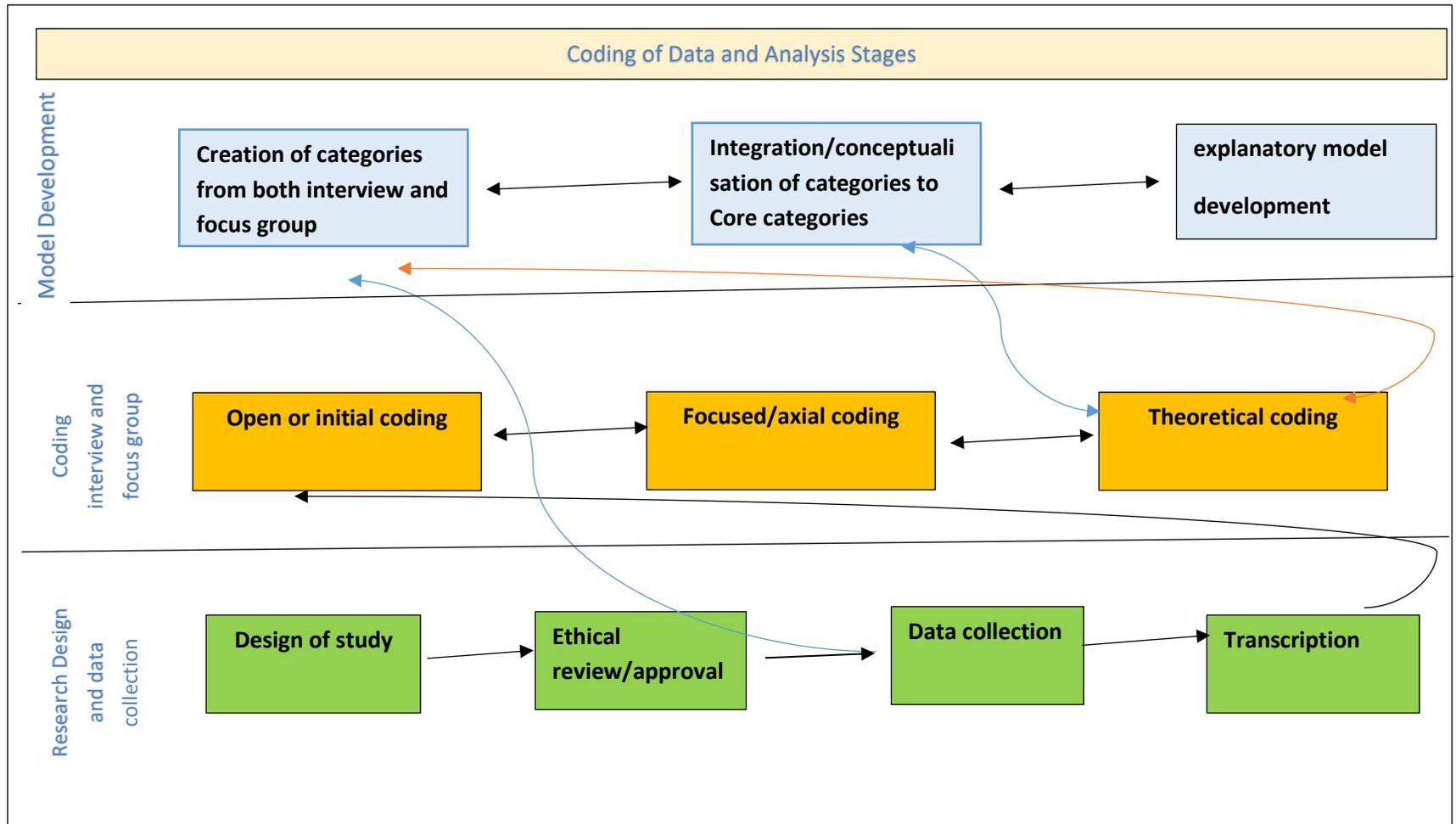
There have been arguments on how data can be analysed, however literature on DA has shown that analysis goes beyond just basic generic analysis to a more procedural and strategic way (Strauss and Corbin, 2007; Stake, 1995; Creswell, 2009).

Phenomenological research for example uses the analysis of significant statement. It is described as the development of essence description that generates units of meanings (Moustakas, 1994). Case study and ethnography on the other hand employs a detailed description of the individual and settings the study is been carried out in before analysing the data in themes (Walcott, 1994). Narrative

research restructures the participants' stories using structural devices in the form of plots, settings, activities and denouement to portray their meanings.

GT data analysis which is used in this study is perhaps less methodical in its approach. As stated in chapter 3, the various schools of thoughts of GT (Glaser and Strauss, 1967; Strauss and Corbin, 1990; Charmaz, 2006) present a more procedural or systematic guide for analysing data. The constructivist GT distinction lies in its methodological flexibility, which is employed during the DA process. I took this reflexive approach into account to gain fresh insights into understanding the factors affecting participation in the cervical cancer screening (Charmaz, 2006). The DA followed the format in Figure 7 (next page), adapted from GetanehAlemu, Brett Stevens, Penny Ross and Jane Chandler, 2015 and Charmaz, 2006.

Figure 7 Stages of Data Analysis



The arrows on the diagram above show that the GT methodology is evolving and non-direct, and hence an iterative approach occurs concurrently and involves the integration of data collection, analysis and synchronised theorising. This process was continuous until the theory was developed. Although potential interviewees are not to be prearranged, it should be iterative and evolutionary, however this was not possible in this study because of recruitment and ethical issues (see Figure 4). Efforts were made to incorporate some of the methodological concepts after transcription of initial interviews and reflection by exploring the upcoming concepts and information by conducting a focus group to include participants from ethnic minority groups to gain a different perspective of the phenomena under study and to elaborate on emerging themes from the data.

In addition, some parts of these processes happened interchangeably. Constant comparative methods are a distinguishing feature of GT, where data, categories and concepts are compared with each other (Charmaz, 2003).

Most grounded theorists recommend that initial analysis and data generation should be done concurrently i.e. data generation should be done immediately after initial analysis. This will in turn direct the upcoming sampling and data collection (Strauss and Corbin, 2007; Mills et al., 2006). This is because key issues raised by participants in an initial interview can be followed up in a subsequent interview or explored further in a group setting (Glaser and Strauss, 1967).

By using constructivist GT, I was able to reflect upon and consider my role in the process of data collection (in terms of coding and interview questions) down to the analysis. Although the participants provided the key information, I posed the questions and identified specific areas to be explored including those that needed further clarification or exploration.

It was difficult to follow through the step by step procedure shown in Figure 7. This is because some of the interview sessions were conducted based on the availability of the participants and this left me with little or no time to go over previous sessions (i.e. in terms of transcribing and conducting initial analysis). However, I listened to previous sections, kept memos of emerging themes and explored these where appropriate in the next interview session.

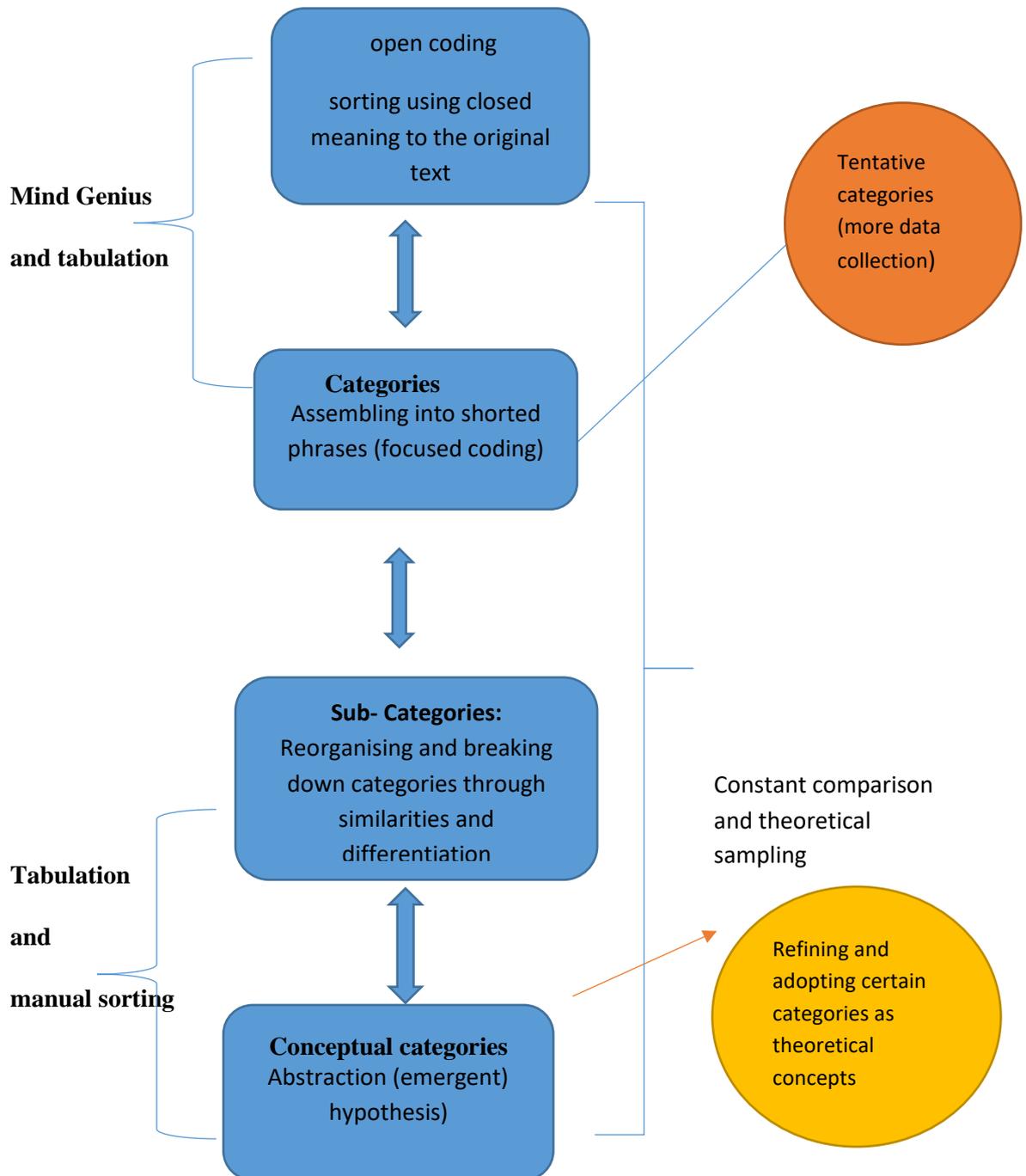
16 interviews and a focus group session (8 participants) were used in the study. The focus group and 7 interviews were transcribed by me while a colleague transcribed the rest. Transcribing some of the interviews was fundamental to the overall analysis process because it allowed me to immerse myself in the data. Opportunities were made available as a result, to evaluate myself not only by opinions and views received, and questions posed, but also to observe some mannerisms (behaviours) such as participants' body language and emotional pitch changes.

Transcription of interviews formed part of the analysis, although it is time consuming and may not be possible before the next interview (as in this study). It is more difficult when the focus group is inclusive. I ensured a diary was kept with theoretical memos, which aided in the subsequent interviews. In the case of focus group, I solicited the services of a note taker during the session, whose notes were used to compare whilst listening to the recording and the subsequent transcribed copy of the focus group session. It is important to note that enough time was left between some interviews, giving me time to transcribe some of the interview sessions before attending the subsequent one. Transcriptions by my colleague were not done before any session.

Additionally, I ensured my colleague was briefed and told to approach me for clarity on any areas of confusion and a debriefing was carried out after transcriptions for feedback (this was done one-on-one).

In this research, 'theoretical possibilities' was availed based on information gained during the research process. The documentation of activities can be impossible or tedious to present in a manner that truly reflects the complications involved. The presentation of this DA section was through 'written accounts' of the process taken for the emergent theory (or theory created). Coding of data was done in 2 stages, open and focused (Charmaz, 2014; 2006). The figure below, adopted from Ford (2010), provides some specific outlines of the analysis process from data collection to theory generation (Chen and Boore, 2009, p7).

Figure 8. specific Data Analysis Process.



The first 2 stages were carried out separately for the interview and focus group, while the 3<sup>rd</sup> and 4<sup>th</sup> stages integrated both the interview and the focus group analysis. A series of constant comparison occurred during stages 3 and 4.

## **Coding**

There are different stages of coding. The first stage, 'open coding' is the phase in the analytical process where information in the data is gradually being made sense of and ideas and their properties become recognised. This stage best characterises the process where identification and creation of numerous codes representing different ideas, or a combination of ideas are identified (Charmaz, 2014). These emerging concepts are solely from the data collected. I adopted an open mind (i.e. I did not force themes from the data, but instead allowed them to emerge), which was achieved by using simple codes that assisted in moving quickly through the data. Through constant comparison, codes were captured and condensed (i.e. capturing codes that reflect meanings related to a phenomenon happening within the data and are seen as important or draw the researcher's attention (Charmaz, 2006, p. 48).

The initial (open coding) stage was carried out line by line. Gerunds (codes or words ending in 'ing') was initially opted for in the beginning of the coding process. However, it was imperative to use words or direct phrases from the data if deemed important to the topic area. The reason for such an approach was to have a pictorial perspective as well as not to deviate too far from the meaning of the information provided. Table 5 shows an example of a participant's coding process.

Table 4. Sample tabulated coding process.

| <b>Participant's comments</b>   | <b>Open coding</b>  | <b>Focused coding</b>  | <b>Broader context/<br/>selective coding</b>                                   |
|---|---|--|--|
| <p>...yea, I mean I know I have been talking recently kind a bit about emm, starting going back to the gym, I think abit probably partly for my health but probably also for my general wellbeing emm <u>I think it just makes me happier feel more confident, more comfortable and I think I have kind of lost that a little bit in doing the PhD, as it kind of all-consuming and emmm so I so yea, I am also in the process of joining the university gym.</u></p> | <p>Making effort to implore a healthy life style not just for her health but general wellbeing</p> <p>Going to gym to be happier, more confident and comfortable</p> <p>Feeling of losing control of health due to tight schedule</p> | <p>Take back control of life</p> <p>Lack of control of life circumstance</p> <p>Health and wellbeing</p> <p>Healthy life style</p> | <p>Personal power/<br/>In control/taking charge<br/><br/>(self management)</p> |
| <p>er i am not sure, whether its kind of a cultural sort of thing i picked up, emm i have probably not always have the <u>best experiences with doctors' in</u></p>   | <p>Family culture that was picked up over time</p> <p>Past experiences with Doctors</p>   | <p>Cultural factor</p> <p>Past experiences</p>   | <p>Social norm</p> <p>Health professional influences</p>                       |
| <p>she told me err its kind of half joking like to be a woman err we have to <u>undergo all these horrible things that men don't have to.</u> Errm and i am</p>   | <p>Associating female gender with exposure to unpleasant health check</p>   | <p>People's unpleasant past experiences/<br/>stories</p>   | <p>Negative Anticipated Emotions</p>   |

|  |  |  |  |
|--|--|--|--|
| <p>not sure what age i would have been when she first mentioned it, and kind of said, and <u>sort of described it as them using something to scrape the inside and</u> then she made it really <u>horrible and painful and uncomfortable and when i probably got that first letter, i probably thought of all my experience, of something like that, was all i knew what my mom has told me and i was probably like that point sound very unpleasant and i wouldn't really bother booking for this just yet.</u></p> | <p>painting a horrible and painful story of the screening procedure by mum</p> <p>Recalling all the negative stories of the screening upon receipt of letter</p> <p>Postponing going for screening</p> | <p>Delayed screening due to fear</p> <p>Threat perception (Apprehension)</p> |  |
|--|--|--|--|

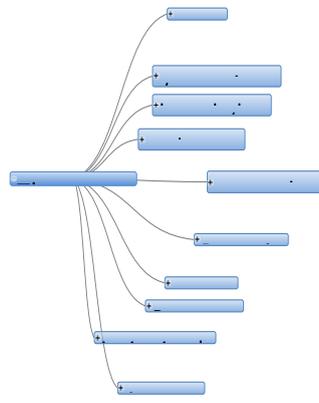
Table 5. Sample coding comparing 4 interviews.

| Sub-headings   | Raw Data  | Initial coding Analysis  | Focused coding   | Selective/broad er context  |
|--|---|--|--|---|
| <p>Perception and feelings about going for the screening</p> | <p>P.D <i>Deep. Sigh, to be honest it is a bit of emm. In terms of like, I was a bit afraid to do it because I didn't know what it was and I didn't look it up, but I didn't have any doubt.</i></p> <p>P.S <i>"Yeah, like what it would actually be like.</i></p> <p>P.E <i>"Yeah, 'cos I think I've definitely spoke about it. 'Cos like of my friends went for it when she was quite young, 'cos she was worried about something and she told me how horrible it was and stuff, so that's like, everyone's like "Eugh, smear tests are disgusting" and all this stuff, so we've definitely talked about it amongst our friends.</i></p> <p>I: <i>And di that kind of have a positive or negative impact on your attitude to...</i></p> <p>P: <i>Well it made me more scared of going for one, but I'd still go, 'cos I know how important it is</i></p> <p>P.S <i>"It's quite exposing, isn't it? It's quite an uncomfortable and strange situation to be in, that you would never normally being. Like... It was just the thought of like... Kind of having an idea of what to expect, but not necessarily knowing completely</i></p> <p>P.S <i>"I guess I remember being worried that it wouldn't be a woman and so I was like, will I get to say that I want it to be a woman and not a man and... I just... Concerns like that that I guess weren't detailed in the letter, so it's kind of..."</i></p> <p>P.H <i>"... My sister; she's really upset about it and before I went, she told me how she felt violated a little bit and I was like</i></p> | <p>Fear of what to expect due to insufficient information on what the screening entails</p> <p>Procedure been painful and embarrassing</p> <p>Fear of feeling been exposed and in an uncomfortable/ strange situation</p> <p>Fear of not knowing the gender of the screen taker as well as autonomy of requesting for a female.</p> <p>Sisters account of how she felt exposed and uncomfortable</p> | <p>fear</p> <p>Embarrassment</p> <p>Anxiety</p> <p>Exposure</p> <p>Invasiveness</p> <p>Compromise</p> <p>Negative past experience</p> <p>Peace of mind</p> | <p><b>Negative Anticipated emotions</b></p> <p><b>Social influence/Norm</b></p> <p><b>Acceptability</b></p> |

|  |   |  |                              |   |
|--|---|--|------------------------------|---|
|  | <p><i>P.S :” She just feels uncomfortable. Some people really don’t like... You know... I think it’s a lack of... Would it be a lack of knowledge? No, that’s not true. It’s just an interpretation</i></p> <p><i>P.D “I thought now that it time to do it and I can I will just do it.It’s just to make you feel better isn’t it? I mean if you do it and you get your result, it’s always good to know if something is wrong then they can do something about it or if everything is normal which puts me at ease, then I don’t have to you know worry”</i></p> <p><i>P.S . I just... I remember I didn’t really want to go, but I guess I kind of thought that I should.</i></p> <p><i>I: Why didn’t you want to go?</i></p> <p><i>P: Well, it’s not exactly the nicest thing to have to do, is it? Um, yeah. It’s kind of scary. Especially the first time. I guess it gets a bit easier after that. But the thought of going the first time is quite [upsetting?].</i></p> | <p>To feel better and have peace of mind</p> <p>Thought of it been upsetting</p> <p>Fear of it been the first time</p> | <p>Negative anticipation</p> | <p><b>Expectation and Knowledge</b></p> |
|--|---|--|------------------------------|---|

The next step was the focussed coding, which is more direct, selective, theoretical and abstracted than open coding. Focused coding often referred to as axial coding was employed to categorise and sort out the recurring codes identified and created during the open coding phase. It was also used for building categories around them (Charmaz, 2014; Saldana, 2013). Saldana (2013) states that “it is used to sort out codes frequency, relationships, and central codes” (p. 264). I used it to develop subcategories from the identified categories and to link them together as I began to understand what the categories represented. This allowed for emergence rather than being too procedural. The linkage of the categories and subcategories represent how I made sense of the data collected. I moved across interviews and their interpretations of what was happening, using Mind Genius software to track a pattern and to get a clearer picture of participants’ knowledge levels, perceptions and experiences of cervical cancer screening. Figure 8 and Appendix 10 (a more detailed representation of figure below) provide a sample of how Mind Genius helps in organizing the data as well as helping in this coding process.

Figure 9. Sample of focused coding and sorting using Mind Genius software.



In addition to the diagrammatic representation of the patterns, memos were kept for each participant to show a trajectory of their individual views, although there emerged some variations depending on the screening status. These patterns include:

1. Participants' general health view and health influences
2. Their viewpoint before receiving the invite to take part in cervical cancer screening
3. Participants' feelings and perceptions towards the screen and the accompanying information with the invitation letter
4. Their experiences and motives associated with their decision about screening participation

The patterns above assisted in the 'theoretical sampling' through comparison of information collected and derived codes, and the subsequently developed explanatory model. The diagram in figure 7 shows how codes were created into categories. "A category is a theme or variable that aims to make sense of what the participant has said. It is interpreted in the light of the situation, and other interviews, and the emerging theory. Categories explicate ideas, events, or processes in the data" (Ford, 2010; Charmaz, 2014). The categories derived initially were referred to as 'conditional', to allow openness and for additional investigative (analytical) opportunities. Evolving comparative analysis and 'conceptualisation' led to the interview categories being further broken down into 4 main categories (chapter 5) and the focus group into 4 main categories (see chapter 6).

The selective coding or theoretical coding stage led to the translation of the evolving theoretical model into a firmly intertwined interpretation, which cuts through several interviews, as well as the focus group, representing recurrent themes in the data. This led to the categories being further deconstructed into three main conceptual categories, as well as associated subcategories. These 3 main conceptual categories were developed after constantly comparing themes and categories from both the focus group and interview data. These 3 main categories are: health view relative to self; knowledge and health service influence; and practicalities (issues associated with participation). It is noteworthy that my definition of reality influenced the shaping of the categories constructed, because I was searching for some specific evidence to address the study objectives and clarify seemingly interesting themes.

One interesting point was how the emerging data further altered my defined reality. Some subcategories which emerged from the 3 main categories provided some interesting issues/themes that I couldn't ignore. This led to further sorting of all the interviews and focus group and to 2 more interviews to further probe these themes. These unpicked issues were linked to sex (privacy, violation, exposure, embarrassment) and notions of perception of inside and outside the body. These themes were unpicked when participants were talking about perceptions and experiences of the screening process. It was observed that the subcategories in the identified 3 main categories were linked and directly/indirectly influenced these themes. This formed and influenced the creation of a

core category, 'sexual association', which forms the basis of the model created. The development of the core category was focused on abstraction and refining and adopting certain categories as theoretical concepts as seen in the last stage in figure 7.

Theoretical saturation (terminating data collection) is an important aspect of GT and is deemed attained when the derived 'main categories' yield no further insights even after integration with newly or freshly collected information (Charmaz, 2014; Strauss and Corbin, 2008). In other words, according to Charmaz (2006), saturation "refers to the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory" (p. 189).

Saturation was deemed reached once the core category (sexual association) was generated alongside the other 3 secondary categories (health view relative to self; knowledge and health service influence; and practicalities and issues associated with participation).

Memo writing was a vital part of the data analysis process and writing of the draft. Through memo writing, I was able to explore, capture and place my thoughts on how I view and see the data and how these ideas influenced the codes and emerging categories. An example of a memo during the data collection is shown in Table 6, below.

Table 6 Sample of Memoing

This interview was conducted after '**sexual inactivity**' was coded as a factor for non-attendance. This participant was theoretically sampled after a random conversation and she was found to be unscreened.

Overall, she postulated to be in good health compared to her friends and attributes good health to the centre of life. A good understanding of one's body is important in tackling bad health. The participant had very little/ minimal knowledge of cervical cancer. Have received a letter but hasn't been for screening. Non participation was attributed to sexual inactivity and no history of cancer in the family. No anticipation toward screening due to negative perception triggered by negative stories as well as family member horrible experience of the screening procedure in terms of pain and the invasiveness of the screening.

Also in terms of information/awareness of cervical cancer, the invitation letter/leaflets, and discussion with friends/colleague acted as a means of awareness of both cervical cancer and the screening. Her awareness level was fairly reasonable and she also vocalised her perception of cervical cancer awareness stating it was still relatively low, referencing friends and family.

Potential reason for future attendance was the fact that it was free and women's susceptibility (women are at risk of cervical cancer) to cervical cancer. Friend's attendance and also sense of responsibility. In spite of providing a reason for future attendance, anticipation to screened as low.

Question around influence of parents/upbringing on health seeking behaviour was theoretically sampled with the participant as this was a common theme from past interviews. This was further categorised to **social cultural influence/social norm**.

In addition to family influence, a major influence on her sexual life was her religious belief about sex before marriage. The stigma and guilt associated with pre-marital sex played a bigger role in her sexual behaviour. This was further categorised under social norm/ social influence.

Unlike previous participant, she was very open to talk about personal and sexual health issues with friends and family. She however acknowledged that it might vary with individuals. Giving examples to her family not been opened to talk about health issues but her upbringing didn't influence her in that respect.

In terms of ways to improve screening, she highlighted difficulties of preventative services. Use of emails/text messages, TV adverts, voluntary offer were some of the suggested ways of improving uptake.

#### **How this memo influenced future data collection?**

The issue of social cultural norm such as sexual activity in the context of religion and difficulties talking about sex or sexually reported issues was drawn from this interview. This unpicking led to **social norm** being chosen as a theme which needed further exploration. It however raised a point in terms of religion and cultural influences on deciding to stay sexually active. This raised some concerning/issues that I needed to explore around this new theme/code.

In addition, this was one of the first interview where attention was paid towards reservation around sexual association and its associated issues with cervical cancer and its screening.

This interview also highlighted the effect of negative information on decision on screening participation. This participants' intention to screen was centred on other people's experiences. I subsequently incorporated this into my subsequent data collection, if the participant doesn't bring it up in the course of the interview.

In addition to helping in theoretical sampling, memo writing also helped conceptualisation by supporting relationships, similarities and connection within data as well as the location of codes and categories (Charmaz, 2006).

'Theoretical sampling' was used for refinement of emergent categories and development of linked properties. For example, as illustrated above, in the course of analysing information, I recognised a category that was related to individual sexuality (sexual inactivity), leading to the theoretical sampling of the participant in the memo sample above. This was to get first-hand information on their perception and thinking process regarding cervical cancer. This led to generation of other themes (social norms/social influence), which were refined and explored through theoretical memos and in subsequent interviews.

A conceptual framework, the linking of concepts, acted as a catalytic impulse in the creation and development of a theory or model. (Bowen, 2006). "Theorisation is achieved when there is a shift of the analysis from the coding stage to raising main categories to concepts or major/core categories" (Charmaz, 2006, p.138). Only categories extracted from the data that were considered to be more theoretically significant and effective were raised to theoretical level (conceptualised) and included in the generated theory (Charmaz, 2006). Acknowledging the criticism (Charmaz, 2006; Strauss and

Corbin, 2008) that some GT studies are too descriptive, the findings presented in chapters 5 and 6 were quite descriptive. However, this presentation created a better understanding of how data from both chapters were unpicked (data with significance and recurring words) and led to the generation of the more conceptual and theoretical findings in chapter 7. According to Holton (2007), cited in Ford (2010), “conceptual abstraction directs attention to and isolates a part or aspect of an entity or phenomenon for the purpose of contemplation... While the descriptive findings of a qualitative research study are most certainly valuable, they do not provide a conceptual abstraction. A grounded theory must offer a conceptually abstract explanation for a latent pattern of behaviours (an issue or concern) in the social setting under study. It must explain, not merely describe, what is happening in a social setting”. The core conceptual category was sexual association, which is comprised of 4 concepts or elements: the body knowledge, emotional attribution, human issues and acceptability.

The data analysis led to generation of a substantive overarching explanatory model, created from theorisation. Theorisation emphasises understanding rather than explanation. In other words, theorising encompasses both the emergences of concepts/categories as well as the presentation of the relationships between them (Bryant & Charmaz, 2007). There have been arguments regarding the way abstract models/theories are derived. Charmaz (2006) and Locke (2007) suggest that the theorisation process is very ambiguous and leads to uncertainty regarding how the theory was generated. This causes the researcher to ask questions such as ‘what is going on here’? This question in this study gave a better understanding of how participants constructed meanings and actions through their words/views and observed body languages.

In this research, theorising was carried out to explain the relationship between the core category and the 3 side categories and associated variables/subcategories, and how these relationships interpret factors influencing participation and non-participation. The substantive explanatory model generated (explained in chapter 8) was tailored according to Bryant and Charmaz, 2006.

The findings are chronologically presented in chapters 5 and 6. The findings presented in chapter 7 shows how the focus group and interview data were integrated and conceptualised, by unpicking/untangling certain concepts/issues. The core category seems to play a major part by influencing young women’s insights and decision-making as well as actual attendance in the cervical screening programme as reflected in the explanatory model in Chapter 8.

### **Enhancing rigour**

Rigour can also be referred to as thoroughness in grounded theory (Charmaz, 2006). Given that researchers enter the research world with their own worldviews, the adopted criteria for rigour and quality of their research should reflect their research assumptions of what reality means to them in

line with their chosen methodology (Lincoln & Guba, 2000). To reflect these assumptions, the researchers are required to show how the adopted method was applied in their research and how this influences the quality of the research process and the derived outcome (Ezzy, 2001; Strauss & Corbin, 1998). It can be argued that contrasting quantitative research approaches, where research is based on positivist notions of validity, with qualitative research evaluation, will be problematic in terms of using set of rigid procedures (Lincoln & Guba, 2000).

There are various ways rigour can be enhanced in GT. Glaser's criteria for GT evaluation include: fit, workability, relevance and modifiability (Glaser & Strauss, 1967; Holton, 2008). On the other hand, the constructivist GT advocated by Charmaz uses the criteria: credibility, originality, resonance and usefulness as a means of evaluating GT studies (Charmaz, 2005). She also argued that a rational explanation of the research process explaining how it drew on the principles of GT methodology will further add to the acceptability of the research (Charmaz, 2005). The Charmaz constructivist criteria and trustworthiness and transferability criteria created by Lincoln and Guba (2000) was adopted in this research.

The credibility of a chosen methodology should 'in principle' reflect how researchers utilised the findings or data collected in generating their theory. It should also reflect the participant's reality, not the reality created for them by the researcher (Tobin & Begley, 2004; Charmaz, 2006). As there was no specific stage within the research to show credibility, researchers should endeavour to reflect this throughout the research process from beginning to end. However, as already identified in the literature, the standard constant comparison of 'theoretical sampling' was problematic due to recruitment issues. It has been acknowledged in the literature that challenges may arise in the course of the GT study, making feasibility difficult (Strauss and Corbin, 2008). I choose a different approach to stay true to GT principles and to reduce criticism (see data collection section). Audio recordings and verbatim transcription of information collected helped establish rigor.

I always confirmed with the study participants during the course of data collection to ensure that my understanding of their views was truly representative. However, checking with all participants during the analysis stage was not possible due to time constraints. In agreement with the literature on how this could influence the worthiness of the findings (McBrien, 2008; Morse, 1998; 2001), I used a 'comparison approach', in which the views of participants from both focus group and interviews were compared (i.e. interviews with interviews, interview with focus group). Table 6 shows an example of how 4 sets of interviews were compared, based on the similarities between participants' views. This notion of forming the reality of the researched from the data collected was supported by Morse (1998), who stated that the expertise of the researcher could compensate for lapses encountered when analytical conformity with participant is impossible.

Triangulation was carried out by discussing the findings with the supervisory team and my colleagues. These discussions aided in moving my findings from a more descriptive to a more conceptual level. This approach has supported and has been utilised by other researchers (Holloway & Wheeler, 2002; Graneheim & Lundman, 2004; Azodo, 2013; Brookes, 2007). In spite of consultation with my peers and the supervisory team, I am aware that I am the only person who can validate that all aspects have been covered in terms of research aims and data interpretation and as such, the findings will be hugely influenced by me.

Finally, the use of reflexivity throughout the research process also enhanced rigour and credibility (Charmaz, 2014; Holloway & Wheeler, 2010). The use of memos was carried out before and after interviews, and aided in the analysis of the findings.

### **Maintaining reflexivity**

In constructivist GT and in GT in general, reflexivity is an essential part of the research process (Charmaz, 2014; Seale, 1999). This involves the researcher critically appraising their influence on the entire research process (Robson, 2002; Charmaz, 2006). This was one of the ways credibility and rigour was attained in this study. As a novice researcher, I was cognisant of the psychological implication of undergoing doctoral research, especially in qualitative research. There is a possibility of meeting people who further contribute to the already developed tension that could have been unnoticed or ignored. This oversight might be due to me being engrossed with the research process as well as dealing with unanticipated issues, e.g. with recruitment. Nonetheless, it should be known that such emotions could be passed on unconsciously to the participants. I was therefore mindful and tried to restrain such emotions for the benefit and integrity of the data collected and overall study. This self-evaluation and awareness was very important for transparency.

Taking a cue from Chesney (2001), I support the autobiographical analysis of self, not as separate from or in competition with the ethnographic words of the women, but as a nurturing bed to place the research findings in and as part of the transparency of the research process. Reflecting honestly and openly has helped me retain some integrity and develop insight and self-awareness, and has given me some self-confidence.

Due to my philosophical stance and the chosen GT approach, reflexivity was deemed important in this research study. However, arguments abound in the literature on the practicability and degree of usage of reflexivity in the research process, in spite of the degree of agreement of its use (Charmaz, 2006; Strauss and Corbin, 1998). Reflexivity is a 'bi-directional' process of 'self-consciousness' about our position in the research process and as researchers and is therefore important to the participants in conveying their views (Finlay, 2002; McGhee et al., 2007). Charmaz (2006) and

Strauss and Corbin (2008) advocate the use of reflexivity to show the relationship between the researcher and the researched as well as how much the researcher's preconceived ideas are present in the interpreted data. This is to eliminate bias, although Olesen (1998) argues that it is difficult for the researcher to completely separate themselves from the research process (Cutcliffe, 2003). It is noteworthy that research findings go beyond systematic analytical process, but contain the researcher's derived theories from the data, i.e. creating a single picture by pulling together different sections into a 'whole'. Reflexivity therefore aids in achieving this (McDermott and Varenne, 2010). Memo writing and explaining how each section was derived could increase the acceptability of the study (Seale, 1999).

The value of reflexivity cannot be overemphasised and can be achieved through: examining the impact of the position, perspective and the presence of the researcher; promoting rich insight through examining personal responses and interpersonal dynamics; empowering others by opening up a more radical consciousness; evaluating the research process, method and outcomes; and enabling public scrutiny of the integrity of the research through offering a methodological log of research decisions (Finlay, 2002 p.532).

Because of the chosen GT methodology, I had to be as reflexive as possible by questioning and justifying every decision. However, Holloway and Freshwater (2007) warned that care should be taken during reflexivity not to be too 'self-absorbed'. I realised during the research process that I have actually grown during the course of the research. I noticed a change in my personality and outlook with regard to the study. I was now more open minded and noticed that the research journey was a process not just achieving or discovering something new, but my growth as an individual and a researcher. According to Ryan and Golden (2006), the researcher can be viewed as a student and a willing participant in a dynamic relationship with the research and what it entails and teaches you as an individual.

Reflecting on the research journey from data collection to theory generation, I can infer that I went through a prolonged emotional rollercoaster. These emotions included: excitement, frustration and relief. Using memos and journals, I was able to be more practical and subjective, adding to the transparency of my position in the research (Charmaz, 2006). This process led to a significant boost in my emotional wellbeing and made the research process easier. In addition, it also enhanced my focus on both the research participants and the data being collected. Through the Memo writing, I was able to recognize opinions and views that competed with my preconceived opinions, and dealt with these at an early stage of the data collection (McGhee et al., 2007). Reflective notes, according to McDermott and Varenne (2010), enable us to question our assumptions inherent in the research process such as the topic, data, evolving concepts and the theory.

Once the ethical approval was received, my excitement level heightened and I was looking forward to data collection. I had reservations about my level of expertise with regard to interviewing skills but after conducting some test interviews with my housemates, I received a confidence boost. The success of the first interview led to my looking forward to more interviews. Reflecting on my methodology and stance, I misconstrued my own concept level of open-mindedness. My reconsideration and reevaluation of self was based on the following reasons: first, my anxiety level whilst actually collecting data may have led to unconscious enforcement of my preconceived notion by asking leading questions during the test interviews; and second, the unanticipated issues encountered. I therefore increased my sensitivity to the views of the participants throughout the research process to reduce bias due to what I termed ‘researcher’s personal influence’.

I ensured that the data contained the views of the participant and not my assumed views of what they meant. This proved to be a difficult task, but speaking constantly with my supervisors and reflecting on my memos eased the process (Gergen & Gergen, 2003; Finlay, 2002). I used Bowling’s (2000) ethical principles of health research, which are ‘autonomy’, ‘non-maleficence’, ‘beneficence’ and ‘justice’.

“As I began to overcome the ‘researcher voice’, other exciting and challenging issues occurred. It was exciting because I was happy that I am now doing something practical, but on the other hand challenging as I was interviewing, transcribing and trying to make sense of the data all at once. I became frustrated trying to build categories and concepts. I was trying to present the finding in a creative and persuasive way the reader can relate to, but I could not find the right words” (Mason, 2002).

*“I hope I am doing the right thing, is this how coding should look like, why does my coding look different and looks like I am just rewriting what the participants are saying? I think I will try the Mind Genius [software] to put everything in front of me. Now everything is in front of me, maybe I should go consult the literature or better still go see my supervisors for a second opinion. Wait a minute; if I go back to the literature, which I have been doing for the past weeks, nothing might change. I should just go to my supervisors to save time. At least they can physically see where I am going wrong. I am tired of feeling confused and anxious”* (researcher’s own notes).

After using the Mind Genius software to get a better and more representative view of the emerging findings, I was faced with the dilemma of presentation. This presented me with another set of negative emotions, as an important part of the research process is the ability to present the findings in an inventive and ingenious method (Silverman, 2005). This dilemma, compounded with time constraint heightened my anxiety level. In order to move past this stagnation, I consulted with my supervisory team. This was to get a second opinion and a fresh perspective on the data. I remember

one of my supervisors vividly cautioning me of overthinking stuff and advising me to follow my instincts. That particular meeting was a turning point for me and led to great progress. Similar meetings continued from that point to the end of analysis (theory generation). Arriving at this stage of coordination, control, creativity and confidence was a lengthy but worthwhile process. The emotions and self-doubts expressed earlier accumulated to being constructive, and enhanced my growth as a researcher and an individual

Finally, it was imperative to take a stand between ‘pragmatism’, ‘originality’ and ‘innovativeness’. My knowledge of ‘subjectivity’ influenced the research process positively, thereby reducing negative influences. This was made possible through reflexivity which, according to Finlay (2002), differs from reflection, which is a means of looking back to gain insight. Reflexivity is a bidirectional process of self-awareness and scrutiny, and also involves more self-consciousness about our researcher role and how our decisions during the research process impact on research view.

### **Summary of Chapter**

This chapter defined the research design process from recruitment through to the development of emergent theory. It also highlighted the difficulties encountered during the recruitment and sampling and the subsequent methodological and research impact. Methodologically, it was difficult to follow 100% faithfully any of the GT approaches and schools of thought. However, a reasonable attempt was made, by drawing on the principles of some of the modern approaches such as Charmaz’s constructivist approach.

This chapter also reflected on the method and justification of data collection, which was achieved using the interviews and a focus group. This method aided in the investigation of substantial issues with flexibility identified within the study, although the limitations of these methods were also acknowledged.

GT principles drawn upon included constant comparison, memo writing and ‘theoretical sampling’, which aided in the development of the theory as well as the analysis process. The above principles and maintaining of reflexivity throughout the study also enhanced its credibility and rigor. The next 3 chapters present the results and explain the emergent theory (chapter 8).

## **CHAPTER 5: Interview findings**

This chapter includes findings from the interviews encompassed within the main categories, which were further conceptualised after comparative analysis with the focus group data (see chapter 7) (Charmaz, 2006, p139). The table below provides the characteristics of the participants accompanied by vignettes of some of the participants to give an insight into their backgrounds.

Table 7 Characteristics of interview participants

| S/No. | Pseudonym | Educational background                    | Ethnicity                                    | Screening history                 | Age       |
|-------|-----------|---|--|-----------------------------------|-----------|
| 1     | Jane      | PhD student (in a health related subject) | White British                                | Screened (regularly attends)      | Late 20s  |
| 2     | Vivian    | BSc holder                                | White British                                | Not screened                      | Late 20s  |
| 3     | Fran      | PhD student (in a health related subject) | White British                                | Not screened                      | Late 20s  |
| 5     | Jessy     | Worker/part time masters' student         | White British                                | Not screened                      | Late 20s  |
| 6     | Kimly     | PhD student (in a health related subject) | EU National (in the UK for approx. 6-7years) | Screened                          | Late 20s  |
| 7     | Kim       | PhD student (in a health related subject) | Far Eastern Country                          | Screened                          | Early 30s |
| 8     | Joy       | PhD student (in a health related subject) | Far Eastern Country                          | Not screened                      | Late 20s  |
| 9     | Bec       | Worker                                    | White British                                | Not screened                      | Early 30s |
| 10    | Lydia     | PhD student (in a health related subject) | White British                                | Screened                          | Late 20s  |
| 11    | Lola      | BSc student                               | African (came to UK as a small child)        | Not screened                      | Late 20s  |
| 12    | Faith     | University worker                         | White British                                | Screened                          | Late 20s  |
| 13    | Zara      | PhD student                               | White British                                | Screened                          | Early 30s |
| 14    | Stephan   | University worker                         | White British                                | Screened                          | Late 20s  |
| 15    | Beth      | PhD student                               | White British                                | Screened                          | Early 30s |
| 16    | Linda     | PhD student (in education related field)  | Middle eastern (in UK approx. 4-5 years)     | Screened but repeated non-attende | Early 30s |

In addition to the table above, 5 participant vignettes are presented below, to provide additional information giving an insight into participants' circumstances and how these might have influenced their views of the screening programme and decision-making process for participation.

- **Fran-** Is 26 years old, born and raised in a rural area in the southern part of the UK. Access to health services was limited and was location-bound, so health-related issues and access to healthcare was treated with minimal importance. She is currently studying a health-related subject but has never attended screening. This she attributes to family attitude to health-related issues, which she ultimately adopted. A very distinct observation about this participant is the overall attitude or vibe given when issues around attendance of cervical screening was raised

during the interview. Her body language, specific use of distinctive words and her quick resolve to dismiss reasons of non-attendance implied an undertone of denial.

- **Lola-** Is a 26-year-old born in Africa but relocated at a very young age to the UK. She is currently undergoing a BSc programme in a health-related subject. She has never attended for screening and said this was because of her religion, which played a huge part in her screening status (not sexually active). The experience of a family member (who was also not sexually active at the time of screening) during the screening also left a negative impression and was voiced as a reason screening might not be carried out in the near future even when she becomes sexually active.
- **Kimly-** Is a 29-year-old southern EU national who moved to the UK for study 6 years prior to been interviewed. She currently works and studies in a health-related department and subject. She sees herself as an individual who isn't health conscious and does not have a great attitude towards her own health. Her mother's diagnosis and quick recovery from cancer was attributed to her poor health choices. However, her screening status (screened) was propelled by her mother's diagnosis but not a factor in continuous attendance.
- **Vivian-** is a 27-year-old born and raised in the North of England. Her fiancé's mother was diagnosed and died of cervical cancer, an event that seemed to play little or no factor in her screening status. She has never attended for screening and doesn't intend to attend in the near future; a reason she attributed to personality and family culture (longevity and no history of cancer in her immediate family).
- **Joy-** Was a student from the Far East and resident in the UK for 5 years at the time of the interview. She was not registered with a GP, due to lack of understanding and variation in health services between her home country and the UK. She is studying a higher degree in a health-related subject and has never attended for screening, due to factors around the nature of the screening and lack of comprehension of the mandate placed around attendance.

The categories derived upon analysis covered various aspects such as personal, environmental and contextual factors contributing to the decision-making process to attend for screening. This chapter contains data from the interviews conducted. These interviews are undoubtedly grounded in the participant's views and experiences, whilst acknowledging the importance of other types of data or information.

Figure 9 shows the 4 main categories with each accompanied by their subcategories. The main categories include:

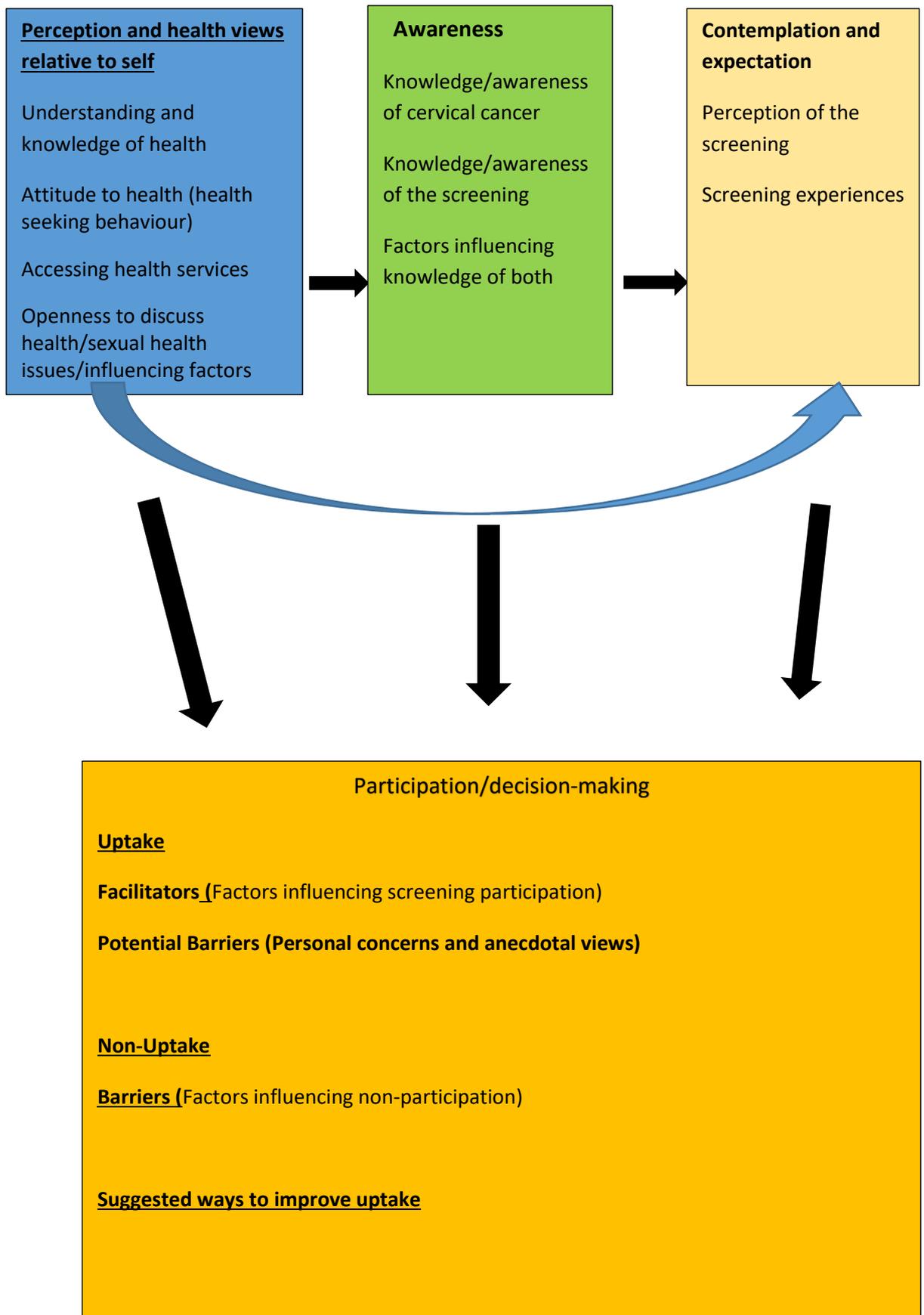
- Perception and health views
- Awareness

- Contemplation and expectations to and for the screening
- Participation/decision to screen

The first 3 main categories underpin or feed into the 4<sup>th</sup> category. A clear construct of how these categories are related is shown in

Figure 10 below. However, these categories will also be presented individually.

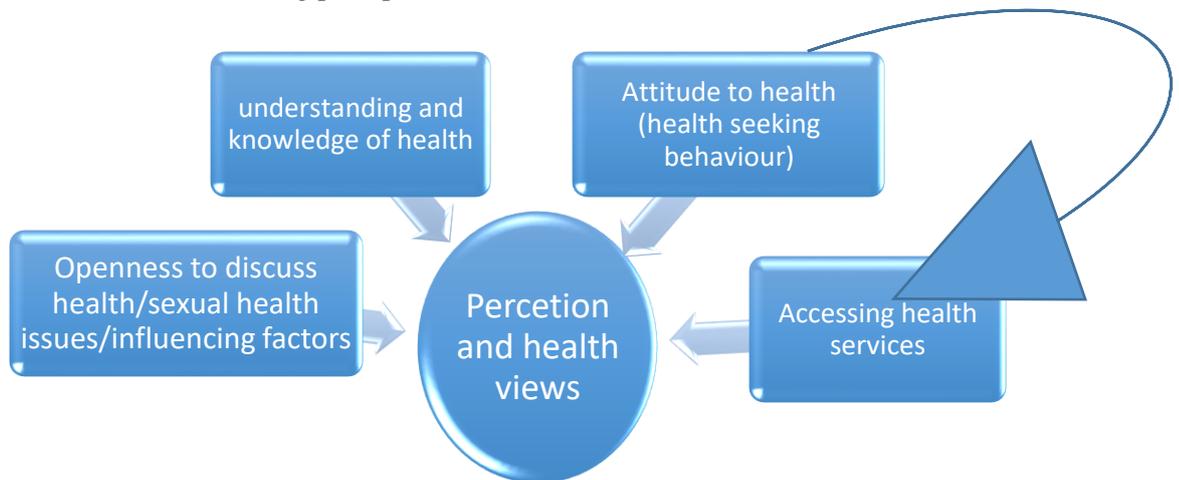
Figure 10. Diagram of the interview categories and their subcategories.



## 5.1 Perceptions and health views - Main Category 1

Perceptions and health views consist of ideas or opinions a person has about their health over a long period of time. They include knowledge and understanding of health, culture and attitudes to health (health seeking), and accessing health, as well as wider societal perceptions and influences, and openness to discuss health and health-related issues (see figure below). These perceptions and views act as potential barriers and facilitators capable of impacting acceptance and decision-making towards taking part in cervical cancer screening programmes.

Figure 11. Factors influencing perceptions of individual health.

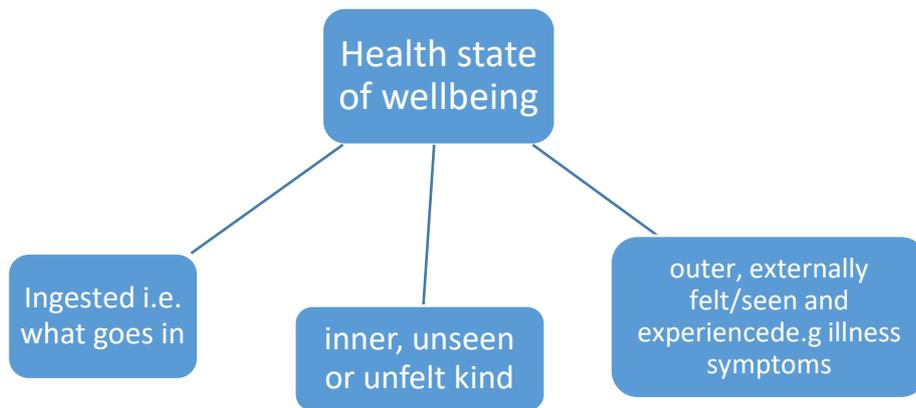


### Understanding and knowledge of health

This subcategory explores the understandings of health relative to self. Participants' views of health are formed based on their understanding of what health means to them, which could be influenced by several factors. Although health was generally viewed as important and central to life by the participants, definitions of health varied across individuals. Some participants describe health in terms of wellbeing (both physical and emotional), whilst others related it to a feeling inside of physical or outward health (i.e. absence of illness and understanding/knowledge of your body). Others still related it to what is put into our bodies (food/nutritional intake, i.e. healthy eating).

*Figure 12* shows these distinctions.

Figure 12. Participants' definition of health.



Participants' views about health that make associations to a state of emotional and physical wellbeing would collectively be referred to as 'holist'. The quotes below illustrate this.

*Faith: "What does it mean to me? I feel like I'm in good health, erm, if I feel physically well and mentally well. So if I'm feeling happy and on top of things and... kind of fit and healthy... So yeah, I suppose it's how I feel. Yeah, physically and mentally, I think health is both of those things"*

*Faith: "I would say that's... So that means you have a, kind of, normal life and... Physically and emotionally. Mentally, I mean. Yeah. So no illness. I think that's it"*

Practising a healthy lifestyle was linked to maintaining that state of wellbeing. The quote below mirrors the views of the 2 other participants, but differs in reference to self-knowledge or understanding of one's body (feeling unwell or knowing when something is amiss).

*Jessy: "I have good health as I have good friend, who have bad health... I generally believe, you should kind of, you know (**knowledge and feeling**) when your body is going wrong"*

Physical fitness and eating healthily, as highlighted above, was a popular view of health maintenance from within one's body and by doing things (exercise) to one's body. E.g.:

*Zara: "health is very important. I am somebody that takes pride in leading a healthy lifestyle. I do a lot of exercise, I eat a fairly balanced diet; I obviously have the off bad thing, but I think that's part of a normal lifestyle"*

It was observed that knowledge and perceptions of health sometimes contradicted practice. Some participants admitted to practising unhealthy lifestyles/habits attributable to external influences such as friends/peer influence, a busy schedule, or a parent's successful cancer treatment as stated below.

*Jane: "Okay, erm, well I probably have a bit of a bad attitude to my health, to be honest... I do notice if there's something wrong; I usually don't go to my doctor because I'm too busy. So I'm probably quite bad with it in that way..."*

*Kimly: "emm yea, not massively, I am still a bit for example when she got diagnosed and stuff about 2 months after she got diagnosed I quit smoking, I have been a smoker for years emm I quit smoking for a year.. Now I am smoking again, you know it lasted for about year (Laughing)... Oh well (laughing). It's not the best attitude"*

Staying healthy and health conscious was associated with gender by some of the participants. It was presumed that women and young women are more prone to health problems as illustrated below.

*Kimly: "emm... well I think health is really important and especially for women, I just think we need to be more careful ...But you know as women we are more likely to get it I suppose. Emm personally I am concern about my health and I do try to emm u know do check-up and things to make sure everything is okay"*

*Lydia: "so I think it's pretty important to stay healthy... especially when you're young"*

The subcategory above revealed feelings and knowledge of health on a personal scale. This shows that there is no standard definition of health views, but rather health views vary across individuals. Influences on these views and subsequent access to available services are could pose possible limitations to addressing or creating health improvement initiatives.

### **Attitude to health (health seeking) and accessing health services**

There are some common perceptions and attitudes widely held by individuals, which could influence their attitudes to health in terms of health seeking or attitudes to health services. Attitudes to health correspond partly with individual understandings of health and how it affects them as individuals. Attitudes to health varied across participants but overall there seem to be positive attitudes with very few reporting negative attitudes to health influenced by underlying factors. Most participants who aren't yet screened and a few who have been screened expressed a relaxed attitude towards their health, influenced perhaps by factors such as upbringing, personality (being laid back), geographical location and negative experiences with health services.

### **Upbringing/learned behaviour**

Health seeking behaviour is influenced by upbringing (family influence) or a continuous practice of adopted behaviour, which is difficult to change. These learned behaviours have both negative and positive effects. The quotes below illustrate instances of both positive and negative influence to health.

*Stephan: "it's weird, because i come from a family, a kind of working class family, and my mom is long term disabled, but in my family we kind of have this really bad habit of not wanting to bother the doctors of not wanting to be a bother despite the fact that there is quite a member of my family who have long term chronic health conditions,"*

*Fran: "Just... It's the way I've always been brought up. My parents are just like: "well, what happens will happen" and sort of, I've got that mentality that you just live for now and then work out what happens later"*

This type of influence needed to be explored further, as they could unravel more insights when examined in greater detail in terms of the specific influences and their impact on not just health seeking behaviour but decision-making about cancer screening.

### **Laid back syndrome**

This has negative implications for accessing health services and could play a part in the screening behaviour of an individual. One participant stated that they only access health when the illness is at a critical level (as illustrated in the quote below). However, upbringing/learned behaviour could act as a variable or direct influence on the development of this personality, which has a high possibility of influencing access to health services like the cervical cancer screening. Geographical location and variation in health services also contributed to the adaptation of the personality above.

*Stephan: "if something is immediately apparent, i would probably wait even though i know i probably shouldn't emm I would probably wait until i start to be worried"*

*Fran: "I've been brought up in a rural community, so never having had access to doctors, so you sort of learned to look after yourself until it's really bad. Because we're an hour and a bit to the local town, so obviously you have to be quite sick before you want to drive an hour and a bit, so we normally just... we never bother; never look out for things, but that's just..."*

*Bec: "So I'm a little, probably... I'm a little bit too laid back...My boyfriend's mum died of cervical cancer, so I do understand the importance of it...And you would... You would think that that would maybe make me a little bit keener to go. But I suppose I'm not. I'm too laid back"*

Waiting until last minute before seeking help could lead to late diagnosis of illness, which could have been picked up if help have been sought early, with potentially fatal consequences. In the case of cervical cancer, which is asymptomatic, avoiding screening due to laid back-ness could lead to late diagnosis and in extreme cases, avoidable death.

### **Negative past experience/lack of trust**

Previous negative experiences with the health service also play a role in attitudes towards accessing health services. This could lead to lack of trust not just in health professionals but also in the health system at large. Some of these experiences were related to time, service provision and quality of service. Not having access to a particular GP, having to see different GPs, misdiagnosis, lack of empathy from health professionals negatively influenced attitudes to health.

*Joy: “No, no, I would be reluctant to go to the health service... Yeah, because it always costs me lots of time and I don’t... Not many outcomes or results. Yeah, so... That’s why... sometimes I think it’s not worth the time”.*

*Stephan: “emm i have probably not always have the best experiences with doctors in the past. i think when i was younger, i have always had ...probably arthritis but it’s never been diagnosed... i have always had the impression that anything i would go to the doctors for i wouldn’t be taken seriously, because so many of my previous encounters”*

Positive attitudes to health/access to health were also influenced by various factors. Standard and easy access to health services in the UK, contrasting with some of the points highlighted were some of the stated factors. These views also reflected the views of some focus group participants (most of whom were not born in the UK and were raised in other countries). It is however noteworthy that these factors led to the selective abstraction of ‘health service influences’ as one of the final conceptualised main categories.

Ease of access to health services in terms of cost and good service delivery (appointment time) was interesting reasons for accessing the service. Availability of opportunistic and standard health screening (which are unavailable in some other countries) further influenced this positive attitude to health seeking.

*Fran: “Round here, they’re really good. There’s a lot of... Like, the doctor’s appointments around here are really good to get access to, I’ve found. Compared to other regions of the country...”*

*Zara: “Yeah, I think the NHS is brilliant. I think a lot of people in this country take for granted the healthcare system that they are provided with. I’ve worked in other countries...”*

External factors such as educational background/career, family upbringing (parental influence), history of health issues family (family member’s death and any maternal diagnoses) and personal health issues, some of which are explored above, had a positive influence in health-seeking and subsequent access to health.

In contrast to some participants’ views in terms of ease of access to health service, some participants complained of dissatisfaction with the health service, which caused their negative attitude and subsequent health seeking behaviours. These included appointment systems/times, opening hours, having different GP or a different appointment (which is a structural issue of the health service).

*Jane: “Er, I find it quite difficult in general. Erm, I feel like if I want to see a doctor, it has to be Monday ‘til Friday, 9-5...Erm, my doctor’s surgery isn’t open on a Saturday or a Sunday, as far as I’m aware. So I find that kind of off putting, that I feel I’m quite limited in that I have to take a bit of time out of work, or go on my lunch break, or whatever, so that’s a bit annoying”*

It is interesting to note that positive health seeking behaviour in some cases played little role in practicing healthy lifestyles, even in the presence of a long-term health issue. Other factors such as

parent influence/mother concern, intuitiveness/perturbation which will be explored extensively under the ‘participation’ category also prompted to health seeking.

The factors influencing health seeking behaviour and access to services highlighted above were concerns voiced by some participants, which could act as potential barrier. Some of these concerns/factors acted as actual barriers to participation in the screening process as will be discussed later on in this chapter.

### **Openness to speak about intimate or sex-related topics**

Being open to speaking about health-related issues varied between participants irrespective of their educational background, screening history or level of awareness of health-related issues. Openness around talking about intimate or sexual issues was considered taboo by most focus group participants, perhaps due to cultural, religious and ethnic reasons (see next chapter). However, openness discussing sex-related topics (although not an outright taboo) was still not a habit adopted by some interview participants. It was considered too private and in some cases an embarrassing or uncomfortable topic to discuss. Cervical cancer and the screening procedure have been considered intimate due to the link with sex and sexually transmitted infection, and the invasive nature of the screening procedure (Waller, et al., 2009; Marlow et al., 2015). Expression of embarrassment as well as its private and personal nature was due to stigma associated with sexual connotations. Some interviewees showed hesitation discussing this, whilst others were more forthcoming but admitted speaking with only close friends about it.

*Lydia: “sexual topic? ...not really. Not particularly. I just think it’s a bit embarrassing. Yeah, I don’t really talk about it that much, ... I just think it’s kind of private, really”*

*Faith: “Erm, with some friends, not with all. You know, I’ve got some friends who I’m really close to and we would share all of this stuff and have them, so... But yeah, not with everyone... Like some of my closer friends”*

A participant who acknowledged coming from a home where intimate or sex-related topics were discussed, expressed her willingness to talk about sex-related topics. In addition, her knowledge of health-related topics including cervical cancer was through discussion with friends in addition to the invitation letter.

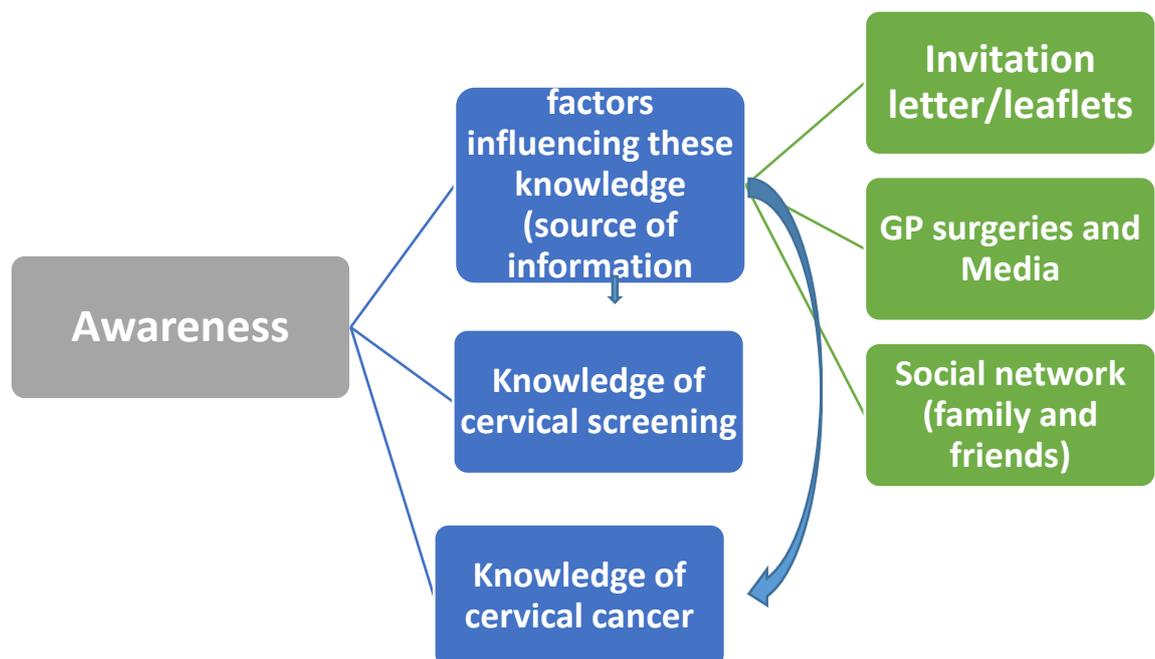
*Jessy: “I am very open to talk about personal things with people, but a lot of people might not be. Like in my family, we weren’t very open about health issues, but I am with my friend... and also obviously for cervical cancer, I got the letters from the doctors, that kind of opened up discussion about ... but I think I just took the leading from both of my parents who don’t really talk about health that much, they just said if there is a problem, we just go to the doctors, it wasn’t kind of a push”*

There were presumptions by the participant that the intimate and private nature of the screening could act as a potential barrier. This main category was created to understand participants' health views, attitudes and perceived notions around accessing health and how this influences their decision-making. Other factors that influenced these ideas and behaviours could further help the understanding of any correlation between their views and possible reasons for participation and non-participation. In addition, some aspects of the sub categories (e.g. openness to speak about intimate or sexual-related topics) were unpicked and further abstracted to the core category 'sexual association'.

## 5.2 Awareness - Main category 2

The second main category focuses on knowledge of cervical cancer and its screening as well as factors influencing the knowledge or awareness of: information sources or means of awareness from participants' perspective. Awareness is the possession of certain perceptions and comprehension of the information about cervical cancer and screening. This can be in the context of their awareness before receiving invitation letters and leaflets as well as how their understanding of these artefacts affected their attendance history and choices regarding the screening procedure. Figure 13 illustrates this category.

Figure 13. Subcategories of awareness.



## Knowledge of cervical cancer

An exploration of participants' awareness of cervical cancer in general led to the discovery that most had varying knowledge/information regarding cervical cancer before even getting an invite to screen (i.e. have heard of cervical cancer or have a vague knowledge of cervical cancer), but this knowledge was limited, as illustrated below.

*Jessy: "Apart from the name, which is you get cancer in like your sexual organs, yea not massively, but" ...*

*Lydia: I think it's probably quite hard to treat, compared to some of the other ones and there's... They're not quite sure... I know there's the HPV that can cause some cases, but not that many and there's a vaccine that they've got for it now"*

There were misconceptions around what cervical cancer is in terms of symptoms and susceptibility, with some participants associating it with old age.

*Kimly: "right, no not really, i didn't, i just knew it's a form of cancer that obvious women get but that's about it, i didn't know about the symptoms or anything"*

*Zara: "I don't know a lot about it to be honest, specifically. Erm, but I know that it can be obviously an issue for older women particularly. Well, this is what I think I know about it."*

In contrast, some participants expressed in-depth knowledge of cervical cancer.

*Jane: "Yeah, erm, it's a cancer of the cervix, which can be caused by various different factors, but I believe one of the main causes is HPV, the Human Papilloma Virus, erm, which you can get through... it's sexually transmitted, so you can get it by having sex without a condom, erm,.."*

This study shows a limitation in knowledge of cervical cancer, although it did not solely act as a factor in non-participation. One participant even suggested that her field and level of education had no impact on her awareness level:

*Fran: "Because it's not really well-known and you'd have thought like being in my second year of PhD, I should know basically about stuff, but all I know is that and I'm a scientist, so you'd have thought I should really understand these sort of things."*

Cancer in general was closely linked to death by most participants. This negative perception or attribution was due to knowing someone who had died from cancer.

*Lydia: "Ugh. Not nice things. I've had a really close family member die of cancer not that long ago, so every time I hear the word, it kind of makes me feel a bit ill, thinking about it."*

It is interesting to note that despite findings showing limited knowledge of cervical cancer in the majority of participants, this had little or no impact on their intention to screen and actual participation in the screening programme.

## **Knowledge of cervical screening**

In terms of knowledge of the cervical screening programme, there was better awareness. Over half of the interview participants had been screened, which was reflected in their response to the question around knowledge of cervical cancer screening. All participants had a good knowledge of the screening programme, with most of awareness stemming from the invitation letter sent as a result of the organised screening programme in the UK.

*Lydia: "Oh okay, yeah. They send you a letter when you're 25, though I got mine when I was 24, which I don't quite get. Erm, and then used to go every... I can't remember how many years it is... Five years, I think? To get re-tested."*

Some participants had limited knowledge of screening before attending, but clarification and in-depth understanding was received during and before the screening

*Kimly: "like what do i know about it? I didn't know what it was before I did it. I actually did it without knowing what it involves. I just went there when I got my invitation to do it...then they basically explained what it is and what they are going to do..."*

## **Source of information and its impact on intention to screen**

People would probably attempt to find information about a health issue or get help after it has become serious or something bad ensues. In addition, knowledge of cervical cancer and the screening programme prior to the screening invite, was a prompt in the decision-making and subsequent attendance for screening. It is noteworthy that this information came from different sources. These include invitation letters and leaflets (GP or health service), family, friends, educational and career (jobs and career interest). The young women interviewed were either employed with or have previously been employed in the NHS or the health sector or are studying health-related fields, so they had at least some knowledge of cervical cancer. The GP and media were information sources for a small portion of participants, as explained below.

## **Invitation letter and associated leaflet**

A major source of awareness of cervical cancer was the invitation letter and accompanying leaflet. Some women are aware of cervical cancer and the screening programme. However, the known information was not enough for all women to make a tangible decision to attend for screening, although it played a pivotal role for some in deciding to participate in the screening programme.

It is noteworthy that a decision to screen is influenced by more than one factor (as discussed later in the chapter). The decision to screen may have been influenced by the content of the attached leaflets and invitation letter as it pertains to cervical cancer and some basic information on the screening.

These contents may have acted as additional information and helped clarify some misconceptions around both the screening and cervical cancer, thereby acting as a catalyst for screening intention.

*Jessy: "I thought it was really good that I received a letter about it and I wouldn't have thought of doing beforehand, It's not something like, if I went to the doctor..."*

*Beth: "Yeah. I mean, if I hadn't received a letter, I don't think I would have perhaps... I don't know. I don't know how I would have found out about it otherwise"*

However, a few participants stated dissatisfaction/inadequacy in information regarding the screening procedure, while some admitted to not looking at the leaflet when they received the letter and couldn't really comment in detail on the level of information relating to the screening procedure. The quotes below illustrate this.

*Faith: "Erm, they sent a letter and I think there was a leaflet in the letter, but it didn't really kind of talk about the procedure...of thing. I don't know the gritty details of what's actually being done"*

*Kimly: "[Deep. Sigh], to be honest it is a bit of emm. In terms of like, I was a bit afraid to do it because I didn't know what it was and I didn't look it up, but I didn't have any doubt"*

It was also expressed that the information provided with the invitation was enough to help make a positive decision to screen. The knowledge level of the study participants as a result of the screening invite they received acted as a cue to action or prompt for screening attendance for some, but not others.

### **Information at GP surgeries and in the media**

Only five participants cited the GP surgery and the media as their source of information on cervical cancer. One participant referred to leaflets at their GP surgery, while another was even offered a screening opportunity at the GP surgery but refused. Two participants referred to the death of Jade Goody, a popular TV personality, whose death raised awareness of cervical cancer. Although one of them admitted that the information and awareness gradually faded after some years, with her prompt for screening being the receipt of invitation letter.

*Fran: "They [GP Surgery] offered it to me, so I'll admit, they did say to me "do you want it", but I don't really know what it was, so I was just like, yeah, okay, I'll think about it next time".*

*Jane: "Erm, I think... Well, at the moment, I don't read any newspapers as such, but I remember a few years ago, when Jade Goody died, there was a massive hoo-ha about cervical cancer and I think it made a lot of people aware. Erm, yeah, at the moment... I guess I kind of just because aware of it through kind of just sciencey stuff, or"*

### **Social network (friends and family)**

Social networks or peer groups could be a potent factor especially among young individuals. These influences could include information or behaviour change (both positive and negative). The need to conform is high within peer groups (Reitz et al., 2014). This contact with a social network group, such as friends and colleagues provided a platform for acquiring knowledge and an awareness platform for some participants.

*Joy: "Because... It's because my friend, she has got that letter – that's how I know about screening. Otherwise I wouldn't know about this"*

*Stephan: "somebody that I worked with when I was 23. Erm, she demanded to have the screening...And then I don't know... She got it anyway, because... I don't know. Some drama. So that's the only reason I really knew about it".*

Family members played a part in some participants' knowledge of cervical cancer. Sometimes misconstrued information received from a family member could act as a means of concern or potential barrier to screening. The participant below described one such instance regarding a family member's screening procedure and experience.

*Stephan: "Erm and i am not sure what age i would have been when she first mentioned it, and kind of said, and sort of described it as them using something to scrape the inside and then she made it really horrible and painful and uncomfortable and when i probably got that first letter, i probably thought of all my experience, of something like that, was all i knew what my mom has told me and i was probably like that point sound very unpleasant"*

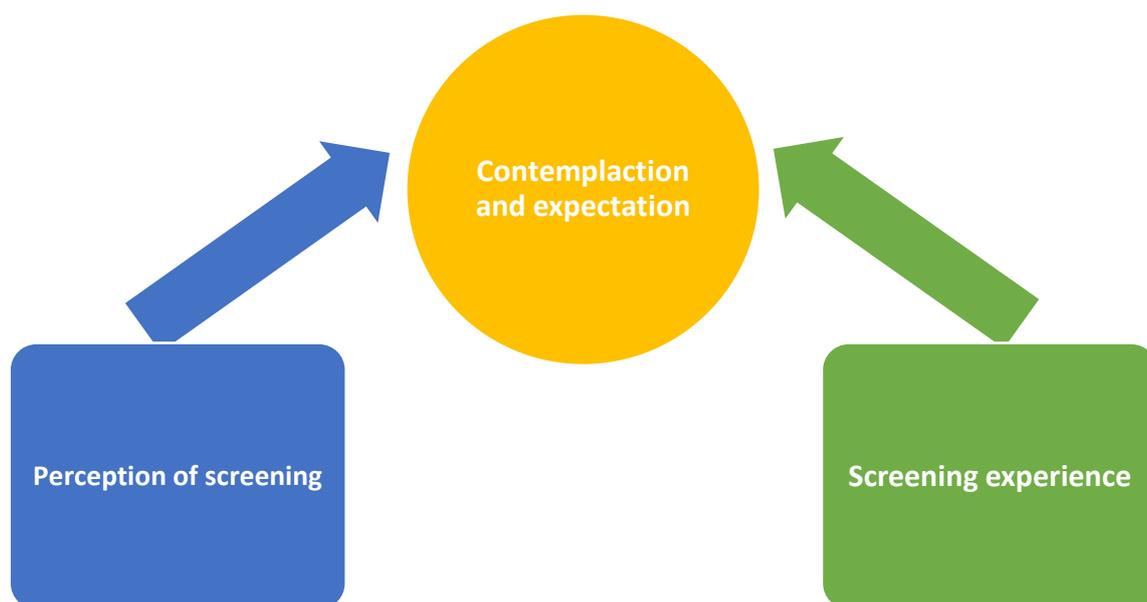
As stated above, the level of knowledge was not assured based on the information received. This is because information received might not have been read by the individual and, as such, attendance cannot be guaranteed. Non-attendance can also be influenced by life issues including a busy schedule, appointment difficulties and childbirth among other factors. However, knowledge and awareness could have a positive influence by amplifying the advantages of screening whilst removing negative misconceptions associated with screening. Increasing awareness and demystifying some of the misconceptions around screening and cervical cancer as seen from the participants' perspectives could lead to a potential increase in participation.

### **5.3 Contemplation and expectation - Main Category 3**

This main category was centred on intention to screen, which led to the identification of 2 further sub-categories; perception of the screening and screening experience (see

Figure 14). Participants held certain shared misconceptions or insights about cervical screening which influenced their attitudes or behaviour as a result.

Figure 14. Intention to screen.



### Perceptions of screening

Despite acknowledging confidence in the screening programme, perceptions of screening were mainly negative. These were based on various factors explained below. These took the form of concerns voiced by participants and may have acted as potential barriers, though for some, there was no effect on their decision to attend screening.

Cancer has a strong connotation of mortality and arouses certain negative emotions such as fear. As such, there is some discretion around cancer related issues. For example:

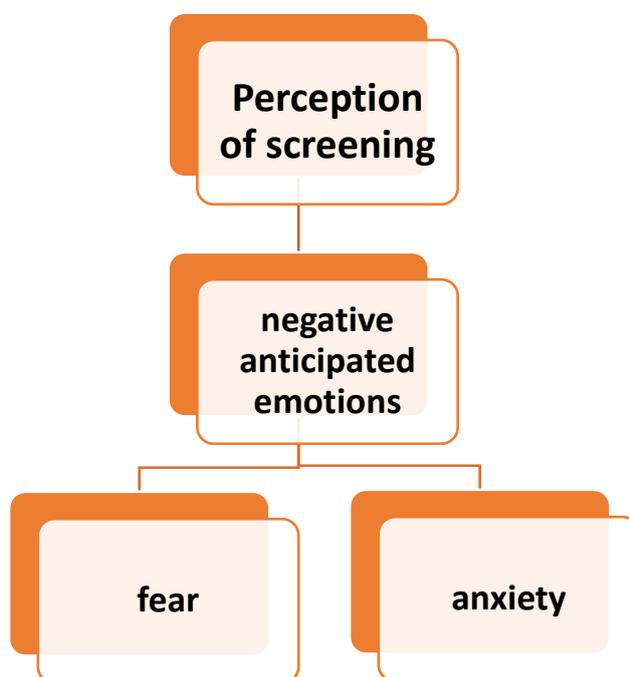
*Fran: "Ugh. Not nice things. I've had a really close family member die of cancer not that long ago, so every time I hear the word, it kind of makes me feel a bit ill, thinking about it."*

*Kimly: "death... i know i know it's awful, that's the first thing that come to my mind. even though i know a lot of people that suffer from cancer survive, i think my personal fear... I think its death, that's what scares me, ...I just think like it's the worst case scenario you never know if..."*

Other concepts/themes within this subcategory are presented in

Figure 15. This aided in explaining the context of participants' perception.

Figure 15. Context of perception towards screening.



### Negative anticipated emotion

These are emotions that are felt in anticipation of the screening programme. These emotions, if not curbed, could lead to delay in screening and potentially act as reason for non-participation. The participants also reported reservations around the invasive nature of cervical cancer screening. This was relative to the location of the cervix.

*Bec: "And it's one of those things where I wouldn't be comfortable with any of the nurses in there, because... Certainly not for anything that personal. Because although there are some pleasant staff, it's not... It doesn't feel..."*

*Fran: "Yeah, I did. The cervical screening just sounds a bit... Just the location and stuff like that and it seems really personal and I don't want other people you don't know"*

Two participants were visibly uncomfortable talking about cervical cancer and their experiences while responding to the questions. Observation was quite useful here, as I could unpick in depth the level of effect this view had on the participant. This feeling and reaction was attributed to embarrassment and worry over the invasive nature and it being a very personal and private issue. In another instance, a participant received a distress call from their sister after her screening due to issues such as fear and anxiety.

*Kim: "...My sister; she's really upset about it and before I went, she told me how she felt violated ...I was like..."*

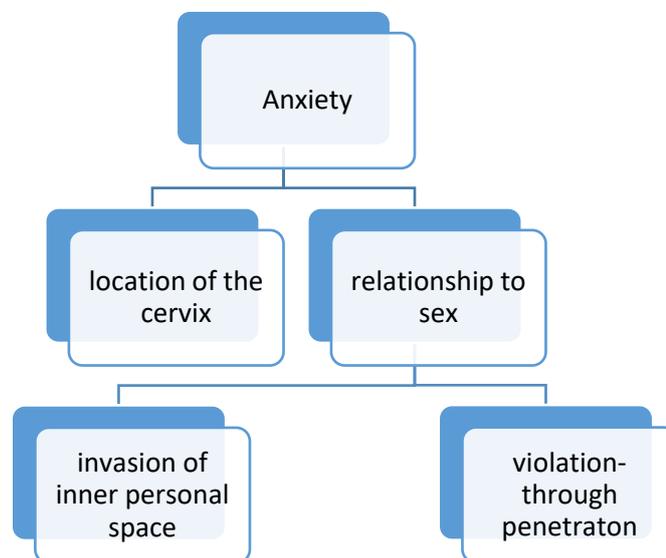
*Faith: “She just feels uncomfortable. Some people really don’t like... You know... I think it’s a lack of... Would it be a lack of knowledge? No, that’s not true. It’s just an interpretation”*

These emotions varied among individuals depending on how they interpreted the information they had received in addition to other factors that could be linked to culture, religion and upbringing. The following negative emotions were further expressed in various contexts by participants:

### **Anxiety**

The context in which anxiety was instilled in the participants is centred on some of the variables shown in the figure below.

Figure 16. influencing factors on anxiety.



Limited/inadequate knowledge of what the screening will entail. Information of what to expect in terms of pain, gender of the clinician and concerns around invasiveness and exposure were some of the views expressed.

*Kimly: “[Deep sigh], to be honest it is a bit of emm. In terms of like, I was a bit afraid to do it because I didn’t know what it was and I didn’t look it up, but I didn’t have any doubt”*

*Faith: “It’s quite **exposing**, isn’t it? It’s quite an uncomfortable and strange situation to be in, that you would never normally being. Like... It was just the thought of like... Kind of having an idea of what to expect, but not necessarily knowing completely”*

*Zara: I guess I remember being worried that it wouldn’t be a woman and so I was like, will I get to say that I want it to be a woman and not a man and... I just... Concerns like that that I guess weren’t detailed in the letter, so it’s kind of...”*

As expressed above, and in past studies on uncertainty around gender and non-familiarity with the test taker, this could act as a barrier for some participants and potential barriers for those still in the contemplation stage.

## **Fear**

Fear acted as a possible hindrance in attending of cervical screening. This is because of apprehension due to latent issues which created a high degree of hesitancy coupled with indecisiveness regarding the intention to screen.

*Zara: “when i probably got that first letter, i probably thought of all my experience, of something like that, was all i knew what my mom has told me and i was probably like that point sound very unpleasant ...I probably postponed for about i don’t know, trying really hard to think about the timeline now, maybe about 6months”*

*Faith: “I just... I remember I didn’t really want to go... Um, yeah. It’s kind of scary. Especially the first time. I guess it gets a bit easier after that. But the thought of going the first time is quite [upsetting]”*

This ambivalence and uncertainty expressed above in terms of delaying going for screening could inform decisions regarding non-attendance for some women and these delays could be detrimental to health as it could lead to late diagnosis.

Negative emotions were based on friends’ negative experiences/stories of the screening procedure or invasive nature of the test (embarrassment, arousing feelings of exposure and loss of dignity) were expressed in the quotes below.

*Faith: “they just sort of said it was quite painful. They said that it feels like, when they’re taking the swab, they’re reaching up a very long way, as if they’re reaching up into your stomach”*

*Bec: Well, it’s not pleasurable, is it? And it’s not something you would ever look forward to happening. It’s not something where you’re getting anything out of it, really. Because it’s... Because it’s either going to be everything is fine, which I assume it is at the moment, or bad news. So I suppose it... It’s not very **dignified**, having things like that done. It’s not very nice having your bits out in front of people... “*

The views expressed in these subcategories set a premise for further exploration, especially in the selective/theoretical coding. Upon further constant comparison with the interview and focus group data and a further verification through further data collection, some of the components of this subcategory informed the elements of the conceptual core category.

## **Screening experiences**

A positive screening experience has the potential to encourage re-screening or continuous participation in any health check. Participants expressed conflicting views on their experiences of

the screening process. Views of participants who have gone for screening were mainly based on their position in regard to continuous screening.

### **Exceeded Expectation**

For some, the expectation of the cervical screening experience was negative, but the actual screening experiences were reported as exceeding expectations.

*Joy: "i knew what to expect erm, and it wasn't anywhere near as bad an experience as i thought it would be. ermm i did sort of i dont know, like it was a bit, that afterwards i felt abit like hmmm, i dont know i felt abit like you ve been exposed, i dont know, it felt abit weird i just wanted to go home..."*

*Jane: "Erm, it wasn't as bad as I thought it was going to be, to be honest. I was a bit dubious about what would happen; I was a bit nervous, but it wasn't that bad. The nurse was really lovely and she kind of explained everything that was going to happen ...I thought it was going to be much worse than it was, so... Yeah"*

Although some of the concerns regarding invasiveness and embarrassment were experienced, these were factors that were beyond the control of the screening program. This is due to the location of the cervix, although alternative screening methods were suggested by some participants (this is addressed in depth in the next main category; participation). Unpleasant and uncomfortable feelings – but not pain – were expressed, as illustrated in the quotes below

*Kimly: "the actual process was a bit uncomfortable, but it wasn't actually painful or anything, it was a bit awkward"*

*Kim: "I wouldn't describe it to be uncomfortable in any sense; I would just be "It's different". Yeah. So yeah"*

Many factors were attributed to what made a positive experience. These included health professional/staff help and professionalism. The psychosocial and attitudinal perception in the form of beliefs stated above have the potential to impact an individual's intention to screen or their attendance. Professionalism, experience and attitude of a health professional can be crucial in minimising the negative emotional mind-set (such as high levels of apprehension, which may hinder attendance). Some participants reported that health professionals were friendly and helpful, and provided an in-depth explanation of the procedure before the screening. This helped ease participants' worries.

*Kim: "And the nurse... The nurse probably, for the benefit of the doubt, in case I am really uncomfortable with the whole procedure, she was like very calming and I was like: Meh. It's fine. It's for my own good anyway, so I'm okay with it"*

A more interesting finding regarded advocacy and awareness. The positive experience for some participants led to them sharing their perceptions with friends and encouraging them to participate.

Kimly: *“I was talking to my housemates and friends when i did it, it so happens that i am the oldest as well, i was the first one to do it, and i just said the minute you get your letter just go ahead and do it. It’s not the best thing in the world, but at the end of the day if it’s going to save your life or you know...”*

### **Screening appointments**

Views varied around the scheduling of appointments. Some participants expressed ease of appointment whilst others expressed difficulty in getting suitable appointments.

Zara: *“Yeah, erm, they were very good... They were very accommodating, to say that I’m somebody who generally works from 9 to 5; they said they would provide me with an appointment that was before work...You don’t have to be skipping work or having to rearrange appointments or things like that, to actually go to your screening, so that was something that was very helpful, and it helped me make an appointment faster and make it all a lot easier quite...”*

Some participants had waited for a long time of the day of appointment, which added to their anxiety, but expressed relief and comfort based on the attitude of the staff/clinician, further reiterating how professionalism and a bit of consideration can ease screening anxieties and encourage future participation, illustrated in the quote below.

Lydia: *“Erm, well I remember waiting for a long time for... To get seen, ‘cos I think there must have been some kind of hold up, ‘cos I was sitting in the waiting room for about... It must have been about 45 minutes, which I thought was pretty bad, which... I wanted her to explain anything and I felt quite comfortable about it, really”*

In contrast, some participants had a less positive view on their experience. One particular participant expressed dissatisfaction in the ways results were presented and how the follow-up test led to a nightmarish experience.

Stephan: *“...yea I had a letter saying that it was abnormal and i would be called back again within 6months/ a year, and to monitor any changes. but to be told it was abnormal, that's like really vague word...No the only thing with that letter was a leaflet about cervical cancer... i felt it was worse than my previous experiences with the services like in the past. i just think there is not enough information and it really upset me”*

However, perception and experience of the cervical cancer screening seems to have had no direct effect on their screening behaviour as they had already been screened. The overall attitude of attendees was positive; even the non-participants expressed similar feelings of positivity, although actual participation was hampered by various factors, discussed in the 4<sup>th</sup> main category. The idea of getting screened in spite of the unpleasant feelings towards the screening procedure was necessary in order to prevent and in some cases, get early cancer diagnosis. i.e. the bad and negative feelings towards the screening was overpowered by the desire to be well and the associated fear of cancer.

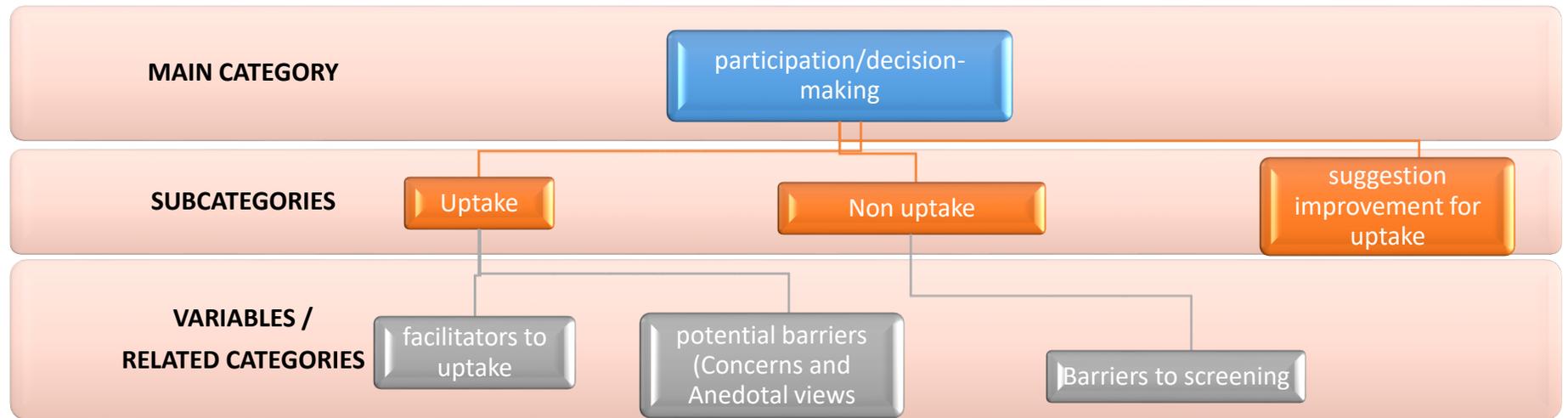
This suggests that individuals find it valuable to undergo unpleasant experiences based on their associated advantage.

However, the views explored above could be potential barriers to other non-participants or potential facilitator participants, as individuals have different constructs and perceptions.

#### **5.4 Participation and decision-making - Main category 4**

This section reflects views on actual cervical screening attendance/non-attendance. Although previous main categories highlighted some of the concerns and possible factors, they all are interconnected with this main category. Like the others, this main category encompasses several subcategories, which in turn have related categories. Figure 17 shows how this section was categorised and linked.

Figure 17 Factors influencing participation/decision-making



## **Uptake**

This subcategory presents factors that influenced participation in the screening process and concerns or views expressed by the study participants that could act as potential barriers to screening. Decisions to participate in the screening process are influenced by more than one factor. These are explored below.

### **Facilitators to screening**

A range of factors influenced screening participation. These were psychological (fear of cancer, apprehension or peace of mind) and social/external (invitation letter, parental and partner's influences, family history of cancer). Although a range of feelings were described, fear of cancer and peace of mind was the overarching emotion expressed as one of the reasons for participating in the cervical cancer screening programme. The word 'cancer' often arouses fear due to its fatality if not diagnosed on time. The fear associated with cancer could lead to physical illness in some participants as illustrated

*Lydia: "Ugh. Not nice things. I've had a really close family member die of cancer not that long ago, so every time I hear the word, it kind of makes me feel a bit ill, thinking about it."*

The above point, which was a perception, could influence deciding to attend screening with respect to fear of late diagnosis of cancer. There seemed to be a fear of cancer and of mortality, which motivated participation. The possibility of cancer being caught early, for the sake of those around them, was a motivating factor. This altruistic thinking was expressed in the quote below

*Faith: "I think it's very important for everybody to be screened. My auntie has had cervical cancer and she's had a hysterectomy, so I've sort of a personal story as to cervical cancer as well"*

In contrast to these views, a participant actually expressed her view in form of denial and avoidance to hide her fear finding something untoward using the term "Not wanting to look for trouble", to hide her fright in taking the cervical screening and possible diagnosis.

*Fran: "I'm not sure. I'm sort of one of those people who is quite laid back in some respects. I'd rather not look for trouble, if that makes sense. I'm quite laid back; I'm just like: I'll deal with it when it happens"*

Denial/reluctance to attend screening could be an outward expression of fear, which could yield unpleasant health effects if not overcome. This has possible implications for public health intervention aimed at minimising such behaviours.

Peace of mind, a form of emotional wellbeing, influenced participation and was given as a reason for participants attending the screening programme as shown in the quote below

*Kimly: "I thought now that it time to do it and I can I will just do it. It's just to make you feel better isn't it? I mean if you do it and you get your result, it's always good to know if something is wrong then they can do something about it or if everything is normal which puts me at ease, then I don't have to you know worry"*

A sense of responsibility, of being responsible for your health and open mindedness in things regarding health was also stated as reason for participation.

*Bec: "I think it's sensible because you can die from cancer, so I think it's good. If there is any service on the NHS where you can find things early, emm which means you don't have to die from cancer early, then it's good, so go for it"*

*Lydia: "Oh, I can't imagine. But I'm generally quite an open-minded person. It's very hard to take myself out of the field, because... It's hard"*

Psychological influences such as those stated above were further explored and conceptualised/abstracted as part of the Core category in chapter 7.

As stated, invitation letter was one of the information sources and an educational tool for participants. The receipt of the cervical cancer invitation and leaflet facilitated participation, as illustrated in the quote below.

*Faith: "Because I got the letter. So I wouldn't have been aware of it if I hadn't had anything through the post. I wouldn't have done it off my own back. So I had a letter through, saying it's quite important, if... You know, it's a screening and if you catch stuff early, it's more treatable and I just kind of figured it's the same as you go to the dentist, even though there's nothing wrong, just to get a check-up and..."*

In contrast, one of the non-participants stated that the letter and leaflets had no direct impact on her decision to participate in the screening programme. She viewed these as a potential barrier as they were actually telling her what to do.

*Bec: "Yeah, from me being... From just before my 25<sup>th</sup> birthday up until... Well, basically they were sending me about a letter a month for about 6 months. And it was to a point where I was feeling quite harassed about it...I'm a very independent person and if anybody was to tell me to do something like that, no matter how good their intentions were, I wouldn't take it well"*

In addition to the invitation letter acting as a reminder, the impact of the content of both the letter and leaflets were also revealed by the participants. As stated in the previous category (awareness), participants had conflicting views on the content of the information leaflets. The majority of participants stated that in terms of the content, its readability and depth, answered most of their question as illustrated below.

*Kimly: "I got my invitation to do it. I just went there, then they basically explained what it is and what they are going to do and what they are looking for, and that was about it"*

During analysis, the focused coding led to a group of codes that were contextualised into the category called 'social norm'. Some of the variables within the categories were: family history of cancer, parental influence/concern and partner influence. These acted as facilitators to screening. Having a family member diagnosed with cervical cancer or knowing someone who had died of cervical cancer seemed to play a major role and impacted on the decision-making process regarding screening for cervical cancer. Susceptibility to any form of cancer arouses fear and acts as prompt to screening. One significant concern was death.

*Stephan: "Erm, and I've got cancer in the family. Not cervical cancer, but a few different kinds, and so I thought: better to be safe than sorry"*

The influence of close family member such as a concerned or overprotective parent could potentially trigger making a conscious decision to go for screening as expressed below.

*Jane: "Erm, I guess in general, she does worry about me and I've got two brothers. Erm, she worries about all of us, but I suppose probably when she's reminded that she needs a screen, she probably reminds me as well, because kind of like she worries about me just kind of naturally, as another would, I guess"*

In contrast, parental influence, such as upbringing and the parents' attitudes to health acted as a negative influence and was a reason for the apathetic attitude to screening and health by the participant below.

*Fran: "Just... It's the way I've always been brought up. My parents are just like "well, what happens will happen" and sort of, I've got that mentality that you just live for now and then work out what happens later...I'm just one of those like "Yeah, whatever" people"*

The encouragement and presence of a significant other acted as a decision-making tool for most young women. This view was sought theoretically (theoretically sampled) through a question to finalise or settle for a category on partner's influence from the focus group session. It is noteworthy however, that although a partner's influence acted as a potential motivating factor in the interviews, it was considered a barrier by the focus group participants (see next chapter). Partner influence helped in curbing issues such as procrastination as seen in the quote below.

*Kimly: "And my boyfriend has influenced me that way to just say you have to go to the doctors to see what this is about or whatever. In a positive way to say, no you can't leave that for next month, you have to do it now...it's just that he is worried, i am worried, emm it works in both ways and i have seen it in other relationships as well where the boy says you need to go to the doctors and you know make sure you are okay"*

Altruism due to the presence of a partner or a family member was an indirect influence and as a motivating factor or prompt to screen.

*Faith: "...but I'm sure my, mum said something about it to me, so there was like an influence of someone else saying "Come on, you do need to do this". So yeah, I can*

*definitely see that side of it. Erm... I don't even know if [my partner is] even aware of it. He definitely hasn't been on my back about going... think here is an element of looking after yourself when you've got other people in your life as well..."*

### **Potential barriers/concerns or anecdotal views**

These are either negative sociopsychology influences affecting intentions to participate in the cervical screening. The term 'potential barriers' was chosen as it draws on concerns from other people's (anecdotal) views, not personal views. These views either acted as barriers or motivations to screening.

Fear associated with the invasive nature of the test or embarrassment was presented in more depth under the 'contemplation and expectation' category, which also raised anecdotal evidence and its impact on screening decision-making process. This was stated as a potential barrier or reason for delay in screening as indicated in the quote below.

*Lydia: "It's hard, I mean... I know some of my friends who are very private and against invasive things like this... they are even more private than I am, which is probably hard to imagine (referring to herself as very private), So I don't know if they would even want to go to the doctor's and have one"*

Practical issues, similar to those reported in the literature, were also voiced by some participants. In the core category 'sexual association', focus was placed on psychosocial and socio-cultural factors and their relationship, because from their use of words and body language, there seemed to be a need to make these a focal point in contrast to the practical issues explored in the literature. Practical factors such as appointment difficulty/health service, busy schedule/time influenced participation. Such barriers were both participant and other people's views. In terms of appointment difficulties, wider issues with respect to access to GPs and health service structure, and how that conflicts with individual schedules, were reported. Both practical issues are interlinked as shown in the quote below

*Zara: "and I just couldn't get in during the day, 'cos I'm at work, so it just kind of didn't happen and I haven't been back in touch, so... Yeah. I think that's just a wider issue with access to GPs anyway, but"*

The decision-making process to participate in screening is temporally bound because of busy schedules. The decision to screen was also temporally bound, so time constraint was an identified barrier. Screenings are by appointment only at local GP surgeries, which most participants expressed concerns about. Due to their busy schedules, it was difficult to make an appointment for screening in their local practices (e.g. during a weekday).

*Lydia: "cos people have busy lifestyles, don't they? And I don't know how high priority going for cervical screening is, so I think... I don't know if people have actually said about going; they just might be thinking: Oh, you know"*

*Kimly: "It might be you know they might get the letter, they are like you know i am busy now and I will do it at one point and they never do"*

It can be presumed from the views of participants that what influences participation varies across individuals, irrespective of educational background, circumstances and influences.

### **Non-uptake**

Non-participation in cervical screening is often not a conscious decision and is due to uncontrolled or unknown concerns or issues. The reasons for non-uptake cited by the 5 participants who had not been for screening are multifactorial. These factors ranged from a combination of practical (temporal), psychosocial and individual/personal factors.

### **Barriers to screening**

Perceived susceptibility and low prioritisation were featured barriers. Feeling fit and healthy may act as a decoy that inhibits accessing health services or delays screening participation. In the case of cervical cancer, this might lead to fatality because early stages of the cancer are asymptomatic. This idea of low susceptibility was also associated with factors such as longevity and an absence of cancer in the family as illustrated below:

*Bec: "Actually, yeah. Not... It's not something I've ever thought about before, but... My relatives on both sides have all... There's nobody in my family who's died before they've been 80. I've had quite a few family members go on past their 100<sup>th</sup> birthday... Nobody in my blood family has ever had cancer that I'm aware of. Not even died of cancer ... My granddad has got problems with his lungs but that's from smoking. That's not genetic..."*

One participant felt nonchalant about the screening programme, as it was not a thing of consideration with respect to her health check. This attitude cannot be attributed to low susceptibility as the participant has previously expressed the importance of the screening but purposely made it a point of no priority. Her exact words were:

*Fran: "Possibly, but... I've never really given it much thought, to be honest, until today. Erm... Yes, because you hear about cases in the news... I mean obviously, it is increasing in girls that are our sort of age, but... I don't like the idea of it [this could be alluding to the nature of the test e.g. invasive, private bits etc.], to be honest. I think that's half my freaked out idea"*

Having an altruistic personality acted as a barrier for some participants as they would rather help others or take up work than prioritise their own health and wellbeing:

*Bec: I've all... I think it's reflected in I've always prioritised other people over myself. And that's just who I am, and that's the way I've always been ... I was a young carer my mum was poorly when I was little. So I've always prioritised other people over myself, and I always will. That's just who I am...I do put myself at the bottom of a list of priorities..."*

The participant above cited underlying factors affecting her behaviour, which she attributed to her childhood as a young carer, being independent, and how those learned behaviours became her personality. These behaviours are indicative of how certain life events can shape a person's behaviour and character. This has implications in the way life is viewed in terms of prioritisation of health (prioritisation of self), whilst inadvertently negatively influencing screening participation or general access to health.

Being laid back or stoic, or being indifferent and unbothered about things with potential benefit, such as screening, despite perceived susceptibility, could hinder participation. This behaviour or viewpoint could have fatal consequences in the case of cervical cancer, which is asymptomatic in nature. Quotes reflecting such views are shown below.

*Bec: "My boyfriend's mum died of cervical cancer, so I do understand the importance of it... And with cancer in general it's a big deal. And you would... You would think that that would maybe make me a little bit more keen to go. But I suppose I'm not. I'm too laid back"*

*Fran: "I'm not sure. I'm sort of one of those people who is quite laid back in some respects. **I'd rather not look for trouble** [Avoidance], if that makes sense. I'm quite laid back; I'm just like: I'll deal with it when it happens"*

As expressed in the previous category, these attitudes or behaviours are based on geographical variation and health service accessibility in terms of distance. These excuses could indicate a bigger issue such as fear, leading to denial and reluctance. The fact that 2 participants expressed this similar view may indicate that more young women harbour such views, leading to possible delays or non-participation.

Non-registration with a GP surgery is a practical issue that influenced non-participation. Most participants within the study age group are either staff or students (including international), who frequently moved to a new house. Invitation letters sent to the old address may be missed and GP surgeries may not be updated. This could lead to delays in screening due to non-receipt of the invitation and leaflets as indicated in the quote below.

*Jessy: "I haven't and that's because I am really bad and I haven't, am erm I have not been registered with a doctor at my correct address for a very long time. So the doctor, the NHS has not had my correct address for about 4years"*

*Stephan: "I'm thinking is that because they cancelled my registration with the GP? Because at the time, when I registered with the GP and saw... But when I registered, they didn't tell me this. So I didn't re-register... Yeah, so for the last three or four years I didn't register with any GP..."*

Most young women within the study age group are migrants, or international students or workers who have lived in the UK for some years but may lack an understanding of the UK health system. This, and low prioritisation of health, due to other issues such as housing, registration and studying

the English language could reduce the likelihood of GP registration, thereby leading to delays in screening. Such views are expressed below:

*Beth: “Yeah, because I... What I can see is that here they... So they are lots of information provision – but still it’s not, like, handed to you. You need to, kind of, seek it, to look for it. Yeah. But if you have been in a society or an environment that lack of information you think there is no information outside. So they kind of have been used to, like, just staying where they are”.*

### **Suggestion for improvement**

Suggestions for improving services centred on awareness in the form of education campaign and improving the information available, making it more explicit.

### **Knowledge/awareness improvement**

All participants felt positive about cervical screening and suggestions centred on awareness to help people make informed decisions about participation. Participants expressed ideas and suggestions about improving perceptions and uptake. Suggestions about reducing misconceptions around the screening procedure through the provision of information, was a key area of intervention advocated for.

Social campaigns are a positive awareness-raising tool. Providing information on cervical cancer with regular updates through avenues such as mass media (TV and radio advertising), community campaigns (like those of breast cancer) and creative social media campaigns (Facebook, Twitter or Instagram) might demystify negative perceptions of the screening programme. Increasing awareness through uplifting/encouraging stories from celebrities who have had a lucky break with cervical cancer based on their screening compliance was proposed. Great thought needs to go into marketing tools if the desired result is to be achieved.

*Kimly: “I am thinking national campaign on TV or things because that’s just a great medium to go with, you know if you have small adverts of emm a minute of saying the important stuff, emm then you can get to many women”*

The community-focused awareness campaigns suggested were similar to other well-publicised campaigns, e.g. breast cancer, and involved ideas such as a national awareness day. This will help reach young women within local communities and encourage participation in the cervical screening programme.

*Zara: “they have to raise awareness around it and you have got the national days emm for breast cancer, mental health awareness or sort of things like that. i think things like that do promote...same as other campaigns i mean now the Stoptober is all over the place, the stop smoking thing, i think something similar can be done”*

There is an increased popularity in the use of social media platforms such as Facebook, Instagram and Twitter among young women. One suggestion is quoted below:

*Bec: "Yes or no, i think they would have an influence yea. But personally i wont yea, i don't think, you see things on Facebook don't you about health or things. ... if i saw something on Facebook for too long or like a major campaign you know like the ice bucket challenge that raised awareness about ALS, that's what i mean i didn't know what it was, ... i think smart things like that yea do raise awareness"*

Surprisingly, social media as a medium of awareness was only suggested by 2 participants, which is surprising due to its popularity. This might have been due to the fact that most participants are postgraduate students. It would be interesting to see if this would be the case for other participants from different social backgrounds.

Educational campaigns were also suggested as an awareness tool in target locations such as schools. (i.e. high schools, colleges and universities). This is to instil information on cervical cancer at an early age to help in the decision-making process. The topic of cervical cancer and the impact of the screening could be included in school curriculums.

*Jane: "I think if we started targeting maybe high schools and sixth forms and getting the information there before the girls reach 25, that would be one thing to do, but that said, in terms of the 25 to 34 age group, it's quite difficult, because obviously you've got such a wide variety of people and they're not all going to be..."*

In addition to young women, the inclusion of male students in such classes would provide them with enough information to encourage their future wives and partners on the importance of being screened, i.e. serving as future cervical cancer screening advocates. This was also followed by suggestions around work place awareness.

*Faith: "so i think if you can explain that and raise awareness around that and i would say for boys as well because many 25 years old women are married and in a relationship and things like that"*

*Beth: "And then even in jobs i mean even in i mean for women when they are employed by somebody it should be promoted by the employers by saying, if you need half an hour to go and do your cervical screening of course you can do it..."*

### **Improvement in information and service delivery**

Improvement in the detail of information available could reduce negative anticipated emotions such as fear and embarrassment. This can be achieved by providing detailed information on what the screening entails and what to expect in the leaflet and invitation letter. Distinguishing each area of

concern by providing answers could help reduce barriers around uncertainty about the screening procedure.

*Faith: "Erm... In terms of just generally encouraging people, I think just being a bit more, erm, clued up about what it's actually going to be like and just that... 'Cos that fear of being really exposed and... You know, that was quite an issue for me, so I think just knowing that the staff are really friendly and supportive and really respect your dignity and your privacy..."*

The content of the information and how it is portrayed is important. People relate well with positive messages and less well with 'fear factor' approach that focused on the negative side of cervical cancer. Some participants suggested using positive messages through survivors.

*Bec: "I would say that anything needs to be positively spun. Just because, speaking for myself, if somebody comes at me, doom and gloom and doom and gloom, I'll just think... "This is how we help... Not "If you're miserable, you're depressed, you're about to kill yourself – come and see us"*

In terms of service delivery, suggestions included encouraging uptake by providing a wider range of services to improve access to screening, such as more appointment options, drop-in services or out of hour screening services. Flexibility in appointment to accommodate students and staff with busy schedules was also cited.

*Zara: Erm... I mean like... Obviously having appointments available that are sort of before work, after work and stuff like that is very helpful... it would be quite embarrassing to kind of, you know, go to your boss and say "Oh, I've got to go for my cervical screening, they're not going to want to know that and you don't really want to disclose that information to them".*

*Kimly: "Yeah, like drop in just... You know, it would be easier to perhaps go before work, or during lunchtime..."*

In addition to the suggested appointment and drop-in services, participants felt that the involvement of health professionals in reaching out to women of screening age through proactive means such as volunteer offer of screening could help increase uptake. Other suggestions include: signposting people to health resources to help increase; awareness; and reminder services through a text messaging system, as a way of being proactive in helping to improve uptake within their local surgeries.

*Jessy: "no ... that something they could offer when you go for appointment, like have you been... Laughs...also using of text messages might be good..."*

*Joy: "Well, at least they can remind me to take some leaflets. Yeah, sometimes they... If they say is there under... I am, kind of, like a curious person and I like to see what's out there. But I know some people, they don't... so I think the staff, they can, like, mention where you can find this information and what is it about"*

Past studies have shown contrasting effects of actively involving health professionals in trying to improve uptake. The study carried out in the USA (Crone et al., 1998) using phone call reminders proved to be very effective, while the study carried out in the UK (Stern et al., 2005) found that in addition to not being cost effective, text messaging was the least effective intervention of all the 4 intervention trials explored in the randomised control trial. Such interventions have the potential to work in young women as they are very busy and constant reminders, by whatever means, could be helpful. All the suggested interventions by the study participants were coined to help reduce their concerns and the actual barriers they faced in making decisions to participate. It is also noteworthy that the study by Stern et al. (2005) agreed to utilise their resources in terms of reaching out to all the participants, hence the result outcome.

### **New less invasive screening procedure or other test taking options-**

A less invasive or self-testing screening procedure to combat the associated embarrassment of the current procedure was suggested. Although the suggestion was made around creating alternative screening methods, there was acknowledgement of it being a difficult option due to the position of the cervix and cost of creating a new alternative procedure. They advocated creative ways of making the screening process more comfortable and less awkward.

*Lydia: "I mean, it probably could never happen, but it would be a lot easier if it could be done like at their homes or something, or if they could do it themselves. Like, you know, with the whole chlamydia thing. But I just don't think that could be possible"*

Self-examination services at home were advocated by a participant. HPV self-testing has been introduced, but it is not a replacement for the cervical cancer screening. The HPV virus can remain inactive for years without causing harm and the possibility of it not leading to cervical cancer is very likely (NHSCSP, 2013).

*Bec: "Yeah and I just think it's just the hassle as well..., but it would be a lot easier if it could be done like at their homes or something, or if they could do it themselves. Like, you know, with the whole chlamydia thing..."*

### **Summary**

This chapter presented the 4 main categories and subcategories of factors derived from the interviews that could potentially influence participation. Change of behaviour and attitude towards cervical cancer and the screening participation could be achieved by understanding people's perceptions and health views, awareness and expectation levels. The next chapter will show how categories from analysis of the focus group were derived.

## **CHAPTER 6: Focus group findings**

The focus group data presented a diverse insight. Issues around sexuality and socio-cultural influences on screening attendance were theoretically explored in depth. This enabled the researcher to understand participant views within a sociocultural group dynamic, their impact on decision-making regarding their health and their participation or non-participation in cervical cancer screening. Analysis was carried out simultaneously with the interview analysis, although the results are presented separately.

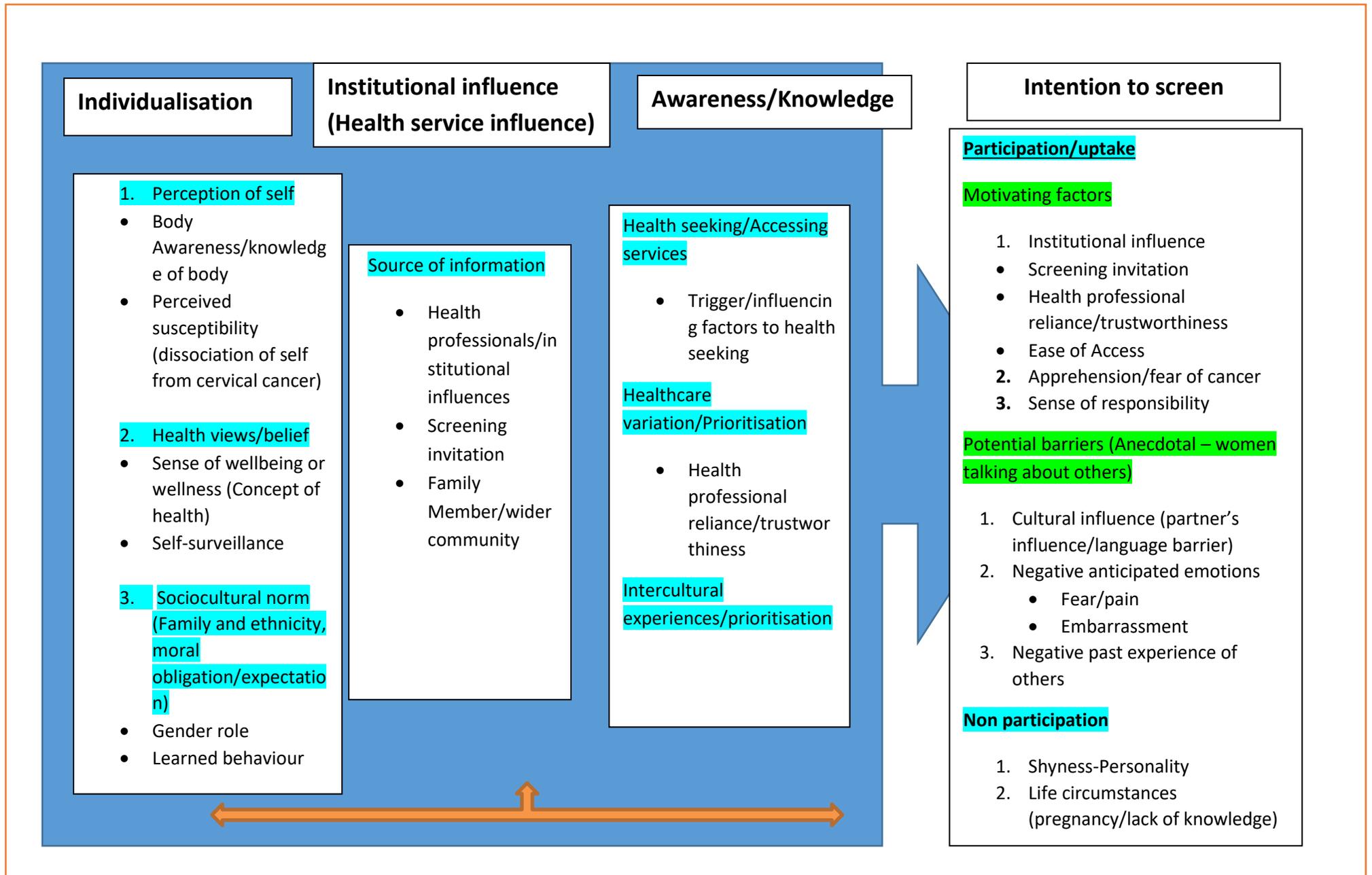
Table 8 Characteristics of focus group participants

| <b>S/No</b> | <b>Pseudonym</b>        | <b>Ethnicity</b> | <b>Age</b> | <b>Knowledge demonstrated</b>   | <b>Screening history</b>                         | <b>Place of Birth</b>                |
|-------------|-------------------------|------------------|------------|---|--|--------------------------------------|
| <b>1</b>    | Jules                   | Pakistani        | 30         | No (Non-English speaker) displayed little knowledge of topic                  | Not yet screened                                 | Pakistani                            |
| <b>2</b>    | Amnat                   | Pakistani        | 34         | Very basic knowledge of the topic and general health issues                   | Have been screened continuously                  | United Kingdom                       |
| <b>3</b>    | Annie                   | English          | 24         | Undergraduate with detailed knowledge of the topic                            | No (centre staff and familiar with participants) | United Kingdom                       |
| <b>4</b>    | Jamila                  | Pakistani        | 34         | Some knowledge of bit of education and topic of study                         | Screened   | Pakistan                             |
| <b>5</b>    | Lin                     | Indonesia        | 31         | No formal education but exhibited basic knowledge of screening in focus group | Screened only once                               | Indonesia                            |
| <b>6</b>    | Laila                   | Bangladeshi      | 25         | No (Non-English speaker)  | Not yet screened/undecided                       | Bangladesh                           |
| <b>7</b>    | Rakiya<br>(Interpreter) | Bangladeshi      | 31         | Exhibited basic knowledge of screening having previously worked in healthcare | Screened but undecided about future screening    | Bangladesh - came to UK in her teens |
| <b>8</b>    | Evelyn                  | Malaysian        | 35         | unknown   | Yes (screened only once)                         | Malaysia                             |

To present an in-depth background of some of the participants above, I have included vignette of 3 of these below.

- **Lin:** is from the far east and came to the UK a few years ago. From her demonstrated knowledge, it shows she has some education. The difference in health service system in the UK and her home country was very large and the availability of certain health services such as cervical screening in the UK was a thing of joy for her. She has been screened and attributed her screening decision to cervical cancer prevalence in her country and lack of adequate care and information regarding cervical cancer and its screening available to her in her home country. Having the services and facilities to go for screening in the UK was a motivating factor for her screening attendance.
- **Jules:** is from Asia and can speak very little English. She needed an interpreter. She came to UK a few years ago. She has not gone for screening and is still deciding on whether to attend. She stated that her sister in law has given her a great insight of what cervical cancer is and what the screening entails but will need to get further details from the doctor or nurse at her GP surgery before making a final decision to attend. She also attributed her being unscreened to pregnancy, stating she was pregnant when she received her first invitation to screen. She stated she is very religious and culturally oriented.
- **Rakiya (Interpreter):** demonstrated a good knowledge of English and of cervical cancer. She moved to the UK from Asia as a teen and was very much exposed to the UK culture and the health system. Although she has gone for screening, she expressed unwillingness and hesitation whenever she had to go for the screening. In the past, she has had a bad screening experience which was very painful and expressed fear for future screening. She also hinted at the difference between emotional exposure during childbirth and screening stating that the psychological impact is very distinct.

Categorisation followed a similar pattern to the interviews, resulting in 4 main categories and related subcategories. The first 3 main categories fed into the 4<sup>th</sup> main category as shown in figure below. The themes and variables within the subcategories are interrelated.



Participation in cervical cancer screening was multifactorial, with each view overlapping. These factors were contextually bound. The 4 main categories: individualisation, health service influence, awareness/knowledge and intention to screen are presented alongside their subcategories and associated themes/variables as follows:

### **6.1 Individualisation**

This main category emerged from the participants' propensity to personalise or relate their responses to a personal context reflected in terms of knowledge, intentions or decision-making process and accessing health services. Explanations regarding factors that influence their thought process or define their personal ideology are also discussed under the sub-categories; perception of self, health beliefs and sociocultural norms/ethos.

#### **Perception of self**

How an individual perceives himself or herself, or the importance placed on oneself as a person and in terms of health, is based on different factors such as knowledge and other influences both within and outside.

Body knowledge and awareness was one of the major references cited by participants in the context of understanding their health. Most women made use of the term "inside and outside the body" to refer to internal health, i.e. in terms of ailments that are asymptomatic like cervical cancer and explaining the importance of being 'body aware' or understanding one's own body.

*Amnat: "Er, it's not only about physical health, 'cos we can't see what is going on inside of our body, so we have to prepare our self from there..."*

*Evelyn: "For me, health inside and outside. Like, I agree with [name], er, [indecipherable], in my body; in the outside, we can see and then inside, like mentally, I agree with [name]"*

Knowledge of the body in terms of symptoms associated with cervical cancer reflected a lack of knowledge and acted as a barrier to screening. Some responses are presented below:

*Jamila: "Just a little bit, the cancer in the woman; in the inside of the woman especially. I don't know what else in the..."*

Here, the participants alluded to not knowing what is happening inside their bodies and the feeling of internal health being 'unknown' or hidden from them and requiring an external person (doctor) to check and control or monitor that hidden aspect of their being:

*Lin: "Mentally prepare yourself to where we are going; what is going on inside [...our body and when a doctor will check us, what he or she can tell what is going on. So ..., or to examine what is going on inside your body. So it's not only physical; mentally healthy as well"*

Perceived susceptibility to either illness or danger plays a part in the way actions and reactions are made to either seek professional help or avert danger. Lack of knowledge can lead to a perception of low susceptibility and subsequent dissociation from a situation that could lead to poor decisions, which could become fatal. In terms of knowledge and intention to screen, most women stated anecdotally that a possible barrier to screening was level of knowledge, which is evident in the response below:

*Lin: "Yeah, the day I talked with one lady, she said that I had this test, but I didn't know what is all this about and saying we had some ladies heard, but we don't know exactly what cervical cancer is? Most of the ladies know what the uterus is, but they don't know what this is... Where is the place exactly?"*

*Rakiya: "Anyone can happen this one... But our countries, like Bangladesh, Pakistan, they think that: no, no, you are so young, you don't need this examination. That's why we are not..."*

These responses were made in, and connected to various contexts, including knowledge, openness to discussing sensitive issues such as sex, and cultural/national correlations.

The importance placed on health irrespective of other factors such as negative experiences, lack of better understanding of procedure as well as family upbringing sometimes boils down to our sense of responsibility. This sense of responsibility could be towards oneself or to those around us. This was evident in the decision-making process, thereby acting as a facilitator to participate in screening.

*Jules: "I went on my own decision".*

*Lin: "One more thing, in our country, the government and the doctor are not worried about this and when I came here and when I saw the GP doctor care about the women, so when they told me, like if you do the screening test, so I got a letter and I was very excited that: yes, this is good for health, so that's why I go there".*

The response from Lin above was centred on issues of 'permission' needed from her partner as part of the decision-making process to access services or make crucial personal decisions. This will be further explored below when talking about the factors influencing participation.

Although most of the women were aware of the implication of their responsibility to themselves in terms of their health, the issue of permission could act as both a barrier and facilitator to screening. Information seeking and health seeking also reflected their supposed self-obligation to look after their own health, irrespective of external influences or restrictions around decision-making and the implementation of those decisions.

*Evelyn: "The reason I have information... Because in my country, we don't have more information and it is easy to get it here. In my country, there is just a special clinic and then in my country, I worry... I scare easily, because the doctor will see my [genitalia], but*

*here, I know the information available in the GP and it is very important and I see in my country, the people have cancer and... So I must go in to the screen and see the GP*"

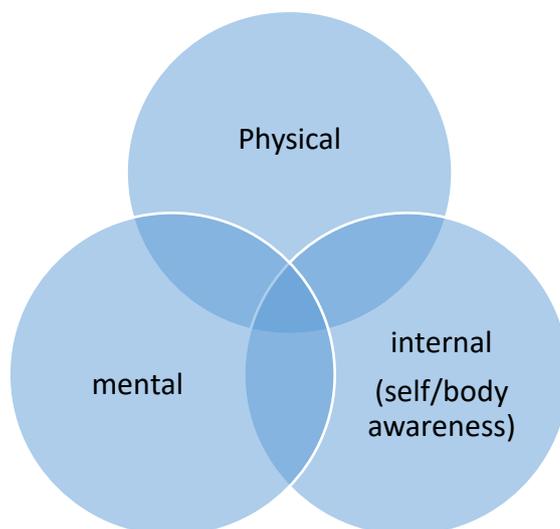
### **Health views/beliefs**

The health views held by people can be indicative of how they care for and respond to their own health. Positive attitudes/views could lead to positive health seeking/decision-making. One of the study objectives was to understand health views and the influence of these on screening participation. To the focus group participants, health was mainly viewed as holistic and associated with wellness/sense of wellbeing (both physical and mental). The importance placed on health and its understanding acted as a contributory factor in the decision to access health services, or as a factor in non-attendance as indicated below.

*Rakiya: "Er, health means. I think is, if I feel good and if I feel bad. It's like: if I go outside and if I eat proper food and if I feel nice, it's good health and if I don't go outside, I feel always dizzy and I feel sick. It's like I'm not healthy. So it's very important for one person to keep fed and healthy, because it is all the various [things], like happiness and everything, so..."*

The response above can be likened to the concept/dimension of health that relates positive health in a person to a multidimensional state of being as represented by the quality of life (Nordenfelt, 2007). This is illustrated in Figure 18.

Figure 18 Definition of Health



Adapted from Marmot, 2007

As shown above, most women referred to their body in terms of symptoms, which reveals their level of knowledge, but more importantly is understood as a valid attempt at health seeking. However, some women made reference to self-surveillance in deciding their state of health. This surveillance also assists them in making decisions regarding if or when to seek health advice. For example, one participant stated that she does not seek health advice unless she feels unable to cope or feels it affects her daily activity. Another related it to the type of food consumed. This was unpicked in the interview and was part of the abstracted themes discussed in chapters 7 and 8. Some illustrative quotes are shown below:

*Rakiya: "I wait one day, or two [depending] on what's going on, like my condition is like really bad or not. It's okay. If I feel very dizzy or weak, then I call the GP and I go to see the doctor".*

*Evelyn: "For me, I am always watching what I am doing, like if I eat bad food or not, probably this is the problem; if normally it is good food, I go to the GP. This is the problem..."*

*Jules: "My first step is: if I'm not feeling good and if I feel sick, so that I understand that I'm not okay; I'm not healthy, then I contact my GP and then I see the doctor".*

Reliance on self-surveillance has huge implications and could be disastrous in a case of cervical cancer or any illness/disease that is mainly asymptomatic or only shows symptoms during the late stage of the illness. As in the case above, many women would access services only when they are very ill or show symptoms of being unwell.

### **Sociocultural norms (family and ethnicity)**

Our personality, habits and decision-making processes are influenced by various factors with some being contextual. Most of the participants expressed knowledge levels, decision-making processes and attitudes to health service participation based on, or influenced by, cultural beliefs and family values/morals.

Cultural influences and the role of a woman in a society, as well as expectations and moral obligations, influence decision-making around general life situations and health decisions. Responses around reasons and restrictions regarding access to health services were often centred on cultural and religious beliefs and role of the woman. In some cultures, women are expected to gain permission from their partners in making certain decisions. There may be certain moral expectations regarding sex, which may be associated with sensitive issues such as cervical cancer and heightened by the fact that cervical cancer is correlated to sex via HPV transmission. Some cultures and religions expect women to be sexually inactive until after marriage, but little expectation is placed on the men. The statements below illustrate the paternalistic attitude and power of men in comparison to the women.

*Lin: "We, like... Our Asian country depends... We are dependent with my husband, but our... Some husbands do not do this test; they said "why you do this? It's not good for them". So some husbands are not interested in this..."*

*Rakiya: "yeah. They are not allowed to go there. Some husbands don't give permission"*

*Interviewer: Why?*

*Rakiya: "Our culture"*

*Lin: "That's why maybe... I remember my husband saying "Oh, it's not important for you, because you know..." So maybe it's all about in the UK, the ladies who have boyfriends, or more than one boyfriend, so that's why it is... I think 60, 70% of Asian ladies think that it's not for us."*

The expression of role and place of women and the superiority placed on men over women sometimes acts as a barrier.

Learned behaviour is closely related to cultural or traditional influences. This theme deals with the issue of openness in talking about sensitive issues such as sex and sex-related diseases. Stigmatisation of sex was evident in the women's responses, as sex was referred to as a taboo and as such, was never discussed within the family and rarely discussed amongst friends. Limited knowledge of sex and sex-related illness was expressed and evident in responses around cervical cancer.

*Amnat: "So she said... It is like... It is a part of her culture, I think... Our mothers; the mothers of mothers... They still... They don't... I know my mother discussed with me a little bit, so I knew a little bit, but my friend didn't know about all this sex and this, because her mother... It's very big shame. Don't share with me".*

*Lin: "You know, if I talk openly to... You know, in our country, where I came from, even when we got married, we were not told what is sex..."*

Due to the stigmatisation of sex and moral expectations around sex, sex issues are not discussed among women from certain ethnic groups and the topic of sex generally ignored in the home. This has implications for participation, as women tend to ignore information on sex-related issues that could help them make better decisions and take control of their sexual and general health.

*Jamila: "I'll tell you something, like our country, like Bangladesh, I don't know the Pakistani life, like, if we discussed a taboo, like the smear test, like the sex, it is like very shy. Because we don't... We never discuss... Like this thing, in our family, in our parents, in our friends; we don't know before...we never [had] this discussion. Because we think that it might be when you're older when you need this test. Not at a younger age..."*

The main categories and subcategories cut across the various aspects of the focus group session, from knowledge to possible influence on decision-making processes and actual participation in the cervical screening process.

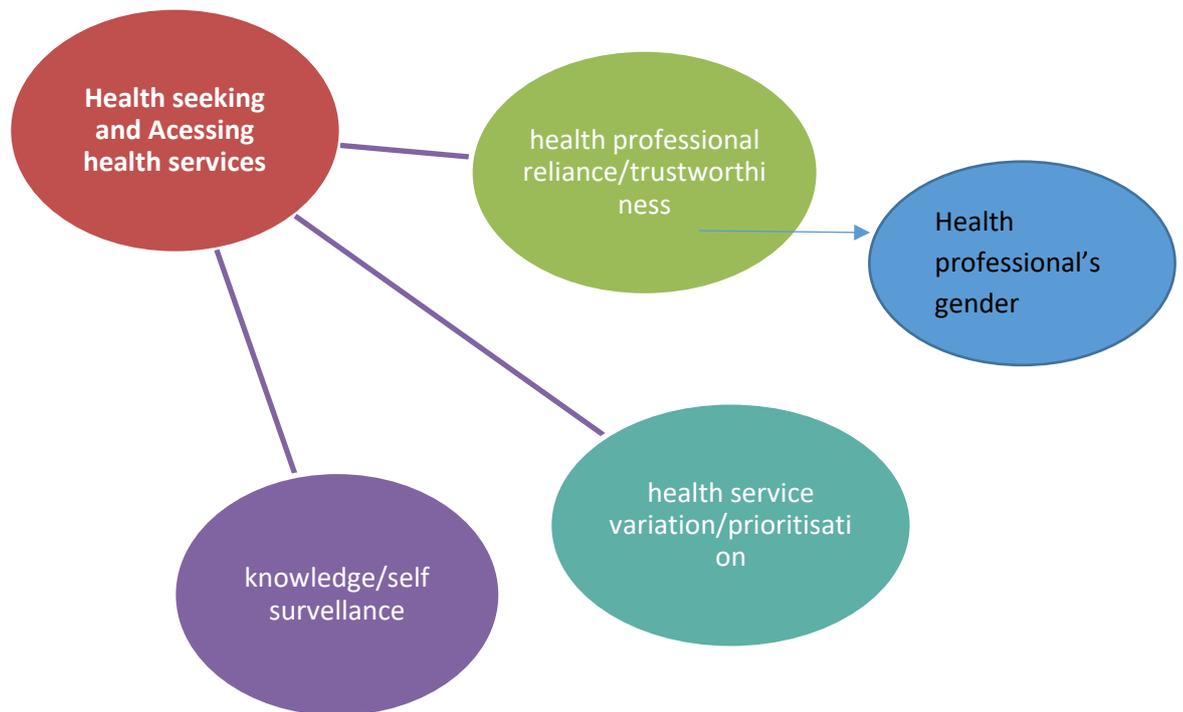
## **6.2 Health service influence**

This main category centred more on the responses regarding influences on participation, as well as possible multifactorial influences, which in most cases are linked. Subcategories under the main category above are discussed below.

### **Health seeking/Accessing services**

Findings from the session led to the categorisation of the data into factors affecting health seeking behaviour and trust in health professionals. The figure below represents the themes from these categories.

Figure 19. factors influencing health seeking and access to health.



The variables in the subcategory, as shown in the figure above, provide a premise for presenting this section. Various factors outside the family unit influenced decision-making in terms of health seeking behaviour and access to health. There were various triggers for attitudes towards health seeking and access to health services. One of the major factors emerging from the women's response was the variation in health service delivery and health priorities across different countries. Most women who participated in the focus group session were migrants living in the Northeast, so the services available to them were very influential in their decision to participate in the screening. This variation and priorities played an influential role in their decision to participate in the cervical cancer screening. One of the women cited access to information as an influence in deciding to screen.

*Evelyn: "Because in my country, we don't have more information and it is easy to get it here. In my country, there is just a special clinic and then in my country, I worry... So I must go in to the screen and see the GP"*

Prioritisation of cervical cancer through the screening program acted as an influence to screening as shown in a participant's response below:

*Lin: "One more thing, in our country, the government and the doctor are not worried about this and when I came here and when I saw the GP doctor care about the women, so when they told me, like if you do the screening test, so I got a letter and I was very excited that: yes, this is good for health, so that's why I go there".*

The influence of health professionals was positive and one of the reasons for deciding to go for screening. From the data, it appeared that women from minority ethnic groups tend to trust the advice and information from their GPs, and this tends to impact on their decision-making process in accessing services. As shown in the subcategory above, one woman revealed her trust in her GP in the excerpt below:

*Jamila: "Erm, I think there's enough information, but if the doctor told you before, like what this is, what the cancer and... That's why the women [are] more excited, so if the doctor told before... Like any session, like this is very important for women; this is why we did this, so..."*

The health professional's gender also influences the decision to screen. Trustworthiness in the health professional is more effective if the GP/health professional is female. This was associated to the sensitivity of cervical cancer (as linked to sex), as well as the location of the cervix (in relation to other sexual organs). This helps reduce the apprehension and nervousness associated with going for screening. Some of the responses were:

*Laila: "Especially if it is a nurse, a lady doctor or a nurse".*

*Jamila: "Lady doctor told before, because it helps... Some of our Asian women are shy; they feel nervous. This is very important. So I think there might be one session, r two sessions..."*

One reason for including the influence of health services as a main category was based on the reported professionalism of the GP as experienced by some participants in comparison to GP experiences in their country. A quote illustrating this is shown below and prompted further exploration.

*Amnat: "Because it's important for any woman to... If the doctor has said: "Do this", so that's why I go and got the screening".*

I initially coded it as "Doctor Say", but after further exploration of the data, I had a better understanding of the depth of influence health professionals exerted in participants' decision-making (in minority groups), as presented in this category. Contextualising the statements and correlating the instances and level of influence led to a broader context, moving it beyond the health professionals to the health services/system in general.

### **6.3 Awareness/knowledge**

Awareness in this context regards cervical cancer and the screening. The women exhibited differing levels of awareness of cervical cancer and of the screening programme irrespective of their screening status. Some had little or no knowledge of cervical cancer and seemed to have little understanding of the screening process/programme. Nevertheless, some showed recognition of the importance of

screening based on their level of knowledge and their sources of information regarding cervical cancer.

*Rakiya: "Like lots of women have had cervical cancer, like what the reason is for this cancer, we don't know. Like exactly why did that happen? Like most of the woman... Everybody's suffered this cancer, so we are worried that why is this happening to us now, day by day? So I want to know why is cervical cancer..."*

The limitation was evident in the responses. Most women correlated susceptibility to deficit in moral obligation, age variation and number of sexual partners. In addition, responses were categorically negative.

*Jamila: "They might not be good in their life and they have cancer and they lose [the ability] to have children again"*

The source of information also influences the knowledge level of the participants. Most women indicated health professional (GPs), invitation letter/leaflets, as well as family members and the wider society as ways of getting information about health, including cervical cancer and the screening programme.

*Evelyn: "Mmhm...The invitation letter from the NHS, with the information leaflet as well..."*

*Jamila: "Erm, I think there's enough information, but if the doctor told you before, like what this is, what the cancer and...I think that my GP, or any doctor told the patient before..."*

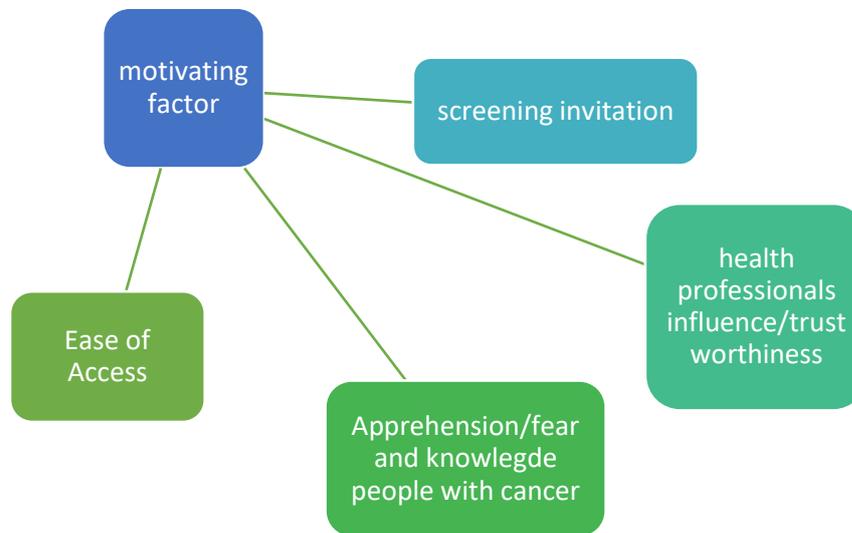
*Lin: That's why maybe... I remember my husband saying "Oh, it's not important for you...Maybe the Asian lady, who came from outside, as I'm telling you Asian ladies and there has been UK born men and you don't know [if] you are their first... Not wife..."*

#### **6.4 Intention to attend screening/decision-making**

This main category shows factors that actually influenced participation and non-participation. It also illustrates how the other main categories fed into or influenced these decisions (i.e. relationship between these categories). The decision-making process is linked and multifactorial. In addition, this section reflects the constant comparison and further exploration of themes like those identified in the previous chapter (perception of the screening). These are discussed under the subcategories below.

## Uptake/Motivating factor

Figure 20. Motivating factor.



### **Motivating factors**

The findings suggested some competing factors in the decision-making process as seen in the main categories discussed above. There emerged a series of positive influences (Figure 20), which facilitated the decision-making process for cervical screening attendance which are presented below.

As indicated in the main category (health professional influence) the influence of health professionals cannot be overemphasized as they played a role in helping some participants undertake the cervical cancer screening. Varying experiences in the context of health professionals' influences included relationships with, and proactivity of, the health professional (GP and nurses) in initiating an invitation for screening. Some women speculated that getting information directly from the health professional would encourage and have greater influence in ethnic minority women accessing health care and participating in the screening process. The quotes below illustrate this:

*Jamila: "Erm, I think there's enough information, but if the doctor told you before, like what this is, what the cancer and... That's why the women [are] more excited, so if the doctor told before... Like any session, like this is very important for women; this is why we did this, so... I think that my GP, or any doctor told the patient before..."*

Apart from trust in GPs, some participants stated that they were influenced by multiple factors. One of the women in the illustration below stated that health professional proactivity influenced her attendance to screening.

*Rakiya: "... so I didn't go when I came here, so after that, I got information from the nurse and GP and is it important or not? And then I read the leaflet...So that's why I went."*

The cervical cancer screening invite and accompanying leaflet acted as an information tool in the decision-making process. The content of the information leaflet, as described by the participants was 'easy access' (that is, it was readable and understandable). The impact of the invitation artefact on awareness was acknowledged and evident because before the receipt of these artefacts, the women's knowledge and understanding of cervical cancer and the screening procedure was low.

*Lin: "so I got a letter and I was very excited that: yes, this is good for health, so that's why I go there"*

*Jamila: "Actually, it was quite informative for me, so that's why I thought... 'Cos it is clearly written there that it is... It can save you from the cancer. Or even [if] you've got [it], don't worry and everything is quite informative in the leaflet for me"*

Due to the variation in health service and health priorities across countries, which was highlighted in the health system category above, some of the participants reported the existence and accessibility of the screening programme as a reason for attending. In addition to ease of access, structure and drivers for implementing the screening service in the clinic through awareness among staff also influenced one of the participants in her decision to go for screening.

Apprehension and perceived susceptibility to cervical cancer influenced the decision to go for screening. One of the participants who had a long-term illness as well as exhibiting symptoms in the genital area went for screening after fearing she was susceptible to cervical cancer. Her illustration is presented below:

*Laila: "She had diabetes and she still has and she has a urine problem as well, so she thought that it might be... maybe she got an infection there, or something."*

In addition, knowledge of people with cancer, fear of having cancer, as well as increasing incidence of cervical cancer and cancer in general, acted as a catalyst for attending screening as illustrated below:

*Evelyn: "and it is very important and I see in my country, the people have cancer and... So I must go in to the screen and see the GP"*

*Rakiya: "Like lots of women have had cervical cancer... Like exactly why did that happen? Like most of the woman. Because in our country, in Bangladesh, it's like 30% of women nowadays, breast cancer and this cancer, cervical cancer."*

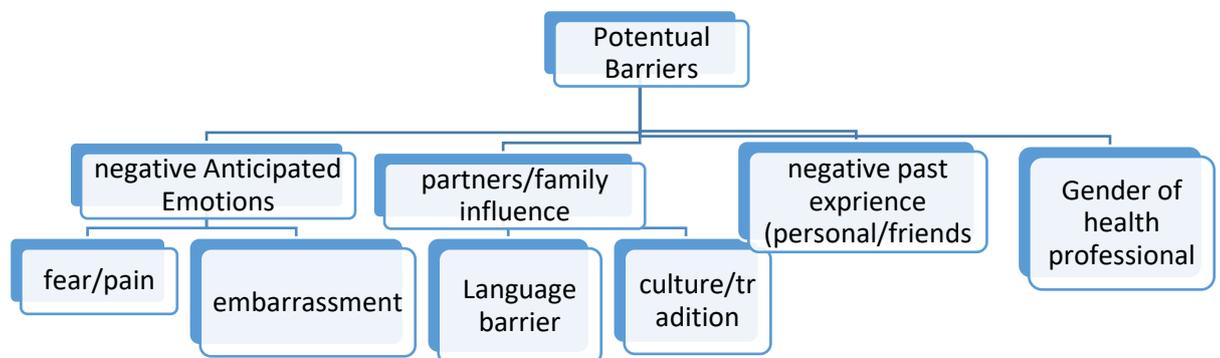
### **Non-participation**

This is presented under potential barriers and actual barriers.

## Potential barriers to screening

The potential barriers presented in the figure below were either the anecdotal views of the participants or experiences from their friends. These barriers could have potentially hindered attendance for individuals within this study's demographic but not those who actually participated in the research. However, participants felt strongly enough about these issues to voice and describe them.

Figure 21 Potential barriers to screening



The barriers in the figure above did not seem to have any direct influence on actual participation in the screening process, but may perhaps have led to hesitations and delay in screening. As illustrated earlier in this category, (individualisation under sociocultural norms), partners' influence negatively influenced participation. Some of the women stated that although they can make individual decisions about their health, the permission of their partner is crucial as it has implications not just for their health but also their personal relationship and extended family relationships. It was further clarified that these factors were influenced by culture/tradition and language barriers.

*Lin: "We, like... Our Asian country depends... We are dependent with my husband, but our... Some husbands do not do this test; they said "why you do this? It's not good for them". So some husbands are not interested in this..."*

Some of these women have low SES in terms of education. It is noteworthy that investment in education for women in certain minority ethnic groups is seen as waste of resources, since their duty and responsibility is to their spouse and home, thus indicating the potential importance of cultural expectations. Irrespective of the length of time spent in the UK, integration into UK society is low,

as external contact is minimal in most cases, while close family and cultural/religious ties are strong. Most women tend to depend on their husbands for information, thereby giving them control in the decision-making process.

*Jamila: "There is another reason; I know many ladies who can't speak English and like... So they are dependent not only for other purposes; they are dependent on their husbands... There is a language barrier as well. Everything they get... There is a nurse's letter... But I don't give that husband that letter... the women can't read and speak English, so they ask their husband and their husband says "Oh, you don't need to go..." "*

However, partners' influence could also be a facilitator in participation if they have the right information and understand the implications of screening in women.

### **Negative past experiences (personal or reported experience from others)**

Some women reported hearing negative reports about the screening experience that could discourage them to attend for a smear. The information they heard from friends and relatives seemed to reinforce some negative views of cervical screening. The associated fear increased willingness to attend for screening because of "not so pleasant stories" from their friends.

*Evelyn: "For me, it was [different, because my friend found it very painful],"*

*Lin: "Lots of cautioning... Negative... From what people have said about the experience".*

Some expression of negative experiences was seen as a potential hindrance to future participation and was linked to a lack of professional skills in health professionals. One participant felt her previous experience was far better, as it was uncomfortable but not painful compared to subsequent screening experience. In this case, this procedure was conducted by 2 different health professionals.

*Lin: "But this was the last time. I think this year. It was horrible for me.... it was a little bit hard that the nurse couldn't find the ...So she couldn't find the place, so she moved me right, or left, or... The general direction and it was quite painful. So in my experience... The last time, not the first time..."*

Although this experience did not have any effect on the participant's perceptions of screening attendance, this could potentially hinder others from going for screening. One participant expressed how she always convinced herself to not return for screening after every session. For her, it was not painful, but the associated discomfort always stirs up negative emotions, as illustrated below:

*Jules: "I told you already. She said that every time, she says "next time, I'm not going to do this"*

*Evelyn: "Maybe uncomfortable"*

Negative anticipated emotion in this context was theoretically sampled. Negative views arising from the emotions and perceptions of screening were expressed by participants. These seem to stem from inadequate knowledge and understanding of what the screening achieves or what the procedure

involves. These emotions also stem from the negative experiences and feedback from other people who may or may not have been screened. They might have heard it from someone else. These fears or emotions could lead to certain amount of stoicism.

*Rakiya: "Er, a little bit scared, because I don't know if it would hurt or not, because in my country they say it hurts... and also the GP will see my ..., it is something sacred for your husband alone...."*

*Evelyn: "Yeah. For me, this is easy. Because [I'd heard] this is a long process and painful and... as it wasn't as painful as anticipated only just uncomfortable".*

*Lin: "I worry... I scare easily, because the doctor will see my [genitalia], but here, I know the information available in the GP and it is very important...."*

The issue of exposure or privacy was also correlated to the lack of knowledge of the gender of the health professional. The women felt they would be more comfortable around females than males. This preference was linked to the exposing nature of the test and associative social anxiety (shyness and apprehension). These were also linked to sensitivity of the topic, its association with sex and cultural implications/expectations. A quote is presented below to illustrate some of the points above:

*Jamila: "Lady doctor told before, because it helps... Some of our Asian women are shy; they feel nervous. This is very important. So I think there might be one session, or two sessions..."*

However, despite acknowledging that they would be attending or continue to attend for screening, there was still some resistance about the overall feeling after the procedure, which they felt they could ignore.

### **Actual barriers to screening**

These are actual factors that influenced participation as expressed by the non-attendees in the group. These include shyness (due to personality and associated with sexual stigma) and life circumstances, such as pregnancy and lack of knowledge.

Shyness as a result of personality – and in this case, low susceptibility – was given as reasons for non-participation and delay in screening even after receiving screening invitation letter, discussing cervical cancer with GP and family member encouraging them to go for screening.

*Jules: "I didn't need to go. I think she's here for two years, or... She was shy. She said that I got a letter. The GP discussed with me what this is and you get a letter and if you want, you have to... She said I was shy... (interpretation for a participant who couldn't speak English) ...: She don't know She was shy..... I think as far as I know here, she is like that. She had some problems as well, so that's why. Marriage problems and... yes..."*

Shyness was expressed in various contexts and was influenced by various factors. For the participant above, shyness stems from her change in personality due to an abusive relationship. Shyness was also associated with location of the cervix and association of cervical cancer to sex due to the invasive nature of the screening procedure. Although, none of the participants stated this as a reason for non-

attendance, most of the participants expressed concerns and provided anecdotal views from other women as a significant potential barrier.

*Jamila: "I felt shy because... Somebody checked the inside. I felt shy and shame as only my husband is allowed to see it, I just feel shame... but it is a part of the health checking..."*

Shyness associated with sexual stigma was around the topic area of cervical cancer and its association with sex. Openness to talking about sex is limited and considered a dirty topic and in most cases, a taboo. Sex is associated with promiscuity and its association with cervical cancer has raised many concerns among young women, thereby acting as a potential barrier to attending screening. This was reflected in their knowledge and information seeking behaviour, especially around sex-related topics like cervical cancer. This has led to misconception around susceptibility to cervical cancer. This section is linked to the cultural norms highlighted in the individualisation category above as they are cultural related.

*Lin: "You know, if I talk openly to... You know, in our country, where I came from, even when we got married, we were not told what is sex? So it is... it is all about, or near to sex, because when you make that relation, it is after that you get... Like I know about smear and cervical test, you can get that, erm, germs or whatever from your partner or husband, so we don't discuss about sex. So that's why we don't go..."*

Life situations or life stage also hindered and delayed the decision-making process, as well as actual participation in accessing health or participating in a screening program. Most women within this study's age group are of childbearing age; as such, pregnancy has been expressed as a reason for non-participation by one of the participant, which did not come as a surprise. For this particular participant, it was interesting to note that even after delivery, she was still contemplating going for screening. She displayed an obvious lack of knowledge of cervical cancer screening, which could be an underlying influence outside the pregnancy. Her illustration is stated below:

*Laila [in translation]: "Oh, she is pregnant. She came here 3 year ago and she was pregnant when she came here, so she didn't need to... First she said, after the delivery, of the pregnancy... I asked her: did she intend to... she needs to or she wants to go. She said that I will get information; what this is all about... After that, I'll decide whether to go or not..."*

This further highlights the fact that the decision-making process in terms of cervical cancer screening participation is multifactorial and not based on a single factor. This could help in identifying the barriers and further in implementation of change.

### **Suggested improvement**

Suggestions for improvement were similar to those expressed in the interviews. However, improvements were to be mediated more by education and awareness, which was centred on language and community. Suggestions were centred on concerns/barriers raised within the group session.

## **Awareness through education**

One participant suggested that awareness within the community could be implemented by conducting drop-in sessions in centres where women socialise.

*Annie: "Maybe some education. I think it's kept quite quiet and there's not a lot of education, so maybe, you know, like a drop in session at maybe a centre like this, where women can..."*

Awareness in the form of educating partners (men) should be considered, as indicated in the findings that partners played a major influence in the decision-making process. If the partner is well educated on issues pertaining to women's health, it will aid them in encouraging the women to make better health decisions like going for the screening. Most of the resistance illustrated by the participants are mainly centred on lack of awareness or lack of understanding of cervical cancer and screening.

*Lin: "Erm... I was told, the first time, when I go to the GP, er, I go with my husband and if the doctor told something with my husband, so he might be changing his mind, so this might also help to change the men."*

## **Empowerment and improved information and service provision**

This included creating programs or initiatives aimed at empowering women when it comes to decisions about their health (autonomy). This can be achieved in the following ways: First, through the provision of interpreters and health professionals to visit drop-in centres. The aim is to empower women to be more independent, especially those with language barriers and those from strict culturally oriented backgrounds. Providing interpreters would aid independence. Some illustrative quotes are listed below:

*Jules: "For me, it's very important to, when your husband... And nobody at your home is providing permission, so maybe from the surgery, somebody, they can arrange an interpreter or somebody to explain this for those ladies who... Can't, you know? Just explain them. Because everybody asks..."*

Improved information on the screening procedure and what to expect will go a long way in reducing negative perceptions around the screening experience. As individual experiences vary due to differing circumstances, information could help reduce the apprehension and anxiety faced during the decision-making process.

*Jamila: "I think, maybe if they had a leaflet about the process, like you said before, because some people here, they just hear off other people and like you say, everybody's experiences are different... But it's not always like that, so I think sometimes a leaflet, or even you know, like an educational session, where they don't demonstrate what happens, but they can show what can happen and show you maybe some of the instruments that they use, or something like that..."*

Suggestions for bilingual information in the invitation letters and leaflets in various languages. This could reduce women's dependency on their partners, thereby empowering them to make informed decisions that are beneficial to their health.

*Rakiya: "At my GP, there are Asian ladies as well, so whenever they send any leaflet, they send it in different languages. So that happens, but I don't know..."*

Improvement of service delivery by making services more individual-focused, rather than service-focused. Use of positive stories such as survival tales could aid in changing negative perceptions and misconceptions surrounding the screening programme. This could be done by word of mouth, which may have a bigger impact, as people are drawn to positivity rather than negativity. Negativity could result in avoidance. People respond better when they can relate to stories that are used to illustrate information about cervical cancer.

*Lin: "use of message such as "You have to realise that if you don't do the test, you might be future time you have the cancer, so this is very important. You have to do this test..."*

The findings above are drawn from the focus group session. The main findings in the study were contextually, culturally and temporally bound. Findings from the interview session are shown in the previous chapter. The next chapter integrates both interview and focus group sessions and derives the overarching explanatory model for this study.

## **CHAPTER 7: Conceptualisation of both interview and focus group findings**

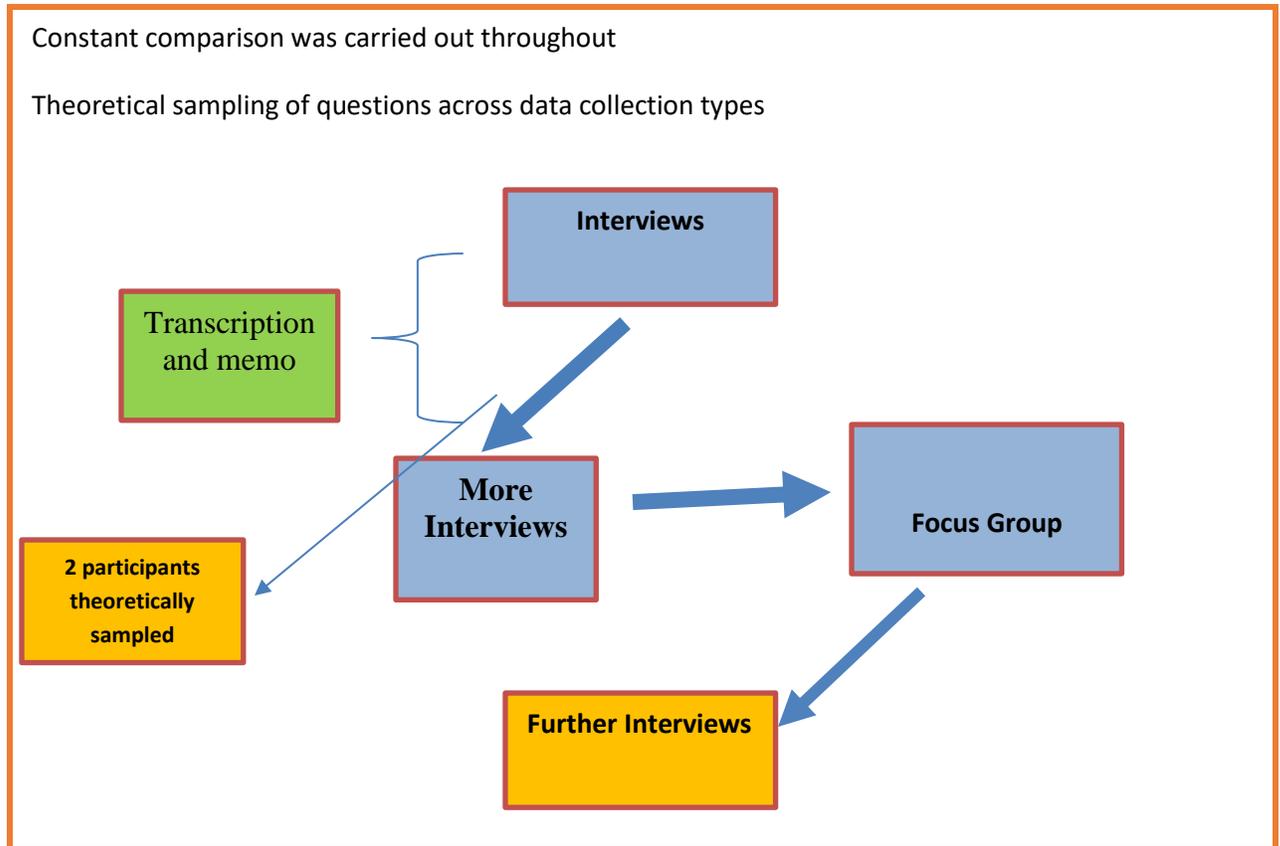
This chapter integrates data (i.e. constructed and abstracted key themes within the main categories) from both the interviews and the focus group. This led to the development of a core category, 'sexual association', which unpicked some of the issues identified from participants' perceptions of cervical cancer screening through either direct or indirect screening experiences. In addition, the direct impact of the relationships between the themes in these main categories (e.g. sociocultural norms) regarding the acceptability and subsequent participation in the screening program was also explored. Essentially, a combination of categories and their interrelationships led to the creation of the core category.

This section will also show how data analysis was carried out through constant comparison. Conventional GT analysis, which religiously follows the constant comparison method, was not completely possible due to the challenges in accessing the recruitment site (see chapter 3). This difficulty also influenced the way data was collected and analysed. It is important to note that the constant comparative method "combines systematic data collection, coding and analysis with theoretical sampling in order to generate theory that is integrated, close to the data, and expressed in a form clear enough for further testing" (Charmaz, 2014; Kolb, 2012; Conrad et al., 1993 p.280).

Based on this definition, I drew on the principles of constant comparison by trying to theoretically sample through the use of questions in this study. This was achieved by comparing interviews and making slight changes to questions in subsequent interviews. When an interview is conducted, I analyse and identify emerging themes, then make a comparison with the first sets of participants. Therefore, the next couple of interviews lead to more questions been asked around the emergent themes (questions were slightly changed in the subsequent interviews). I then convened the focus group, also drawing on the principles of theoretical sampling, which allowed me to take the constant comparison further. It is noteworthy that constant comparison and theoretical sampling in constructivist GT occur concurrently (Charmaz, 2006; 2014) and that was employed in this study. In addition, theoretically sampling people into the focus group was quite difficult, as I couldn't state who I wanted or didn't want, so convenience/purposive sampling was used, based on who turned up on the day. I drew on the principles of constant comparison and maintained this by using themes which emerged from the interviews to create questions for the focus group.

The stages of constant comparison and analysis are presented in the flow charts and accompanying quotes below to make the process more explicit and easily understood. Drawing on the principles of constant comparison and theoretical sampling, the data were analysed and conceptually reconstructed. These data were grounded within the experiences and views of the participants.

The flow chart below shows the analytical and sense-making process from data collection to theory development. This shows how each stage led me explore data in a more detailed sense and explore other avenues in the interpretation of the data



The diagram above shows the data collection process and analytical journey that led to the final category and themes, and the creation of the explanatory model. The process began with the first sets of interviews, which I transcribed then read to make sense of the data through codes. Some themes needed further exploration. There were some common and less common themes, such as ‘knowledge level’ and ‘perceptions of health’. Below are some of the themes.

Body knowledge and the idea of health in relation to attitude towards health:

*Jessy: “I generally believe, you should kind of, you know when your body is going wrong”,*

*Stephan: “...I will make an appointment and go and speak to someone, erm but i sort of feel like i know my own body and to be told by someone that i, feel i know my own body and what's normal and what's not. it's probably a kind of systematic failure to appreciate a lay person, like the actual experience of been unwell, like the lived experience of illness, so of something not been as it should be.i think people quite know in themselves when something is not right, and if that is not addressed...”*

### Perceptions of health:

*Fran: "...I try to be healthy, but it doesn't always follow. Erm, but yeah, it's important to be like healthy; to carry on doing things properly, like you know, your work; you need to be healthy to be able to undertake it properly and stuff. So it is important..."*

*Kimly: "...well I think health is really important and especially for women, I just think we need to be more careful and more to know what it involves and what to look out for, for example breast cancer, cervical cancer things like that. But you know as women we are more likely to get it I suppose. Emm personally I am concern about my health and I do try to emmm u know do check-up and things to make sure everything is okay..."*

### Family culture and being laid back as reason for attitudes towards health:

*Dora: "But then personal experience do come into it don't they? I mean i have friends, they never have any illness in their family so they are not really concerned about it..."*

*Fran (PhD student with bioscience background): "...I'm sort of one of those people who is quite laid back in some respects. I'd rather not look for trouble, if that makes sense. I'm quite laid back; I'm just like: I'll deal with it when it happens... Just... It's the way I've always been brought up. My parents are just like "well, what happens will happen" and sort of, I've got that mentality that you just live for now and then work out what happens later, later on down the line. I'm just one of those like "Yeah, whatever" people..."*

*Stephan: "...I come from a family, a kind of working class family, and my mom is long term disabled, but in my family we kind of have this really bad habit of not wanting to bother the doctors of not wanting to be a bother despite the fact that there is quite a member of my family who have long term chronic health conditions..."*

*Bec (BSc holder working with NHS): "So I'm a little, probably... I'm a little bit too laid back...My boyfriend's mum died of cervical cancer, so I do understand the importance of it...And you would... You would think that that would maybe make me a little bit more keen to go. But I suppose I'm not. I'm too laid back".*

These themes came about through questions exploring participants' understanding of health as influenced their decision-making around health access. As the questions became more specific around cervical cancer, its screening and their views on participation, interesting themes started to emerge. It was observed that most triggers in the decision-making process were multifactorial, from systemic to psychological (closely related to the screening process).

Initial interviews showed invitation letters (systemic) and fear of cancer (psychological) as prompting or considering attendance. Some quotes illustrating this are illustrated below:

*Zara (PhD student who has been screened once but delayed rescreen): "Yeah, I might have heard of it, but I probably wouldn't have known that I could go and get checked, or that I*

*should go and get checked. 'Cos you kind of hear stuff all the time about different things, so I guess it's easy to think: that doesn't really apply to me. So if that letter hadn't come though addressed to me, saying: actually, you know, you are in the group that should come in..."*

*"...Yeah, definitely. Yeah, if I hadn't had the letter, I probably would have still been aware of cervical cancer, but I wouldn't have thought: I need to go in and get checked, unless there was something that made me think I'm..."*

*Kayla (A Chinese PhD student in the health related field): "Yeah. Just the reminder letters. Yeah, that's it. Reminder letters and the fact that it's really... I really should take responsibility of, you know, going for regular check-ups as advised by the health authorities, but I really appreciate the reminder letters, so yeah..."*

*Beth (PhD student in art related course who have been screened once also): "Pretty much, the letter. I thought it was just, erm... I did trust that if they were sending a letter to 25-year-old women, then there would be a reason for doing that..."*

Some of the psychological related quotes related to fear are presented below:

*Jane: "...Erm, just... I don't know. I guess it's a bit scary to think that you can kind of... 'Cos obviously it is one of the major cancers in women, so that kind of scared me and that kind of made me want to go and get screened..."*

*Lydia: "...Ugh. Not nice things. I've had a really close family member die of cancer not that long ago, so every time I hear the word, it kind of makes me feel a bit ill, thinking about it and that is enough reason for me to take the screening seriously..."*

*Kimly (PhD student with history of cancer in her family): "...I think its death, that's what scares me, you know it's not the treatment it's not, and it's just the end of it...but it's that worst case scenario that scares me a lot..."*

Interesting themes arose when two participants who had been screened discussed their experiences. One of such theme was the negative psychological impact as well as the sexual connotations of the screening. These were expressed not only in words but through physical gestures such as shudders, body language, etc.

*Lydia: "... It was just a bit weird. Just kind of, you know, like showing a stranger thing that you don't usually show strangers and...(made a disgusting gesture and irritable gesture)... Just a bit embarrassing. Yeah, I don't really talk about it that much, really... I don't know. I just think it's kind of private, really..."*

*Kayla: "... My sister; she's really upset about it and before I went, she told me how she felt violated a little bit..."*

*Bec: "... Well, it's not pleasurable, is it? And it's not something you would ever look forward to happening...So I suppose it... It's not very dignified, having things like that done. It's not very nice having your bits out in front of people..."*

However, the sexual connotation of the screening and its perception varied between those screened and those not screened. Some quotes from those screened are presented below.

*Zara (Screened): "...Well, it's not exactly the nicest thing to have to do, is it? Um, yeah. It's kind of scary. Especially the first time. I guess it gets a bit easier after that. But the thought of going after the first time is quite [upsetting?]..."*

[Why]?

*"...Just the whole process, like the dipping of the instrument into your vagina, it was just kinda sexual and then having to deal with a total stranger doing that, just made it more weird and uncomfortable.. don't get me wrong, it wasn't painful but..Erm, but yeah, I think, you know, in terms of... that, it could have potentially been a barrier for me, actually going and getting it done again, but its cancer, you just have to get screened..."*

*Stephan: (She raised her shoulders and pointed to her genital area while making a hand gesture of a sexual act) "...what happened was emmm the way I was, asked to stay on the bed it was... and then she placed the instrument into me to take the sample, it was just a bit much, the bed, the penetration and all that sexual kinda stuff, made it a bit uncomfortable you know..."*

Those not screened also made some interesting comments:

*Jessy: "...I would say, I am not looking forward to it because it is quite painful, whether you have, I think it less painful when you have had sex before and I think if you haven't had sex before, it will be relatively more painful, I think that , I know that even when you have had sex, it quite a painful procedure to go through and its quite uncomfortable..."*

*Bec: "... I've had something done before which was... Where it was like that. But I think I was... Where we did the same procedure. And that wasn't pleasurable...But if it's the same procedure, it wasn't very nice and it wasn't very dignified mostly because it's such a private area and also because of its penetrating effect and it get stuck into your bits...that wasn't pleasurable and not the nicest thing... so I guess if it's the same, I wasn't keen to get screened..."*

As more interviews were conducted and the transcripts, memos and notes were reviewed, a pattern of participants' journeys/experiences in cervical cancer screening emerged. These processes helped in making sense of the available data. In addition to memo notes, a table was created for both the interview and focus group participants. The table gave characteristics of the participants to understand their backgrounds more clearly. A vignette was also provided individually for them to show their thoughts about the screening and participation. The table and vignettes (see chapters 5 and 6) helped by allowing me to follow the story of the participants; tracking their similarities and differences in how they perceived the screening and how this influenced their decision. This particularly aided the theoretical sampling

process by enabling constant comparison of data. These short vignettes and direct quotations from participants were also used to illustrate and support the analysis relating to the ‘sexual association’ category (see chapters 5 and 6).

The constant comparison prompted me to gain more information about the screening experience from those who have been screened and those who haven’t, so as to further probe their perception of the screening itself and their expectations of the screening process. In particular, the new link to psychological effects and sexual association was explored in the next set of interviews. I focussed on participants’ experiences and feelings about the screening and this led to a lot of collaboration with existing data, and in some instances negative illustrations of the psychological, emotional and physical impact of the screening.

Another area that led to the theoretical sampling of specific participants (see diagram above) was the issue of sexual inactivity. This arose as some participants referred to those who aren’t sexually active as possibly those not attending for screening. Two further interviews conducted with participants who were not sexually active led to a need to probe or adjust some of the questions in the focus group session. These findings associated pain with sexual inactivity and health professionals.

Some participants’ perceptions of sex related to a better screening experience. Quotes to this effect are presented below:

*Lola (A Christian pastor currently undergoing an undergraduate course in the medical field):*  
“... I haven’t gone for screening because of my sexual status which has to do with my religious belief...”

*Lola: “I also heard that it is very painful and I read in the booklet that there is a small possibility of having cervical cancer if you are not sexually active”.*

*Jessy: “there are particular people who were more prone to it and one of the major things where people who were sexually active and I am not , so I decided not to go.”*

Quotes associating pain and sex (personal and health professionals’ perception) are presented below:

*Jessy: “... I also spoke to ermm emm, one of my friends who did go for it and she is also a virgin, and she said that it was really painful and actually said that the nurse said to her that this would be so much easier if you go on and have sex, and then come back and then it will be so much less painful...laughs... She was joking she was completely joking. The point was that like, it’s a lot easier to have it done if you yea, if you have already had sex...”*

*Jessy: "...I figure the nurse meant since the procedure is much easier when you are sexually active and it is similar to having sex, been sexually active would have made the procedure less painful and traumatic as you will know what to expect and how it feels..."*

*Lola: "A friend of mine who requested for the screening even though she was a virgin due to family history of cervical cancer, explained how horrible and painful the experience was. She was told by the nurse that the experience is not as painful for those sexually active and that further discouraged me from going for the screening..."*

This theme around sex and delays to screening participation started to create a direction for the core category, and the recoding and creation of new themes. However, I knew that these could change with time. Based on the data, I pursued a range of other types of participants and, while I could not choose who exactly would come to a focus group, I thought that would be a good way of accessing different types of participants. I used some of the same questions but included new questions to explore emerging themes and quotes (constant comparison and theoretical sampling through questions). The explorations of these themes in the focus group brought out similar themes but in different contexts. Various themes emerged and further exploration and discussion around perceptions and experiences of the screening as a factor in attendance or non-attendance, led to the choice of the 'sexual association' core category.

In the course of the focus group, the role and importance of health professionals was highlighted by the participants, and sexual associations or connotation were expressed in the context of culture and of the nature of screening.

*Rakiya: "... I called the GP and they said that this you should be [indecipherable] and then I went there."*

*Evelyn (Indonesian): "... I scare easily, because the doctor will see my [genitalia] and then, that is shame for me, as only my husband see my genitalia, for this I scare a lot...the screen was very shameful, because the nurse put this thing into your vagina (Make hand gesture of penetration) and the instrument shape like (make hand gestures describing the shape) and then you shame cos, you don't know what your body will disappoint you and only your husband see that ... so that is a shame for me..."*

*Jamila: "I felt shy because... Somebody checked the inside. I felt shy, but it is a part of the health checking, so it's fine. If she checked me, so it's good for me, so it's fine.."*

This appears to show that shyness goes beyond ethnicity as well as education, and is compounded by the nature of the screening. Also, the thought of exposure and having a stranger view an intimate part of the body also aroused some negative feelings such as fear and nervousness. This is supported by the quote below:

*Annie: “But I get really shy. I get really nervous and that’s not because of my culture or school, or anything; it’s just knowing that somebody is going to have a look and somebody is going to see and you do, you feel really shy, but it’s...*

Although the participant above expressed negative feelings and associated the screening procedure with the ‘act’ of sex through hand gestures and the expression of feeling shame and embarrassment similar to the interviews participants, there is however another underlying reason for the degree of negative connotation:

*Jules (Non-English speaking lady): “Yes. I think as far as I know here, she is like that. She doesn’t like the nature of the screening especially after her sister in law told her about it. She said she doesn’t like someone else touching her and to think it goes into the vagina, she wouldn’t want to do it, that it will be painful and shameful.... (translator speaking). I think it has to do with her situation (domestic violence) just thinking. I have asked her, but she wouldn’t want to talk about the situation, maybe because it is too fresh”*

I did not enquire further, as domestic violence was not the central focus of this study and further inquiry will alter the course of the study. I also had to be sensitive to the needs of the participants as domestic or sexual abuse is a very sensitive and intrusive topic area. However, this participant’s linkage of the screening with ‘fear’ might be associated with her personal experience (sexual abuse) and the cultural or social stigma associated with the sex within her community.

In addition, most of the focus group participants had a form of pessimism towards cervical cancer and screening, as they associate cervical cancer with sex. Within their community, sex is considered taboo and is highly stigmatised especially for unmarried women. This stigmatisation of sex is associated with their lack of understanding and knowledge of cervical cancer, and the screening further heightens this negative feeling, creating feelings of shame, fear and embarrassment.

*Jamila: “... I’ll tell you something, like our country, like Bangladesh, I don’t know the Pakistani life, like, if we discussed a taboo, like the smear test, like the sex, it is like very shy. Because we don’t... We never discuss... Like this thing, in our family, in our parents, in our friends; we don’t know before, when I leave my country, like Bangladesh, we never [had] this discussion...”*

*Rakiya: “Yes... It’s a very dirty topic.”*

*I: “So, you said it’s something ‘dirty’, so why is it considered dirty? A dirty topic.”*

*Rakiya: “So she said... It is like... It is a part of her culture, I think... Our mothers; the mothers of mothers... They still... They don’t... I know my mother discussed with me a little bit, so I knew a little bit, but my friend didn’t know about all this sex and this, because her mother... It’s very big shame. Don’t share with me.”*

*I: “So is it... I know... Someone said it’s... associated it with promiscuity. Is it that... Like a lady who talks about sex; she goes about having sex a lot of the time...”*

*Amnat: “Like erm, I don’t want to use the prostitute... It’s like, you know, that sort of idea. So it’s like somebody who just...(hand gesture of sleeping around)...”*

In spite of the negative feelings associated with cervical cancer and its screening expressed by almost all the focus group participants, this did not deter some from actually participating in the screening. This is because to some participants the benefits of the screening outweighed the shame associated with it, as expressed by the participant below.

*Evelyn (Malaysian): “But even though I shame of the screening, I go because it is important and I see in my country, the people have cancer and... So I must go in to the screen and see the GP...”*

After further constant comparison of the initial interview data, the focus group and subsequent interviews were carried out concurrently until saturation was deemed reached and theory was created.

Acknowledging the fact that other themes were important and influenced the decision-making process with regard to health and access to available services, it was deemed important to further explore issues in the chosen category because of the effect it had not just in their verbal expressions, but also through gestures and body language. These gestures were observed during the interviews and focus group.

Preconceived notions, views and beliefs (fear of exposure, sexual stigma, pain etc.), which the individuals have formed prior to the screening invitations may relate to their age, knowledge of cervical cancer and the nature of the screening. These views or perceived ideas are likely to hinder or delay participation and for some, may act either as facilitator or possible barrier to screening. Most of these emotions seemed more likely to act as potential barriers rather than facilitators and may also be associated with perceptions of risk.

Experiences during screening could lead to either future delays or continuous participation in the programme. There was acknowledgment that future screening decisions were influenced by the participants’ experiences. Variation in experience occurred for both the focus group and interview participants. While some had unexpectedly good experiences, others had unpleasant experiences. The following quotes illustrate some of the experiences:

*Lin: “...So she couldn’t find the place, so she moved me right, or left, or... The general direction and it was quite painful. So in my experience... The last time, not the first time.”*

The participants below anticipated a bad experience but in reality, felt minimal or no pain.

*Rakiya: “Er, a little bit scared, because I don’t know if it would hurt or not, because in my country they say it hurts, because [they do] something totally different here... then there it is easy, because different... In my country... Just quick... It’s okay – it not hurt.”*

*Evelyn: “For me, it was [different, because my friend found it very painful], but after I’d been processed, then “Is this finished?” Ah, good, it’s okay. For me, it was okay”*

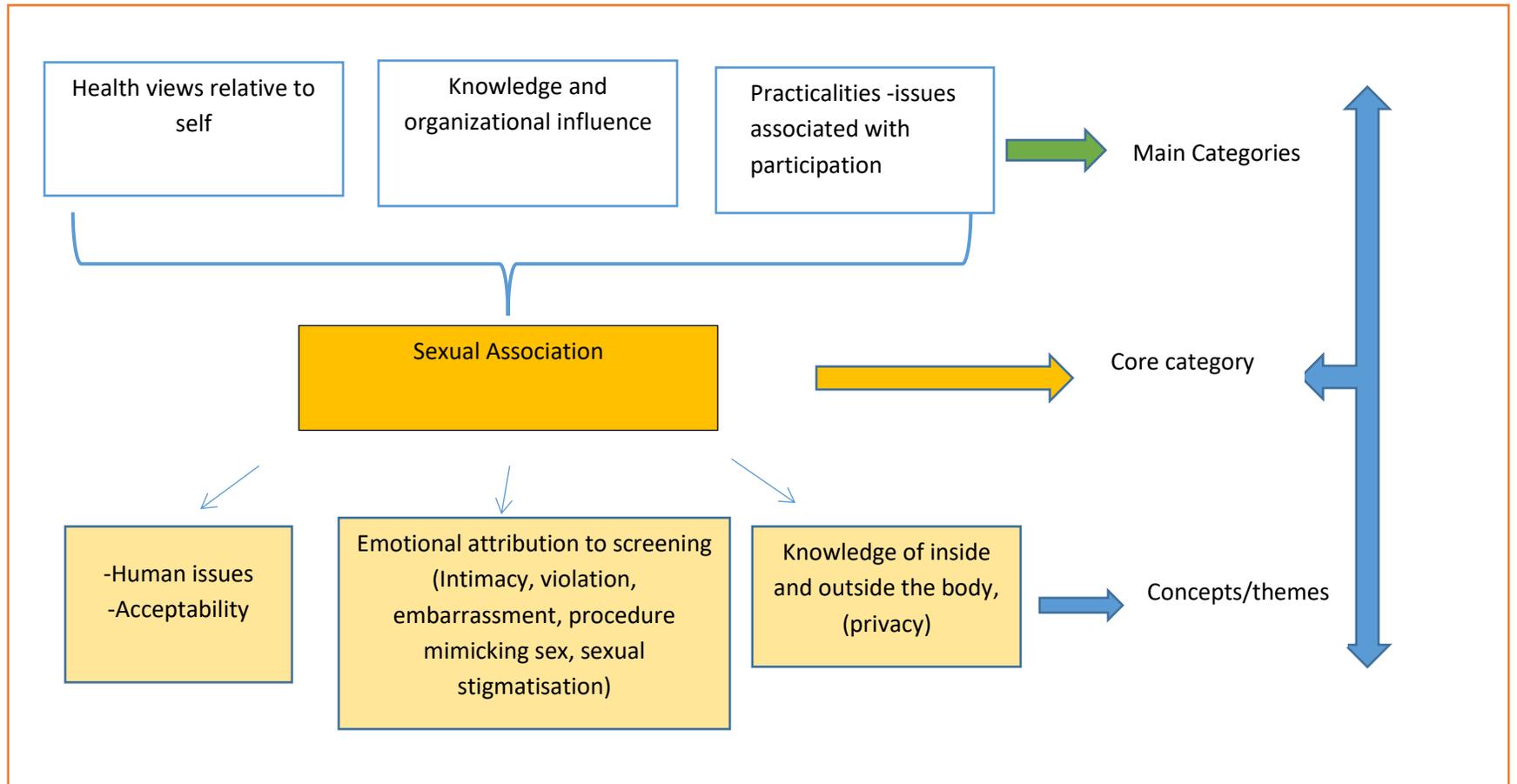
*Evelyn: “Yeah. For me, this is easy. Because [I’d heard] this is a long process and painful and... Because... [Indecipherable]. It’s okay”.*

*Laura: “Erm, it wasn’t as bad as I thought it was going to be, to be honest. I was a bit dubious about what would happen; I was a bit nervous, but it wasn’t that bad...”*

The themes from the analysis will be explored in depth later in this chapter, to enable better understanding of the contexts. The themes led to a conceptualisation of both the interview and focus group data providing a more contextualised interpretation of the findings in both groups.

At the end of the analysis, 3 main categories and a core category were created (see figure 21). The main categories fed into the core category thereby creating deeper concepts of the data constructed drawn from gestures and direct quotes from participants. These concepts within the core category show the overarching relationship that encapsulates relevant aspects of all the content constituting categories. The diagram below provides a clearer understanding of the relationship between the categories.

Figure 22 Relationships between the categories



The main conceptual categories (health views relative to self, knowledge, organisational influence and practicalities) were derived during selective coding, thereby depicting a more advanced conceptual label. The core category ‘sexual association’ (the main finding) seemed to act as a pivotal point in the decision-making process for participation. For example, despite participants’ beliefs and perceptions prior to an invitation for screening, they essentially exhibited similar emotions (as shown in the core category ‘sexual association’) around cervical cancer and its screening. The previous 2 chapters (chapters 5 & 6) offered opinions from the women that evidently supported the notion above. This chapter will now focus on the core category (sexual association). To recap, a summary is provided below of the 3 main categories that have already been explored in the 2 previous chapters.

### **Health views relative to self**

This involves preconceived views, how they translate into behaviours and the factors involved in the formation of those behaviours. These factors include social demographics (geographical location), socio-cultural (customs, tradition, religion and family culture), social (education/level of awareness or exposure) and psychosocial (personal and interpersonal perceptions and attitude). The behaviours on the other hand, include health views, perceptions and attitude towards health, knowledge of health and health services, and individual/body awareness.

### **Knowledge and organisational influence**

This involves various ways information is received (source of information); knowledge of cervical cancer and the impact of the screening programme; elements such as accessibility, experience, health service variation, invitation letters; and social or behavioural issues. The impact of the health professional’s influences on the decision-making process to attend the screening/actual attendance of the screening programme was also reviewed.

### **Practicalities**

These include anecdotal/potential/practical factors affecting participation or non-participation, including the impact of some of the elements from the 2 categories above, such as: culture and health service influence, and awareness. Acceptability varies across individuals because of perceptions based on the screening experiences of other people, which arouse emotions with a potential for negative or positive influence on participation.

This integration of both interview and focus group data will be centred around the core category ‘sexual association’. This core category was derived from the words as well as the body language/gestures of

participants. Gestures analysed include body movement and rolling of eyes. The step-by-step description of the analysis and themes are highlighted below.

### **Core category ‘sexual association’ analysed.**

The core category ‘sexual association’ focuses on sexuality or sexual associations related to cervical cancer screening and how this impacts on what implicitly makes up a woman (i.e. the intrinsic nature of the woman and her primordial human instincts). After a constant comparison of both the individual interviews and focus group, two levels of understanding of the core category of sexual association emerged. The interview data mainly associated the nature of the screening procedure to the nature and act of sex. The focus group data reflected a general understanding based on the stigma associated with sex and its association with cervical cancer from a social and cultural perspective. Both datasets explored knowledge levels and emotions, and contributed mutually to the conceptualisation of the core category ‘sexual association’ and the themes (elements). Further breakdown of the elements shows that it also touches on key feminine human issues related to reproduction (the sacredness of the genitals, sex and child birth) and mortality (death by disease or dying). These deep sexual feelings associated with cervical screening appeared to be linked to or created by a variety of factors such as culture (taboo, privacy, sacredness) and societal/social influence (body image debates or expectations).

The themes within the elements were in the context of knowledge or perceptions of the screening procedure and the emotions attached to the actual behaviour. These feelings and emotions towards cervical cancer, its screening and experiences of the procedure can be viewed as having a strong relationship with reproduction (sex and childbirth) and death (as cervical cancer could lead to death if not diagnosed on time). These represent some of the fundamentals of the human existence. The location of the cervix is associated with the issue of inside and outside the female body as stated below as well as, privacy and intimacy (the vagina area, where the procedure is carried out). Most participants used terms such as ‘privacy’, ‘intimate’ or ‘violated’ to express their feelings about the screening experience, as expressed below:

*Zara: “Erm, ‘cos I was kind of concerned about the privacy of the whole thing, ‘cos obviously, you have to get undressed and it’s quite undignified and just generally a bit unpleasant”*

*Beth: “probably because its very intimate, erm it’s not pleasant, i mean its not awful but its not you know you would like mark it out in your diary because you are dead excited about going for cervical screening (laughing) like its not pleasant, it not...”*

*Laura: “Erm, I think because of the nature of the screening, ‘cos you know, it’s down there and it’s a bit intimate and things like that”*

*Kim: “My sister; she’s really upset about it and before I went, she told me how she felt violated a little bit and I was like: Hmm. I think it’s just nice to have it checked”*

It is important to note that the demographics of both the focus group (mostly BME) and the interview participants (predominantly white/British decent) are different and may have influenced their responses and views. More detailed information about the participants is available in chapters 5 and 6. The elements or themes within the core category are highlighted below and presentation of the integrated data will be highlighted under these headings.

- Knowledge and personal experiences (body knowledge)
- Emotional attribution
- Human issues
- Acceptability (the issue of control, as well as the nature of the screening/procedure)

### **7.1 Knowledge and personal experiences; knowledge of the inside and outside the body**

This is in the context of body knowledge in general and how it correlates with knowledge of cervical cancer and screening. That is, it refers to the way we make connections to, and see the body, ranging from perceptions of ‘control’ as well as the emotional reaction in comparison to other substances or objects. These views and how they relate to emotions are based on overall health knowledge, knowledge of the body, cervical cancer and the screening itself. The body is perceived and sensed from various perspectives. Some of the focus group and interview participants perceived their body from both an external and internal context, likening it to the general concept of health, where health is viewed as being based on physical, mental and emotional wellbeing (although in some contexts, it is based on symptoms and mood).

*Lin: “Mentally prepare yourself to where we are going; what is going on inside [...our body and when a doctor will check us, what he or she can tell what is going on So it’s the first step, to go inside a hospital or surgery, or to examine what is going on inside your body”*

*Evelyn: “For me, health is inside and outside. Like, I agree with [name], er, [indecipherable], in my body; in the outside, we can see and then inside, like mentally, I agree with [name]”*

*Evelyn: “For me, health inside and outside. Like, I agree with [name], er, [indecipherable], in my body; in the outside, we can see and then inside, like mentally, I agree with [name].”*

*Jessy: “I generally believe, you should kind of, you know when your body is going wrong”*

The quotes above show that the participants viewed their health not only from the physical body/anatomy perspective, but also from what is happening internally. The literature on body awareness often takes for granted the fact that our bodily experiences seem exclusively based on our body senses. It is often

difficult to assess people's knowledge and perception of their body from verbal descriptions alone. Perceptions of health through definitions of body form and function are evident in how people describe/perceive their health and how that subsequently affects their attitude to health seeking or access to health services.

While the understanding of the body influences how health services are accessed and utilised, there exists a misunderstanding between what body knowledge means to health professionals and the service users, which could act as a hindrance to access. As can be seen in the quote below, there is an obvious disparity between how participants feel about their body knowledge and the perceptions of the health professional.

*Stephan: "...I will make an appointment and go and speak to someone, erm but i sort of feel like i know my own body and to be told by someone that i, feel i know my own body and what's normal and what's not. it's probably a kind of systematic failure to appreciate a lay person, like the actual experience of been unwell, like the lived experience of illness, so of something not been as it should be. I think people quite know in themselves when something is not right, and if that is not addressed..."*

The understanding of the inside of the body is drawn from ideas around what is unseen or unknown (the feeling of parts of the body being mysterious, deep within and unknowable, i.e. you can see what's outside and may even be able to see inside a little way, but there will always be deep dark bits where you cannot see what is going on), unfelt, and areas that cannot be self-monitored. Whereas the outside refers to and assesses what is seen, observed, felt and can be self-monitored. Socially, health is mostly defined by outward perceptions of body, its form and function, leading to healthy practices such as exercise and healthy eating, with the outcomes assessed through external physical changes. Some participants defined health based on physical actions, which provide evidence of its impact on their physical/outer body.

*Lin: "Physical and mental health. And especially for women and especially for today's topic. Er, it's not only about physical health, 'cos we can't see what is going on inside of our body, so we have to prepare ourself from there..."*

*:" Mentally prepare yourself to where we are going; what is going on inside [...our body and when a doctor will check us, what he or she can tell what is going on. So it's the first step, to go inside a hospital or surgery, or to examine what is going on inside your body. So it's not only physical; mentally healthy as well."*

*Faith: "I think health is very important. I am somebody that takes pride in leading a healthy lifestyle. I do a lot of exercise, I eat a fairly balanced diet; I obviously have the off bad thing, but I think that's part of a normal lifestyle. ... I think it's important to have a good, healthy lifestyle".*

The inside of the body was related to in more mental and psychological wellbeing terms, as shown in the quotes above. The perception of the inside of the body was also associated with sex. This was mostly in terms of cervical cancer and its screening, and is mainly based on the location of the cervix (internal and accessible only via the vagina), and the fact that this is where the procedure is carried out. This area is highly sexualised and led to a lot of mixed feelings – mostly negative. Unlike stomach or ear problems, the genitalia have a close association with sex. The genitalia also have significant sexual implications/issues in terms of cultural norms and taboos, which will be discussed later in this chapter. The quotes below illustrate a participant’s knowledge of the location of the cervix and its association with sex.

*Stephan: “it’s such an internal thing. everything else you have kind of have a sense when something is not right, erm but you are like i don’t feel pain it normal, everything is as it should be, but in actual fact it’s like anything could be going on, and you have just have no idea”*

*Rakiya: “Most of the ladies know what the uterus is, but they don’t know what is this... Where is the place exactly?”*

*Jamila: “Just a little bit, the cancer in the woman; in the inside of the woman especially. I don’t know what else in the...”*

Another area of note about perceptions of inside the body relative to cervical cancer and its associations with sex and death; cervical cancer screening is ‘messing about’ with a core concept/human issue very much connected with the fundamentals of human existence (discussed in-depth in the next session). A major catalyst of the fluctuation of emotions regarding cervical cancer and its acceptability may be seen in terms of knowledge. Many of the participants, and perhaps many women in general, are not knowledgeable about their anatomy. This lack of awareness, as well as negative stories about screening procedures seems to result in negative emotions, which could subsequently lead to non-participation. These feelings are discussed in the next session.

## **7.2 Emotional Attribution**

This focuses on anticipated emotions or emotional associations, which are either personal experiences or anecdotal. The nature and the screening procedure itself was a major challenge to women, whose concerns stemmed from the relationship or association with sex and sexuality. The participants in both the interviews and focus group did not like the way the pap smear was done. These emotions connected to their association to sex and the location of the screening (The vagina area is often seen as ‘sacred’ to varying degrees amongst women but mainly among ethnic minority women). Allusion of sexuality have various factors:

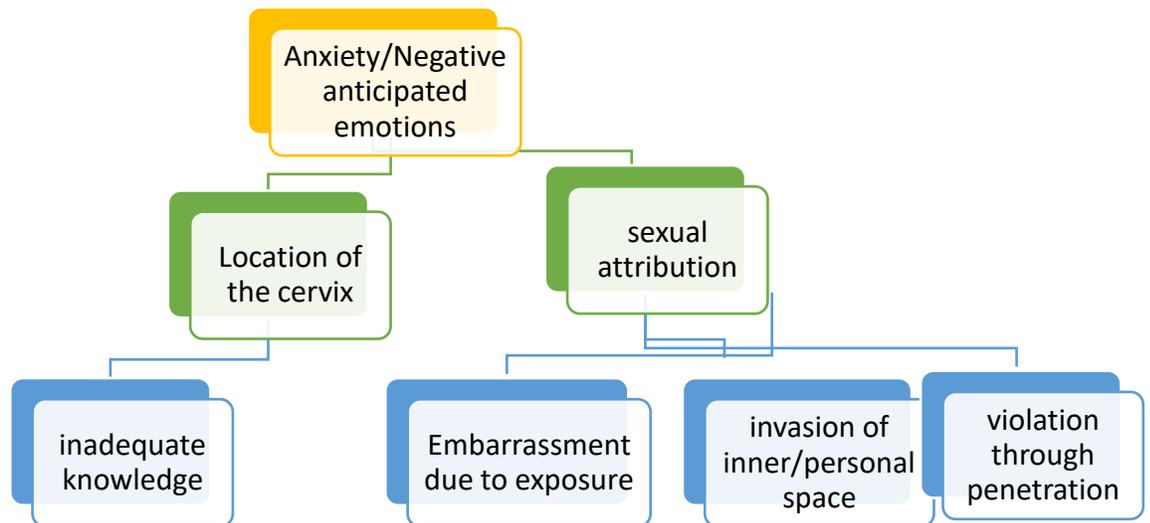
- Links between genitals and sexuality
- Negative feelings such as embarrassment, loss of dignity, integrity, violation, unpleasantness, discomfort, pain, anxiety/fear
- The act of screening mimicking/imitating sexual intercourse (expressed verbally and through gestures and rolling of eyes)
- Sexual experiences and maturity (impact of first screening experiences and childbirth)

Unlike past studies, which made reference to sexuality, this study showed a deeper/closer connection to sexuality, expressed in various ways. These feelings varied between women, but were related to by all of the women in spite of their sexuality or sexual history. It is noteworthy that although most of the participants expressed some level of dissatisfaction with the Pap smear test, four participants – two from the interview and two from the focus group – believed there was nothing unusual about the test. This category of participants expressed that the test was neither painful nor embarrassing and that there was nothing personal about the Pap smear test. These views are expatiated upon subsequently within this chapter.

### **Anxiety/fear/negative anticipated emotions**

Anxiety was associated with the location of the cervix and its relation to sex. This was experienced mostly before and during the screening procedure. Inadequate knowledge of what the screening entails also added to the anxiety levels, as illustrated below:

Figure 23. Findings on negative anticipated emotions.



Some of the illustrations shown below reflect anxiety issues. Negative emotions are exhibited because of the nature of the screening, which is invasive, and feelings of embarrassment and violation resulting from the penetration of the speculum through the genitalia.

*Jamila: "I worry... I scare easily, because the doctor will see my [genitalia], but here, I know the information available in the GP"*

*Lydia: "It was just a bit weird. Just kind of, you know, like showing a stranger thing that you don't usually show strangers and..."*

*Jules (Non-English-speaking lady): "Yes. I think as far as I know here, she is like that. She doesn't like the nature of the screening especially after her sister inlaw told her about it. She said she doesn't like someone else touching her and to think it goes into the vagina, she wouldn't want to do it, that it will be painful and shameful... (translator speaking). I think it has to do with her situation (domestic violence) just thinking. I have asked her, but she wouldn't want to talk about the situation, maybe because it is too fresh".*

*Evelyn: "I scare easily, because the doctor will see my [genitalia] and then, that is shame for me, as only my husband see my genitalia, for this I scare a lot... The screen was very shameful, because the nurse put this thing into your vagina (Make hand gesture of penetration) and the instrument shape like (make hand gestures describing the shape) and then you shame cos, you don't know what your body will disappoint you and only your husband see that ... so that is a shame for me..."*

*Frances: "... I don't like the idea of how obviously...but I think the whole idea slightly freaks me out. I don't want people to see things, you know opening your bits to someone you barely know (makes a gesture of disgust by shaking her head and shoulder) so I won't do it...Just the location and stuff like that and it seems really personal and I don't want other people you don't know touching or looking. Like I am fine with my boyfriend looking and touching after all he is my boyfriend and that is very personal (made a squirmish gesture)...but the idea and the location seems to freak me out... it is something more personal and in depth and that's just... I don't want... I don't like that sort of stuff..."*

*Karen: "I've had something done before which was... Where it was like that. But I think I was... Where we did the same procedure. And that wasn't pleasurable...But if it's the same procedure, it wasn't very nice and it wasn't very dignified mostly because it's such a private area and also because of its penetrating effect and it get stuck into your bits...that wasn't pleasurable and not the nicest thing... so I guess if it's the same, I wasn't keen to get screened."*

As can be seen in the quotes above, outside the invasiveness or exposure due to the screening, many participants infer through their gestures that the screening process is associated to the sexual act or mimicking sex. This was evident in the use of words like "penetration".. Yet although previous studies and this current study correlate cervical cancer to the word 'sex', no study has actually linked it to the act or mimicking sex. Some participants made this connection explicitly through both words and actions

(gestures). On further investigation with other participants, this thought process was more common than anticipated. The quotes below show more links between the screening procedure and sexual acts.

*Stephan: "...what happened was emmm the way I was, asked to stay on the bed it was... and then she placed the instrument into me to take the sample, it was just a bit much, the bed, the penetration and all that sexual kinda stuff, made it a bit uncomfortable you know..." (while making hand demonstration of sexual act)*

*Lydia: "Like I have said continuously I am a very shy person. Although I have been screened I felt an enormous shame after the screening. You know the screening instrument is pointed and when it went into me, I felt a feeling of sex, you know when you get penetrated. I can't really explain how I felt, but I felt that was something only my boyfriend should do and that was personal... That really made me feel shameful, it not a nice feeling at all..."*

*Zara: "...It wasn't as bad as I expected, so when I went back for the second one, like I wasn't as nervous. Still didn't look forward to it, but who would?"*

*Interviewer: "Why?"*

*"Just the whole process, like the dipping of the instrument into your vagina, it was just kinda sexual and then having to deal with a total stranger doing that, just made it more weird and uncomfortable... don't get me wrong, it wasn't painful but..Erm, but yeah, I think, you know, in terms of... (made hand gestures of penetration) that, it could have potentially been a barrier for me..."*

This had a bigger influence in the conceptualisation process and in deciding the variables for the chosen core category 'sexual association'. The context of sexual association was chosen from knowledge levels and the nature of the screening procedure (expectations and experience). This influenced the direction of the explanatory model in chapter 8.

In addition, the location of the cervix, coupled with inadequate knowledge of what the screening entails, created hesitancy among some of the participants.

*Laila (FGP): "Just the location and stuff like that and it seems really personal and I don't want other people you don't know...I don't have a clue, but the idea and the location seems to freak me out, whereas a vaccination's in your arm and it's your arm. Whereas like, if it's a screen, it might be something more personal and in depth and that's just... I don't want... I don't like that sort of stuff..."*

As expressed earlier in the chapter, negative feelings towards screening go beyond its surface associations with sex or negative psychological emotions. Rather, there are other underlying reasons, like the issue of cervical cancer being associated with sex by ethnic minority participants and screening procedure having a connotation with the act of sex. Sex is seen as a taboo and is often stigmatised. Norms and practices around sex and relationships emerged as important in influencing the ability to fully accept and participate in the screening program upon invitation. There were apparently different sexual

expectations for women in minority ethnic group, with the unmarried expected to remain sexually inactive until marriage. In this context, acceptance and attendance for cervical screening was indicative of sexual activity and was therefore delayed until after marriage, irrespective of sexual status/history.

*Annie (24 years old, English): “You see in their culture sex before marriage is very frowned at. And if you have sex before marriage it is seen as bringing shame or disrespect to the family, so women shy away from things like this”.*

*Bec: “I know it might seem like sex is well accepted within the English culture especially the way the media portrays it. However generally or personally, people avoid any intimate discussion about sex especially when it is not with your partner. Although sex seem acceptable, there is still subtle stigma around it. I wish I have better way to express it”.*

*Jamila: “To be honest sex before marriage is not accepted in my culture or religion. And women who do that are seen as shame. So cervical cancer bring shame as it has to do with sex right? My friends that I know who have made mistake to have sex, hide it and don’t go for screening because of shame and fear, you know not all are married...it’s shameful really it is...”*

According to Little et al. (2012), each society interprets sexuality and sexual activity in different ways. Many societies around the world have different attitudes to premarital sex, the age of sexual consent, homosexuality, masturbation and other sexual behaviours that are not consistent with universally cultural norms. “Likewise, societies generally have norms that reinforce their accepted social system of sexuality” (Little et al., 2012).

Socialisation or social interaction in the context of sex is influenced by many environmental and social factors such as culture, social class and social networks (including family). There is still a big divide between males and females in some cultures with regards to gender and sexuality, which is reflective in the place attributed to women within such societies. Therefore, there is an associative stigma and mockery attached to femininity, because feminine values are still unacceptable in some very patriarchal cultures or countries (Little et al., 2012). This cultural limitation may also be linked to gender role or the presence of a partner, which could either act as a positive or negative influence to accessing services. Positively, some participants exhibited altruistic behaviour by accessing services pertaining to their health because of their partner, whom they felt obliged to. A good example of this is highlighted by the response of the participant below:

*Zara: “Yeah, yeah. No, I think here is an element of looking after yourself when you’ve got other people in your life as well, ‘cos you want to be fit and healthy for them and... Yeah”.*

Conversely, partners could exert a negative influence, especially amongst women from ethnic minority groups in which women are viewed as secondary to men and, as such, permission is required from the male partner before personal decisions, including those about health, such as cervical cancer screening, are made.

*Rakiya: "And the first time, my husband said why you do this it's not important, so that's another reason some ladies are not..."*

This is compounded by the issue of knowledge. Some women and their partners might have little knowledge of cervical cancer. Below is an illustration of how this was made evident among the participants:

*Evelyn: "Because what their husbands I think are saying is: because they've only had one husband and one, like, partner – maybe sexually, they've only had one partner – there's no reason for them to go, because they believe that it might be linked to sex, rather than..."*

The attitude of partners, especially among ethnic minority groups, is due to the expectation that women are supposed to have only one sexual partner in their lifetime, as sex or issues around sex are considered sacred and taboo. There is a considerable amount of stigma attached to sex and, by extension, anything with sexual associations such as cervical cancer and screening, is not talked about. For example, the focus group quotes below illustrate the importance of the issue about sex and expectations of the women by their partner.

*Jules: "When I received my letter, my husband was like why do you go to screening, do you sleep with someone else... Like in my culture women do not have sex before their husband so that's why my husband say so... But I went for the screening for me."*

*Lin: "That's why maybe... I remember my husband saying "Oh, it's not important for you, because you know..." So maybe it's all about in the UK, the ladies who have boyfriends, or more than one boyfriend, so I heard... I didn't know... Now it's changed."*

From the quotes above, some cultures and religions may expect women to be sexually inactive before marriage. This demonstrates the high level of stigmatisation about sex or issues related to sex, discouraging most women from even talking about sex. This has great implications for screening attendance, especially among women within the study age group.

Additionally, fear was also a bigger factor in the creation of anxiety for participants. As addressed above, fear of exposure was one such anxiety trigger. Other triggers included fear of death or fear of not knowing what to expect. Fear in general acted as both a barrier and facilitator in this study. Fear as a facilitating factor stems from cancer's association with death and personal or family experiences of cancer in the family. This way of thinking was evident in both the interviews and focus group participants.

Rakiya: "...so I thought that it is important, so everybody [doesn't want] cervical cancer. So that's why I went..."

Jane: "Erm, just... I don't know. I guess it's a bit scary to think that you can kind of... 'Cos obviously it is one of the major cancers in women, so that kind of scared me and that kind of made me want to go and get screened. It was also my mum kept kind of badgering me about it, like "Oh, you're 25, now and you can go and get your screen". But she's quite... She's quite good at reminding me to go and get these kind of health checks and things like that, so yea.."

Kimly: "generally, I wasn't, **afraid** but about 2 years ago my mom was diagnosed with breast cancer, emm and ever since I have been a bit more concerned about things like that, I try, I know I have a history now ...i know but ever since i do try to keep an eye on my, i do regular blood test and em i went for my cervical screening and things like that i do try to be a bit more cautious.... I think its death, that's what scares me, you know it's not the treatment it's not, and it's just the end of it...but it's that worst case scenario that scares me a lot..."

Beth: "Erm, and I've got cancer in the family. Not cervical cancer, but a few different kinds, and so I thought: better to be safe than sorry..."

Association or fear of death from cancer also acted as a barrier or delay to screening attendance. This led to denial and avoidance of the topic of cervical cancer screening. Also, fear due of lack of adequate knowledge of the screening procedure, fear of exposure, feeling violated could potentially delay screening.

Fran: "...I haven't actually been told anything really, or heard any information about what it is, so I'm sort of freaked out... and you know its cancer and you know what knowing you have cancer does to you... so I'd rather not look for trouble, if that makes sense. I'm quite laid back; I'm just like: I'll deal with it when it happens..."

Bec "...My boyfriend's mum died of cervical cancer, so I do understand the importance of it...And you would... You would think that that would maybe make me a little bit more keen to go. But I suppose I'm not. I'm too laid back..."

Tayo: "I would assume fear, you don't know what it involves and you don't know what it is and some people might think it's painful, that's one side of things and that could delay attendance or put you off screening all together"

Stephan: "...it sounded quite unpleasant, i have heard horror, erm not horror story, my mom has painted it out to be something not very nice...she told me ...to be a woman err we have to undergo all these horrible things that men don't have to... and sort of described it as them using something to scrape the inside and then she made it really horrible and painful and uncomfortable and when i probably got that first letter, i probably thought of all my experience, ...i wouldn't really bother booking for this just yet..."

Bec: "...Well, it's not pleasurable, is it? And it's not something you would ever look forward to happening...So I suppose it... It's not very dignified, having things like that done. It's not very nice having your bits out in front of people..."

*Kim: "Erm. I'm fine with it. I was like: Oh yay. Check-up. Yeah. I know some... My sister; she's really upset about it and before I went, she told me how she felt violated a little bit."*

From the first 2 participants' quotes, it is evident that they have created this illusion of denial and attributing their fear of cancer to being laid back, with one explicitly acknowledging fear of cancer as her reason for non-attendance. Instances like this are some of the deep unspoken issues relating to non-attendance that might be evident in many non-attendees with a potential for influencing uptake. Fear of infertility was also a motivating factor. Being a woman is associated with being able to reproduce. This is explored more in section 7.4 (human issues).

**Embarrassment (dignity and modesty)** - The invasion of women's modesty is an issue and poses a barrier to the success of preventive programs such as cervical cancer screening. A number of studies describe women's expression of embarrassment concerning the screening programme (Teng, 2014; Marlow, 2015). These emotions act as either a driver or a hindrance to screening. Feelings of embarrassment might be associated with a sense of being violated, exposed, discomforted, undignified and associated pain. Feelings were mixed among the women who participated in the study. While some felt unpleasantness towards the screening, others expressed a more intense distress to the extent that it affected actual screening attendance, with some saying they do not look forward to the next screening or do not want to have another test in the future.

The emotions felt during the screening or even when thinking about it may be linked with feelings of modesty. Modesty on its own has different values during sexual and non-sexual encounters. The vagina may be conceptualised as sacred, sexual and any approach must ensure that the taboos are not violated and modesty uncompromised. These emotions expressed towards the screening were complex and difficult for the participants to elaborate and explain in the first instance.

*Beth: "ermm i did sort of i dont know , like it was a bit, that afterwards i felt abit like hmmm, i dont know i felt abit like you ve been exposed, i dont know, it felt abit weird i just wanted to go home and just sit with a cup of tea and gather myself a little bit. erm"*

*Lydia: "I just think it's such a difficult area; I mean, obviously, especially young people; they don't want to be going into doctors and showing doctors their bits and stuff and I just think: it's a really hard thing to do"*

*Stephan: (She raised her shoulders and pointed to her private while making hand demonstration of sexual act)... "what happened was emmm the way I was, asked to stay on the bed it was... and then she placed the instrument into me to take the sample, it was just a bit much, the bed, the penetration and all that sexual kinda stuff, made it a bit uncomfortable you know..."*

There is a natural instinct for women to protect some areas of their body, especially reproductive areas (vagina) from been seen by the outside eyes. Discontentment regarding exposure of the genitals, especially to someone unfamiliar were voiced by the women.

*Lin: "You know. But I get really shy. I get really nervous and that's not because of my culture or school, or anything; it's just knowing that somebody is going to have a look and somebody is going to see and you do, you feel really shy, but it's..."*

*Evelyn: "I know I have got an appointment now, but the only thing that puts me off is when you have to open your legs. That puts me off going, let's be honest that puts off a lot of women from going".*

This discontentment and need to protect the vagina from the view of outsiders/strangers was a general feeling shown by both interview and focus group participants. The feelings were further emphasised in the tone and stresses in their verbal expressions, and reflected the values they have on guarding their private parts from exposure. Women attach bodily meaning to their reproductive areas (breasts and vagina) in comparison to the other body parts. Unlike the breasts, which is also regarded as a private area (but which is used to feed babies and therefore partial exposure may be acceptable and tolerated in some instances), women's emotional response to the breasts and the vagina differs greatly. The vagina/genitals were seen as more private and only to be exposed (fully or partially) during sexual intercourse and childbirth.

*Jules (Non-English-speaking lady): "...She doesn't like the nature of the screening especially after her sister inlaw told her about it. She said she doesn't like someone else touching her and to think it goes into the vagina, she wouldn't want to do it, that it will be painful and shameful..." (translator speaking)*

*Evelyn: "I scare easily, because the doctor will see my [genitalia] and then, that is shame for me, as only my husband see my genitalia, for this I scare a lot..."*

*Zara: "Erm, because I knew what would be involved and it's quite... It's quite exposing, isn't it? It's quite an uncomfortable and strange situation to be in, that you would never normally being... It is very invasive and intimate .... like... It was just the thought of like... (shudders)"*

Negative emotions as a result of body exposure during screening were hugely imparted due to associated societal perception surrounding body image and attractiveness. Body image in this context is defined in accordance with Hebl & Heatherton (1998) as "self-perception of appearance that includes both perceptual experiences and subjective evaluation." In other words, how an individual sees themselves and their associated thoughts/feelings (de Vignemont, 2011). Many women have repeatedly admitted dissatisfaction with their body image. This varies across different parts of the body. A common area of body image debate is invariably related to self-perception of weight or body size. As the screening process includes being completely nude in front of a total stranger, it can trigger a negative response

especially amongst women who are already suffering from low self-esteem, or who might be afraid of being judged. Self-perception of the body could be socially bound. Social perceptions of the body include body size, shape, skin colour and height, and are used to define what beauty is or what is deemed beautiful socially. This has led to how women define their beauty and acceptance of their beauty by internalizing these standards, leading to high level of self-esteem issues. These imperfection issues are amplified when it involves intimate parts of the body, where people don't have much knowledge of how it is supposed to look like and compounded when the person has given birth.

*Jules: "Erm, 'cos I was kind of concerned about the privacy of the whole thing, 'cos obviously, you have to get undressed and it's quite undignified and just generally a bit unpleasant...which is worse when you have babies...trust me I have kids and I feel like that, don't know about others though...this is personal"*

*Jamila: "I felt shy because... Somebody checked the inside. I felt shy, but it is a part of the health checking, so it's fine. If she checked me, so it's good for me, so it's fine."*

*Rakiyat: "But I get really shy. I get really nervous and that's not because of my culture or school, or anything; it's just knowing that somebody is going to have a look and somebody is going to see and you do, you feel really shy, but it's..."*

Exposing one's genitals, as illustrated above, led to feeling undignified, uncomfortable and anxious for fear of being scrutinized by a stranger. A possible example could be having scars from previous sexually transmitted infections or vaginal injuries that are totally unrelated to sex, which could lead to a possible decrease in self-esteem or self-consciousness that is not vocalised by some participants. These chains of perception present as a threat to privacy and honour/dignity, which could lead to non-participation in some extreme cases.

As stated earlier, some socio-cultural practices could also lead to these feelings. Some cultures and religions do not speak about sex related topics.

*Lin: "You know, if I talk openly to... You know, in our country, where I came from, even when we got married, we were not told what is sex? So it is... it is all about, or near to sex, because when you make that relation, it is after that you get... Like I know about smear and cervical test, you can get that, erm, germs or whatever from your partner or husband, so we don't discuss about sex. So that's why"*

Issues of sex were considered 'dirty' and are associated with promiscuity. The quotes below showed the exact words of the participants.

*I: Is it the word 'sex'.*

*Rakiya: Yes.*

*I: ...That makes them shy?*

*Rakiya: Yes... It's a very dirty topic.*

*Lin: "Like erm, I don't want to use the prostitute... It's like, you know, that sort of idea. So it's like somebody who just... (hand gesture of sleeping around)"*

Even having in-depth knowledge of Pap smear test did not guarantee that women will go for the Pap smear. Some women procrastinated by postponing their screening due to these emotions being a barrier. Knowledge on its own did not mean that women would attend the Pap smear or test.

*Bec: "Well, it's not pleasurable, is it? And it's not something you would ever look forward to happening. It's not something where you're getting anything out of it, really... so I just sort of forgot after putting it off for too long..."*

*Fran: "I can't be bothered and also, I don't like the idea of how obviously... Or I don't know how it's done, but I think the whole idea slightly freaks me out. I don't want people to see things, so I won't do it"*

The enormity of their feelings acted as a barrier to participation. The feeling took an overwhelming hold on some participants, affecting their intention to participate in the screening. These feelings were evident in both screened and unscreened participants.

*Fran: "Yeah, it's embarrassing and I'm just one of those shy... And I'm just an 'I don't like that sort of thing' person, but that's personal for me; that's not obviously the reason why you shouldn't go for screening. It's just that.....I just feel...I just didn't go..."*

However, it is worth noting that although a lot of negative emotions were expressed as acting as barriers and leading to non-attendance and delayed attendance in screening, there were few exceptions. These negative feelings or experiences did not deter them from actually participating or thinking of participating in future screening. This is because to these participants the benefits of the screening outweighed the shame associated with participants as expressed below:

*Evelyn (Malaysian): "But even though I shame of the screening, I go because it is important and I see in my country, the people have cancer and... So I must go in to the screen and see the GP"*

*Jessy: "emm yea, it did discourage me from going because I thought, I basically thought it didn't apply to me, since I wasn't sexually active, em, that's what I understood, from what they said to me".*

*Kimly: "...but I didn't have any doubt. The minute I got the letter, I arranged an appointment to do it, I mean I never thought maybe I shouldn't do it or should wait. I thought now that it time to do it and I can I will just do it..."*

As can be seen in some of the quotes in this chapter, apart from expressing their opinions through words, participants' body language has also reflected some of their unspoken thoughts and true feelings about screening. These were captured by the researcher through keen observation. In some instances, they were squeamish and physically wore their irritation on the face and body movement.

Women who have undergone childbirth expressed that childbirth had indeed desensitised the feeling of embarrassment/anxiety felt during the screening. Others argued that despite going through childbirth, feelings of discomfort, anxiety, discomfort and pain were still experienced.

*Amnat: "well for me to be honest, I didn't hesitate when I got the letter, I feel once you have had children, you do not feel shy anymore. I know (add name) mentioned been shy and embarrassed, but I think for me, that wasn't the case, the doctor have already seen everything before when I had my kids, I wasn't really bothered about that to be honest"*

*Jamila: "I have children but every time I go for screening, I keep saying next time I am not going to do this...because it is not pleasant, it's just uncomfortable... I just don't like it"*

One possible explanation could be that the feeling of distress/pain due to the desperation to get the baby delivered was much greater than the feeling of embarrassment or anxiety associated with screening. Hence, it perhaps felt permissible (without being embarrassed) to have the genitals exposed during childbirth/delivery compared to undergoing other gynaecological examinations such as cervical cancer screening.

The relationship between body image, sexual association and other negative issues expressed by women during the study seem to be a logical direction and make conceptual sense as it feeds into other factors and issues. This was therefore included in the developed explanatory model as a variable in trying to understand factors influencing screening participation from a deeper emotional and psychological level.

## **Pain**

Negative information or misconceptions of pain during screening (for those who had not yet been screened), as well as previous experience of screening (for those who have been for screening) were also expressed. This was related to not knowing what the screening procedure would entail. A lack of detailed insight into what the smear test entails in terms of the instrument, health professionals' expertise and gender, or familiarity with the health professionals reflects inadequate knowledge of the screening procedure. This ambiguity of the procedure and negative tales of screening led to a high level of anxiety during the screening.

*Lydia: "Erm, I think when I first got the letter to go, I was a bit scared, because you hear a lot of horror stories about how horrible it is and how painful it is and how embarrassing it is, so I think I kind of went in thinking: it's going to be awful; it's going to be horrific..."*

*Amnat: "...So she couldn't find the place, so she moved me right, or left, or... The general direction and it was quite painful. So in my experience... The last time, was really painful and horrible and it kind of would put me off it for a while..."*

*Faith: "I was a bit apprehensive... Well, I don't know; I obviously thought it was a very necessary thing to ...but obviously leading up to it, I was a bit nervous about what would be taking part in the tests and I think if we maybe told people a bit more about what to expect when they're going for the screening..."*

For many first-time takers, anxiety arises from the expectation to feel pain, based on negative information received from friends or family members, which is still evident even when equipped with enough information about the cervical cancer screening and the screening procedure as shown in the quotes below:

*Zara: "Well, it's not exactly the nicest thing to have to do, is it? Um, yeah. It's kind of scary. Especially the first time. I guess it gets a bit easier after that. But the thought of going the first time is quite [upsetting?]" ... because I knew what would be involved and it's quite... It's quite exposing, isn't it? It's quite an uncomfortable and strange situation to be in, that you would never normally being. Like... It was just the thought of like... a friend of mine said it was like having sex but not a pleasant one if you know what I mean..."*

*Stephan: "...it sounded quite unpleasant, i have heard horror, erm not horror story, my mom has painted it out to be something not very nice...she told me ...to be a woman err we have to undergo all these horrible things that men don't have to... and sort of described it as them using something to scrape the inside and then she made it really horrible and painful and uncomfortable and when i probably got that first letter, i probably thought of all my experience, of something like that, was all i knew what my mom has told me and i was probably like that ...i wouldn't really bother booking for this just yet..."*

However, a few negative cases occurred in that the anticipation of pain did not influence attendance. Also, although some people had actually had a painful experience of screening, others had more positive experiences:

*Lin: "Er, a little bit scared, because I don't know if it would hurt or not, because in my country they say it hurts, because [they do] something totally different here... then there it is easy, because different... In my country... Just quick... It's okay – it not hurt"*

*Evelyn: "Yeah. For me, this is easy. Because [I'd heard] this is a long process and painful and... Because... [Indecipherable]. It's okay."*

*Kimly (Greek girl) "...the actual process was a bit uncomfortable but it wasn't actually painful or anything, it was a bit awkward"*

The idea of going for the screening without adequate understanding of the procedure can be likened to relinquishing control. Allowing the health professional to access a very private area of the body without a prior full understanding the procedure is like relinquishing control to the process to the health professional to attain a perceived benefit. On the other hand, having continuous and sufficient

information of what is to be expected during the process leads to a feeling of comfort, which can be likened to regaining a certain degree of control, which makes the screening less uncomfortable for most women. A participant illustrated the relinquishing and regaining of control below:

*Faith: "But mine was fine. Erm, went in and they were very welcoming, very friendly, they explained what was going to happen and when they were actually carrying out the procedure, they were sort of telling me what was going to happen next, before they actually performed the procedure, so that I was aware of what was happening and that's good, because if you know, then you are kind of... You're a bit more relaxed and you know what to expect, rather than it being... sudden".*

Emotions are psychological barriers that cannot be seen and are difficult to explain and combat. Until these feelings or emotions, especially around sexual connotation during the cervical screening, are better understood, there is a possibility of continuous avoidance of the screening due to this subconscious barrier.

Issues around health professionals/past experience of health service (facilitating the situation) influence were noted, i.e. from expertise to trust. The participants asserted that the screening procedure could be made either easier or less awkward by the level of professionalism, sensitivity, empathy and understanding displayed by the test taker. Some participants reported feeling pain or emotionally low as a result of the conduct of health professional. Reports of feeling more pain on a second visit, after experiencing less pain from their previous visits were made.

*Rakiya: "For me, it was a little bit hard that the nurse couldn't find the... So she couldn't find the place, so she moved me right, or left, or... The general direction and it was quite painful. So in my experience... The last time, not the first time... I felt very uncomfortable after three hours... I am not looking forward to the next one to be honest...i might not even go..."*

*Stephan: "...I still think the way it's done; i just have major problems with it. I just think it's irresponsible to send people really vague information that they feel they can't talk to anyone about it, and just causes anxiety, er...the problem is, they are just really badly communicated to the lay public, like really badly..."*

Sensitivity on the part of the test taker/health professional could aid in the procedure being more accepting. Understanding that each individual is different and is in a unique situation should prompt health professionals to tailor their treatment to the individual needs of participants, rather than providing a routine treatment to all. This could lead to a more trusting and caring relationship, enabling women to feel more comfortable, and less judged and exposed. Some participants stated that some of the health professionals' actions (lack of sensitivity) are influenced by the way the system is structured in terms of time allocation (see quotes below). However, being sensitive is proven to have a positive and profound

impact on participants' screening perceptions and their overall experience. An example of how sensitivity on the part of a health professional helped ease the anxiety of a participant is stated below.

*Kimly: "...I think its this fear that the information given plus the kind of interaction that you have with a health care professional, kind of give this kind of mixed messages and by the time you leave you sort of think, i didnt really like explaining how i was feeling, this or the next thing because you have got to give the information to them in a way its appropriate for them to process it and then say this is what's wrong with you or this is what not wrong with you... Erm and i think its almost like its a bubble and its really hard for health care professionals to step outside of that bubble... sometimes i have done it, the minute i have closed and said thank you to the GP closed the door, walked again and i felt i dont really feel like i explained very well, or i dont really feel like they understood what i was trying to say and thats really frustrating..."*

*Stephan: "Hmm. I think, you know, the staff were brilliant; they were really friendly, they helped me to calm down. Erm, 'cos I was kind of concerned about the privacy of the whole thing, 'cos obviously, you have to get undressed and it's quite undignified and just generally a bit unpleasant, so you know, they shut the curtains and gave me a towel, or a sheet of paper...it did put me at my ease and... 'Cos she chatted to me during it and just took my mind off it and stuff, so... Yeah".*

Previous negative experiences of health services that are unrelated to cervical cancer screening could still have a similar negative effect on an intimate procedure like cervical cancer screening that would result in either a delay or non-participation. This could be mediated by way of a gradual erosion of trust over time because of past failures on the part of some health professionals. This was evident in the case of 2 participants, who highlighted a lack of trust in health professionals as reason for non-participation.

*Beth: "oh yea.. i know that sound really bad but i think its partly to do with the experiences i have had and also my mom has been long term disabled and they have never very adequately been able to help her. i think it's kind of a personal thing that i just sort of don't have a lot of faith in health care system...."*

*Bec: "So I suppose it... It's not very dignified, having things like that done. It's not very nice having your bits out in front of people. And I suppose it's one of those things, because I've been meaning to change my GP surgery. I wouldn't be comfortable with any of the nurses in there, because... Certainly not for anything that personal... It doesn't feel... not after what I have experienced in the past with them... I have totally lost my faith in them."*

The influence of health professionals on participants' decision-making in favour of continuous access to health services cannot be overestimated. Their attitude can either encourage or hinder participation. The need for continuous training of health professionals on the sensitivity issues around intimate procedures such as cervical screening is important, as evident in the above quotes. The issue of trustworthiness is paramount. This is because cervical cancer screening entails temporarily ceding control for a more beneficial outcome and exposing one's most intimate body part to a total stranger. Therefore, the issue

of trust between the health professional and the smear test taker (participant) is very important as this could lead to future access of available services.

### **7.3 Acceptability/unpleasant necessity**

The invasive nature of the screening procedure makes acceptance of the screening difficult. Negative feelings as a result of the nature of the screening, although felt and acknowledged, were not enough to hinder participation. The screening was perceived as beneficial and an unpleasant necessity. Expectations of the procedure were mostly negative, except by a few who had undergone similar procedures for unrelated purposes.

*Faith: "Oh, it was nothing to worry about whatsoever. I mean, I've had sexual health checks in the past and they have been the same checks; the same kind of testing procedure, but I didn't know that it was that simple. I mean I spoke to older friends a little bit about it before I went and they sort of described the procedure not as... I don't know; they made it out worse than it actually was".*

These supposed negative expectations were influenced by experiences from family members, friends, peers or past negative experiences from similar procedures unrelated to cervical screening. These led to feelings of anxiety, fear and nervousness. These negative tales or experiences have already been discussed previously. One example of such negative information or reference is shown below:

*Beth: "they just sort of said it was quite painful. They said that it feels like, when they're taking the swab, they're reaching up a very long way, as if they're reaching up into your stomach, whereas I didn't think it was that bad at all. It was nothing to worry about. I've definitely had the same test before and it's never bothered me at all".*

Despite having these feelings towards the screening, some participants felt that knowing their health status and having a sense of control over their health superseded the unpleasantness. Those who showed enthusiasm towards the screening saw it as an obligation or a duty borne out of a sense of responsibility to themselves to be screened. Those who were less enthusiastic preferred to be in denial, rather than go for screening. The quotes below express the views of those who felt obligated to attend:

*Kim: "yeah, like, I don't know. I just kind of trust that if they're going to the effort to send out letters to ask people to come for screening, then there's a reason."*

*Jessy: "because it thus reduces it that much, so it just seems like a sensible thing to do really...I think its sensible because you can die from cancer, so I think it's good."*

Those who were less enthusiastic and less accepting are below:

*Fran: "I'm not sure. I'm sort of one of those people who is quite laid back in some respects. I'd rather not look for trouble, if that makes sense. I'm quite laid back; I'm just like: I'll deal with it when it happens"*

*Bec: "My boyfriend's mum died of cervical cancer, so I do understand the importance of it. And I'm not ever going to turn around and say it's not deadly or it's not important because he lost his mum at 8, to cervical cancer... I'm too laid back"*

Despite the mixed feelings and anticipated negative emotions, some positive feedback of the screening experiences was received. This was attributed to the high level of negative expectations regarding the screening, geared towards the worst-case scenario. However, the positive feedback was accompanied with feelings of being uncomfortable and it being unpleasant. Experience from the actual screening was more positive and better than expected for some participants, especially from first time test takers or attendees.

*Jane: "Erm, it wasn't as bad as I thought it was going to be, to be honest. I was a bit dubious about what would happen; I was a bit nervous, but it wasn't that bad. The nurse was really lovely ... I thought it was going to be much worse than it was, so... Yeah"*

*Evelyn: "Yeah. For me, this is easy. Because [I'd heard] this is a long process and painful and... Because... [Indecipherable]. It's okay"*

#### **7.4 Human issues**

Issues identified in Figure 22 above are associated with death, privacy and violation. These issues can be classified as human issues and are associated by all women, irrespective of age, ethnicity, education, awareness or screening history. The 3 big human issues are:

- birth
- reproduction
- death

Cervical cancer and its screening are closely related to reproduction and death. The issue of reproduction is due to the location of the cervix (within the reproductive anatomy). Cervical cancer can lead to the removal of the cervix and subsequently infertility. In more advanced cases, cervical cancer could lead to death (this will be discussed separately). The screening procedure also focuses on the female genitalia and is invasive. The quotes below show how participants related the location of the cervix in regard to issues around fertility.

*Joy: "They said that it feels like, when they're taking the swab, they're reaching up a very long way, as if they're reaching up into your stomach, whereas I didn't think it was that bad at all"*

*Lin: “Most of the ladies know what the uterus is, but they don’t know what is this... Where is the place exactly?”*

*Jamila: “Yeah, because some people in my country also have a cancer, who have many children and I don’t know what... They might not be good in their life and they have cancer and they lose [the ability] to have children again...”*

*Lin: “No, she said the doctor already removed the uterus, so she cannot conceive...[Speech overlapping]... Because the cancer is like all the uterus; that’s why they remove..., I fear because I want to have children, that’s why I go...I fear in my culture children is important...”*

Associations linking cervical cancer with death are another area that creates negative emotions. This both positively and negatively influences screening attendance. The word ‘cancer’ arouses a strong emotion of fear because of the relatively high mortality rate of any form of cancer (WHO, 2013; Cancer Research UK, 2011). Cervical cancer can lead to death if not diagnosed early. A late cancer diagnosis could alter an individual’s quality of life, as well as that of those around them. In most cases, it eventually leads to death. Below are some of the quotes where participants associated cervical cancer to death.

*Kimly: “death... i know it’s awful, that’s the first thing that come to my mind. even though i know a lot of people that suffer from cancer survive, i think my personal fear ...I think its death, that’s what scares me, you know it’s not the treatment it’s not, and it’s just the end of it. I just think like it’s the worst case scenario you never know if...”*

*Lydia: “Yeah. I think since my uncle died from cancer, I think I’ve been a bit more kind of conscious about it and kind of reading things a bit more on the internet and kind of... Like risk factors and things kind of scare me a bit more now”*

The association between cervical cancer and death led to both attendance and non-attendance among the participants as indicated in the quote above and as discussed under fear earlier in the chapter. Some participants saw the screening as a great relief, whilst others felt indifferent and did not feel the need to know their status due to fear, as stated in the previous section.

*Jane: “Erm, just... I don’t know. I guess it’s a bit scary to think that you can kind of... ‘Cos obviously it is one of the major cancers in women, so that kind of scared me and that kind of made me want to go and get screened...”*

Other human factors or issues not directly associated to sex but acting as potential barrier or delay to screening are stated below. Some have been discussed in the chapters 6 and 7. However, one human factor not explored in the previous chapters is highlighted below.

### **Pregnancy/reproduction**

As stated earlier, cervical cancer has implications for reproduction as it could lead to infertility. If caught early, reproductive ability may be salvaged. On the other hand, reproduction or pregnancy acted as a delay/barrier to attendance for some participants. Most participants in this study’s age group are within

the reproductive age, with some either married or in long-term relationships. Pregnancy was one of the reasons for non-attendance/delayed attendance to screening. Since pregnant women are not screened for cervical cancer, women who have had multiple pregnancies within a short period of time tend to forget or delay going for screening. Below are some quotes from participants who cited pregnancy as a reason for not being screened.

*Laila: "Actually, when I went the first time, like her, I was pregnant, so I didn't go when I came here, so after that, I got information from the nurse and GP and is it important or not...although I am still not screened."*

*Vivian: "As you can see I have 2 young children, one who is a toddler. I haven't gone for screening because I have fallen pregnant just few months after the birth of my son. When I initially got the letter to come for screening, I was pregnant. The nurse said I couldn't have a screen so I should come back after giving birth. I haven't gone back as I had another baby. I have been too busy with the kids to go for a screen, although it's at the back of my mind"*

The above human issues play a part in the influencing the decisions of participants to go for screening. The internal location of the cervix and the need to access the genitalia during screening could constitute barriers that the women might be unaware of (the bigger picture of unconscious awareness). These issues might be within the depth of the intimate self, which the individual might not be aware of and so not directly acknowledge as a barrier.

### **Attitude to screening (practical issues)**

Attitude is not a predictor of actual behaviour. Research has shown attitude to be a poor predictor of actual behaviour (Marteaous, 2002; Glanz, 2010; Labeit et al., 2013; Clarke et al., 1999). Having a positive attitude towards health and cervical screening does not guarantee attendance, as other practical issues such as job, time factors, difficulty getting suitable appointment time, etc. may affect attendance (these have been explored in the previous chapters). These factors will not be addressed in depth because other deep-rooted issues like the elements of the core category take pre-eminence in the overall conceptualised finding. Some illustrative quotes about practical issues are stated below:

*Jane: "Yes. Regularly, since I go the first letter, although you're asking me to do this interview has made me realize that actually, I've missed my last appointment, ...I've phoned a few times; they can never fit me in after five O'clock, so... Yeah".*

Other factors that influenced attitudes to screening include: cognitive dissonance and ambivalence. This is when an attitude is not equal to behaviour. This was evident in some participants with regards to their health. For example, some participants who are cognisant of the implications of cervical screening and are knowledgeable in terms of education (with some working in the cancer field), surprisingly reported not being screened.

*Jane: “No, I know. It’s just... I’m not a lover of doom and gloom. So I’m an optimist. Which is maybe another reason why I haven’t gone to that – is because I’m an optimist and I don’t think that anything bad is every going to happen and there’s no horrible people or anything like that. And... So maybe I am a little bit too much of a positive person.”*

Ambivalent behaviour/attitudes exhibited by a participant is shown below:

*Bec: “And it’s not something you would ever look forward to happening. It’s not something where you’re getting anything out of it, really. Because it’s... Because it’s either going to be everything is fine, which I assume it is at the moment, or bad news.”*

The reasons presented for non-participation by some participants were quite unconvincing and could even be deemed as frivolous. Some of these include: denial (not wanting to know their status) and anger at being told what to do.

*Fran: “I’m not sure. I’m sort of one of those people who’s quite laid back in some respects. **I’d rather not look for trouble**, if that makes sense. I’m quite laid back; I’m just like: I’ll deal with it when it happens”.*

From this integration chapter, it can be implied that factors influencing participation and non-participation are multifaceted and multifactorial. In this study, issues affecting participation, such as delay in screening are very deep rooted and go beyond the practical issues identified in previous studies. While some issues acted as both barriers and facilitators (such as fear), others acted individually as barriers (nature of the screening, sexual association, knowledge level) and facilitators (altruism, partner’s influence, knowledge level and general positive attitude to health). Whilst acknowledging that past studies have made mention of emotional issues such as fear and embarrassment as a possible barrier, those factors were identified and explored in a deeper and more contextual level in this study. Most prominent was the issue of sexual association that cervical cancer has to screening acceptance and participation. This was in the context of knowledge level, nature of the screening and also health professional or institutional influences. The emotional and psychological impact of these influences cannot be overemphasized when exploring the ways this impacts behaviour and the decision-making process for cervical screening attendance. The explanatory model explained in chapter 8 shows how these main factors and variables influences each other and affect screening decisions overall.

### **Summary of Chapter**

The focus of this chapter was the conceptualisation of the findings, which led to the derivation of the core category: sexual association. Sexual association shows the relationships between the categories derived in chapters 5 and 6, and how they fed into this core category. This was explored through the 4

elements/concepts that make up this core category. These were: body knowledge, emotional attribution, acceptability (attitude towards and actual participation) and human issues. Practical issues, which were the main findings from previous studies (see chapter 2) were also acknowledged but not in depth. These constituted components of the evolving overarching explanatory model described in chapter 8. The next chapter will discuss the key findings of this study by focusing on the core category, sexual association, as guided by the explanatory model.

## CHAPTER 8: Discussion

The study purposes were to consider the health views of young women as they pertain to cervical cancer prevention and screening; to identify and evaluate factors influencing screening participation, appraise the relationships between the factors and assess appropriate interventions to encourage uptake of the screening. Through the methodology and data analysis, these aims have been addressed.

Past research studies, health websites, international and local health promotion policies as well as research covering a range of disciplines and theoretical perspectives were reviewed to justify and inform the present study. Moreover, literature from the fields of sociology and health psychology that focused on behaviour models and theories were also used.

Upon the review of existing literature on factors influencing participation in the NHSCSP, it was revealed that there were inadequate UK studies in the 25-34 age range, particularly in the Northeast of England. Most existing studies and literature were conducted in the Southeast of the UK, like London. However, a few studies were conducted in other countries in Europe and America, although operationally and contextually they showed a huge structural and social variation. A few studies adopted qualitative methods, but none used grounded theory.

This section also shows inclusion of a new set of literature, which is pertinent to the discussion and helps take forward the theorising and thinking about the findings. The analysis and emergent themes pointed me towards a different set of literature to what was included in the literature review chapter. Had I only stuck to the literature I looked at originally, this would not have done justice to the findings or the participants and would have perhaps forced the data to fit pre-conceived categories from the literature rather than allowing the data to 'speak'.

Glaser (1998) argues that the answer concerning which literature is relevant is unknown prior to the study and remains so until the end of the analysis. Only then do we have enough knowledge about our own study to make an adequate literature search and weave it into the GT data. There is a potential that the literature could change during any qualitative research especially a GT study based on theory or data collected (Glaser, 1998), i.e. findings could lead to the introduction or integration of a whole new literature base. Although different schools of thought have argued about literature within GT, Charmaz and Glaser state this could occur at any stage within the study. Glaser advises researchers to be prepared and open to integrating new literatures they didn't think could fit into their study from the beginning as a result of the data collected or theory created (Charmaz, 2006; Glaser, 1998).

Use or introduction of new literature is required to better explain or elaborate on emergent data. This is similar to abduction in GT. The general idea of abduction is to select or invent a hypothesis that explains a particular segment or set of data better than any other candidate hypotheses (Douven, 2011), “where the adoption of the hypothesis is not as being true or verified or confirmed, but as being a worthy candidate for further investigation” (Douven, 2011). By applying the principle of theoretical sampling to the ongoing literature review, the researcher searches and reads literature guided by the codes, concepts, questions and ideas he or she develops during data collection and analysis. This is a highly interactive process in which the researcher’s coding and questions take him or her to some of the literature, which in turn sends him or her back to the empirical field and to his or her tentative codes and concepts with new lenses. This was one of the deciding factors for the approach adopted when I included new literature within the discussion, which was guided by the data analysed and concepts within my explanatory theory (Charmaz, 2006; Thornberg, 2012). It is also noteworthy that there are various types of literature and there is a possibility that literatures with more empirical content are more helpful in the earlier stages of the research, while literature with a more abstract and conceptualized content is more useful in the later stages (Thornberg, 2012).

In a similar method to the one adopted in this study, Hickey (1997) experienced that his pre-study literature review led him in the wrong direction by giving him assumptions that mismatched with his data. Fortunately, he was sensitive to the data and did not treat prior knowledge as sacred truths, and therefore adopted literature based on the data derived from the study. This discussion section will include a number of new literatures whose inclusion was driven by the categories within the data analysed such as the screening programme, mimicking sex, and issues around fertility. Literature was sought from the field of psychology and some feminist literature was included, as it related to the category discussed.

The paucity of research evidence within the specified age group (25-34) acted as a premise for this qualitative study. This study therefore explored and gained an in-depth insight and understanding on the influences/factors hindering and encouraging attendance to cervical cancer screening. Chapter 3 provided an insight into the researcher’s philosophical viewpoint and justification for the chosen methodology as well as a detailed systematic description of the research design. Chapters 5, 6 and 7 focused on the findings, showing a descriptive presentation of emerging themes/concepts from both the interviews and the focus group (chapters 5 and 6), as well as the conceptualisation (integration) of findings from both the interviews and the focus group (chapter 7). Chapters 8 and 9 discuss the findings presented in Chapter 7 against the backdrop of other relevant literature, to contrast with existing public health behaviour theories. This is followed by recommendations for policy, research and practice, then a conclusion indicating how the findings contributed to existing knowledge.

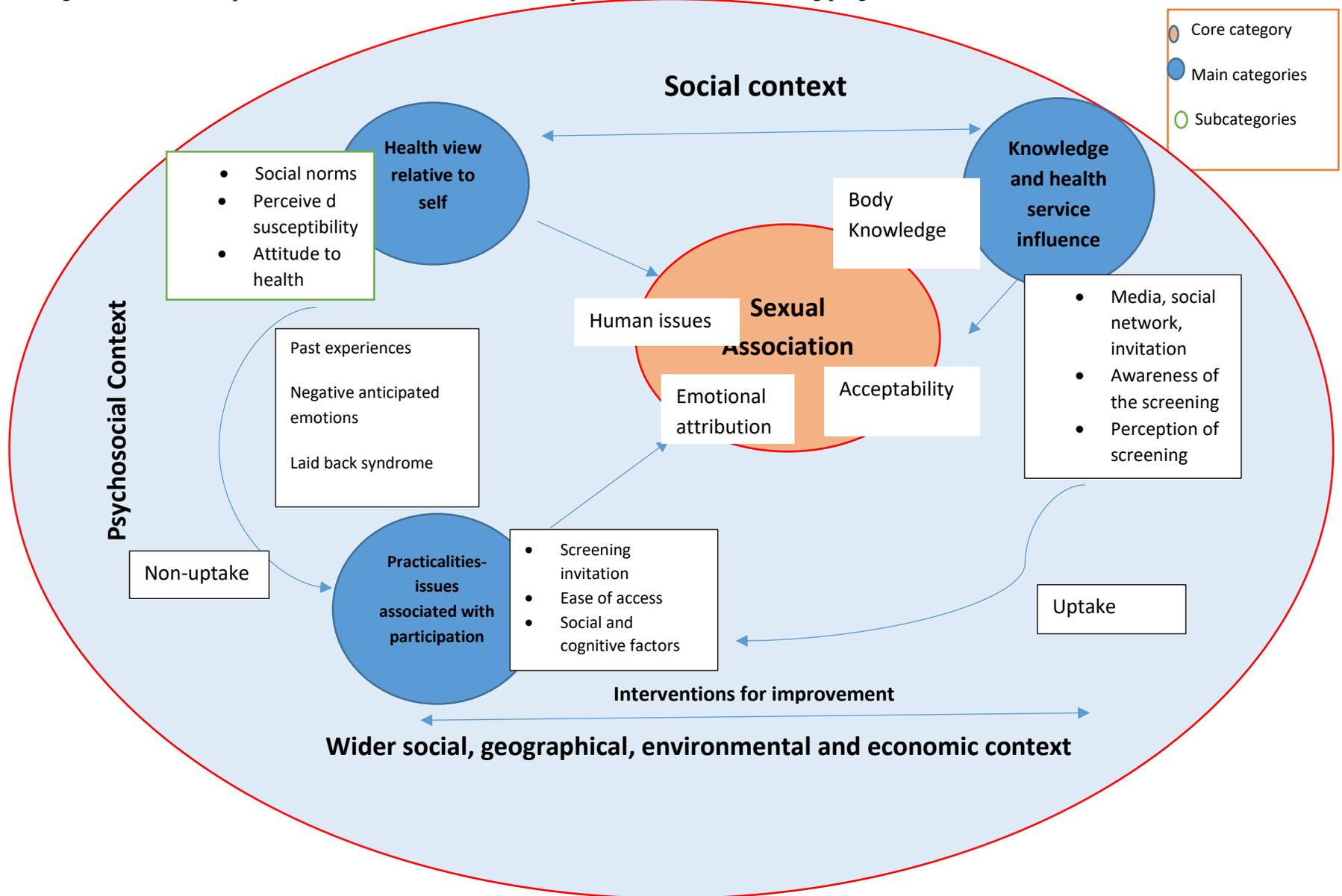
## **Chapter Overview**

This discussion chapter focuses on the core category ‘sexual association’ and issues identified in chapter 7. This will be aided by the overarching explanatory model (figure 24), developed after the conceptualisation of the main finding (sexual association). The model which shows the relationship between the categories (figure 21) captures the personal (individual or psychological) and wider contextual influences (e.g. social, economic, geographical). It further reveals the source of awareness and its effect on knowledge of existing health issues and prevention options (in this case cervical cancer screening), as well as issues and concerns affecting cervical screening intention. This discussion will be embedded within and informed by existing academic literature from relevant areas (such as public health, psychology and sociology). Additionally, the discussion also seeks to demonstrate how the various categories addressed the research objectives.

### **8.1 Explanation of the model**

Figure 24 shows the diagrammatic representation of the relationship between the core category ‘sexual association’ (the main findings), its subcategories (referred to as ‘elements’ in this discussion) and the 3 main categories (health view relative to self, knowledge and health service influence, and practicalities). It also shows how these main categories feed into (or relate with) the core category through the components within their subcategories.

Figure 24 Relationship between factors on health views and participation in the screening programme



Factors influencing cervical cancer participation and non-participation were found to be complex and multifactorial as represented in the model above. A model/theory helps to portray real life issues in a simplified and practical way where it would otherwise have been incomprehensible, thereby reducing ambiguity (Gray, 2007; Hasting, 2007). It could be seen as a cogent and pensive way of thinking resulting in the presentation of a complex, vague or complicated body of work or issues in an implicit form (Gray, 2007). The ‘core emergent category’ which makes up the issues discovered in this research study led to the development of theory within a GT methodology (Hallberg, 2007; Strauss & Corbin, 2008).

This theory provides a level of understanding of the elements of the core category and how the themes in the subcategories within the 3 main categories feed into or relate with the core category. The interaction shows how they influence the decision-making process, to either participate or not in cervical cancer screening.

Sexual association, the core category at the centre of the model, denotes the impact on participation and non-participation by the linkage between cervical cancer and its screening to sex or sexual connotations. The four elements of ‘sexual association’ provide an explanation of the various contexts of these associations, including wider social, psychological, economic and geographical influences. The thought processes, or how a person views the world, could be socially and psychologically constructed and these influences could be adopted consciously or subconsciously.

The 4 elements are drawn from insights into the emotional and psychological impact of the cervical screening process. This is because of perceptions based on preconceived knowledge and awareness of cervical cancer based on the social, economic and geographical status of the individual. This knowledge is constructed from educational, religious and cultural backgrounds, as well as the proactivity of health professionals and the structures of the health system. The right-hand side of the model shows that perception of risk of cervical cancer (due to awareness) and the perception of the advantage of undergoing a cervical cancer screening may have been derived through the screening invitation, social networks or the internet (through self-discovery/curiosity). The decision to participate or not in cervical cancer screening was multifactorial and discussed within the 3 elements: ‘emotional attribution’, ‘human issues’ and ‘body knowledge’ – although most of the barriers and potential barriers to screening were significant within the element ‘emotional attribution’. These barriers or concerns have a strong connotation to sex with regard to the screening procedure. These perceptions of the screening procedure were largely based on personal experiences or ‘hearsay’ (reports from family or friends to those who have not gone for screening). Another tentative discovery was that most of the barriers expressed under the elements ‘emotional attribution’ and ‘human issues’ were mostly subconscious (unknown to the

participants). In addition, practical issues influenced decisions to go for screening, which were not directly correlated to sex as seen in the bottom right-hand side of the model within the main category ‘practicalities’.

The element ‘acceptability’ showed that the perceptions, expectations and behaviours of participants were influenced by awareness. Finally, at the bottom of the model, the suggested way to improve participation was termed ‘improvements’. In addition to raising awareness, alternative interventions were also suggested in this area. These include self-testing at home as an alternative screening method, educational campaigns (such as the inclusion of cervical cancer in school curriculums and making cervical education gender neutral).

Barriers/issues surrounding cervical cancer and the association with sexual taboos can be minimised through awareness and ‘informed knowledge’, leading to the acceptance of cervical screening (acceptability). This implies that individuals who feel embarrassment associated with cervical cancer due to lack of adequate knowledge of the screening procedure may now be more psychologically and physically prepared for the screening. This could subsequently lead to a reduction in anticipated negative emotions associated with the link between sex and the overall screening procedure. In most cases, this means ‘peace of mind’.

It can be suggested, hypothetically, that the generated theory led to the following deductions:

- The link between cervical cancer screening and sex provokes deeper issues that go beyond emotions and touch the core of human existence, especially that which defines a woman (e.g. birth and reproduction). This is denoted in the model under the elements of ‘emotional attribution’ and ‘human issues’.
- Awareness and improvement of information on the screening procedure and attention to the deeper issues have the potential to increase uptake and participation in the cervical screening programme. In addition, exploring the unspoken and sometimes subconscious perceptions/issues/emotions around the screening procedure could lead to an increase in participation, and more acceptability of the screening programme. The concerns and issues identified in this study show that our health choices are also predisposed to other non-health related factors, thereby indicating how future interventions could be created to meet these gaps (through tailored health promotion campaigns and messages). In addition, exploring and evaluating the cost and impact of suggested interventions (such as self-testing at home) could help combat issues around embarrassment, anxiety and

exposure due to the invasive and penetrative nature of the screening procedure (a component of the main category, 'practicalities', in the model).

- Elements from the core category, 'sexual association' (emotional attribution, body knowledge and human issues), are highly influenced by social, psychological, and wider environmental/geographical contextual barriers, and could potentially result in non-participation instead of participation. This link is indicated in the model within the context of the main categories 'practicalities' and 'health view relative to self'.

The notions stated above are not the only inference that can be deduced from the explanatory model, which remains open to additional exploration and reasoning. The model (Figure 24) will be referenced throughout this chapter and the rest of the thesis. The findings are discussed using headings from the elements of sexual association as shown in the model.

## **8.2 Body knowledge (knowledge of cervical cancer and the screening process)**

Body knowledge in this context is centred on knowledge of cervical cancer and its screening. There was ignorance about the location of the cervix by some of the young women in this study. They could not differentiate between the cervix and ovaries, using both terms interchangeably during the course of the interviews and focus group (chapters 5 and 6). In another context, the constant reference to "inside and outside the body" was a reflection of the lack of anatomy knowledge, which was subsequently illustrated in their knowledge of cervical cancer. Female anatomy was not clearly understood among women, especially those from ethnic minority groups. Women could not distinguish between most female anatomy (especially those associated with the genitalia such as the uterus, cervix and vagina). The lack of understanding of female anatomy, especially the parts associated with sexuality, might have led to misconceptions surrounding cervical screening especially what this entails (Cancer Research UK, 2009; Waller et al., 2009; Oscarsson et al., 2008). The lack of understanding of the female sexual anatomy is because information is not received from the primary source (in this case, parents). This was supported by the study by Lindberg et al. (2006) on the changes in formal sex education, which reported that fewer parents were speaking about or educating their adolescent daughters regarding sex and sexuality in 2002 compared to 1995. This lack of information about female sexual anatomy could be linked to the screening processes association with sex, which has a social stigma attached to it, especially in some cultures. This will be further elaborated on when discussing 'emotional attribution'. As seen in the explanatory model, information regarding health is obtained by the study participants mainly via the media, social networks and the health system. The validity of information received by most of these sources, especially from social networks (family and friends) and the media is questionable, as it might have been exaggerated.

These social influences affect their health perceptions relative to themselves and in this case, body knowledge.

Body awareness goes beyond bodily experiences and is sometimes solely based on body senses, i.e. how we feel about our bodies (de Vignemont, 2011; Ciccarelli & White, 2009). De Vignemont (2011) suggested that body perception was from both within and outside the body. As stated earlier, body knowledge and how this influences health perceptions relative to cervical cancer in this study, was drawn from the referencing of the internal body. The internal body consists of what is unseen, unknown (the feeling of parts of the human body being mysterious and deep within), unfelt and an area where you cannot self-monitor. Whereas, the external consists of the seen and self-monitored. Social health is defined by the outward perception of the body form and function, which shows how health is defined in the context of physical activity (fitness), having a particular body physique with the resultant increase in exercise and healthy eating (Korn et al., 2013; de Vinemont, 2011; Ciccarelli & White, 2009). Emotions such as internal feelings are often not expressed as a health component. According to the WHO definition, health is defined in the context of the presence and absence of disease through the presence of symptoms (WHO, 2003). However, the expression of health in this study falls within the following suggested definition: “health is a state of balance, an equilibrium that an individual has established within himself and between himself and his social and physical environment” (Sartorius, 2006). This concept incorporates elements of the WHO definition, but reflects the complexity of health through an individual’s relationship with their environment. In another context, health was viewed by participants in terms of healthy eating and physical exercise. The introduction of cervical cancer screening has destabilised the definition of what is normal, and how to define ‘healthy’. Cervical screening presents results on a scale from normal to pathological; the variation could result in confusion in instances where health can neither be excluded or established (Oscarsson et al., 2008). In this study, ‘feeling healthy’ was linked with ‘absence of signs and symptom associated with any disease’. The ambiguous meaning of ‘feeling healthy’ can be difficult to explain from the participant’s point of view and was not explored in-depth in this study. These health views and other factors such as family traditions (learned behaviours/family upbringing), environmental influences (media, peers, education/knowledge) and past experiences with health services, subsequently influenced attitudes to health. The other factors are briefly discussed below.

Health views and personal behaviour may have been influenced by the factors stated above, as seen in chapter 5, where family and educational background played a significant part in perceptions of, and attitude to, health. From the explanatory model, these influences can be categorised under the social context. Family and education acted not only as an indicator of behaviour, but also of health (attitude to

health). Participants' attitudes to health, such as healthy eating habits and propensity to access health services, were shaped by family values and educational attainment. These had both negative and positive implications on their health behaviours and, in the context of cervical screening, led to either participation or non-participation. Education positively influenced participation as it increases awareness levels and understanding of the cervical cancer and the implications of non-participation. Family influence however, was in the form of 'learned behaviour'. Learned behaviour in this context is defined as attitudes portrayed by older family members and subsequently adopted by the younger family members; thus, positive attitudes to health in the family seemed to suggest participation while negative attitudes equated to non-participation. However, in some participants, this was altered, as explained above, through education. Similarly, and in support of the findings, much literature has indicated a relationship between social influences on health and behaviour (Cohen, 2004; Sutton, 2004; Umberson et al., 2010; Flay et al., 2009).

In addition to the above factors, ease of access to the health service and other available services provided by the health system potentially acted as a catalyst to positive health seeking behaviour and attitudes to health. It is noteworthy that behaviours or attitudes to health also include influences from non-health related issues which are mostly associated with the environment (i.e. social factors) (Earle et al., 2007). From the result derived in this study, it can be deduced that the term 'cancer' or cervix are constructed differently by individuals in different contexts i.e. socially, personally and customarily (Wade & Halligan, 2004). In other instances, they have little or no association with the existing 'biomedical model' employed by health professionals in assessing illnesses and their provision of subsequent intervention (Wade & Halligan, 2004). The association and recognition of the associated social issues or influences in development and modification of new and existing health interventions respectively is recommended.

The perception of self, relative to personal health or feeling healthy, could influence or affect how women respond to available interventions such as screening tests (Borrayo & Rae-Jenkins, 2001). In this study, some young women who felt no indication of the presence of any illness implied that seeing a GP or going to the hospital was out of question. Moreover, absence of symptoms or 'feeling healthy' led to non-participation and in some cases, was referred to as a waste of time. This way of thinking can be referred to as 'self-surveillance'. Self-surveillance in this context is the perceived ability of individuals to monitor their own health (Earle et al., 2007). Self-surveillance could negatively influence the choices made about health, because participants did not know what is happening inside their bodies, as the state of their internal health is unknown and hidden. Therefore, in the context of screening attendance, 'feeling healthy' was deemed an excuse presented by individuals for refusing the offer to screen (Chapple et al., 2008). Moreover, in the context of cervical cancer, the reliance on self-surveillance had huge

implications, as cervical cancer is asymptomatic in the earlier stages, with symptoms present only at the late or terminal stage. Therefore, the perceived feeling of healthiness could have no association with the non-appearance of illness.

The perception or interpretation of health and the use of “inside and outside the body” with respect to describing the body and cervical cancer (misrepresentation of the location of the cervix), indicates participants’ levels of understanding with respect to health, based on information received or not received. Another reflection of body knowledge was evident in the knowledge levels of cervical cancer, which is discussed later in this section.

Overall, knowledge of cervical cancer and screening was relatively low in this study, especially in the context of understanding. Ensuring sufficient knowledge of cervical cancer and the screening is a continuous challenge for health professionals. This is because there is still a lag in the scientific understanding of cervical cancer in terms of the symptoms and risks associated with diagnosis, and also what the screening should entail (Cancer Research UK, 2009; Abdullah et al., 2011). More people have now heard of cervical cancer, largely because of screening programmes, and therefore have an awareness of its existence as reported in similar studies (Waller et al., 2009; Marlow et al., 2015; Fylan, 1998). However, knowledge of some important aspects is still poor. Findings from this study showed inadequate knowledge and understanding on the part of participants. More worryingly, there is an assumption that there is already adequate knowledge in terms of understanding of cervical cancer and its screening (Cancer Research UK, 2014), such that interventions are no longer centred around awareness but other practical barriers such as appointment times.

In the context of cervical cancer screening, the knowledge of what part of the body is prone to cervical cancer is important. In this study, body knowledge was related to sex in respect to the location of the cervix and where the procedure is involved (vagina/genitalia). This area seems to be highly sexualised for the participants, which leads to a strong association of the screening with sex, as influenced by cultural norms and taboos. These will be discussed in-depth in the ‘emotional element’ section. A major catalyst for acceptance or participation in the screening programme is the perception of screening leading to negative emotions that are based on the knowledge level of cervical cancer and the screening process itself.

A plethora of feminist literature has analysed and initiated arguments around the role played by ‘bodily discourses’ in the conception of ‘femininity’ (Ransom, 1993; Lennon, 2014; Gill, 2007). The way women view themselves, which is fundamental to their identity and ‘sense of self’, is regulated by series of broad practices (Lupton, 1994, cited in Bush, 2000; Armstrong, 2005). These views are often

influenced by various factors such as the media and social networks (family and friends) among others. These factors further influence the level of information they receive and how this information is processed. According to Social Cognitive Theory (SCT), which considered to be the unique way individuals acquire and maintain behaviour; knowledge is based on the cognitive, behavioural, individual and environmental factors (Bandura, 2001; University of Twente, 2010), which influence how people behave and are motivated. The environment in this context refers to the social factors that can affect behaviour such as culture, family, friends and media (see Figure 24). In addition, personal factors also influence our thoughts and actions, and how this knowledge can be translated into action (in the context of this study, attendance for screening). Personal factors could be cognitive, such as perception of an activity (knowledge of cervical cancer and the implications of screening). In essence, personal and environmental factors constantly influence and are influenced by behaviour (Bandura, 1997; 2001; 2004; Glanz et al., 2002). In spite of these factors and influences, overall knowledge (as stated above) was below average in this study. This is similar to findings from other studies (Waller et al., 2014; Black et al., 2011; Bradley et al., 2015) and reflects an ignorance of what part of the body cervical cancer affects (Logan & Mcilfalick, 2011; Redwood-Campbell, 2004; Ogedegbe et al., 2005; Al Sairafi & Mohammed, 2009).

Social Representation Theory is used by psychologists to gain a better understanding of the nature and interactions of social beliefs (Marks, 2005). The theory is concerned with broader societal systems and how these shape an individual's interpretation of their world (Wagner et al., 1999). Social representation focuses on concepts that individuals are socially constructed or have collective 'meaning making processes', which result in social connections between the individual and their society (Bleakwell, 1993; Hoijer, 2011; Mark, 2005). In other words, it is a cognitive approach to getting a clearer understanding of the interactive social process of an individual's interpretation of the social world and how this affects communication and association with the society (Bleakwell, 1993; Wagner et al., 1999). In the context of the study findings, this is concerned with information received from the environment and how this affects individual attitudes to screening. Relative to existing health behaviour theories such as SCT and the Health Belief Model (Diclemente et al., 2013; Sutton, 2002), the correlation and differentiation between the levels of relationship of knowledge and attitudes/beliefs towards a health service like screening is more difficult than anticipated. However, trying to proffer a link between both entities (attitude and behaviour) can be regarded as being a closer influence in determining a person's behaviour than the level of awareness (knowledge) the person may possess (Rosenstock, 1974; Azjen, 2002). Epistemologically and ontologically, based on the researcher's stance, truth can be defined as relative and values-based, while 'knowledge' is based on social interaction between the individual and her

immediate environment. However, understanding these concepts depends on contextual variables, which are socially and psychologically bound (Andrew, 2012). In this instance, knowledge and the influence of information on attitudes and beliefs can sometimes be underestimated in terms of their influence on behaviour and the long-term implications on accessing health services like cervical screening.

Overall, the above studies report a high knowledge level around cervical cancer with misconceptions around the screening itself. However, as expressed earlier in this section, the overall knowledge of cervical cancer and its screening found by this study was relatively low, which contrasted with the general opinion that knowledge of cervical cancer cannot be seen as a possible issue since awareness was very high.

### **8.3 Emotional attribution**

Several social and psychological issues arose which had the potential of influencing participation. This led to the arousal of different emotions towards cervical cancer and screening, including embarrassment, fear, anxiety and violation. These emotions were instigated by various factors such as the linkage of genitals to sexuality, negative feelings such as embarrassment, the screening procedure mimicking sex and other factors stated above. The emotional attributions involving the screening procedure was emphasised over other practical reasons and these have both negative and positive implications for screening participation.

The nature of the screening programme and its intimacy is possibly related to the development of emotions such as anxiety and embarrassment; with embarrassment mostly reported as reasons for non-attendance in existing literature (Waller et al., 2014; Black et al., 2011; Carlson, 2002; Amisah et al., 2013; Teng et al., 2014), correlating with this study's findings. The contexts of embarrassment in past studies were vague and ill defined. Only a few studies (Amisah et al., 2013; Teng et al., 2014) explored embarrassment at a deeper level, with others focusing more on the practical issues affecting screening participation (Waller et al., 2014; Black et al., 2011; Carlson 2002; Waller et al., 2009). Studies that attempted to explore embarrassment in a broader context were conducted in developing countries and areas deemed ethnically concentrated. For example, Amisah et al. (2013) explored the emotional implication of embarrassment in the context of trustworthiness (in terms of confidentiality and sex of health workers, and their social or cultural implication). Their findings were similar to those of Teng et al. (2014), whose study sought the views of women of all age groups and health workers about the factors influencing participation. In that study, embarrassment was observed to emanate more from organisational influence, such as the relationship with health worker, fear of breaches of confidentiality and personal lack of knowledge of the screening procedure. Findings from this study also explored

emotions that prompted embarrassment as well as shame, disgust, anxiety, fear and pain, and other deeper associations such as the association with sex, the screening procedure mimicking sex and the perceived loss of modesty by exposure of the genitalia. These deeper unpicked issues make this study different from those in the existing literature.

The association between the emotions of shame and embarrassment felt during screening and the perceptions of sex as well as the social representation of genitalia as one of the taboo subjects will be discussed further in this section. The factors that instigate these emotions will be discussed alongside. From the model above, it worth noting the surrounding categories of social, psychological, and the wider geographical and environmental contexts. These contexts, and how they influence the arousal of these emotions, will also be highlighted.

### **8.3.1 Negative feelings towards cervical cancer and the screening procedure**

These include embarrassment, shame disgust, anxiety and fear, discussed in turns below.

#### **Emotional issues and taboos associated with cervical cancer**

In this study, emotions such as embarrassment, shame and disgust have revealed the role that psychological processes and beliefs about the nature of cervical cancer screening play in its uptake. This was evident in the observed disparities in health behaviours such as participation in screening. These emotions, which were perceived by participants to stem from the revealing and invasive nature of the screening procedure, were ultimately cited as reasons for delaying their screening attendance. Embarrassment in the context of this study is centred on modesty (exposure of genitalia to a stranger), the invasive nature of the procedure, and sexual connotations of the screening procedure (i.e. mimicking sexual intercourse/the-penetrative process of inserting the speculum, similar to penetration of the penis).

Modesty concerns arise from the exposure of the vagina to strangers. The thought or experience of exposure arouses negative emotions, which can be embarrassing. This is seen from the context of body image and the social (e.g. media) influences associated with it (Dittmar & Howard, 2004; Shillings, 1997; 2012). Body image, a complex of self-construction, focuses on emotional attributes and perceived personal beliefs regarding the body and attractiveness (Gallagher and Pecot-Hebert, 2007). Issues around body image are a highly discussed topic, especially amongst feminist researchers (Shildrick, 2015; Martin, 2001). This is mostly in the context of sexualisation of the woman's body and expectations of how women should look, often leading to low self-esteem, hysteria and frigidity (Striegel-Moore & Franko, 2002; Butters & Cash, 1987). An individual's personal feelings, or opinion about their looks or appearance, can hugely influence their thoughts and behaviours within their immediate environment

(Cash, 2004; Teng, 2014), especially in cases like attending cervical cancer screening. This provides an avenue for the body to be scrutinised, which has implications for a person who is already dissatisfied with their body due to unrealistic expectations placed on ideal body image (Striegel-Moore & Franko, 2002). Shildrick (1997; 2015) explains that the female body is continuously evolving and has been represented differently at ‘various times’ within ‘different communities’ (Lennon, 2014).

There are many misconceptions around what the body is expected to look like. However, this has been influenced by social and cultural norms. A societal expectation, mostly influenced by the media, has led to objectification and, as inferred earlier, sexualisation of the female body. Women in general are often relegated to the status of sex objects, making them feel more vulnerable and helpless than males (Nussbaum, 1997; Szymanski et al., 2011). Nussbaum, further categorised objectification as ‘loss of independence’, ‘violability’, ‘denial of subjectivity’ and ‘ownership’ among other things. Further to this, Langton (2009) added more features to the categories of objectification, such as ‘reduction in the body appearance’ and ‘silencing’. This feeling of objectification can lead to a loss of self-belief, leading to feelings of vulnerability and self-consciousness. Langton (2009) likened the feeling to being ‘silenced’, as losing the capacity to speak, which could in some cases lead to unconsciously conforming to societal expectations/norms and in extreme cases, body alteration. This self-consciousness may result in an intimate procedure, e.g. cervical screening, arousing negative psychological emotions such as embarrassment. This was expressed by participants in this study, who felt that the screening opened their body to scrutiny by a total stranger. One theory that explored this concept of societal influence on body image and psychology is the Social Comparison Theory. This can be reasoned as an evaluative comparison method that individuals use to measure themselves against their social world or environment. This evaluation is carried out with people from the same social class or social status and in varying proportions. Judgment of self or place within the social environment could be either positive or negative, despite the motive behind such comparisons (Milkie, 1999). This individual assessment increases when another person within that social group is perceived as being more successful in terms of wealth or physical appearance (Milkie, 1999).

In the context of public health, body image has been identified as a public health issue leading to the creation of the ‘Body Confidence Campaign’, which raises awareness of other definitions of beauty beyond physical appearance, such as character and individuality, and the existence of all body shapes, by providing information on how to evaluate media images (Government Equality Office, 2015). Burrowess (2013) carried out a study on behalf of the Government Equality Office that identified the following ways to minimise negative effects of body image. These include: protection (creating individual resilience), prevention (identification of social triggers of negative body image) and

improvement (interventions to change negative perceptions). Effective interventions are still being debated and assessed.

Another feminist perspective of the body, which supports the views of those stated above, shows how the body (especially intimate parts) is viewed in terms of outward appearance. Beauvoir (1984) cited in Lennon (2014) indicated how women are instilled from birth to focus and pay more attention to their body in comparison to men. These expectations over time become habitual and adapted. This expectation sees women perceive their body as an object for other peoples' gaze or approval. This is socially construed not only from the anatomical point of view, but also from the surroundings and education. Consequently, this has a potential to lead to issues around self-esteem, when those expectations fall below the standard of the surroundings. However, Beauvoir's view has been criticised as situational (Whitford, 1991) and is not representative of feelings of all women. However, they were in agreement with the aspect of his view that women manifest a deep consciousness of their bodies, especially the intimate parts mostly associated with sex and reproduction (such as breast and vagina). Findings from this current study support Beauvoir (1984), in that some women expressed discomfort when exposing their vagina to a total stranger, arising from the fear of been judged in terms of hygiene and appearance.

Various studies have indicated embarrassment as a major barrier to screening (Waller et al., 2009; Adolfsson et al., 2012; Thomas, 2005; Nolan et al., 2014; Black et al., 2014). As stated earlier, unlike other studies, (Amisah et al, 2013, Teng et al, 2014), this study provides a deeper meaning to the word 'embarrassment', explored in the context of sexual association.

Emotions around exposure stem from its relations to sex and culture. Psychological theories, such as the theory of triadic influence (Flay et al., 2009), present situations in which an individual feels a social obligation to behave appropriately in accordance to social expectations within her environment. Hence, inappropriate behaviour such as exposing the genitals arouses the feeling of embarrassment, shame and disgust in most instances. However, the negative emotions felt during or even when thinking about the Pap smear test arises from perceptions of modesty, or rather the violation of modesty by the act of exposure. Henslin and Biggs (1998) pointed out that modesty has different values during sexual and non-sexual encounters. The vagina is conceptualized as sacred, therefore any contact or approach towards it must ensure that the taboos are not dishonoured. Taboo, in this context, is seen as a set of reservations (negative norms) regarding certain issues held by a social group or individuals within a given society, that lead to restrictions towards some particular behaviour, deeds and attitude (Douglas 1979; Shoemaker and Tetlock, 2012). The genitals have bodily meaning to all women, irrespective of ethnicity, educational background or social circumstance. When likened to other intimate body parts such as the breasts,

women exhibit a different reaction. Unlike the breasts, genitalia are considered more private as it cannot be freely seen by others (due to cultural definitions of modesty). Quite understandably, most women may feel uncomfortable exposing their genitals, especially to strangers during the screening procedure and having them feel inside the vagina. There is a feeling or uncertainty about whether the vagina is normal, as many women are unaware of what the structure of the cervix or genitalia is supposed to be and, as explained earlier, this might have to do with issues surrounding body image. This feeling was expressed in this study as well as in past studies (Waller et al., 2009; 2014; Amisah et al., 2013; Teng et al., 2014). In this study, this feeling was expressed especially among those who have been screened, while those not screened expressed concern because of their perceptions of screening due to the type of information they had heard about the screening.

The emotions surrounding exposure have to do with the location of the cervix and the taboo attached to the subject of cervical cancer in some societies and cultures. Exposure in this case is synonymous to immodesty. This is similar to reports in some studies (Thomas, 2001; Stones, 2005). The present study's findings suggest that the perception of cervical cancer is formed from socially constructed views (e.g. religion, culture) that could either negatively or positively influence participation in cervical cancer screening or any available screening programme. Taking a cue from the model above, this is influenced by the social context feeding into the core category, as can be seen in relation to sexual association and social norms (in the category 'health view relative to self'). Social context, in this study, is defined as the sociocultural influences such as individual and personal trajectory (such as religion, culture, family), institutions and organisations (educational background and health services available) that shape people's belief system and day-to-day experiences, ultimately affecting their health and behaviour either directly or indirectly. It is noteworthy that "culture is not synonymous with ethnicity or race; it is integral to all social structures and institutions (religion, politics, kinship, class dynamics), including social determinants of health such as poverty" (Joseph et al., 2009). Culture can have a far reaching impact on a woman in terms of the expectations, permissions and restrictions it places on her. It entails varying degrees of freedom and restrictions depending on the particular culture of the woman within society.

There are two sets of taboos linked with the cervical cancer screening based on the associated terms 'cervix' and 'cancer'. The taboo of cancer was in the context of cancer being associated with fear and death (this is explored in mortality under 'human issues'), while the taboo of the cervix was characterised by feelings of embarrassment, shame, violation and intrusion. Therefore, it can be inferred that the introduction of screening programmes has led to increased awareness and subsequent significant changes around the perceived taboo associated with the cervix in some communities. This concern around taboo and psychosocial aspects in relation to sex and the cervix are discussed below.

The taboo associated with the cervix arises due to its location. It also has to do with associated beliefs regarding sex and sexuality, which in turn relate to issues about sexual norms, also discussed below. In this study, there was overall agreement among participants associating taboo, or that taboo was due to the position of the cervix and the screening procedure. These views are interesting because they were aired by women who do not usually openly talk about such issues. These findings support the views of Mosavel and Elsharaavi (2007), and Thomas et al. (2005) in their studies that dealt with women from societies where sex was not openly talked about due to cultural and religious reasons. Furthermore, the findings of this study were similar to previous studies, most notably because a significant percentage of the focus group participants were women from certain ethnic minority groups, as was the case with previous studies referred to (Abdullahi et al., 2009; Cadman et al., 2014; Black et al., 2011). Hence, the link to cultural and religious beliefs is prominent with this group of women (i.e. association of cervical screening with promiscuity). On the other hand, for women who are not from ethnic minority groups, taboos surrounding cervical cancer were based on exposure of the cervix and genitalia. Like their ethnic minority counterparts, these women displayed obvious signs of unease when talking about their experience of screening, albeit subtle (like being squeamish). For example, a woman repeatedly showed physical unease while answering questions about cervical cancer. Upon further enquiry, she mentioned that the screening was too private and personal, and that talking about it makes her feel uncomfortable. The embarrassment due to exposure of the genitalia during the screening procedure shows the depth of emotion at play in the decision to attend or continue to attend cervical screening.

**Emotions associated with the nature of the screening procedure (mimicking sex) and social norms around sex.**

Feelings of embarrassment, shame and disgust also arose from the invasive nature of the screening procedure and the suggestion that it mimics the sex act. This is because the procedure is penetrative, involving inserting the speculum (shaped like a penis) in the vagina, a process which is similar to the penetration of the penis during sexual intercourse. This similarity could elicit feelings of disgust in young women, which manifests as aversion to cervical cancer screening (Chorley et al., 2016). This feeling of disgust may have distinct behavioural and psychological implications relative to the idea of the insertion being conducted by a total stranger, with whom no emotional attachment has been formed, unlike in normal sexual intercourse between two consenting adults, where a certain level of emotional connection exists. Sex (which in the context of this study refers to heterosexual relationship) is a motivating power, which involves a physical attachment between a male and female. Sexuality is a fundamental feature exhibited by all individuals in their lifetime, which involves ‘pleasure’, ‘intimacy’, and ‘reproduction’, and is voiced in thoughts, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships

(Bancroft, 1989; Mazzich & Hernandez-Serrano, 2006). The suggestion that the cervical cancer screening procedure mimics sex often stokes negative emotions from most women, in that it impairs the natural act of sexual intercourse by robbing it of the pleasure, excitement, fulfilment and the relationship the sex act usually entails, despite the feeling of penetration by the speculum.

As stated earlier, sex in the social context is associated with taboo. Sex is surrounded by multiple social norms, religious and cultural restrictions and moral taboos, as discussed in the section above and relating to social and ethical guidelines governing sexual conducts (Fog, 1999). Fog (1999) further suggested that there are some well-defined interrelationships amongst ethical and societal structures. These taboos surrounding sex are rooted in patriarchal societies, which had strict sexual values (Goethals, 1978). Over time, the boundaries around sexuality have been eroded in some communities, but still hold strong in others under the guise of culture and religion (Fog, 1999). This creates a belief system around sex within members of that society. In a society where, sexual life is inhibited/limited by negative norms, these norms are easily internalised, and people therefore engage in disputes when they have an unconscious need to break the morals rule around sex. This could lead to psychological development of defence processes such as 'reaction formation' and 'projection'. Reaction formation is the tendency of a repressed feeling to be expressed at a conscious level in a contrasting form that gives rise to the need to 'overconform'. Projection on the other hand is an effort made by an individual to resist the repulsive impulse by aggressively transcribing their negative energy to someone exhibiting a similar tendency to theirs (Fog, 1999). This is the case with people who stigmatise others if they go outside the 'societal expectation', e.g. attending for cervical screening when unmarried.

In the context of cervical cancer screening, the procedure encroaches into that internalised moral compass and as such creates a plethora of emotions such as embarrassment, shame disgust, anxiety and fear. The emotions surrounding exposure and invasiveness of the cervical cancer screening procedure stem from the social norm surrounding nudity being considered broken. In the current study, the presence of these social norms and attempts to conform to them leads to delays in undergoing screening by some participants.

Moreover, for some of those women who have not attended screening because of anticipated negative consequences, their decision could be explained by the perceived threat within the Health Belief Model (Glanz et al., 2002; Rosenstock, 1974; Nutbeam et al., 2014). This holds that a person is likely to avoid a particular action if they perceive that the action would lead to potential serious consequences. Likening it to the issue of social norms surrounding sex in some communities, women who belong to such cultural and religious communities might perceive that going for cervical cancer screening could lead to

perceived serious consequences in the form of stigmatisation and social alienation. These outcomes are even worse when the woman involved is unmarried because sex outside marriage is linked to promiscuity and considered taboo in some communities. In addition, looking at the model in Figure 24, there is a strong link between the element 'emotional attributions' and social norms within the social context, showing how social context influences a person and their subsequent intentions to participate in health services like the cervical cancer screening.

In another context, patriarchal societies place importance on gender, which has implication for attendance. Gender is socially constructed and broadly documented as a health determinant, classified under inequalities in health and how the norms and roles of both genders affect health behaviours and attitudes to health (Men et al., 2013; Smith, 2006; Loadsman, 2013). Cultural norms emanating from cultural beliefs and family values influence how health is viewed. In turn, this influences decision-making in terms of how females access health services relative to males. As stated earlier, attitudes and behaviour are mainly influenced by socio-cultural constructs such as traditional values and religion, combined with a desire to gain acceptance within the identified community or broader imaginative network. This network was referred to as "narrative reconstruction" by Williams in 1984 (Addler et al., 2008; Williams, 1997). This factor is most prominent in people from ethnic minority groups, where religious beliefs and culture are highly regarded. Past researchers revealed ethnicity as a major predictor of non-attendance (Marlow, Waller & Wardle, 2014; Ogedegbe et al., 2005; Behbakht et al., 2004). In such patriarchal societies or cultures, women are placed beneath men and their level of control in decision-making, even for health related issues, is limited. For example, women are expected to have permission from their spouse as part of cultural expectations and social norms. In terms of access to cervical cancer screening, this presents a conflict between a health priority and cultural obligation. Women from these kinds of communities are more inclined to adhere to their cultural obligations at the expense of their health. Hence, the women from these communities end up perceiving screening as non-important because culturally, they are expected to be sexually inactive as unmarried women, and to only engage in sex with their husbands after marriage. However, there are no such sexual expectations of men. These cultural practices and expectations have implications for cancer incidences, such as HPV, which is a major risk factor for cervical cancer and is transmitted sexually mainly from men to women (Cancer Research UK, 2015). Asking for permission within the context above can prove difficult, as suggested by some participants in this study who provided personal anecdotes where this led to non-attendance due to a partner and his family's interference (refusal to give consent to screening). Therefore, this would suggest that incorporating issues surrounding 'gender' into the preparation, development and

implementation of public health interventions and services (especially for ethnic groups) is recommended to achieve a higher attendance.

In the current study, this interplay with cultural beliefs is showed in the model above (Figure 24). Knowledge and external influences such family, friends, media and partner's impact were a major cue for action to instigate change in health behaviours, despite negative perceptions and opinions regarding cervical cancer and the screening programme. This is in line with the cue to action construct of the Health Belief Model, which suggests that series of external influences such as media, family and peers move people to change their behaviour (Nutbeam, 2014; Rosenstock, 1974; Janz et al., 2003). In this case, invitation letter, history of cancer in the family and peer conformity constitute such cues to positive action of screening uptake.

### **Anxiety**

Emotions aroused during the decision-making process in regard to attending cervical cancer screening may include embarrassment and anxiety. These views are shaped by attendees and non-attendees alike. Anxiety and embarrassment are closely related as the thought of embarrassment due to the nature of the screening and other factors (like the procedure mimicking sex and taboos associated with cervical cancer screening as a result of its sexual connotation) addressed in the previous section could lead to anxiety. Anxiety will be addressed in the context of fear due to pain (anticipated and personal), unpleasant stories about the procedure, personal negative past experiences, or inadequate knowledge of what to expect, as well as the invasive nature of the screening.

According to the American Psychological Society (2014), anxiety can be defined as an “emotion characterised by feelings of tension and thoughts of worry that, in some extreme cases, could manifest in physical changes such as increased blood pressure”. These feelings have both positive and negative implication for screening. Anxiety that comes about because of the procedure nature is compounded by inadequate knowledge of what the screening entails. As indicated in the section above, individual beliefs and behaviours that result from those beliefs are both are socially constructed and influenced by knowledge levels. In this study, inadequate knowledge and lack of understanding of the screening process led to misconceptions around the screening experience. It was observed that the experience of pain and discomfort reported by those who had been screened was misconstrued for physical pain by non-attendees. This misconception had an influence on their eventual decision around screening for many non-attendees. On the other hand, those who have been screened experienced similar feelings of anxiety before their participation, however, in spite of the experience being better than expected for some

attendees, some expressed extreme pain as part of their experience, leading to delay or non-participation in subsequent attendance (see chapters 5 and 6). The bio-psychosocial model of intentional change, which is derived from the trans-theoretical model of behaviour change, helps to illustrate the exact stage in the participant's decision-making process that anxiety impacts to either delay or influence a negative screening decision. The bio-psychosocial theory is made up of five main constructs: 'pre-contemplation (unprepared)', 'Contemplation (consideration)', 'Preparation (ready)', 'action' and 'maintenance' (Prochaska, 2008; Prochaska & Velicer, 1997). Anxiety could prevent a person from moving past the pre-contemplation or contemplation stages. If a person was anxious about screening, they may remain in denial about the risk they are taking by not being screened. Alternatively, they may acknowledge the risk and move forward to contemplate the factors involved in making a change. However, anxiety could again stop them at this stage as they consider the factors involved in cervical cancer screening. Perhaps they are anxious about the procedure or about the possibility of receiving negative results. Due to these anxieties, they may not be willing to move from contemplation to planning (Scott, 2015; Prochaska & Velicer, 1997).

A person undergoing fear/anxiety tends to focus on the associated feelings of pain, discomfort irritability and insecurity the screening event entails, rather than the benefit of the said process/phenomenon. This process/feeling can be referred to as a 'narrow frame of reference'. In a psychological context, avoidance behaviour occurs when an individual avoids a possible threat by reducing avenues for any trouble/problems (Blustein et al., 1995; Hamilton, 1980). Avoidance behaviour can be compounded by an individual becoming obsessed with avoiding a situation that causes them distress, thereby subconsciously allowing anxiety to have a strong hold in their life. Hence, in the context of screening, this could lead to non-participation due to the factors stated above (pain and discomfort) because of inadequate knowledge and, as explained in the previous section, exposure and mimicking of sex.

In the current study, another emotional feeling associated with anxiety, which has little correlation to sex but is associated with the screening procedure, is perceived pain. In this study, this was manifested in the observation that some of the women who had undergone childbirth were more accepting, willing and keen to go for future screening than women who have not experienced childbirth. Researchers and healthcare providers have argued that feelings experienced during the screening are exaggerated and overemphasised, and use childbirth as a comparative example (Grundstrom et al., 2011; Anisah et al., 2013). They stated that undergoing childbirth was a painful procedure, which requires the exposure of genitalia to total strangers. It is noteworthy that women who have undergone childbirth have been desensitised to pain and emotions such as anxiety and embarrassment when it comes to cervical cancer screening. Findings from previous studies concurred with this (Waller et al., 201; Adolfsson et al., 2012;

Amisah, 2013). A Slight distinction in my findings was the reports of anxiety towards screening by some of the participants with children. They explained that both circumstances were different, with childbirth influenced more by pain than the exposure, whilst cervical screening being influenced more by exposure and invasiveness than by pain or discomfort. In the latter, there was no pressure or physical pain from the procedure, hence the emotional impact of feelings of anxiety due to exposure of the genitals (Grundstrom et al., 2011; Anisah et al., 2013). However, in this current study, previous experiences of childbirth and screening helped reduce anxiety in some of the participants. This was also seen in the study by Thomas et al. (2005), which showed that women who were married and within the reproductive age group are more likely to go for screening as they relate the screening to part of a gynaecological check-up.

Bandura (1998), while reviewing the Health Behavioural Model, made an assumption that confidence building occurs when an individual believes that that they can change and maintain behaviour through recurrent engagement with such behaviour. This is also referred to as self-efficacy. Under the construct of Health Belief Model (Rosenstock, 1974; Bandura, 1977), experiencing anxiety could be seen as a potential cue to action due to the screening procedure, regardless of their views about susceptibility or how strong individual beliefs about cervical cancer are. This is because, to some people, feeling anxious about cervical cancer and its screening could outweigh the benefits of been screened. Anxiety, which is closely associated with emotional attribution (an element of the core category within the explanatory model), also fell within the Health Behaviour Theories (both HBM and TPB). This was an interesting observation despite the study not intending to make connection between HBTs and intention to screen. In addition, how this relates to the explanatory model in this study is also stated. For example, the issue of anticipated pain and emotions built up because of negative stories about people's experiences of the screening procedure, which has led to a belief system about the screening process. This is well illustrated in Figure 24.

Similarly, Van Til et al. (2003), in their study with older women, observed that avoidance of cervical screening was also because of unpleasantness felt towards the screening. However, some attributed their attitude to past negative experiences (both screening and sexual-related). The feeling of vulnerability (due to exposure and the sexual connotations of the screening procedure) as well as painful experience of the screening can be linked to incidences of violation and sexual abuse as expressed by the women in Van Til's study. In the context of the psychological linkage of a cervical screening procedure to violation, the arousal of negative feelings (especially amongst those who have experienced sexual abuse) was reported. Because of the sensitive nature of sexual abuse and its associated stigma, participants who might have experienced a form of sexual abuse would not acknowledge it as a barrier, as this is a sensitive

and traumatic issue, which survivors want to forget through avoidance. Therefore, sexually abused women are less likely to attend for screening than women who have not been sexually abused (Cadman et al., 2014). In the literature, reported barriers to the disclosure of sexual violence/abuse stems from myths around stigma and blame, as well as previous negative experiences of disclosure (Carlson, 2002). Therefore, as the cervical screening process resonates with their experience, consideration or sensitivity during the screening process should be employed by health practitioners to help ease the process for anyone who might have experienced sexual abuse. Health professionals administering the screening test should pay close attention to emotional mannerisms (e.g. anxiety) such as detachment, uncooperativeness, sudden withdrawal and even tearing up during the actual screening procedure (Lewis, 2008).

### **Past experiences**

Past negative experiences can influence compliance or continuous participation in the screening programme. As stated earlier in this section, pain associated with the screening was linked to the health professional's expertise and skills. These findings support previous studies on the role of health practitioners (Brown et al., 2011; O'Connor et al., 2013; Thomas et al., 2005; Abdullahi et al., 2009). Negative past experiences in the health service were also expressed in this study. This led to a lack of trust in health professionals and a general lack of faith in the system. This has negative implications for participation because cervical cancer screening is very invasive and requires a high level of trust in the person carrying out the procedure. As previously suggested for those who have sexual abuse, overall sensitivity from the health professional could aid in the procedure being more acceptable. In addition to the suggestion of alternative screening method above and in accordance to the British Society for Clinical Cytology's (2013) recommendation, anxious emotional states could be overcome through sensitivity on the part of the health professionals by adequate communication and providing of information. This includes responding and replying to queries, using a systematic approach to the procedure and presenting the screening apparatus to the individual during and after the procedure.

### **8.4 Human issues**

This element touches on the intrinsic nature of a woman as a human being. It refers to the deep human instinct related to the 3 core human issues such as birth (being born yourself), reproduction (sex and childbirth) and death (mortality). Our relationship with these human issues is expressed by way of emotions (due to health beliefs), and perceptions of cervical cancer and the screening programme. Birth and reproduction will be discussed simultaneously, while mortality will be discussed separately.

### **8.4.1 Reproduction and birth**

The issue of reproduction is associated with all women irrespective of their SES, age, education, ethnicity and marital status. Bourdieu (1984; 2001) and Lennon (2014) explain that the woman is prepared from birth to focus and pay inert attention to their body to enable it to perform its reproductive duties among other things. Cervical cancer and screening affect the female reproductive organ. Screening is done on the genitalia, whilst cervical cancer itself can lead to the removal of the cervix. Where it does not lead to death, it may lead to infertility. This affects the female, whose reproductive ability is of intrinsic importance (Martin, 2001). According to Lawler (1991), women are seen to be more involved in and accountable for reproduction and are hence more closely tied to their bodies than men. Moreover, they are also more open to manipulation, especially in the medical world. There has been an argument by feminist researchers (Martin, 2001; Shildrick, 1997; 2015) that the female body is perceived as a machine for the production of children, and that these perceptions should be rejected. The determination of expectation and how behaviour or life activities must be lived by women in a social context is based on their reproductive ability or “biological reality” (Lawler, 1991). Similarly, Lennon (2014) stated that society alone has been the arbiter in the imposition of the burden of reproduction on the female. With such socially conceptualised expectations, cervical cancer and its screening impede on that aspect of a woman’s reproductive ability (infertility). Some patriarchal societies and social groups employ this underpinned and presumed reproductive role of the female gender to construct, assign and enforce the role of women within their communities/environment. Beliefs and views regarding female expectations relative to self is built on existing norms. This relationship is seen in the link between the element ‘human issues’ with the category ‘health view relative to self’ in the explanatory model in Figure 24.

Cervical cancer diagnosis touches on this fundamental role of reproduction. This is because the cervix is part of the physiological organs responsible for reproduction, therefore, a positive diagnosis of cervical cancer could lead to infertility, unless the cancer is diagnosed early (Cancer Research UK, 2014). Emphasis on the fear of cervical cancer and its association with infertility was voiced by ethnic minority women in this study and acted as a motivating factor for screening uptake for some participants. Accounts of previous experiences of cervical cancer survivors who lost their reproductive capacity created fear and anxiety. Hence, the decision to go for screening; to have some autonomy over their physical childbearing abilities. Aside from the real threat of the loss of reproductive capacity for the women, much of the fear and anxiety about childbearing stems from the cultural expectations placed on women from ethnic minority backgrounds. These are reinforced by the influence of male gender roles (Lorber, 1994), in spite of arguments around gender roles and social constructions around these. Traditionalist theorists of the family, argue that nature necessitates the division of tasks within the family

and that woman naturally want to have children (Satz & Edwards, 2013; Rousseau, 1762). This idea of getting married and having children resonated among most participants in the current study, when references were made about future life expectations.

In agreement with the HBM concept of 'perceived benefit', perceived susceptibility to cervical cancer was a consensus among most of the study participants with a belief that undergoing screening would give them autonomy over their birth capabilities, through early diagnosis. Hence, screening is understood as valuable in reducing the predisposition to and severity of cervical cancer. Perhaps it can be assumed that attending screening is a way most young women protect themselves from potential infertility instead of waiting through non-attendance on fate. Therefore, cervical cancer screening is deemed to be a helpful and worthwhile investment in terms of the personal cost of non-attendance.

Although previous studies in the UK (Black et al., 2011; Logan & Mcilpatrick, 2011) have focused on the altruistic behaviour of living for a family member and having peace of mind (Marlow et al., 2015), few have focused on the effect of this on the reproductive health of the woman as seen in this present study. Available studies that highlight issues of the reproductive effect of cervical cancer screening, were carried out in developing countries (Lim & Ojo, 2016; Gor et al., 2010). One systematic review on the reasons for non-participation in sub-Saharan Africa reported that fear of infertility acted as a barrier to screening. This contrasts with our study, where fear of infertility acted as a motivating factor for screening. Again, the issue of reproduction is an example of how the social world may perhaps form and be formed by people's insights and conduct, as seen in the social cognitive theory of behaviour, which argues that a person's knowledge attainment is relative to that of similar people within the framework of social interactions, practices, and outside media influences (Bandura, 1986; Macdowall et al., 2006).

Conception and age also acted as a reason for non-participation. As participants in this study were of reproductive age, multiple pregnancies could have implications for screening attendance. This delay due to pregnancy could have negative effects. This is because early diagnoses of cervical cancer could be missed since screening is not undertaken during pregnancy (Cancer Research UK, 2014; Waller, 2009). In this study, pregnancy was stated as one of the reasons for non-participation by a few participants. Multiple pregnancies coupled with responsibilities that come with having young children could lead to delays and sometimes non-participation in cervical screening. This is because the arrival of children brings greater responsibilities and more demands on time, further limiting the possibility for screening attendance. This is compounded by the fact that the absence of physical symptoms makes it less likely to be a priority when the woman has a busy schedule. Debates around participating in screening have led to the advice that screening can be put off until 3 months after childbirth, however, there are exceptional

cases where screening could occur while pregnant, due to past results, risk susceptibility or if previous appointments have been missed (Kothari, 2012; Cancer Research UK, 2014). Like this study, pregnancy has been reported as a reason for non-participation in the literature review (Ostensson et al., 2015). This issue creates the need for continuous awareness-raising of the importance of screening and continued participation.

#### **8.4.2 Mortality**

Mortality, like reproduction, touches on the primal issues that affect humans. Consciousness of and dread associated with death have been part of the human condition since the pre-historic era (Yalom, 2008, cited in Iverach et al., 2014). Yalom (2008, p.1) stated that human beings are “forever shadowed by the knowledge that we will grow, blossom, and inevitably, diminish and die”. Therefore, not out of context, death has the authority to induce uncertainties associated with powerlessness, separation, loss of control and meaninglessness (Yalom, 2008, cited in Iverach et al., 2014). Cancer has been associated with the fear of death and the word ‘cancer’ arouses many emotions such as fear, as the mortality rate from any form of cancer is still relatively high. Cancer evokes a sense of dread and has been renamed the ‘Big C’ by survivors, reflecting its insidious ability to cause death (WHO, 2013; Cancer Research UK, 2011; Robb et al., 2014). This could also be linked to anxiety and issues discussed previously and forms part of the taboo in the ‘emotions’ section above.

Mortality in the context of cervical cancer can be discussed as one of the taboos linking cancer to death. The issue of cervical cancer screening may lead to a salient experience of mortality. From a behavioural perspective (Baum et al., 2001), when an individual perceives “fighting” as being too risky and “flight” as being ineffective, the resultant action might be “freezing” (Murray & McMillan, 1993). In other words, this mortality induced fear could lead to an individual not attending screening (running away) or undergoing the test when provided with the available information (fighting back). In this situation, it could act as a barrier either to participation or to the factors motivating participation.

The association with death led to participation and non-attendance in this current study. As cancer is usually associated with death, fear is a cogent emotional response expected from people at various contextual levels (Penson et al., 2004). In this study, death from cancer was acknowledged as a personal fear. Though the women understood that the cervical cancer survival rate is high if detected early, their perception of illness was always towards the worst-case scenario. The apprehension surrounding death from cancer was an actual motivating factor to screening attendance. For those in a relationship and/or married, undergoing a smear test was in the context of altruism. Their altruistic decision was beyond participating for themselves but for the sake of their loved ones. This social and psychological notion

indicated that individual attendance for cervical screening goes beyond perceptions of the associated advantage but is for the sake of other people. In addition, concerning marital or relationship status, women from ethnic minority backgrounds expressed their decision to go for screening as a responsible health behaviour. This was borne out of perceived ethical responsibility concerning the state of mind or 'coping' by loved ones in the case of death from cancer or its complications as well as the desire to enjoy time with the family. This is because it is argued that women from ethnic minorities are more family oriented than those from non-ethnic backgrounds (Lum, 2015).

Previous studies have also reported the dread of cancer death as a major catalyst to participation. In most cases, this acts as a motivator, though it sometimes acts as a barrier (Waller et al., 2009; 2014; Robb et al., 2014; Abdullahi et al., 2011). Robb et al. (2014), in their study exploring public perceptions of cancer by weighing the balance of positive and negative beliefs, reported that fear of a positive diagnosis, apart from death, also has negative implication for health and finances. Contradicting this, negative perceptions of cancer were overridden by the availability of options like screening for early detection. In another context, Fylan (1998), reported that the fear of cancer was a reason for non-participation, similar to findings in this study. However, a distinction in the findings from my study was that fear led to a state of denial and aversion to cervical cancer screening. Fear of positive diagnosis due to a fatalistic view of cancer, generally aroused negative emotions such as anxiety and worry as discussed earlier. This has implications for denial as expressed in this study. Outright statements like "*I would not like to look for trouble*" (chapter 5), expressed a reason for non-participation. Interestingly, working in the health sector or cancer research, with an in-depth knowledge of the severity of cervical cancer, had no effect on intention to screen. Teng et al. (2014) found similar results, with the sense of fatalism linked to a positive diagnosis being too difficult to handle, leading to avoidance of screening. Denial has been defined in cognitive psychology and psychoanalytical theory as "an avoidance with adaptive properties used to temporarily protect oneself against overwhelming feelings and events" (Horowitz, 1983). Denial could be used either as a defence mechanism or as a responsibility avoidance tactic, but whatever the reason for adopting such behaviour, it could be potentially harmful if it affects health seeking and can lead to fatality or death in the context of cervical cancer screening.

Swain (2011) acknowledged that breaking taboos such as death due to cancer could be liberating for the individual. Awareness therefore might lead to the reduction or elimination of myths. Swain terms this 'misconceived taboo', by providing people individual autonomy to make personal decisions as well as breaking free from the societal stronghold. This could potentially lead to behaviour change and increase intention to participate in screening programmes. In essence, it can be inferred that there is improved knowledge about cervical cancer and continuous breakthroughs in research towards a cure for cancer,

thereby leading to little attention been placed on the supposed ‘social taboo’. Instead, attention has shifted to the individual advantages that come with the screening programme. Campaigns and social media awareness are some of the awareness tools/interventions credited for contravening these social obstructions or taboos (Albrow et al., 2014).

In the context of HBM (Rosenstock, 1974; Nutbeam, 2014), the perceived threat was noted as a reason for changing or accepting health behaviour. As stated earlier, knowledge associated with the seriousness of cervical cancer if undiagnosed acted as a motivation or cue to action for participating in screening. Although a few exceptions were highlighted, interventions to encourage participation were discussed as part of this study’s recommendation (see sections 9.2 and 9.3).

### **8.5 Acceptability**

This section focuses on perceived susceptibility and how this affects acceptability of cervical cancer in the context of the barriers discussed above, of other (practical) barriers, and of motivating factors that influenced participation in this study.

From the explanatory model (Figure 24), perceived susceptibility was one of the socio-cultural contextual influences on the intention and decision to screen. The perceived degree of risk significantly influences women’s reactions to the health issue. For example, where risk is seen to be high, ‘suppressive prevention’ is chosen if the ill health is due to life choices such as food intake or smoking. This is because these types of illness are manageable and preventable through lifestyle changes as people have the autonomy to make decisions that affect their life.

Perceived susceptibility to illness or danger plays a part in health seeking or accessing health services (Rosenstock et al., 1994). Lack of knowledge, low susceptibility and dissociation of self from a situation could have fatal consequences. Nevertheless, these notions are in dissonance with the assumptions surrounding HBM, that people will take the best approach to health if they feel the health issue is addressable. They are susceptible to the said health issue but their action (e.g. attending for screening) will positively and effectively reduce the impact of such illnesses giving them a better quality of life (Glanz et al, 1997; 2000).

Self-obligation/responsibility - responsibility to self and consideration of others (e.g. partner and family member). This is the obligation to stay healthy and take responsibility for one’s own health irrespective of external influences or restrictions around decision-making, or the implementation of those decisions. In other words, the perception of one’s own health plays a major influence in health seeking. For instance, in the context of cervical screening if a woman feels healthy and shows no symptoms of cervical cancer

she is likely to avoid screening (Borrayo & Rae Jenkins, 2001). Individuals would rather participate in cervical cancer screening on a regular basis if they perceive themselves to be susceptible to cervical cancer alongside other influencing factors stated above.

Where perception is high, the HBM construct suggests that the possibility of accepting a behaviour (screening), even without the presence of noticeable symptoms is very likely (Rosenstock, 2005). However, there have been exceptional cases where perceived susceptibility does not lead to better choices regarding health. For example, a study by Kasmaei et al (2014) on oral health hygiene found that adolescents in spite of their awareness of the perceived severity of bad hygiene, still reported brushing only once a day, with some admitting missing out on brushing on some days.

In the context of its association with death and, as reflected in this study and supported by Chapple et al. (2008), a history of death from cancer or awareness of someone who has had a cancer diagnosis acted as both a barrier and facilitator to cervical screening attendance. Hence, screening attitudes can be influenced by things that have happened in the past, which turned out well or badly. For example, an individual who lost a loved one to a serious illness like cancer could have reservations around the effectiveness of screening and available treatments. Therefore, perception of vulnerability and severity might result in feeling threatened when an apparent risk is present, thereby leading to possible behaviour change, e.g. if an individual carries a hereditary gene for cancer (Stretcher & Rosenstock, 1997; Mullens et al., 2004; Forsyth & Goetsch, 1997). This behavioural change is not applicable to all individuals with similar histories or experiences. An example from this study is the participant whose family member's death from cervical cancer, meaning she had a high likelihood of carrying the cancerous gene, affected her attitude/behaviour towards screening attendance. Her indifferent behaviour and attitude to screening goes beyond her susceptibility to cancer, but rather is deeply rooted in various factors such as denial. This goes beyond beliefs or constructs as expressed in HBM and other health theories like the Social Cognitive Theory. In this study, emotions such as fear of cancer and knowledge of cervical cancer and the screening due to the invitation received or social network (family and friends) played a part in enhancing 'self-efficacy', thereby influencing or acting as a prompt to attend screening (cue to action).

## **8.6 Evaluation of the study**

The study was evaluated using principles from Charmaz (2006), and Strauss and Corbin (1990). This was followed by further evaluation reflecting on the sampling, data collection, analysis and how my model added to the existing health behaviour models.

**Credibility:** credibility (Holton, 2008) was achieved by ensuring that the data presented, and the theory developed were grounded in the participants' opinions, insights and understanding, not my interpretation. Personal views of health and the unspoken accounts of the women on why they did not attend screening offered a varied perception and understanding from the participant's viewpoint (young women aged 25-34) without generalising (Strauss & Corbin, 1990). A vital part of obtaining credibility is when rigor is observed throughout the research from data collection to theory development. Using criteria from Charmaz (2006) helped in defining the credibility of the study as presented below.

1. "Does the research present intimate familiarity with the setting or topic?" The research presents 'intimate familiarity' with the topic through a review of multi-disciplinary literatures on cervical cancer screening and issues around participation. This presentation of new insights into influences on participation or screening attendance was achieved by taking into account a range of debates and suggestions of issues around participation whilst comparing these with new insights or findings emerging from this study.

2. "Are the range, number and depth of the data gathered sufficient?" The sample group consisted of a range of participants from various ethnic, educational, social and marital backgrounds with various screening statuses. Data was collected using various methods (interviews and a focus group). I was therefore also able to tap into both retrospective views of factors influencing participation and anticipated difficulties and concerns around the screening process. Sixteen in-depth qualitative interviews and a focus group were conducted, with participants recruited purposively from university campuses, church, friends of participants and a support centre for women from ethnic minority groups in the Northeast. I conducted the interviews and focus group in a location that suited the participants. These interviews lasted on average around one hour, allowing for a relatively in-depth conversation with sufficient time to explore areas of relevance to the participants, covering a broad range of topics. In order to gauge the depth of the data gathered, the preliminary findings were discussed on an ongoing basis with colleagues and supervisors in regard to emerging categories.

3. This study employed the use of 'constant comparison' to compare between emerging categories from the data. This was achieved by comparing interviews one another and with the focus group.

4. The emerging data was compared with existing literature on issues surrounding cervical cancer and screening participation. Turning to the literature enabled me to draw upon key concepts in the field of participation and decision-making research, and build upon existing studies. The logical links between

the data and subsequent analysis was further ensured by ongoing discussion with colleagues about the data and emerging categories.

5. Initial findings from this study based on discussions with my supervisors were presented to colleagues as well as at research conferences in the form of poster and PechaKucha. This presented an avenue to receive and discuss feedback regarding the emerging themes. For example, when initial coding began, and descriptive results were available, feedback enabled me to see other perspectives to the findings.

Another possible criterion for measuring credibility of a qualitative research is ‘relevance’ (Hamersley, 1992). Relevance demonstrates how new insights from the study can be applied alongside existing theory or studies (Holton, 2008). In other words, “relevance for the grounded theorist means bringing tangible benefits to the experts” (Fernandez et al., 2002). This new knowledge should be easily understood and applicable in a practical sense within the chosen field of study. Partington (2000) adds to this point by stating “getting new knowledge which is useful, relevant and up-to-date”. The theoretical viewpoint of the researcher allowed knowledge creation by expressing how these multiple views fit into the created knowledge and how reality was constructed in several ways by the participants, whilst gaining further understanding of their actions and obtaining fresh insights. These were manifested in the study findings and demonstrated in the explanatory model of understanding created.

In the context of this study, the findings reiterated how the social world and human condition influence how a person perceives themselves and how these create emotions that are deeply rooted in the subconscious. These emotions and feelings are often hidden or unspoken, as altering opinions regarding the subject matter could lead to criticisms or disapproval from influences such as the context within the social world above (see section 9.4 for a detailed contribution to knowledge).

**Transferability and usefulness:** This is the degree to which the interpreted results can be used by people within the field in their everyday world and on a daily basis, irrespective of their situation or background (Charmaz, 2014; Holton, 2008). Based on geographical, sampling and numerical limitations, the findings cannot be generalised and might be open to criticism as being not representative of all the young women required to come for cervical cancer screening (in terms of social class and varied ethnicity). This study focused on the depth/variety of views within the data collected. The study’s strength is its ‘grounding’ in participants’ views and experiences of cervical cancer and screening of women in Northeast England via a robust qualitative methodology and the intuitiveness of GT research.

This study drew on GT principles to explore opinions and insights from a certain group of people regarding factors influencing their participation in cervical cancer screening. As GT emphasises the

development of a theory/model, the theory generated in this study showed the influences and links within the viewpoints of the study participations. This was enhanced by the use of a concept to get a better understanding of these links, rather than providing a descriptive account of participants' views (Glaser, 1976; Strauss & Corbin, 2008). In the context of public health, it can be argued that the theory generated in this study can be adopted in practice either directly or in a related subject. This could act as a guide in the creation of interventions that might help improve the lives of people or increase screening attendance.

**Dependability and trustworthiness:** This approach aided the study to ensure that the findings went beyond presenting “nice stories/experiences” of the participants. According to Bowen (2009), trustworthiness helps in “conceptual soundness” from which the worth of the study may be evaluated. This was discussed in the context of dependability within this study (Guba and Lincoln, 1997). Conceptually, dependability is closely related to reliability in quantitative studies (Cooney, 2010; Sikolia et al., 2013). It confirms that the data represents the changing conditions within the study as it affects the stated aims and objectives. In this study, triangulation and keeping an audit trail of the data collection and theory development was a way of measuring trustworthiness. The research activities within this process, such as theme development, coding and categorisation were supported by the supervisory team and inputs from colleagues and peers. In addition, the use of theoretical sampling also added to the richness and variety within the data collected. Outside the influence of the supervisory team and peers/colleagues, I did a personal audit trail to measure my influence in the process. This was carried out using memos (see section 4.3) and keeping records of both the interview and focus group transcripts, using Mind Genius software to arrange and sort themes, and personally transcribing some of the interview transcripts.

**Confirmability:** Dependability and confirmability are closely related and are often used interchangeably. They are used to measure trustworthiness (Sikolia et al., 2013). Confirmability is a way of showing the researcher's level of influence in the study based on their presented theoretical stance adopted for the study (Lincoln & Guba, 1985). this was done through reflexivity and keeping an audit trail. I also employed GT procedures such as coding and theoretical sampling in both the focus group and interviews, to ensure that the generated theory came from the data rather than my own preconceptions. This was also to remove bias, as it is impossible for the researcher to completely eliminate their influence in qualitative research (Charmaz, 2006).

**Ethical issues:** The ethical implications of the study were not only for the participant, but also for the researcher, in terms of the emotional impact of conducting research on potentially sensitive topics (Johnson, 2009; Lalor et al., 2006; McCosker et al., 2001; Lees, 1993). Although ethical consideration

is detailed in chapter 3, a reflection of some of the ethical issues considered is stated here. Ethical issues for participants focused on how they were recruited, how permission was acquired, privacy of information, data protection and organisation, as well as reducing any foreseen danger to the women. Consent was sought from the participants and coercion was avoided by providing information sheets and a consent form. Information provided included: purpose of study, methods, intended use and how they can contribute to the study. In addition to consent, confidentiality was also explained and employed. This was done by anonymising the personal details of participants.

Although there were no significant ethical incidents, a few participants expressed discomfort whilst discussing cervical cancer and their screening experiences during the interviews. This raised the question of my role as a researcher in managing this. In one instance, when one participant was quiet for a long time, I gave her time to process her emotions and reminded her of her freedom to opt out at any time. However, she regained composure and continued with the interview.

In this study, I was frequently amazed at the sensitive nature of some of the views expressed by the participants, which on some occasions led to me reflecting on my own experience of the screening programme. I tried to separate my personal experiences from the findings, as I could personally relate with some of the women, especially those from the minority ethnic groups. To eliminate my influence, it was particularly important for me to avoid adopting a preconceived endpoint and to ensure that the findings reflected the participants' perspective'. A flexible approach was therefore most useful for me. In addition, the GT methodology highlighted the key roles and influences of external factors. It also covered how individuals perceive themselves and certain topics of discussion, as well as how their belief process works (how they make sense of things), influencing not just their health but also their decision-making (Blumer, 1969). These belief processes have implications for participation.

### **Reflection on sampling**

As stated in chapter 4, this study encountered some delays due to structural changes within the NHS leading to recruitment delays. These delays resulted in some limitations in sampling with respect to the GT methodology and this was evident during data collection and analysis. Practical issues arose in theoretical sampling, as it was difficult to decide the right participants in terms of attendees and non-attendees. Charmaz (2006, p.96) defines the role of theoretical sampling as: "to elaborate and refine the categories constituting your theory". Time, ethical and resource constraints also influenced theoretical sampling and, as such, in order to give credence to the study, effort was made to theoretically collect data.

Most participants included were purposively sampled/recruited to the study by various means, and as such may be limited or atypical in representation of the actual characteristics of the non-responders. When the issues around recruitment through the call and recall centre was resolved, only a few responses were received. Only five out of the 24 participants were non-attendees (non-responders) of the cervical screening programme. Although the non-responders provided views on their reasons for non-participation, many of these were anecdotal, i.e. they were other people's experiences. Since most of the participants were purposively sampled (20 out of 24), it could be argued that the participants recruited were only those willing and enthusiastic to take part in the study, which could also be reflected in their screening status.

However, a major strength in the recruitment was the diversity and inclusion of participants from a range of socioeconomic statuses such as education, ethnicity and marital status within. This was done purposively to gain the views of young women from varying backgrounds. Also important was the inclusion of women who did not understand English in the focus group, adding further credibility to the findings. An interpreter was used, as views from minority ethnic women were sought and included irrespective of language barriers and SES. This was in answer to a direct call from the literature, to seek the views of women from ethnic minority groups living in suburban, rural, or socially deprived areas or regions.

### **Reflection on data collection**

Data was collected through semi-structured interviews and a focus group session. These methods were adopted because of the sensitive nature of the topic being studied. The topic may be embarrassing to some individuals because of social and cultural beliefs surrounding cervical cancer and the screening procedure, as well as it being private and intimate, and because the screening mimics sexual intercourse. It could be argued that those who choose to participate in a research study about a topic as sensitive as cervical cancer screening may be atypical and as such may hold back their true thoughts and views for fear of being judged. To reduce the risk of data being lost and to enable participants' freedom to share positive and negative personal and intimate issues, the interviews and focus group method were felt to be the most appropriate. Although the focus group might not be the best method for discussing intimate issues, some women from minority ethnic groups are more comfortable in groups due to culture and are likely to express their opinion in a group setting rather than in individual settings (Creswell, 2007) hence the inclusion of the focus group.

The interview and focus group guides aided the discussion and interview process to raise issues of importance to the participants. I have undertaken training in interviewing in my previous employment and education, so I thought the interview process would be easy as I was comfortable around people. However, I was quite nervous during my first interview and focus group session. The nerves disappeared as the sessions progressed and interestingly, I did not have to rigidly follow the guides as my renewed confidence helped in using the participants' responses and views to guide data collection.

Although I was known by some of the participants (not on a personal level but as colleagues/student in the same university), I ensured that I conducted myself in a professional manner, reassuring them where possible of confidentiality and my own non-judgmental approach. Participants were allowed to choose a place comfortable to them, i.e. either the school or at home for interviews, while a community centre was chosen for the focus group because all the women visit the centre for social and personal issues, and had a relationship and trust in the staff, and a sense of comfort within the centre.

Most of the interview participants were comfortable with the words and terminology used in the question and as such I didn't have to restructure my sentences, however, some participants in the focus group were less educated and I was more conscious in my use of words. Those who struggled with English language had the interpreter to provide clarity. Since most participants were within my age group, it was easier to relate to some of their views and responses and this made it easier for them to open up about both negative and positive personal feelings. This level of trust enhanced the quality of the data collected.

Conducting the interviews, myself allowed me to gain understanding of not just the participants' views, but also my view as a researcher. Although I felt a degree of anxiety as a novice researcher in terms of ensuring the interview was conducted properly, I felt I understood the views of the participants in their entirety and did not colour the data with my own values. Those fears were actually related to reflexivity and my contemporary thoughts or values could endorse the richness and insight it affords.

Although the concurrent transcription, coding and analysis (constant comparison) was time consuming, it ensured the explanation of information/findings and the emergent theories reflected the aim of the study.

### **Reflection on Data Analysis**

One of the beliefs associated with using GT is that researchers should follow a reflective approach to enhance the theory generation process. (Strauss & Corbin, 2008; Charmaz, 2006). I was able to consider my role and reflect on the process of gathering the data in terms of coding, interview questions and

analysis. During the data analysis, I found this process physically and emotionally draining and regular debriefing of my feelings and difficulties to the supervisory team played a valuable part that helped me in maintaining a professional approach (Charmaz, 1991; Bowling, 1997). Other studies have identified the emotional impact of conducting qualitative interviews on researchers (Lalor et al., 2006). An important self-realisation during the analysis process was the difficulty in reconciling my preconceived expectations and reality of the findings, which was very different. This was difficult for me to handle as I kept looking for ways to navigate my findings to meet my expectations, resulting in me forcing the themes in the initial analysis process. However, after speaking with my supervisors, I was reassured that my confusion was not isolated, but an experience felt by many early career researchers especially PhD students. This reassurance led to the acceptance of the findings and working solely from the views of the participants, not my preconceived ideas or expectations. It was also a reflection of my growth not just as an individual but a researcher during the course of the study.

Flexibility during the analysis process was possible by drawing on the constructivist GT approach rather than adopting other approach, which was more systematic and procedural (Charmaz, 2014; Strauss & Corbin, 2008; Glaser & Strauss, 1967). Using this approach, I was able to examine the data in terms of 'action and thought process' to facilitate insights into the participants' views of cervical cancer and screening to understand their feelings about participation. Exploring the data thematically led to the identification of deep emotional and psychological issues, like associating cervical cancer to sex.

Finally, it is important to note that although it can be difficult to include all individual experiences and views in the provisional emergent categories described in the findings chapters, as a researcher, it is my responsibility to translate participants' views and activities as accurately as possible (Corbin & Strauss, 2008; Charmaz, 2006; Mills et al., 2006). The inductive-deductive reasoning of the constructivist GT adopted during the analysis process helped in addressing the aims and objectives and led to the creation of an explanatory model to explain participants' views of the phenomena under study.

### **Reflection on behaviour theories**

Health Behaviour Theories (HBTs) are often psychosocial theories developed for changing, understanding, explaining and even predicting health behaviours (Sutton, 2002). Areas of this research that touched on current HBTs were explained. In addition, how the explanatory model added to the constructs/variables of these identified HBTs was established. Although the complexity and dynamism of humans has largely been explored and put into consideration during the course of this study, it was identified in the design stages to have an open mind concerning the use and application of current HBTs. This was identified as a strength and would mean trying not to force findings into existing theories.

Humans have been known to exist in a dynamic group, rather than as isolated entities and therefore influence, or are influenced by, their immediate physical and social environment such as family, friends or colleagues etc. These influences are termed ‘reciprocal determinism’ (Bandura, 1989). From the discussion within this chapter, it can be assumed that some influences identified in this study such as ‘perceived susceptibility’ fall within some of the existing HCTs such as the Health Belief Model and Social Cognitive Model (Sutton, 2002; Diclemente et al., 2013). The influence of the interpersonal and environmental factors on health behaviour was apparent and very influential in creating the belief system of participants (socio-cultural beliefs, religion, social norms). The Social Cognitive Theory (SCT) suggested that personal characteristics alone are not predictive of a person’s behaviour, but rather the social environment also plays a huge part in the prediction of behaviour (Diclemente, 2013; Sutton, 2002).

One of the key constructs of SCT is ‘self-efficacy’, which proposes that people measure their ability and willingness to change behaviour, or engage in a new behaviour, by how much belief they have in themselves to engage in or change such behaviour (Bandura, 1982). According to Redmond (2010), an individual’s self-efficacy is measured using three scales: magnitude (level of difficulty), strength (level of conviction) and general efficacy (degree to which the expectation is generalized across situations). Efficacy varies across individuals, with individuals who achieved a greater behavioural change being inferred to have a higher degree of efficacy than those exhibiting less behaviour change (Bandura, 2004). It is interesting to note that self-efficacy is task-specific and therefore can be difficult to measure as it is influenced by various factors beyond our awareness. It is also known that behaviour change can either go towards a negative or positive route. For example, in the context of smoking, and identified in this present study, a participant aware of the dangers of smoking picked up the smoking habit because members of her social circle all smoked. She thereby conformed to peer pressure for acceptance. In this context, conformity outweighed awareness. In this study, information received (invitation letter, media, family and peers) acted as cue to action to adopting the health behaviour (cervical screening). It is therefore noteworthy that although various barriers were described, whilst acknowledging the associated advantages of the cervical screening, there was variation in actual attendance. This is because despite the level of efficacy shown, negative emotions towards the screening procedure, in the context of the main findings (issues such as exposure or the screening procedure-mimicking sex), could contribute to young women avoiding or delaying screening.

In addition to the argument above in relation to this current study, environmental or social influences were a major catalyst in the decision-making process for screening attendance (Hasting, 2007). Some of the reported broader social influences that directly influenced participation included religion and culture,

geographical location, immigration and immediate social network (family and friends). Although some of the identified barriers and influences fell within the construct of HBM and some of the SCT, it is worth knowing that these health behaviour constructs are interrelated and do not work in isolation in most cases.

This study's findings fill a gap in the existing health behaviour theories where emotions that play an important part of health behaviours are neglected in understanding or predicting health behaviours (Rosenstock et al., 1998; Azjen, 1991). This was done by developing an explanatory model (Figure 24) to throw light on the impact of these emotions on health behaviours and the intention to adopt behaviours. It also accounts for the effect and emotional responses to undergoing cervical cancer screening on an individual's decision-making process. As stated earlier, one of the criticisms of existing social cognitive models, such as SCT, TPB, HBM and PMT, is their failure to explicitly consider affective influences (feelings and emotions) on behaviour. There is a lack of explicit theoretical models relating emotions to screening behaviour. It is noteworthy that these models do not preclude consideration of affective outcome, however, they do not focus on affective states and the context of that state (Conner & Armitage, 1998). The explanatory model drew on these affective outcomes and how they influence behaviour, in this case cervical cancer screening. Only a few studies (Lawton et al., 2009; Glasman & Albarracin, 2006; Sandberg & Conner, 2008) have explored the affective outcomes on behaviour. For example, Sandberg and Conner (2008), in their review examining the impact of expectations of affect in performing behaviour, using TPB, found that anticipated regret negatively influenced subsequent behaviour. These affective states act as a predictor of intentions and may be particularly important in relation to certain affective behaviours such as condom use, as seen in Glasman & Albarracin (2006) and Conner (2010). However, in this study, affective influences such as fear, anxiety, embarrassment or pain caused by the association of cervical cancer with sex and mediated by socio-cultural factors, influence behaviour. According to Vernon (1999), "Attitudes and beliefs do not develop in a vacuum... an individual's choice is largely determined by social cultural conditions".

Those factors referred to as primal issues could lead to the formation of attitudes, often without conscious awareness by the individual (unconscious bias). These affective influences on health behaviours resulted in delays in participation and in most cases non-participation. In other cases, they acted as a trigger or cue to action in participation in cervical cancer screening. The factors explored in the explanatory model add to the knowledge base and it is anticipated that the current study may inform policy from which affective (emotion-related) interventions aimed at increasing cervical cancer screening could be designed, implemented and evaluated.

## **8.7 Conclusion and summary of the discussion**

In this chapter, the explanatory model was introduced and explained, and guided discussion of the findings in this study. Furthermore, this study's findings were compared with previous studies, highlighting similarities, limitations and inconsistencies among different studies. In addition, the concepts identified in these study's findings were further explained in the context of wider literature in other fields, including relevant areas outside public health.

One of this study's 'contributions to knowledge' was the fact that it provided an insight and deeper understanding of the opinions and experiences of young women living in the Northeast of England that could inform the delivery and planning of age-specific health interventions in this geographical area and could be potentially be adopted in another region. Additionally, this study addresses to the gap in existing health behaviour theories by addressing affective (feelings and emotions) influences in understanding and predicting behaviours, a construct that has been a neglected outcome in other social cognitive theories.

Finally, the results from this study propose and highlight the complexity surrounding influences on cervical screening participation and non-participation. These go beyond the social, psychological, geographical and economical context and also include in-depth primal human issues associated with sex that influence behaviours and decision-making processes in regard to screening. The model developed highlighted that attendance and non-attendance was affected by the complex factors that predisposed cervical screening participation within the social, psychological, awareness and everyday (practical) domains. These factors include psychological and emotional factors that are unspoken and primal in nature as well as factors that relate to the implicit nature of a woman. A combination of these factors leads to the possibility of delay or even non-participation of cervical cancer screening as illustrated in the model.

The participation decision was influenced by knowledge/awareness of cervical cancer and perceived susceptibility. Negative emotional attributes such as fear could also act as barrier in some cases. Non-participation on the other hand was influenced by a combination of factors that are sometimes interrelated, such as the screening processes resemblance to sex or negative emotions like embarrassment (linked to exposure, procedure mimicking sex), fear (pain and cancer linked to death). These barriers are further influenced by health and cultural beliefs due to misconceived knowledge and stigmatization of sex. Increased awareness, education of health professionals and creating of alternative testing option or interventions that focus on emotional as well as practical issues could lead to improved uptake.

Evaluation of the research process and journey was carried out by reflecting on the sampling to analyse the process and how the health behaviour theories/models informed the discussion of the findings.

The following chapter will highlight some of the strengths and limitations within the study and the contribution of this research to existing knowledge as well as its implications for research, practice and policy.

## **CHAPTER 9: Study implications and conclusion**

This chapter will highlight the strengths and limitations that arose from the research process, the contribution of this research to existing knowledge and implications for practice, policy and research.

The implication for policy and practice will be grounded in the data collected as it draws on participants' suggestions of ways to improve uptake and participation. Recommendations were offered by participants on how various forms of awareness raising might help improve knowledge levels to help in the minimisation of cost, mortality and morbidity arising from late diagnosis of cervical cancer. In addition, uptake, which has remained significantly low, can be improved by looking at developing alternative screening methods as well as improving health professionals' training on sensitivity. The main finding was centred on sexual association. This sexual connotation of cervical cancer and its screening was revealed to be because of awareness/knowledge level, sociocultural influences, and physical action of the screening procedure.

### **9.1 Strength and limitations of the study**

All research methods have complications and limitations; however, the acknowledgement of these restrictions does not devalue the research. This acknowledgment therefore enhances it by allowing for transparency and openness to critique/evaluation.

Results and opinions from this study were obtained from 24 participants through interviews and a focus group of women who were within the cervical screening age of 25-34 and living in the Northeast of England. This study is rooted in the 'interpretive tradition', as the investigation was contextually situated in age, place and time (Charmaz, 2014).

The inclusion of a focus group allowed for in-depth exploration of influences/factors in cervical screening participation including knowledge of cervical cancer in a diverse range of socio-demographic and socio-economic perspectives.

In addition, due to the number of participants included in the study, there might be criticism in terms of representativeness. The small number of participants was because of challenges faced during the recruitment period (see chapter 4). We opted for the chosen sampling method and size due to time and ethical implications. On the other hand, in terms of generalizability in qualitative research approaches, this is not of much concern, as all methods/methodologies vary in the way they capture different individuals' opinions, insights, understanding and experiences (Denzin & Lincoln, 2005). Furthermore,

there is no single interpretive truth in research approaches; “it is the world of lived experience and so can deliver significant insights and knowledge” (Denzin & Lincoln, 2005).

This study provides valuable insights of young women’s views of the cervical cancer screening and how this influenced the decision-making process to participate or not. The eventual worthiness of this study lies within the “richness, depth and sufficiency of the data” (Charmaz, 2006, p.18). Acknowledging that personal bias can influence the research process and eventually the viability of the findings, was addressed and minimised using reflexivity and triangulation (Charmaz, 2014).

The issues encountered with the call and recall centre were due to NHS restructuring (see chapter 4) and changed the dynamics of the study. This is seen as a limitation and it is recommended that future research includes recruitment using only the call and recall centre, which might give a different configuration of samples. Using this approach would also mean that the participants will be recruited blindly and would eliminate the influence of the researcher, thereby removing the criticism of bias connected with the multiple variation sampling employed in this study.

Another possible limitation is in the area of saturation. Although a level of data saturation was deemed to be reached in this study, this is debatable, since issues around sampling (see chapter 4.1) made standard theoretical sampling impossible, which could have influenced my stance on reaching data saturation. However, I can say that saturation of data was attained in my study, although it is recommended that future research samples participants following the standard GT theoretical sampling approach to better argue issues around data saturation.

Other limitations and strengths are stated throughout this thesis. The study implications are explored in the section below.

## **9.2 Implications for policy and practice**

Implications for policy and practice will centre on suggestions around improvement as indicated and presented by the study participants. Knowledge of cervical cancer screening was limited and inadequate in some participants. There were misconceptions around cervical cancer and the screening procedures due to their informal awareness, often gained through social networks, past medical experiences (e.g. STI test) or working in health. Suggestions on improving knowledge and awareness included improving the invitation letter and accompanying leaflets, and educating both individuals and health professionals on their use of campaigns (media and social media).

### **Implications for policy**

The content of the information leaflets accompanying the invitation letter was considered lacking in detailed information such as what the screening procedure involves, details of the screening apparatus and sex of the test taker. The findings indicate that future policy should channel attention into the invitation's acceptability and readability in terms of structure, fonts and wording, and the inclusion of answers to some of the concerns stated above. Options suggested from the study, was the use of fear appeal in a subtle manner as well as positive messages from survivors and people who had an early diagnosis through participation in the screening programme. Arguments abound on how messages are to be portrayed in order to change behaviours. One of such area is in the tone of the message, which could be positive (benefit focused) or negative (fear inducing). According to Van de Velde et al. (2010), the effect of the tone of the message in their study was influenced by age, SES and gender. Women were more likely to change behaviour than men who are above 3 years of age and with little or no education. They suggested that communication strategies aimed at behavioural change should also include the other factors stated in addition to tone. Achieving a desired effect from the tone of a message can be complex, therefore suggestions around including certain themes in the content of a message aimed at knowledge-induced behaviour change have been provided. Three such themes are 'rational' (relative to individual's self-interest, i.e. message = designed benefit), 'emotional' (arousing both positive and negative emotions for a desired change) and 'moral' themes (a sense of what is right) (Fredrickson, 2001; Andreasen et al., 2003).

Future policy should channel attention into campaigns and educational approaches to improve or increase awareness. Inadequate promotion may influence cervical cancer screening participation. The need for increased awareness was advocated by the study participants. As stated, awareness was quite low, indicating the importance of health communication or promotional campaigns as an integral element in health interventions; in this case, cervical screening uptake (Rimal and Lipinski, 2009; French et al., 2009). Health intervention promotion can be carried out using various means, including word of mouth (advocated by women from ethnic minority groups) or media advertising including through social media. In recent years, the media has played a key role in public health awareness-raising. Thus, it can be used in the context of cervical screening to remove misconceptions and reiterate the need for continuous participation. A collaborative campaign across a range of media is deemed to be more effective compared to using one media channel (French et al., 2009).

Focusing on this current study, media such as TV and social media e.g. Facebook, Instagram and Snapchat appealed more to our study participants. Successful awareness campaigns have been used in other health issues and, in the context of cervical cancer, as part of the yearly cervical cancer awareness week, several charities spearhead various campaigns to raise awareness of cervical cancer and screening.

One such campaign is the annual ‘smear4smear’ social media campaign organized by the Jo trust UK as part of the cervical cancer awareness week. Although such campaigns have attained a level of success, they only occur once a year. A continuous campaign or at least increasing the frequency of such campaigns should be encouraged and invested in. Local commissioners and local authorities can take up such initiatives and include the cost in their yearly budget.

In terms of educational approaches to increase awareness and subsequent uptake of cervical cancer screening, educational policies should incorporate cervical cancer into the sexual health curriculum in schools. This should be made available to both male and female pupils, so as to raise awareness among both genders, thereby creating awareness in the future for women through their male partners. Educating men on cervical cancer has shown to yield high levels of awareness and improve uptake especially among women from minority ethnic groups (Devi Manivannan et al., 2014; Thomas, 2005). This approach was one of the suggestions for improving uptake. It would also help in the reduction of issues discussed in chapter 3 because of the patriarchal nature of the BME communities.

### **Implications for practice**

A major issue raised was the level of professionalism and lack of sensitivity of the test taker. This raises an important policy and practice issue in regard to Continuous Professional Development (CPD), which should include annual training on sensitivity due to the invasive nature of the screening. This is because, due to structural and time factors, health professionals can easily revert to medicalisation and objectification due to the nature of their jobs. “It is important for those who deliver health interventions to have an understanding of their clients beyond the particular health behaviour (e.g. those behind on screenings), but as people with complex life stories and circumstances that affect the meaning of health and health-related behaviour” (Joseph et al., 2009). There is a need for this training, if increase in uptake is to be achieved. This is because these training will reiterate the need for sensitivity in order to encourage continuous uptake and prevent participants avoiding their next screening due to a negative past experience.

Consideration of GPs’ and health workers’ involvement is highly recommended in terms of constant reminders during routine check-ups. It is a consensus especially among the women from minority ethnic groups that the level of trust in their GP is relatively high. Moreover, information received from the GP is taken to be of the utmost importance compared to information from non-medical practitioners. GPs and other health workers can act as additional resources for the screening programme by sending

reminders through text messages or face-to-face during routine check-ups. Getting GPs' and health workers' opinions on the most convenient way to get women interested in the screening was suggested.

Also with regard to the nature of the screening (invasiveness), there were suggestions to remodel the screening apparatus in a way that will make it easy for self-collection at home. Home testing kits were suggested, although the difficulties in achieving this were acknowledged. In terms of cost and feasibility/acceptability, existing initiatives have already yielded positive outcomes. Vagina swab (Nobbenhius et al., 2002; Budge et al., 2005) and HPV self-testing (Pathak et al., 2014; Barata et al., 2008; Lorincz et al., 2013; Racey et al., 2013) for cervical cancer screening have received a high level of acceptability. A systematic review carried out by Racey, Withrow and Gesink (2013) of eight European studies of under-screened women reported that compliance with HPV self-testing was significantly higher than with cervical cytology. Gravitt et al. (2001) reported similar findings. Due to findings on acceptability in the literature, policy aimed at moving the self-testing for cervical cancer from the clinical research level (RCOG, 2016) to practice/implementation level should be considered if uptake or the issues raised in this study are to be minimised.

Additionally, in order to counter possible difficulties associated with invasiveness, sending health workers to specific locations such as community centres on a weekly basis could help encourage women from minority ethnic groups to participate. Choosing Health (2004) recommended changes should be made in the ways health is promoted, with a recommendation of the use of health trainers within local communities to train and raise awareness among local people. This encourages healthy living and choice-making within the communities. Using health trainers could help encourage preventive health behaviours such as participating in cervical screening in young women within ethnic minority communities. In addition, this could also partly reduce practical barriers, such as appointment difficulties and busy schedules, thereby increasing options for those in such situations.

Finally, policy makers and commissioners in charge of organizing public interventions such as cervical screening programmes should consider this study's findings in addition to the existing cognitive and individual-focused markers of health behaviour. Consideration should also be centred on some of the psychological and hidden issues such unexplained shame or disgust, which is rarely voiced, when considering intervention for improving uptake. This can be achieved through continuous investment in large-scale research that reevaluates or validates findings like those in this study.

### **9.3 Implication for future research**

Based on the aforementioned limitations and challenges faced in the course of this study, there is a need to highlight some of the areas identified for future research. First of all, as outlined previously, barriers and concerns were centred on the nature of the screening procedure. A few studies look at alternative ways of screening, such as the HPV self-testing. The evaluation of specific methods e.g. effectiveness of the home vaginal swab and the cost implication and continuity of such method if effective as a way of improving uptake, were also debated upon. This future research can be done in the form of Randomized Control Trials (RCTs) and systematic reviews of studies carried out in other parts of the world showing the influence on uptake. If a more cost-effective home kit is produced, further RCTs can be carried out to evaluate or measure outcomes and impact on young women aged 24-35, thereby countering issues around emotional and practical issues surrounding the screening procedure.

Secondly, quantitative research studies that focus solely on emotional factors identified in this study e.g. sexual association, focusing on an in-depth contextual exploration of the influences, should be carried out. Due to the small sample size, future large-scale studies should further correlate the elements of sexual association and participation in screening. The studies should be void of all the issues identified in this study by looking in hindsight at all barriers, even those that were beyond the control of this study. This can also act as a means of evaluating the explanatory model created in this study with changes made to the attached variables.

Furthermore, there was non-inclusion of women from some of the deprived areas in the Northeast according to the “index of multiple deprivation”, due to financial implications (this study was self-funded), time limitations and ethical implications. It is important that a fully funded research study with enough financial and human resources to explore the issues identified in this study, includes women living in such areas. It will be interesting to know if emotional issues attached to sexual assault or early pregnancy, which are more common among people living in such areas are part of the findings. This will help in the inclusion of these issues during the intervention development process to improve uptake in young women.

Our findings suggest that women who attended screening and those who do not, sanctioned these negative attitudinal and emotional factors, indicating that they do not provide a true explanation for non-attendance. In other words, there is difficulty in trying to understand the exact influence of these factors. Psychologists have identified that individuals have restricted ability to discern the actual drive or intention for behaviour change (Nisbett & DeChamp, 1977). Consequently, more sophisticated methods

may be needed to better understand non-attendance. Although the explanatory model above provides an in-depth insight into these factors, further research to test and validate the model is needed. In addition, research focused on the sexual connotations and emotional factors described above on a larger group of young women (and women of other ages) will help further strengthen this model and findings, and help in evaluating interventions for uptake that address the concerns raised here.

#### **9.4 Contributions to knowledge**

This study shows original contribution to knowledge, policy, practice and theory within the topic area and the field of public health.

This study clearly identifies deep-rooted complex issues (which are sometimes not explicitly evident) implicated in the decision to access screening, such as emotional and psychological impacts with a potential for anxiety creation. These deep human issues are often unspoken and subconscious. Clearly, understanding reasons for deciding to participate or not participate in cervical screening is complex and not clear-cut, as it is based on many profound moral, cultural and social beliefs, as well as how women view themselves. It is worth noting that earlier studies on the psychological perceptions of screening, e.g. negative emotions such as disgust, embarrassment and anxiety, remain at a more superficial level and could be seen as underexplored.

This study, through the 4 elements of the core category, ‘sexual association’ (see figure 24 for explanatory model) within the developed model, goes further to present the contextual levels influencing these emotions relative to cervical cancer screening participation and the decision-making process. The model also illustrated participants’ socio-demographic and health characteristics, perceived severity and perceived susceptibility to cervical cancer, perceived barriers and experienced barriers to cervical screening.

These barriers or concerns identified within the model as “sexual association” stem from the nature of the screening itself. The inability of people to explicitly express these deep-rooted issues such as the degree of the emotions they feel, or psychological impact of the screening have implications for practitioners. Practitioners, therefore, need to be more patient, attentive and be more sensitive and try to bring themselves to an understanding of each individual. However, this may be difficult in a time pressured environment, where perhaps one-person blurs into another and a ‘medical gaze’ may take over resulting almost in an objectification of the individual. Working at this ‘population level’ may lead to this blurring building overtime as a result of working within the health sector for so long.

My research therefore indicates a direct impact of the screening on the individual both from an emotional/psychological stand point as well as highlighting the gap in knowledge of cervical cancer and the screening procedure at varying degrees amongst both the screened and unscreened participants. Therefore, these concerns should not be overlooked but rather be considered in the creation of future interventions for increasing screening uptake.

This study contributes to the body of knowledge around cervical screening by highlighting that there are various issues in play, some of which are to do with knowledge and education, and some to do with very fundamental human issues about birth, reproduction and death, which are linked to emotions and psychological issues. This research has focused on these issues and shown their importance in varying degrees in decisions to either attend or delay/ignore screening invitations. This also shines a light on the way screening services are medicalised, and some practitioners don't pay attention to the individual. Practitioners should be reminded through continuous regular training on the sensitivity of the screening. This is because, as described, practitioners can become so blinkered, or used to what they are doing, they tend to lose sight of the person (note that each individual walking in to be screened will have different emotional responses, education, culture, personal life and health experiences which this research has indicated). Practitioners should learn to treat people as individuals rather than as a collective entity.

Policies tend to deal with people as a collective entity and there is a constant tension in any healthcare work between attending to individuals and trying to do something for the whole population, which is made up of a broad range of individuals. In Public health (PH) Interventions, there is still tension between population based PH approaches such as screening and the individualistic models. The tension stems from variation in intervention models. Whilst population based intervention approaches, such as cervical screening, are geared towards the general population, individualistic approaches focus on the health needs of individuals (Greggs, 2015). Health Promotion over the years has focused and operated more on population level/context than the individual context (Whitelaw et al, 2001). This creates a tension for health promotion practice within the health system. Although there have been debates regarding how these approaches differ, they can be said to be relative and dynamic as individual approaches are felt to be encompassed in the population dynamics (Arah, 2009). In General practice, the approach generally adopted is however geared more towards treatment rather than prevention (Peckham and Exworthy 2003; Kings Fund, 2010).

Some empirical studies suggest that some health professionals (e.g. nurses) have adopted a general individualistic approach and a behaviour-changing perspective regarding treatment, but it seems that the development of the health promotion concept has little influence on their practical health promotion

practices (Casey, 2007a; Irvine, 2007). As part of the debates around both approaches, a study by Kemppainen et al, 2013 revealed that when nurses' interventional/health promotion activities were guided by individualistic perspectives, a holistic approach which focused more on the individual patient's need and decisions was adopted. This included patients' participation from a personal aspect such as deciding on a menu, bedtime hours and clothes they want to wear (Kemppainen et al, 2013; Casey, 2007; Irvine, 2007). They suggested that planning, implementation and evaluation of health promotion interventions or projects by nurses (such as screening) should include advanced clinical skills as well as constant supervision to maintain effective and acceptable services. However, organisational culture as stated earlier was seen as a barrier to the effective delivery and implementation of health promotion at the individual level within the health system (Kemppainen et al, 2013). In light of the above, the Royal College of General practice (RCGP) have included in their curriculum a section encouraging GPs and other health professionals within Practices to be proactive in maintaining health promotion, by being more attentive to the needs of patients, and where appropriate providing health promotion in a therapeutic and preventative way (RCGP 2007). Despite, the recommendation by the RCGP, the United Kingdom in comparison to other European countries has a low involvement by health professionals in health promotion activities (King fund 2010; Grielen et al 2000).

Health services seek to help people as an entity, but in doing so, they generalise things so much that they lose sight of the individual. It is understood that health practitioners are following recommendations within public health policies. However, I acknowledge that the problem with policy has to do with population, and that there is inevitably a tension in trying to have a policy that covers everybody whilst also taking individuals into account. It is therefore recommended that the policy include a section which builds a little more time, education and insight into practitioners' interactions with the public around things like cervical cancer screening, e.g. increasing appointment time. For example, due to shortened appointment times within the NHS currently, this could impede on not just other services but also on the screening programme itself, meaning practitioners are limited in the amount of time spent with individual service users leading to less satisfactory experiences. Employing or reiterating an individual approach within the screening programme's recommendations could further remind health professionals of the need to put the individual first and could improve experiences and possibly increase participation.

In the context of broader public health education and health promotion, interventions are based on collective entities, however, there should be shared decision-making between the policy makers, practitioners and service users in reaching an agreement on how best to meet the needs of the service users, rather than just what policy makers think would work. This will foster community participation and active involvement in policy making on issues affecting individuals (McHunu, 2009). The model

developed in this study therefore represents another contribution to knowledge and creates avenues for interventions to be explored at an individual rather than a group level. It tends to cater for deeper issues by factoring in cultural, psychological and social influences as well as the relationships between these influences.

My research indicates that these emotional, cultural and deep-rooted human issues impact screening attendance. Therefore, perhaps a way for dealing with such issues in order to get more people to attend screening would be recommending for policy to develop new ways of doing the screening. It is acknowledged that due to the physical position of the cervix, it might be difficult to have alternative screening methods, however, there are ways to minimise the impact screening might have on individuals, by providing safer or more convenient locations for screening to be carried out. For example, some participants suggested that they would accept home screening, a urine or blood test, so perhaps new screening kits could be developed. Some participants further suggested different appointment times, education or training in schools and community centres, mobile reminders and GP practice reminder letters. Also, policy makers, developers and researchers might think about alternative types of screening, for example creating specialised panty liners that could collect secretions to be tested for the presence of HPV or other cervical cancer indicators. In Australia, their new cervical screening program is considering the use of self-collected specimens, where women will be required to take a sample of cells from their cervix using a tampon or cotton-tipped swab for testing (Department of Health and Aging, 2013). It is anticipated that self-collection will provide some level of privacy to women and help reduce the barrier of fear of exposing the genital area to another person or total stranger. This may increase participation in cervical screening. If successful, this can act as a model for creating interventions for increasing participation as a way of dealing with some of the deep-rooted issues highlighted in this study.

Behavioural theories and models of behavioural change cannot bring about behaviour change, nor can they predict with certainty what changes in behaviour will occur (Prager, 2012). Nevertheless, they can inform policy makers, implementers and others involved in trying to bring about change, prompting them to consider the likely success of initiatives and interventions (Darnton, 2008). “The sheer complexity of human behaviours and motivations makes it very hard to predict with certainty what the impacts of policy interventions on people’s behaviour are going to be.” (Jackson, 2005, p. 119 cited in Prager, 2012). “It is important to note that choices are influenced by moral, normative, emotional, social factors, as well as facilitating conditions and the force of habit, and the (so-called) rational deliberations and intentions” (Jackson 2005, p. 105 cited in Prager, 2012). As evident in this study participation and non-participation in cervical cancer screening were influenced by deep-rooted psychological and emotional issues in the context of sexual association that were driven by other social, cultural, religious, institutional factors.

With regard to service provision the implementation of an intervention that could help address issues highlighted within this study would be useful both for individuals and the wider cervical screening programme. A number of Public health approaches/models could be used as bench marks for intervention creation, however as noted above there are a number debates around existing models and how these can fit into the needs of individuals and effect positive behavioural changes. Major approaches include individual level frameworks (Stages of Change Model; Health Belief Model; Consumer Information Processing Model; Theory of Reasoned Action and Theory of Planned Behaviour), interpersonal level frameworks (Social Cognitive Theory/Social Learning Theory) and community level frameworks (Diffusion of Innovation Theory; Community Organisation Model) (Prager, 2012). Models of behaviour focusing on individual perspectives for explaining behaviour are limited as they touch on the processes of change but may not constitute explanatory or comprehensive frameworks for understanding health behaviours. For example, the theory of reasoned action is perhaps the best-known social-psychological attitude-behaviour model and incorporates external factors (normative social influences) on behavioural intention (Ajzen and Fishbein, 1980). However, this theory looks at intentions rather than actual behaviour. My Model focuses on behaviour change influencing individuals and also changing the conditions and drivers which influence behaviour. For example, the behaviour (screening attendance) in the context of screening procedures was influenced by its association with sex, with cultures, moral expectations, and social constructions around sex acting as a driver for behaviour (intention to screen).

However, another interventional approach could be utilising social marketing, although there are still debates about its effectiveness or proper usage in creating health promotion interventions. Nonetheless, Social marketing (SM), similarly to public health approaches, draws on disciplines such as psychology, sociology, communication and economics (Donovan, 2005). However, SM distinguishes itself from other public health efforts through its emphasis on the “strategic integration of the elements in marketing’s conceptual framework” (Grier & Bryant, 2005). This involves the application of a consumer orientation, using exchange, audience segmentation, the marketing mix and understanding of the competition. Currently these considerations are not systematically applied within the general public health context. In addition, there is debate around social marketing being overly focused on the individual and perhaps disregarding the wider determinants such as social, economic and environmental factors (Perese et al, 2005; Smith, 1998; Donovan and Henley, 2003). In the context of social marketing as a model there is also a risk that an insensitive individual approach could be seen as centred on a victim blaming mentality (Perese, et al 2005). However, the premise of a consumer-orientated approach in social marketing could address the cultural values, needs and aspirations of populations with an aim to address the issues around wider determinants.

Consumer orientation implies that the consumer is central to, and an active participant in, the social marketing process and therefore social marketers and those intending to adopt this approach must be aware of, and responsive to, consumer needs and aspirations. Although SM focuses largely on informed participation it also strikes a balance between respecting individual autonomy and the goal of achieving greater public health effectiveness, (Rimer et al., 2004). Additionally, in spite of these debates some aspects of social marketing are accepted as influencing upstream activities such as policy and regulations to address wider determinants of health. SM intervention begins with an understanding of factors that influence behaviour such as knowledge, environmental, family, religion and self-efficacy, (individual insight).

This doctoral study can be seen as providing insights regarding individual decisions to attend screening that may help to tailor SM interventions. Possible interventions to change behaviour towards cervical cancer and screening, as well as increase the awareness level of cervical cancer and the deep-rooted issues which emerged in this study can draw on consumer oriented approach with social marketing.

With social marketing and existing public health approaches the development and implementation of educational activities such as continuing professional development (CPD) could be useful. Such CPD for health practitioners could include issues raised within this study such as sensitivity to their personal circumstances, culture and religion. Also, possibly using models such as person-centred care (Dow et al., 2006) could channel service delivery more towards individuals with a focus on more specific individual needs that could help address issues around insensitivity and desensitisation. Similarly, trustworthiness or trust-building between service users and health practitioners can be enhanced through improving communication and relationships.

In addition, ways of generally increasing knowledge through raising awareness of cervical cancer and screening programme in the general population could be done by including relevant materials in school curriculum and distributing information via community centers. Social media or media could also be harnessed to raise awareness and the inclusion of explanations of the step by step process of the screening procedure within the invitation letter might reduce identified emotional and psychological issues.

With regards to policy structural and institutional approaches, other than training, could help in gradually addressing or reducing some of the issues and concerns highlighted within this doctoral study. For example, the NHS Yorkshire and Humber created a 3-level framework called the prevention and lifestyle behaviour competence framework, to support health professional (staffs and organisations) and act as a guide for everyday delivery of service aimed at changing behaviour (NHS Yorkshire and Humber, 2010).

This framework follows an individualistic approach as it is centred on service delivery aimed at the individuals need. In summary, the framework includes level 1 which focuses on ensuring individuals can make informed choices to manage their needs; that individuals have access to appropriate information to make such choice and manage their needs; as well as providing opportunistic advice. Level 2 involves staff ensuring their actions support care, protect the individual's overall wellbeing, enable an individual to change their behaviour in order to improve their health and wellbeing. Level 3 includes providing an environment for people to address issues related to their health and wellbeing, enabling individuals to choose and optimise their choices and maintain individual lifestyle (NHS Yorkshire and Humber, 2010). Although the framework was not centred solely on screening delivery this framework could act as a model for cervical cancer screening to address the issues or concerns raised in this study which can be seen as cutting across all 3 levels.

However, public health policy makers should apply caution when adopting or creating frameworks or interventions, as they sometimes lead to resistance from the service users. For example, the wording within the invitation letter or screening campaigns should be structured in a way that does not seem to dictate or 'sermonize'. This was evident in this study, as some participants refused to look at the invitation letters and accompanying leaflets because they felt it to be too direct and therefore delayed participation as they didn't want to be told what to do. Also, future policies around ways of improving the screening experience and increasing participation should explore adopting a similar approach to Australia (alternative testing procedures) and include some of the suggestions within the study in their future policies and research.

My study also contributes to existing behaviour change models by filling a gap in the existing health behaviour theories, where emotions that play an important part in health behaviours are neglected in terms of understanding or predicting health behaviours (Ajzen, 1991). The explanatory model developed in this study accounts for the emotional responses to undergoing sensitive screening such as cervical cancer screening and how these affect an individual's decision-making process. It is noteworthy that existing models do not preclude consideration of affective outcome (details in chapter 8.6); however, they do not focus on affective states and the context of that state (Conner & Armitage, 1998). The explanatory model drew on these affective outcomes and how they influence behaviour, in this case around cervical cancer screening, by contextualising these deep-rooted emotional and psychological issues. Like this study, only a few studies (Lawton et al., 2009; Glasman & Albarracin, 2006; Sandberg & Conner, 2008), have explored the affective outcomes (see on behaviour by measuring psychological variables of intentions for decision-making (Sandberg and Conner, 2008). However, in this study, emotional influences such as fear, anxiety, embarrassment, pain (which in the context of this study were

caused by the association of cervical cancer to sex), influenced by socio-cultural factors, can affect behaviour. These influences (also referred to as primal deep-rooted issues) on health behaviours resulted in delays in participation and in many cases, non-participation. In other cases, it acted as a trigger or cue to action for participation in the screening. These factors could enable the current study to inform cervical cancer screening policy that takes into account affective (emotional) influences on intervention design.

As the researcher conducted all the fieldwork personally, there was consistency in participant recruitment and data collection. This offered the participants the chance to share their experiences and express their views in their own words. This study has implication for existing literature, as drawing on GT principles has provided appropriate means for gaining a deeper understanding of young women's perspectives by unravelling complex issues around the study phenomena. In addition, this study also recognizes the co-construction of knowledge between the participant and the researcher, leading to the derivation of combined set of 'theoretical concepts' and the development of an explanatory model. This model contains and encompasses rich data, which would have been unobtainable had a quantitative approach been adopted. Similarly, employing multiple data collection methods added value to the study instead of restricting to a single form of data collection. This increased diversity and created richness in the data collected. Integrating interviews, focus group data and sometimes observation of the participant's body language resulted in ensuring that the data and findings were solely from the research participants' viewpoint (Charmaz, 2006; Lambert et al., 2008). This also enhanced the evaluative strength of this research study.

Finally, educationally, the findings from this study are expected to benefit the service area in both academia and practice. Inferences can be made from this research by students and researchers for future academic and research needs.

## **9.5 Conclusion**

While several studies have been undertaken around cervical cancer screening participation, there was gap in research around young women's reasons for participation and non-participation. The reason for undertaking this research was to develop an in-depth understanding of the views and factors influencing intentions to participate or not in cervical cancer screening and to explore where possible relationships between those factors.

These views were sought by exploring:

- Factors influencing participation/non-participation by exploring knowledge of cervical cancer and the screening programme, including views regarding the acceptability of the screening by looking at women's understanding of available information about the screening, and their experiences and perceptions of the screening.
- Their health views and beliefs and how these influence their decision to participate in the screening programme.
- Views from different groups of young women, including those from minority ethnic groups, on suggested ways to improve uptake of screening and their experience of the programme overall.

Findings revealed some interesting themes centred around deep human issues that are often unspoken and subconscious. Clearly, the reasons for deciding to participate or not participate in cervical screening are complex and based on a number of profound moral, cultural and social beliefs. These beliefs can inform the way an individual views themselves with respect to what is available to them (in this case cervical cancer screening). Many of the comments made by participants were also raised in the literature (practical concerns such as appointment difficulties, having a busy schedule, low prioritisation, etc.), but some of them were new, and were explored in-depth during abstraction and conceptualisation of the main finding, 'sexual association' (presented in chapters 5 and 6).

Like previous research (Waller et al., 2009; Ackerson, 2008; 2009; Marlow et al., 2015; Oscarsson et al., 2008), the findings from this study suggest that cervical cancer is perceived as a very serious health issue and that screening is seen as an effective preventative measure. There was however, dissatisfaction around the information on the invitation letter and accompanying leaflets, and their effectiveness in terms of being a cue to action or object of self-efficacy (as an educational tool). Facilitators to screening were mostly around self-obligation and responsibility, fear of cancer and the need to stay healthy, and in most cases, altruism due to the presence of a partner or family. In terms of barriers to screening, outside the challenges around unresolved practical issues as indicated in other studies, the main barrier disclosed was around deep-rooted emotions (often unspoken) around the intimate nature, intrusiveness and stigma around the screening procedure and its close association with sex. Although there was agreement on the importance of the cervical screening, the impact of its associations with sex created negative emotions of disgust, embarrassment, shame, anxiety and pain. These emotions, when coupled with existing practical issues, dissuaded or delayed participation. The views held with relation to cervical cancer being related to sex and the associated emotions could be relative to the basic psychological process of human information processing (Robb et al., 2014). The processing system is characterised into 2 parts: the fast (emotional and intuitive) and the slow (deliberative and rational) (Robb et al., 2014; Kahneman, 2011). In the context the main finding, sexual association falls within system 1, since decision-making was

influenced by unspoken deep primal issues as a result of the association of cervical cancer and its screening to sex. System 2 was associated with practical issues (with less focus in this study) and was regarded as priming, because most people would rather state the practical issues than address the emotional issue, as they feel that this would be a more acceptable reason for non-attendance (Kahneman, 2011). The issue of priming is raised here because most emotional barriers in the context of sexual association (the main finding) are often unconscious. They are called unconscious barriers, as they are often unspoken and hidden within. An example of priming comes into play when a person has issues with the penetrative nature of the screening procedure but may not voice that as a distinctive reason for their hesitation to screen. Instead, they state known practical reasons that are felt to be more acceptable. This study was able to contextualise the basis of these emotions in depth, as shown in figure 24, rather than stating them based on past studies, which have less depth.

Available interventions focus on raising awareness and resolving practical issues, thus omitting to consider deeper primal issues (unspoken feelings or views) or the psychological issues that come with social and cultural norms, which consciously and unconsciously influence participation. Creating alternative screening methods or interventions that consider these issues, and increasing awareness through education, could improve or increase participation.

A number of qualitative studies (Oscarsson et al., 2008; Waller et al., 2009; 2012; Ackerson et al., 2008; Abdullahi et al., 2009; Thomas et al., 2005) have explored the factors influencing screening uptake in women. There is however, limited published research on factors influencing participation and non-participation in young women, especially those aged 25-34 and living in the Northeast of England, as in this study.

This study's original contribution to knowledge, conceptually, methodologically, practically and educationally, has shed light on the views, perceptions and experiences of participants in their own voices. This is formulated in the explanatory model (Figure 24) presented in chapter 8, which shows the complexity around decision-making and the relationships between factors that influence behaviours toward participation in the screening programme. It also relates and adds to constructs in existing health theories.

Undertaking the research has not only enabled a voice or platform for young women to express their views and experiences of the screening programme, it has also enhanced my insight as a person (an individual service user) as well as my growth and skills as a qualitative researcher. Notwithstanding the challenges and emotions, it was a fulfilling and worthy experience.

In terms of impact, this study has been presented at both national and regional conferences in the form of oral and poster presentations. Abstracts are already being submitted for future conferences with a notification of the publication of an abstract of my study in the Lancet by November 2016. Dissemination will also be done by making the study available on the open access Northumbria university online link. In terms of its impact at both a local and national level, the final thesis and report will be made available to the Quality Assurance Reference Centre (QARC) in the Northeast region and other stakeholders that have indicated interest in this study through emails and verbal communications.

It is anticipated that the suggestions offered in this study will elicit and inform future studies, and help health experts and policymakers in planning and implementing age-appropriate interventions by accounting for some of the concerns raised here. This could increase uptake, moving the cervical screening programme towards being a more individual-centred service.

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## Appendices

### Appendix 1: Research Outputs

#### Accepted Abstract to be published, The Lancet Nov 2016

Title: Psychological factors affecting participation in cervical screening for young women: a qualitative study

Mabel O Okoeki, Alison Steven, Lesley Geddes

Faculty of Health and Life Sciences, Coach Lane Campus East, Northumbria University, Newcastle upon Tyne, UK (M O Okoeki MSc, A Steven PhD, L Geddes MSc)

#### Abstract

**Background** There is a continuous decline in cervical cancer screening uptake, especially in young women, even though screening saves over 4500 lives annually in the UK. Psychological factors that could influence participation identified in previous studies included anxiety, embarrassment, and fear. The context of these factors is broad and ill-defined. This study aimed to unpick the deeper issues and factors affecting participation and non-participation in young women aged 25–34 years.

**Methods** The method drew on the principles of grounded theory to understand how participants' form meanings and make decisions on issues such as screening. Maximum variation purposive sampling was used to recruit 26 participants from communities (cervical cancer screening call and recall register, three universities, community centre). Data were obtained by semi-structured interviews (16 participants) and a focus group (eight). Analysis aided by mind mapping software (MindGenius Business 6) led to the organisation of data into codes, themes, and categories.

**Findings** Data analysis showed that sexual association was the core underlying category. This association was drawn from four elements: awareness, human issues, emotional attribution, and acceptability. Low awareness was mainly about screening procedure and body anatomy (location of the cervix). Overall, perception of the screening was positive and acceptability was expressed. Factors within emotional attribution and human issues were major impacts on screening behaviour and decision. Non-participation or delayed participation were strongly linked to the basic social psychological process, associating screening with sex, and created negative emotions such as embarrassment and anxiety. These associations included the screening procedure mimicking sex (penetration), the intrusive nature of screening (exposure, intimate, private), and sociocultural beliefs (promiscuity, taboo, and body insecurities). Screening touch on fundamental human issues such as reproduction (infertility) and mortality (death from cancer) affected participation. These identified issues were sometimes unspoken and unconsciously influenced screening decision in some participants.

**Interpretation** Our findings suggest that sexual association is a hidden issue affecting participation in cervical screening. This research is expected to inform future practices and policy implementation towards increasing screening uptake. Suggested service improvement strategies included alternative screening methods (e.g., home self-testing), educating health professionals on sensitivity, and an invitation letter explaining in-depth details of the procedure. These changes could help improve the perception of screening among women of all ages.

**Funding** None.

#### Contributors

MO contributed to the literature search, data collection, study design, data analysis, data interpretation, and writing of the study. AS and LG were involved in development of the design of the study, and contributed (reviewed and corrected) to the writing

**Declaration of interests**

We declare no competing interests.

Correspondence to:

Miss Mabel Okoeki, Faculty of Health and Life Sciences, Coach Lane Campus East, Northumbria University, Newcastle upon Tyne NE7 7XA, UK

mabel.okoeki@northumbria.ac.uk

## Appendix 2: Project Approval letter



Professor Kathleen McCourt CBE FRCN Dean

MABEL OKOEKI  
29 NORWOOD AVENUE  
HEATON  
NEWCASTLE UPON TYNE

**This matter is being dealt with by:**

*Faculty of Health and Life Science*

*Coach Lane Campus West*

*Newcastle upon Tyne*

*NE7 7XA*

*Tel: 0191 215 6276*

*E-mail: Julie.blackwell@northumbria.ac.uk*

5<sup>TH</sup> September 2013

Dear Mabel

I write to inform you that the Faculty's Research Committee has considered and approved your application for Project Approval (PA) and I can confirm to you that you are now fully registered for the degree of PhD on a full time basis, with effect from 11<sup>th</sup> March 2013.

**Please note that progression will be monitored by the annual review process.**

please see below for your next annual review submission date:

|                                       |            |
|---------------------------------------|------------|
| 12 month: annual review submission by | 11/01/2014 |
|---------------------------------------|------------|

Your required thesis submission date is 11<sup>th</sup> March 2016. Once you have submitted your thesis the University aims to hold your oral examination within two months of the submission of your thesis.

If you require any further information or assistance, please do not hesitate to contact me.

Yours sincerely

**Professor Olivier Sparagano**

**BSc, MSc, PhD, CBiol, FSB, FSTVM, FHEA**

**Professor of Health and Biotechnology**

**Associate Dean of Research & Innovation**

**Faculty of Health and Life Sciences**

cc Principal Supervisor

## Appendix 3– Ethics approval letters

### a. University ethical approval letter



*Professor Kathleen McCourt, CBE FRCN  
Executive Dean*

This matter is being dealt with by:

*Professor Olivier Sparagano  
Associate Dean  
Faculty of Health & Life Sciences  
Northumberland Building  
Newcastle upon Tyne  
NE1 8ST*

11<sup>th</sup> March 2014

Dear Mabel

#### **Faculty of Health and Life Sciences Research Ethics Review Panel**

**Title:** Young women and cervical screening: Developing an understanding into factors that influence participation and non-participation in the cervical screening programme by young women aged 25-35years in the North East England

Following resubmission of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this resubmitted proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent Disclosure & Barring Service (DBS) and occupational health clearance if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available from the following web link:  
<http://www.northumbria.ac.uk/researchandconsultancy/sa/ethgov/policies/?view=Standard>

You may now also proceed with your application (if applicable) to:

- NHS R&D organisations for approval. Please check with the NHS Trust whether you require a Research Passport, Letter(s) of Access or Honorary contract(s).
- Research Ethics Committee (REC). [They will require a copy of this letter plus the ethics panel comments and your response to those comments]. If your research is subject to external REC approval, a 'favourable opinion' must be obtained prior to commencing your research. You must notify the University of the date of that favourable opinion.

You must not commence your research until you have obtained all necessary external approvals.

Both the University and NRES strongly advise that the supervisor accompany the student when attending an external REC.

All researchers must also notify this office of the following:

- Commencement of the study;
- Actual completion date of the study;
- Any significant changes to the study design;
- Any incidents which have an adverse effect on participants, researchers or study outcomes;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely

Jim Clark  
Chair, Faculty Research Ethics Review Panel

*Vice-Chancellor and Chief Executive  
Professor Andrew Wathey*

Northumbria University is the trading name of the University of Northumbria at Newcastle

## Appendix 3b

### Public Health England R & D Recommendation letter



**North of England  
Commissioning Support Unit**

2<sup>nd</sup> Floor  
Riverside House  
Goldcrest Way  
Newburn Riverside  
Newcastle upon Tyne  
NE15 8NY

Tel: (0191) 217 2586

E-mail: [NECSU.researchanddevelopment@nhs.net](mailto:NECSU.researchanddevelopment@nhs.net)

28 August 2014

Miss Mabel Okoeki  
Research Student  
Northumbria University  
Coach Lane Benton  
Northumbria University  
Newcastle upon Tyne  
NE7 7XA

Dear Miss Okoeki

**Study Title:**

**Young women and cervical screening: Developing an understanding into factors that influence participation and non-participation in the cervical screening programme by young women aged 25-35 years in the North East England**

**REC Ref: 14/EE/0208**

Thank you for submitting your application which has been reviewed by the North of England Commissioning Support Unit. We provide research assurance to Primary Care Providers in Northumberland Tyne and Wear, County Durham & Tees Valley and North Cumbria to assist them in deciding whether to participate in research studies and provide a recommendation for studies that fall within the remit of NHS England.

I am pleased to confirm this application has been reviewed on behalf of NHS England and a recommendation made that the study should proceed.

Our recommendation is issued on the basis that the research study is conducted in accordance with the version of the protocol and supporting documents submitted with your application. All amendments need to be submitted in accordance with the guidance in IRAS and our recommendation will continue following submission of amendments unless we notify you otherwise. The sponsor is responsible for ensuring systems are in place for notifying Primary Care Providers of any amendments and providing amended documentation to site staff.

**NB: This letter does not place any obligations on any service to participate in the research.**

Hosted by NHS England



If you do require advice in relation to the conduct of the research at the above sites/PICs please contact the **NECS R&D Office**. We also welcome feedback about your experience of this review process to help us improve our systems.

May I take this opportunity to wish you well with your research. We look forward to hearing the progress and outcomes for the study.

Yours sincerely



Shona A Haining BSc PhD  
Senior R&D Manager  
North of England Commissioning Support

cc.

*Barbara Oliver, Information & Governance Manager, Durham, Darlington and Tees Area Team*

*Dr Alison Steven, Northumbria University*

*Dr James Gossow, Assistant Medical Director, Durham, Darlington and Tees NHS England*



## Appendix 3 c: NHS REC Approval

**NHS**  
**Health Research Authority**  
NRES Committee East of England - Norfolk  
The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 883 9525

03 June 2014

Miss Mabel .O. Okoeki  
Research student  
Northumbria University  
Coach Lane Benton  
Northumbria University, Newcastle upon Tyne  
NE7 7XA

Dear Miss Okoeki

|                         |   |
|-------------------------|---|
| <b>Study title:</b>     | <b>Young women and cervical screening: Developing an understanding into factors that influence participation and non-participation in the cervical screening programme by young women aged 25-35years in the North East England</b> |
| <b>REC reference:</b>   | <b>14/EE/0208</b>   |
| <b>IRAS project ID:</b> | <b>139450</b>   |

Thank you for your letter of 2<sup>nd</sup> June 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Tracy Leavesley, .

### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations*

involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

#### **Approved documents**

The documents reviewed and approved by the Committee are:

| <i>Document</i>  | <i>Version</i> | <i>Date</i>     |
|--|----------------|-----------------|
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) | UMAL           | 28 January 2014 |
| Letters of invitation to participant                               | 2              | 30 May 2014     |
| Other [Reply slip]   | 1              | 04 May 2014     |

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/EE/0208

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



**Dr Michael Sheldon**  
Chair

Email: [NRESCommittee.EastofEngland-Norfolk@nhs.net](mailto:NRESCommittee.EastofEngland-Norfolk@nhs.net)

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Alison Steven

*Dr Shona Haining, Senior Research & Development Manager, North of England Commissioning Support (NECS)*

## Appendix 4: Interview topic Guide



### Interview Topic Guide

#### **Always record the interview number and demographics**

The interview will follow a semi-structured format which means that research may not follow specific questions as it can be instinctive and will change. This is because question will emanate from the response of the participants over the course of the interview. The list below will however serve as a guide.

**First, Introduction: Introduce myself and confirm that I am at the right place and speaking to the right participant.**

**Thank them for agreeing to be interviewed. Explain what I will be doing:**

**Go through the information sheet and consent form, audio recording, clarify any issues. Get them to sign the consent form and then begin the interview.**

**Reaffirm that there are no right or wrong answers, that I am only interested in their views and thoughts about their experiences or perceptions about participation/non participation in the ongoing cervical screening programme.**

- Information about their attitude to their health  
How often do they utilise the health services?  
  
What is their understanding and attitude to available health services? i.e. what do they think about screening activities, do they see it as a health service available to them? What other health service do they use when do they use them e.g. when they are ill or as a preventative measure
- Knowledge of cervical cancer and the screening programme  
  
General understanding, experience, awareness and perception of cervical cancer (e.g. incidence and symptoms, etc.)  
  
Their knowledge of the screening programme - (Do they know what the procedure is? - a smear test- and how it is carried out?)  
  
What was their feeling about going for a smear, did you consider its importance and personal relevance?
- Knowledge of HPV and the screening?  
  
General knowledge of HPV and the available vaccination.  
  
What are their views on the HPV vaccination?  
  
Has HPV vaccination been taken in the past?
- Understanding of the process and what is needed for the cervical screening?  
  
Was the explanation/information easy to understand? (How easy or difficult) was the instruction /procedure? What can be done to make it better/easier?
- Attendance for cervical smear?  
  
If you have been for a smear test what made you go for the test?  
  
If you have been for a smear test and haven't gone for a recall test, why haven't you gone for the test?

If you haven't been to any smear test, what are your reasons?

- Screening process or experience? (for those who have been for a screen)

How would they explain the experience of the whole screening process?

How satisfied were their experience?

Would they or did they go for a rescreen when invited again

- What would have increased their interest in going for a screening/rescreen (for those who haven't been screened)

What would make them go for the test on invitation? - What impact did the letter have? (Trying to find out if the invitation is a motivator or a barrier some previous research I was involved with this was a turn off and it resulted in change to the invitation letter- the colour of the paper / where it was from / the information provided/ the personal touch etc).

And also, what would make them go for the screening in the future?

- What way do they feel the screening process could be improved/ uptake could be increased?

What improvements would they like to see in the screening programme; information about the screening, venue and the screening process itself. Any general suggestion on how the screening could be improved to make it more acceptable.

Closure of interview: Is there any question you would like to ask or issues to clarify? Thank them for participation in this study.

## Appendix 5: Focus group guide



### Focus Group Discussion Guide

#### **Introduction:**

#### 1. Welcome

Introduce myself and send the Sign-In Sheet with a few quick demographic questions (age, gender, ethnicity,) around to the group while you are introducing the focus group.

*Review the following:*

- Who we are and what we're trying to do
- What will be done with this information
- Why we asked you to participate

#### 2. Explanation of the process

Ask the group if anyone has participated in a focus group before. Explain that focus groups are being used more and more often in health and human services research.

*About focus groups*

- We learn from you (positive and negative)
- Not trying to achieve consensus, we're gathering information
- No virtue in long lists: we're looking for priorities
- In this project, we are doing both interviews and focus group discussions. The reason for using both of these tools is that we can get more in-depth information from a smaller group of people in focus groups.

*Logistics*

- Focus group will last about 1-2 hour
- Feel free to move around
- Where is the bathroom? Exit?

#### 3. Ground Rules

Ask the group to suggest some ground rules. After they brainstorm some, make sure the following are on the list.

- Everyone should participate.
- Information provided in the focus group must be kept confidential
- Stay with the group and please don't have side conversations
- Turn off cell phones if possible
- Have fun

#### 4. Turn on Tape Recorder

5. Ask the group if there are any questions before we get started, and address those questions.

*Discussion begins, it will be ensured that people are given time to think before answering the questions and don't move too quickly*

**Questions: (the interview topic guide questions will be used to explore issues in the focus group session)**

- Knowledge of cervical cancer and the screening programme  
General understanding, experience, awareness and perception of cervical cancer (e.g. incidence and symptoms, etc.)  
Their knowledge of the screening programme - (Do they know what the procedure is? - a smear test- and how it is carried out?)  
What was their feeling about going for a smear, did you consider its importance and personal relevance?
- Understanding of the process and what is needed for the cervical screening?  
Was the explanation/information easy to understand? (How easy or difficult) was the instruction /procedure? What can be done to make it better/easier?
- Attendance for cervical smear?  
If you have been for a smear test what made you go for the test?  
If you have been for a smear test and haven't gone for a recall test, why haven't you gone for the test?  
If you haven't been to any smear test, what are your reasons?
- Screening process or experience? (for those who have been for a screen)  
How would they explain the experience of the whole screening process?  
How satisfied were their experience?  
Would they or did they go for a rescreen when invited again
- What would have increased their interest in going for a screening/rescreen (for those who haven't been screened)  
What would make them go for the test on invitation? - What impact did the letter have? (Trying to find out if the invitation is a motivator or a barrier some previous research I was involved with this was a turn off and it resulted in change to the invitation letter- the colour of the paper / where it was from / the information provided/ the personal touch etc).  
And also, what would make them go for the screening in the future?
- What way do they feel the screening process could be improved/ uptake could be increased?  
What improvements would they like to see in the screening programme; information about the screening, venue and the screening process itself. Any general suggestion on how the screening could be improved to make it more acceptable.
- What can be done right now to make you go for screening?  
That concludes our focus group. Thank you so much for coming and sharing your thoughts and opinions with us.

**Materials and supplies for focus groups**

- Sign-in sheet

- Consent forms (one copy for participants, one copy for the team)
- Information sheets
- Pads & Pencils for each participant
- Focus Group Discussion Guide for Facilitator
- 1 recording device
- Batteries for recording device
- Extra tapes for recording device
- Permanent marker for marking tapes with FGD name, facility, and date
- Notebook for note-taking

Appendix 6: Consent form



**CONSENT FORM**

**Research Title:** women and cervical screening: Developing an understanding into factors that influence participation and non-participation in the cervical screening programme by young women aged 25-34 in the Northeast of England

**Research Aim:** This study aims to develop an understanding of the factors that influence participation and non-participation in the national cervical screening programme amongst young women aged 25-34years living in the Northeast of England.

**Researcher: Mabel Okoeki**

|   | YES (Please tick) | NO (Please tick) |
|---|-------------------|------------------|
| I have read, and I understand the research participant Information Sheet dated _____  |                   |                  |
| I have had a chance to ask questions which have been answered to my satisfaction.   |                   |                  |
| I understand that I do not have to take part. If I do take part I may withdraw at any time, without giving a reason for withdrawing.                                      |                   |                  |
| I agree to participate in the interview which will be tape recorded.  |                   |                  |
| I understand that it will not be possible to identify me from the information I have given in this study and this information will also be kept private and confidential. |                   |                  |
| I understand that the information I have given in this study may be used in the future as part of   |                   |                  |

|   |  |  |
|---|--|--|
| further work on this subject. But the information used will still not identify me.  |  |  |
| I understand that no third persons will have the information I have given and any<br>Information that may identify me will be removed or replaced with names that are not real. |  |  |
| I understand that I will not receive any form of payment to participate in the research.  |  |  |
| I would like to receive a summary of the results of the study.  |  |  |

**Signature of Research participant:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Signature of Researcher:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Appendix 7: Information sheet



### Participants Information Sheet (Interviews)

#### **Title of the Research**

Young women and cervical screening: Developing an understanding into factors that influence participation and non-participation in the cervical screening programme by young women aged 25-35 years in the Northeast England

#### **Invitation Paragraph**

You are being invited to take part in a research study that aims to understand more about why some young women attend for cervical smears and others don't. This information sheet has been provided to help you understand why the research is being done and what it will involve for you to and to help you decide whether you would like to take part or not. Please take time to read the following information carefully to understand the purpose of the research. If you have any concerns or would like any additional explanation, please do not hesitate to contact the researcher (See details below). Thank you.

#### **Who will conduct the research?**

The research will be conducted by Mabel Osebhajimende Okoeki, a PhD student from the Faculty of Health and Life sciences at Northumbria University.

#### **What is the purpose of the study?**

The purpose of this research is to develop an understanding into factors that influence participation and non-participation of cervical screening among young women aged 25-35 living in the Northeast of England. With the hope that findings from the study will help increase uptake of cervical screening and also help reduce the number of deaths from cervical cancer.

#### **Why have I been invited?**

You have been invited to take part in the study because

- You are a young woman aged 25 to 35 years old
- You haven't attended any smear test even though you have been invited
- You did attend for your first smear test and haven't attended for any more
- You are up to date with your smear test.

#### **What will it involve?**

This research involves taking part in a one to one face to face interview with permission to be audio-recorded, to express your views about cervical cancer and the ongoing screening programme and what might influence your decision to participate or not participate in the screening programme.

The interview will last a maximum of 1<sup>1/2</sup> hours.

The interview will take place at a venue of your choice. It could be in a local private meeting room arranged with the researcher or at your home.

At the interview, the researcher will review this information sheet with you and answer any questions you may have. Then you will be asked to fill the consent form if you agree to take part in the research.

**Do I have to take part?**

It is up to you to decide to join the study. We will describe the study and go through this information sheet. You are free to withdraw at any time, without giving a reason.

**What will happen if I don't take part?**

It is completely your choice to take part, and participation is voluntary. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

**Are there any risks in taking part?**

It is anticipated that there are no risks connected with taking part in this study, however if any participant becomes concerned or nervous during the interview, it would be discontinued immediately. Participants can withdraw from the study at any stage without any detriment or having to give reasons.

**What are the possible benefit of taking part?**

It cannot be promised that the study will help you directly but the information from the study will help to increase the understanding of reasons why people do or do not go for cervical screening as well as providing possible ways to address this issue which might encourage more people to go for cervical screening.

**What will happen to the information collected at the interview?**

After the interview, the researcher will type the conversation with name and other identifiable information removed. The information will then be analysed and used to complete the final report. Any direct quote or comments that are used in the final report or subsequent publications or presentations will be anonymised. Names and details of the participants will not appear in any printed documents. The tapes will be stored securely in a cabinet at Northumbria University and destroyed a year after the end of the research. The transcripts will be kept for three years and then destroyed

**What will happen to the results of the study and how will it be disseminated?**

The final report of this study will be submitted to the Northumbria University's appropriate examination panel as part of the chief investigator's PhD thesis. A summary of the key findings will be distributed to all the research participants. The participants may also request the full copy if they wish. The research finding will also be disseminated to the Public Health England Quality Assurance Reference Centre (QARC) who may wish to publish the result on their website/newsletter.

Also, the result will be presented at seminars and conferences

**Will my participation in the study be kept confidential?**

Yes, your taking part in the study will be kept confidential, only the research team will know about your participation in the research. Any information about you will not be recognisable.

**Contact details**

Please contact me if you have any concerns about the proposed study on 07552808573 or [mabel.okoeki@northumbria.ac.uk](mailto:mabel.okoeki@northumbria.ac.uk). My supervisor Lesley Geddes can also be contacted on [Lesley.geddes@northumbria.ac.uk](mailto:Lesley.geddes@northumbria.ac.uk).

Thank you for your time.

Mabel Okeoki

Appendix 8

Reply Slip



Durham, Darlington and Tees Area Team

and working on behalf of Cumbria, Northumberland, Tyne and Wear Area Team

Our Ref:  
Your Ref:

2<sup>nd</sup> Floor, Partnership House  
Regent Farm Road  
Gosforth  
Newcastle upon Tyne  
NE3 3HD  
Tel: 0191 275 4200  
Fax:  
Date

Reply Slip

Please tick the right box that applies to you and return the slip in the prepaid envelope provided, **only if you wish to take part in the research**, thank you.

**Yes, I would like to take part and be contacted by the researcher. My contact details are...**

**Name: .....**  
**... (Please Print)**

**I prefer to be contacted by (please tick one of the below)**

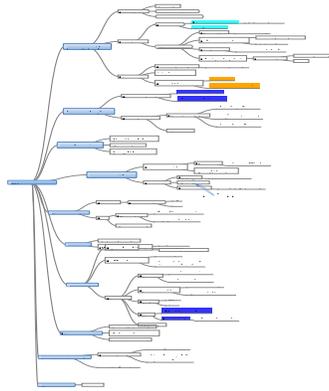
**Telephone/Mobile number.....**

**Email.....**

**You do not need to add a stamp to the envelope just pop it into the letter box**

**Many thanks!**

## Appendix 9: Mind genius representation of the coding with



**extensive branches**

**Themes extracted from interview (sample of how they were outlined).**

perception to attitude to life style and health /access to health service

understanding of health

health is important

attention should be given to health

women more prone to health problems

attitude towards health

concern about health

Assurance through regular health checks

blood test and cervical screening

Information from the internet

Not overly health conscious

family history of cancer

more alert in terms of health

change in perception of health and attitude towards health

mother's successful treatment from cancer

Mother's cancer diagnosis

educational background

present job in public health / studied health psychology

deterioration in health due to relocation and unhealthy lifestyle(diet)

practice unhealthy lifestyle

smoker (quit smoking and relapsed)

poor diet

Accessing health service

regular health check (every 3 months)

ongoing health issue (iron deficiency)

Volunteer blood donor as a way to monitoring health issue

positive experiences with access to health service

easy access to GPs

easy appointment booking with low waiting time

knowledge and understanding of cervical cancer ( and cancer in general)

knowledge of cancer in general and impact

attributed to death and disruption to life

fear of its association to death and possible relapse

understanding of cervical cancer

limited knowledge of cervical cancer

lack of understanding of symptoms of cervical cancer(symptoms)

misconceptions around symptoms associated with cervical cancer(bleeding after sex)

Lack of understanding of what cervical cancer is

Association with HPV

understanding of the cervical cancer screening

limited knowledge of the screening before been screened

Receipt of letter of invitation

health professional explained procedure before and during screening

perception and feeling of the screening process/screening experience

perception and feeling about going for screening

fear of what to expect

insufficient information of what the screening entails

positive about screening attributed to feeling better and for peace of mind

screening experience

Above expectation

**Mental Connections:**

experience of feeling uncomfortable/ awkward had no negative effect on future screening decision ----  
feeling Awkward/exposed

it was uncomfortable but not painful

feeling Awkward/exposed

**Mental Connections:**

experience of feeling uncomfortable/ awkward had no negative effect on future screening decision ----  
Above expectation

**Summary of Mental Connections in map:**

**Above expectation -> experience of feeling uncomfortable/ awkward had no negative effect on  
future screening decision -> feeling Awkward/exposed**