

**Saudi Women's Experiences, Barriers, and  
Facilitators when Accessing Breast and Cervical  
Cancer Screening Services**

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## Abstract

**Background:** Breast cancer is considered the most common cancer among females followed by cancers of the cervix, lung, and stomach. Its mortality can be avoided by early detection.

**Aim:** This thesis aimed to explore Saudi women's barriers facilitators and experiences, when accessing breast and cervical cancer screening services in the United Kingdom (UK) and Saudi Arabia.

**Methods:** A mixed method approach was used to fulfil the thesis objectives. A quantitative questionnaire was administered to 503 Saudi women living in the United Kingdom and in Kingdom of Saudi Arabia. This was followed up by a qualitative study using seven focus groups discussions.

**Results:** Survey and focus groups provided some consistent findings regarding Saudi women's perceptions, knowledge, beliefs of the barriers and facilitators in accessing both breast and cervical cancer screening services in the UK and Saudi Arabia. Fear of having cancer and lack of knowledge of the importance of early detection, particularly in cervical cancer were major findings with regard to barriers to attend screening services. However, being employed and highly educated was correlated with better knowledge and awareness of the signs, symptoms, and treatment of both breast and cervical cancer. Participants shared their responsibilities with health professionals and the structure of the health system in the arrangement of early screening of breast and cervical cancers. Additionally, they suggested the role of media, education, and use of places such as mosques in disseminating information about the importance of early cancer detection.

**Conclusion:** While the data reported in this thesis are encouraging, rich and diverse, conclusions must be drawn with caution. Important barriers included health and cultural beliefs and attitudes, language and unsupportive attitudes of health professionals. A majority of Saudi participants believed educational programs would increase breast and cervical cancer awareness and knowledge and use of screening services.

The health belief model was utilized to structure and explain the thesis findings and analysis.

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## **Declaration**

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

# **Chapter 1: Introduction**

## **1.1 Background**

This chapter provides an introduction to breast and cervical cancer. The epidemiology of breast and cervical cancer, screening, and risk factors are detailed using worldwide statistics as well as in Saudi Arabia. It also discusses the context and justifies the focus of the thesis.

Cancer is a life-threatening illness. Statistics from the World Health Organization's International Agency for Research on Cancer shows that there are ten million new cases of invasive cancer annually in males and females worldwide. Ten per cent of these cancers occur in the breast, making it the second most common site of malignant neoplasms (Parkin 2001). In 2000, breast cancer was the most common type of cancer in females (Ferlay 2001). Where the most parts of the world includes Australia, Western Asia, North Africa, North America, and parts of South America. Regarding cervical cancer, the most parts of the world includes Central America, parts of South America, Sub-Saharan Africa, and India (Jemal, Center et al. 2010).

Breast cancer mortality reductions on the order of 30% to 40% were associated with screening (Gabe and Duffy 2005). Further observational studies have shown a substantial and significant reduction in breast cancer mortality with screening (Kalager, Zelen et al. 2010; Autier, Boniol et al. 2011; Hellquist, Duffy et al. 2011).

In other hand, cervical cancer which considered the second most common cancer seen among women and is also the fifth leading cause of death among women. The disease starts with certain pre-cancerous changes taking place in the cervical tissue. Most of these pre-cancerous lesions are harmless, and revert back to normal tissues with time (Cancers 2012).

In developing countries, the lifetime probability of developing breast cancer is about 1.8% (Ferlay 2004). A report from Institute for Health Metrics and Evaluation (IHME) (Forouzanfar 2011) showed that in most countries, the number of new cases and deaths from breast and cervical cancer are rising, especially amongst younger women in the developing world. Forouzanfar et al. (2011) concluded that if the trends continued in the same direction, within 20 years women under the age of 50 living in the developing world would be as likely to die of breast and cervical cancer as die from complication of pregnancy and childbirth.

Moreover, the incidence of breast and cervical cancer in women of ethnic minority is increasing in comparison to the national majority population (Deapen, D., 2002). Previous researchers have shown that the incidence of cancers in migrant populations shifts to meet figures for the national majority population within one or two generations (Glaser 1990; Georgii 1993; Aul 2004).

Decreasing mortality from some cancers has been effectively tackled as a result of both early screening and treatment (Danaei, Vander Hoorn et al. 2005). However, access to - and use of - existing technologies might not be available to everyone, even in developed countries. A broader approach is therefore needed. As such, reducing the burden of cancers worldwide can also be achieved by the primary prevention and in particular lifestyle and environmental interventions. Developing effective policies and programs depend on reliable and comparable analyses of the effect of risk factors for cancer at the population level.

Breast and cervical cancer are important problems and that loss of life through breast cancer can also be avoided by early detection (IARC 2002). This threat exists for breast but not cervical cancer in the Kingdom of Saudi Arabia (KSA) because cervical

cancer is not considered a life-threatening cancer in KSA. Statistics from the National Cancer Registry in KSA (hospital-based data), reported that in 2003 the Age Standardized Rate (ASR) of breast cancer registered at 13.9, whereas the ASR for cervical cancer registered at 1.9 (Ministry Of Health 2003-2005). However, most breast cancer studies in KSA are clinic based, which does not reflect the real magnitude of the disease. Cervical cancer is ranked in fifteenth place with regard to the incidence of other female cancers, which represents less than 1% compared to other cancers (Ministry Of Health 2003-2005).

## **1.2Breast cancer epidemiology**

Generally, the highest incidence rates of breast cancer are found in Switzerland, U.S (white compared to black), Italy, and many other European countries, whereas low rates are found in Africa, Asia, and South America, Figure 1 (Jemal, Centre et al. 2010). This study has compared rates between different European countries and U.S white and black. They found that U.S white had one of the highest incidence rates, whereas low rates were found in Africa, Asia and South America. However, breast cancer mortality rates in these and several other western countries have been steady or decreasing during the past 25 years because of early detection through mammography and improved treatment (Berry, Cronin et al. 2005; Sant, Francisci et al. 2006).

The Office of National Statistics in the UK (2007) states that approximately 46,000 women are diagnosed yearly with breast cancer and more than 1,000 women die from the disease every month. The report by Forouzanfar demonstrated that the incidence of breast cancer has doubled around the world in just three decades, a rate that has exceeded the global population growth (Forouzanfar 2011). During the same period, death from breast cancer has increased at a slower rate than new cases.

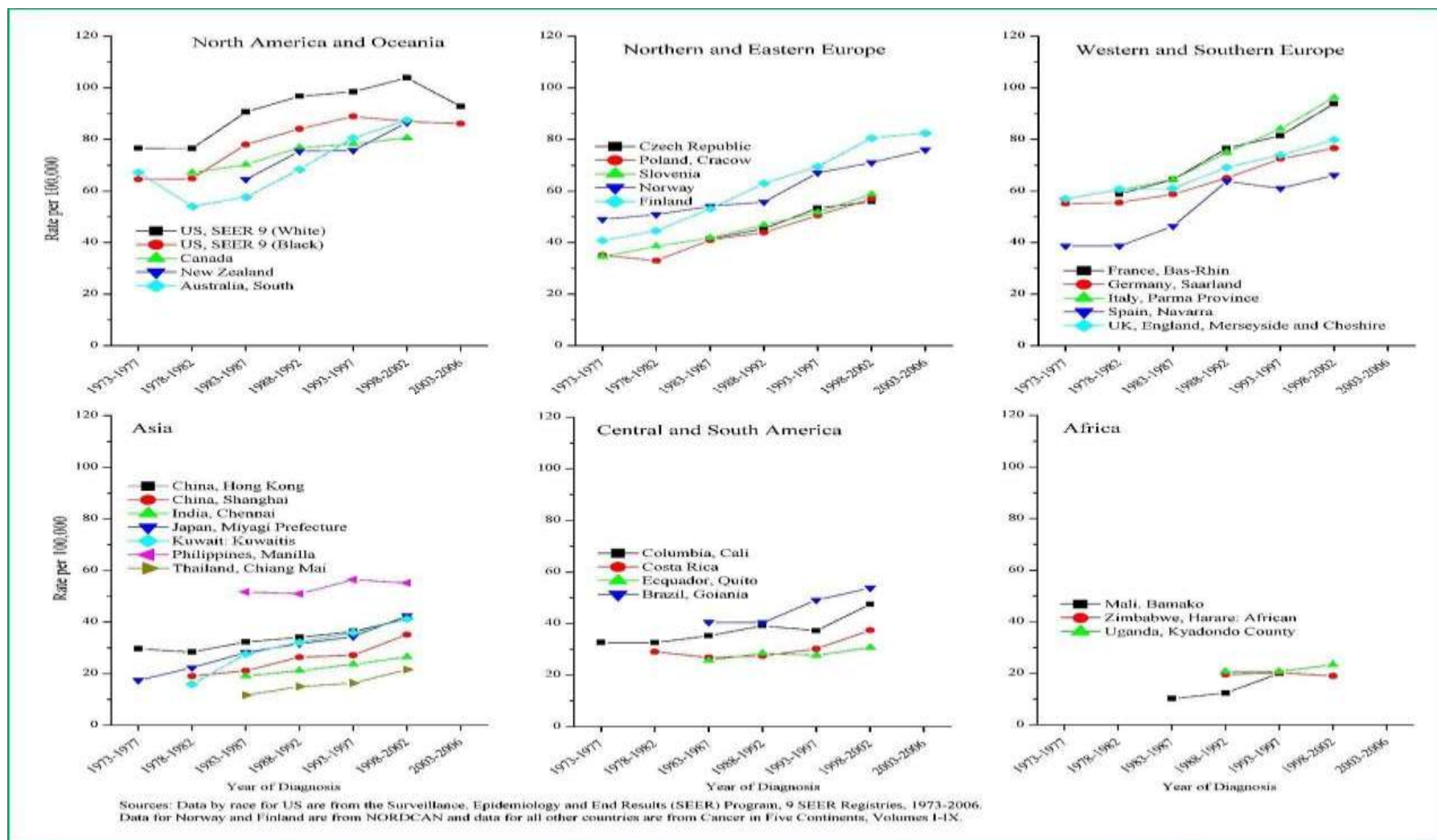


Figure 1: World-wide trends of breast cancer among women

In the US, about 54,010 female carcinoma in situ of the breast were expected in 2010 and about 64,640 in 2013 (Jemal, Siegel et al. 2010; Siegel, Naishadham et al. 2013). Cancer incidence and death rates vary considerably among racial and ethnic groups, with a higher breast cancer incidence rates observed among white women which might reflect a combination of factors that affect both diagnosis (e.g. more regular mammography in white women) and underlying disease occurrence (e.g. older age at first birth and higher use of menopausal hormone therapy among white compared with black women) (Ghafoor, Jemal et al. 2003). Authors recommended that further progress could be accelerated by applying existing cancer control knowledge across all segments of the population and by supporting new discoveries in cancer prevention, early detection, and treatment.

Regarding Arab countries, breast cancer constitutes 13 to 35% of all female cancers. Almost half of the patients are below the age of 50 and median age is 49–52 years. In comparison, the median age is 63 in industrialized nations (El Saghir 2007).

Furthermore, advanced disease remains very common in Egypt, Tunisia, Saudi Arabia, Syria, Palestine and other Arab countries. Mastectomy performed in more than 80% of women with breast cancer. There are only 84 radiation therapy centres, 256 radiation oncologists and 473 radiation technologists in all Arab countries, as compared with 1875, 3068 and 5155, respectively, in the USA, which has an equivalent population of about 300 million (El Saghir 2007).

The incidence rate of breast cancer amongst women from developing countries such as KSA is lower than in Europe and the USA (Ibrahim 1998; Ezzat 1999; Chia 2004). In KSA, between 2008 and 2025 breast cancer was predicted to show a 350% increase in the incidence and a 160% increase in the mortality rate (Ibrahim 2008).

Arab countries: Egypt, Jordan, Kuwait, Saudi Arabia, Lebanon, Morocco, Oman, Palestinians, Syria, Tunisia, Yemen, Bahrain, Iraq, Qatar, United Arab Emirates, Algeria, Libyan Arab Jamahiriya and Sudan



The trends of breast cancer in the UK and KSA differ. In KSA, younger women are at greater risk than older women are. Breast cancer constitutes 18% of all cancers amongst Saudi women. Locally advanced breast cancer disease is unusual in western countries, but it constitutes more than 40% of all non-metastatic breast cancer in KSA (Ezzat1999). The median age of cases captured from the King Faisal Specialist Hospital, KSA, for the period 1981-1992 was around 44 years ( $\pm$  11 years), whereas in western nations 60-65 years was the median age (Ezzat 1999).

In conclusion, the trend in the incidence of breast cancer is similar for the UK and KSA regarding the rate, the differences occur in the age of diagnosis and status of the cancer. Several migrant studies have documented that cancer rates in successive generations of migrants alter in the direction of the prevailing rates in the host country, suggesting that the international variations in cancer rates for most cancers largely reflect differences in environmental risk factors (including lifestyle and culture) rather than genetic differences(Jemal, Center et al. 2010).

### **1.3Cervical cancer epidemiology**

Worldwide, cervical cancer is the third most common cancer and the fourth leading cause of cancer death in women, Figure 2, (Ferlay, Shin et al. 2010). The incidence rates (per 100,000) among select cancer registries worldwide range from less than 5 in Egypt, China (Shanghai), and many European countries to more than 45 in Sub-Saharan Africa countries. The Cancer Research UK website showed that one in ten female cancers diagnosed worldwide was cervical cancer. It is estimated to be responsible for 530,000 new cases of cancer in 2008, which is nearly one in ten of all cancers diagnosed in women. Cervical cancer incidence rates are lowest in Western

Asia and highest in Eastern Africa, with a seven-fold variation in World Age Standardised (AS) incidence rates between the regions of the world (Ferlay 2008).

The annual incidence rates for cervical cancer from 2000 to 2004 reported by the Surveillance Epidemiology and End Results (SEER) database (Ries 2007), indicated that Hispanic women are diagnosed with cervical cancer almost twice as often, and African American women more than 1.5 times as often, as non-Hispanic white women. The incidence rate among Asian American/Pacific Islander women is slightly higher than that of non-Hispanic white women, and American Indian/Alaskan Native women have lower rates of diagnosis (Ries 2007). The incidence rate for cervical cancer is highest for those aged 30-40, reaching around 17 per 100,000. Although rates decrease for the other age groups, a similar peak is reached at the age of 85+ (Peto 2004). The mortality of cervical cancer in England and Wales in women younger than 35 years rose three-fold from 1967 to 1987. By 1988, the incidence was among the highest in the world despite substantial opportunistic screening (Peto 2004). Since national screening started in 1988, this rising trend has been reversed. In the UK, 2,828 new cases of cervical cancer diagnosed and accounted for around 2% of all female cancers. Estimation of the lifetime risk of developing cervical cancer among women in the UK is 1 in 136 (Peto 2004).

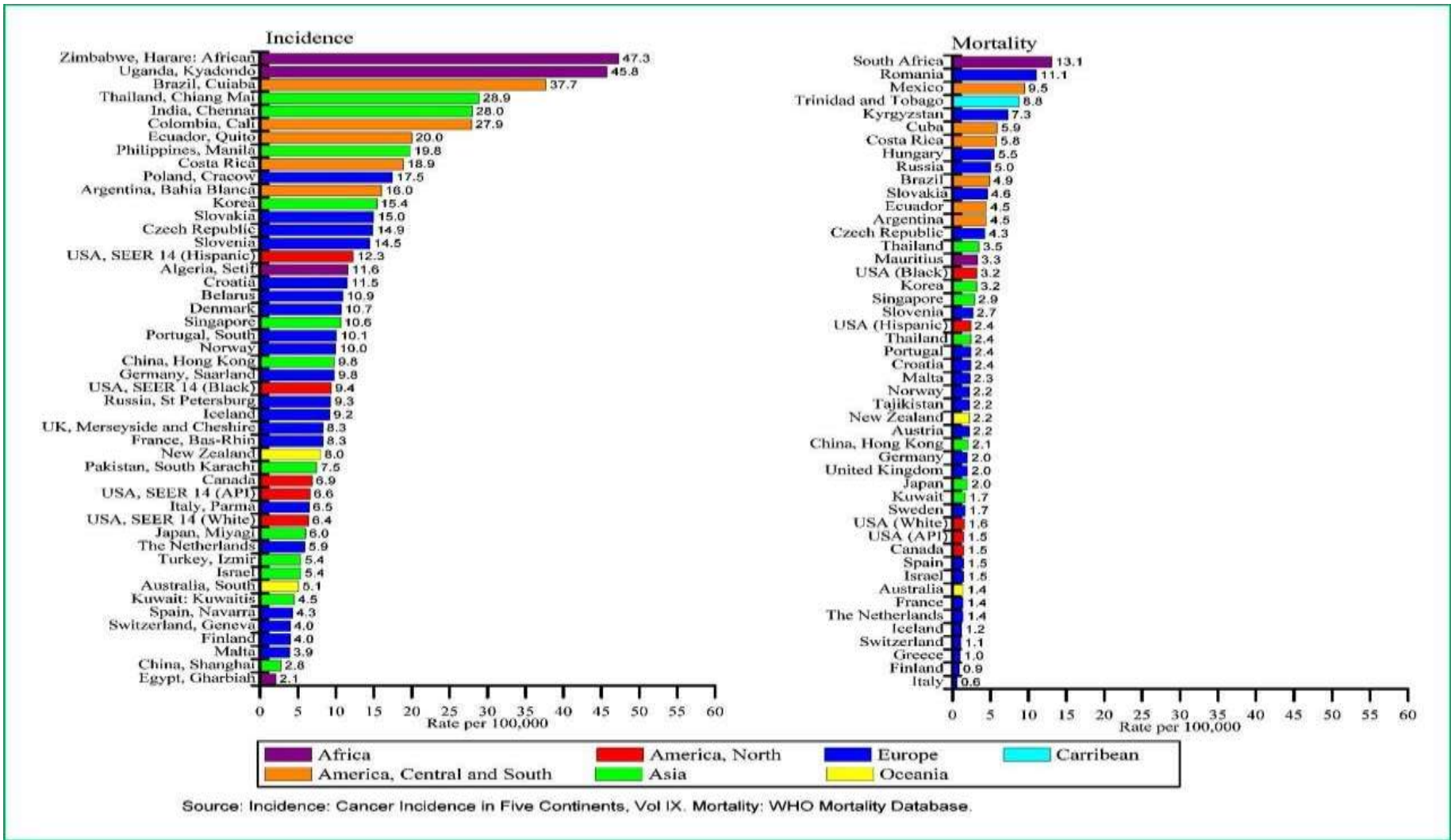
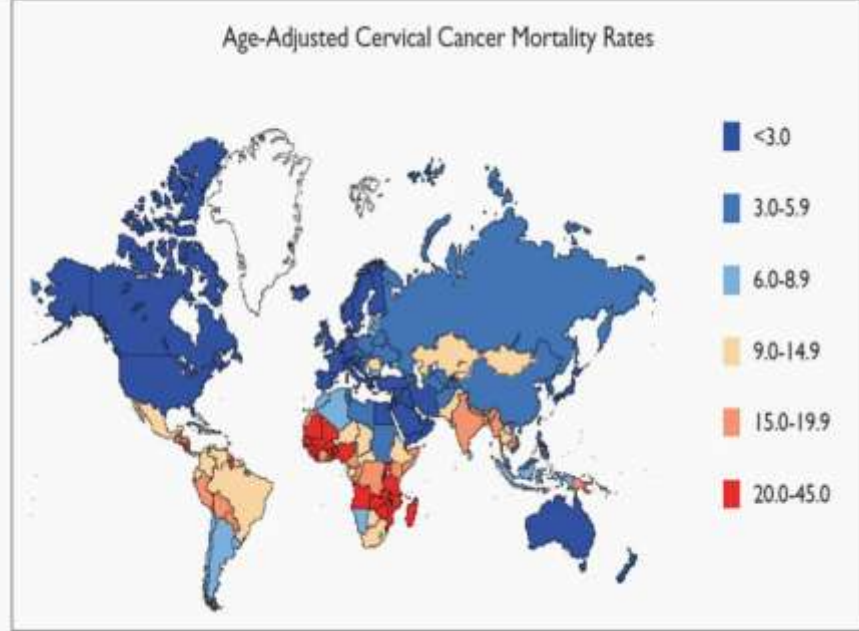
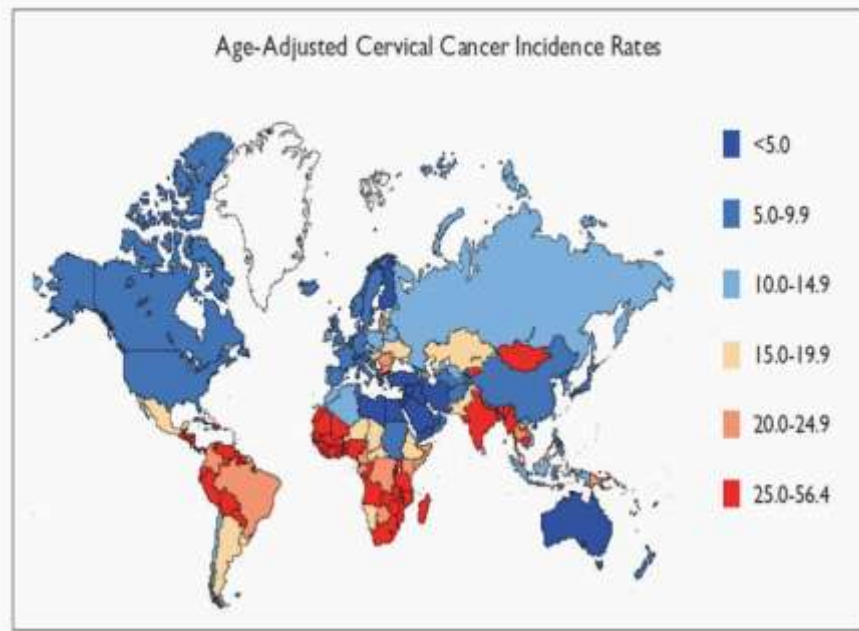


Figure 2: World-wide pattern of cervical cancer incidence and mortality



International Agency for Research on Cancer, GLOBOCAN, 2008.

Figure 3: Worldwide pattern of cervical cancer incidence and mortality

An analysis of mortality from cervical cancer in Europe, age-standardized death certification rates, showed substantial declines in cervical cancer mortality in younger women in all western European countries, except Ireland (Levi 2000).

The incidence rates for cervical cancer for the combined migrant and local Saudi population was 48.4%, whereas for Saudi nationals alone it was 33.5% (incident rate ratio [IRR] = 1.44, 95% CI 1.17-1.88,  $P < 0.001$ ) (Makoha 2008).

Difference of cervical cancer incidence between the UK and Saudi Arabia appears at the age of diagnosis and the number of years of survival. These differences need to be studied in detail as research from KSA is primarily clinic based. KSA is one of the areas where data on the incidence and mortality of breast and cervical cancer are not from population-based studies.

#### **1.4 Risk factors of breast and cervical cancers**

There are several important risk factors affecting the occurrence of breast and cervical cancers. These factors are: age influence (Collaborative Group on Hormonal Factors in Breast Cancer, 1996), hormone replacement therapy (HRT), a therapy used to relieve menopausal symptoms (Rose, 2000, Anderson 2003), reproductive factors (Ferlay 2008, Jemal 2010), socioeconomic status (Mandelblatt 1999), genetic (Key 2001, Lynch 1998) and infectious agents. However, the infectious influence is only described with cervical cancer. The effect of each factor has been supported for both breast and cervical cancer by worldwide studies (Appendix 1).

#### **1.5 Age and breast/cervical cancer**

In general, cancer is more common in the elderly, so a more elderly population will in general have a higher crude rate. After gender, age is the strongest risk factor for breast cancer (Sasieni 2011). In the case of cervical cancer, age is a strong factor in earlier years

and over a wider age range. Women between 25 and 60 years old are more likely to develop cervical cancer as a result of persistent Human Papilloma-virus (HPV), a virus from the papilloma-virus family that affects different area of human' body such throat, mouth, feet, fingers, nails, anus and cervix. There are over 100 types of which 40 can affect the genital area (International Agency for Research on Cancer 1995; Schottenfeld 1996).

After diagnosis, young women with breast cancer are more likely to suffer from recurrence and death than older women are. Anders (2008) explored the potential biologic basis for differences in outcomes and argued that breast cancer in younger women is a unique biologic entity. The study confirmed prior work demonstrating that breast cancers in young women are characterized by lower levels of oestrogen receptor (ER) expression and higher grade (Gajdos 2000; Ahn 2007; Anders 2008). Although this work confirmed that the distribution of breast cancer characteristics varies based on age at presentation, to this point, there would be little basis to claim that breast cancer in younger women is a separate disease.

### **1.6Hormone replacement therapy and breast/cervical cancer**

An analysis of 90% of the worldwide epidemiological evidence on the relationship between the risk of breast cancer and the use of HRT showed that the risk of breast cancer is increased in women using HRT and the risk increased with duration of use (Collaborative Group on Hormonal Factors in Breast Cancer 1997). The effect is reduced after cessation of use of HRT and largely, if not totally, disappears after about five years. A Milano study investigating the link between the use of oestrogens and the occurrence of cervical cancer suggested that exogenous oestrogens do not increase the risk of cervical cancer and may, indeed, decrease the risk (CDC 2005). The study concluded that the effect of hormonal factors is considered to be the key in the development of cervical cancer. Other studies in

the UK have investigated the use of HRT and cervical cancer, but there were no clear conclusions (Parazzini 1997; Lacey 2000).

### **1.7 Reproductive factors and breast/cervical cancer**

There are many factors under the umbrella of reproductive issues, such as the history of birth, contraception and pregnancy, all, which, have implications for breast and cervical cancer in the developed countries. Women in developed countries are at increased risk for breast cancer compared to women from less developed countries. This variation can be explained by smaller numbers of children and a limited duration of breastfeeding amongst women from developed countries (Collaborative Group on Hormonal Factors in Breast Cancer 2002).

Risks for breast and cervical cancers are inversely associated with age at first delivery and directly associated with the total number of pregnancies (Atalah 2001). The age at menarche and the establishment of regular ovulatory cycles have strongly linked to the risk of breast and cervical cancers. An earlier age at menarche was associated with an increased risk of breast cancer with a 20% decrease in breast cancer risk for each year that menarche is delayed (Brian 2003). Based on the data regarding menarche and menopause, it seems likely that the total duration of exposure to endogenous oestrogen is an important factor in breast cancer risk (Rakowski 1995). The effect of age at menarche for the occurrence of cervical cancer has also observed in studies in Europe and the USA. One of these studies confirmed that beginning to menstruate at or after the age of 17 years puts women at 2.6 times higher relative risk than those who started menstruating at age 12 or earlier (Frisch 1999). Early age at menarche has generally been found to increase the risk of cervical cancer (Albreksten 1997).

## **1.8 Socioeconomic status and breast/cervical cancer**

Deprivation also has an impact on the incidence and mortality rates of cervical cancer. In some studies from Scotland, women from more deprived areas have rates more than three times as high as those in the least deprived areas (Cancer Research 2008). Brown (1997) also demonstrated the link between social class and cervical cancer, specifically, that cervical cancer incidence was considerably higher amongst women of working age in manual than in non-manual employment classes. Many women with low incomes do not have ready access to adequate health care services, including Pap tests, which mean they may not be screened or treated for pre-cancerous cervical disease (American Cancer Society 2005-2006). Another study, however, suggested women with higher socio-economic status had greater susceptibility of having breast cancer than those who with lowest socio-economic status. This study controlled for education and other risk factors such as age, mammography use, family history of breast cancer, parity, age at first birth, hormone replacement use, oral contraceptive use, and menopausal status (odds 1.20; 95% confidence interval = 1.05–1.37) (Robert, Strombom et al. 2004).

## **1.9 Genetics and breast/cervical cancer**

All cancers carry somatic mutations in their genomes known as driver mutations that are aetiologically involved in on-cogenesis. The driver mutations and mutational processes operative in breast cancer have not been comprehensively explored (Stephens PJ 2012).

Some women are at risk of developing cancer due to inherited gene mutations especially in the BRCA1 or BRCA2 genes (BRCA stands for breast cancer susceptibility gene). A growing body of evidence also indicates that Polymorphisms in the Methylenetrahydrofolate Reluctase (MTHFR) gene, may modify the risk of breast and other cancers (Gene and Disease; National Cancer Institute; Bethesda 2009). Mutations of the BRCA and MTHFR genes have been associated with breast cancer cases. The



difference between BRCA and MTHFR genes is that BRCA pre-dispose women to breast cancer and are hereditary mutations; whereas MTHFR is a susceptibility gene and the evidence is less conclusive about its role in disease risk (Gene and Disease; National Cancer Institute; Bethesda 2009). For BRCA1 and BRCA2, both are tumour suppressor type genes that help repair damaged DNA or destroy cells if DNA cannot be repaired. A mutated BRCA1 gene usually makes a protein that does not function properly. Researchers believe that the defective BRCA1 protein is unable to help fix DNA changes leading to mutations in other genes. These mutations can accumulate and may allow cells to grow and divide uncontrollably to form a tumour. Thus, BRCA1 inactivating mutations lead to a predisposition for cancer (Gene and Disease; National Cancer Institute; Bethesda 2009).

A study of Mei (2012) revealed that a related protein in yeast participates in repairing radiation induced breaks in double-stranded DNA. It is thought that mutations in *BRCA1* or *BRCA2* might disable this mechanism, leading to more errors in DNA replication and ultimately to cancerous growth (Mei 2012). Regarding mutations of the MTHFR gene, a study of Ding (2012) mentioned that "many rare mutations of the MTHFR gene resulting very low enzymatic activity". This MTHFR genetic polymorphism can lead to abnormal DNA methylation and DNA synthesis, possibly leading to an altered risk for ovarian cancer (Kim, 2005; Dong et al., 2008).

Regarding cervical cancer, strong clinical and experimental evidence linked it aetiologically to the human papilloma-virus HPV infection.

Three major components are considered important to the pathogenesis of cervical carcinoma (Lazo 1999). Two of these are related to the role of human Papilloma-viruses (HPV), while the third is another recurrent genetic alteration, not linked to HPV.

The first component affects viral E6 and E7 proteins, whereas the second integrates viral DNA in chromosomal regions associated with well-known tumour phenotypes. Both components are harbouring HPV18 and HPV16. Recurrent losses of heterozygosity (LOH)

found to be in some chromosome regions such as 3p14–22, 4p16, 5p15, 6p21– 22, 11q23, 17p13.3, without the effect on p53, 18q12–22 and 19q13 (Izumi 1999).

### **1.10 Infection in cervical cancer**

HPV is the most prevalent sexually transmitted infection in the world, occurring in up to 75% of sexually active women (Deacon 2000; Bosch 2002; Castellsague 2002; Smith 2002; Berrington 2004; Smith 2004; Hemminki 2006; Madeleine 2007). Clinical studies have shown that 99.7% of new cases of cervical cancer are caused by HPV (Walboomers 1999; Munoz 2000). Syrjänen found that ASR of HPV ranged from 32 to 36/ 100 women/year for the age group of 15-25 (Syrjänen 2005). Persistent infection with about 15 high-risk human papilloma-virus (HPV) types is the major risk factor for cervical cancer, with HPV-16 and HPV18 infections accounting for about 70% of the total cases (Castellsagué, Díaz et al. 2006). Multiple sexual partners, younger age at first sexual intercourse, immune-suppression, and cigarette smoking serve as cofactors to the HPV persistent infection and progression to cancer (International Collaboration of Epidemiological Studies of Cervical Cancer (2009)). A meta-analysis of social inequality and the risk of cervical cancer found that both cervical infection, by Human Papilloma-Virus, which is linked to both male and female sexual behaviour, and access to adequate cervical cancer screening, are closely linked to the higher incidence rates of cervical cancer observed in different socio-economic groups. The importance of these factors may vary from one geographical region to another (Parikh 2003). In comparison to the favourable trends at all ages combined, cervical cancer rates have been increasing among younger generations in several countries, including Finland, the United Kingdom, Denmark, and China (Bray, Loos et al. 2005). This unfavourable trend is thought to reveal increases in HPV prevalence from changing sexual behaviours. The low overall cervical cancer rates in the Middle East and other parts of the developing world are suggested to reflect low

prevalence of HPV infections due to societal disapproval of extramarital sexual activity (Gustafsson, Ponten et al. 1997).

However, despite long-term research, link between human breast cancer and infection has not identified. Sixty years ago, it was demonstrated that breast tumours in mice were caused by an oncornavirus, murine mammary tumour virus (MMTV) (Manta 2004). Recently, there has been a resurgence of interest in the possibility that a significant proportion of human breast cancers may be caused by two candidate viruses, a human retroviral analogue of MMTV and the Epstein-Barr virus. These two viruses have been reported to occur in up to 37% and 50% of breast cancers, respectively (Manta 2004).

### **1.11 Behavioural risk factor and breast cancer**

The International Agency for Research on Cancer estimates that 25% of breast cancer cases worldwide are due to overweight/obesity and a sedentary lifestyle (McTiernan 2003). Several researchers investigated the association between physical activity and risk of breast cancer, the majority of which showed clear evidence of a lower risk for breast cancer in women who were classified at the highest levels of physical activity (Friedenreich et al 2008; Dirx et al 2001; Lee et al 2001; Harvie et al 2003). This has been explained by the observation that exercise during the reproductive period of life alters the concentrations of sex hormones. Studies found that women who were overweight or obese had a 30%-50% greater risk for postmenopausal breast cancer development than leaner women did. In contrast, overweight and obesity are associated with a lower risk of breast cancer developing during the premenopausal years (Friedenreich 2001). The Nurses' Health Study also found that the 60% greater risk for postmenopausal breast cancer associated with overweight and obesity was limited to women who had never used hormone replacement therapy (Huang, Hankinson et al. 1997).

## **1.12 Development of cancer registry in the UK and KSA**

Understanding the epidemiology of breast and cervical cancer, their risk factors, and socioeconomic determinants would help in establishing a comprehensive registry that is useful not only in managing resources but in prevention and screening services of such cancers. According to the seniority of the cancer registry, data collection and interpretation will be more accurate. In the UK, there has been a widespread effort to establish a cancer registration in order to maintain the systematic collection of data and characteristics of malignant neoplasm. The procedure used by different bodies, such as the International Union against Cancer (UICC), the International Agency for Research on Cancer (IARC), the International Association of Cancer Registries (IACR) (Jensen OM 1991; Parkin 1994), and the World Health Organization (WHO). In April 1996, the Office of Population Censuses and Surveys

(OPCS) combined with the Central Statistical Office (CSO) to form the Office for National Statistics (ONS). The main aim of the ONS is to collect and circulate social and economic data, including labour market and population statistics. In April 2008, the ONS developed into the executive office of the newly created UK Statistics Authority, a non-ministerial department reporting directly to Parliament. As part of this change, the NHSCR (National Health Service Central Register) transferred from the ONS to become part of the NHS Information Centre for Health and Social Care. The overall objective of the UK Statistics Authority is to promote and safeguard the quality of official statistics that serve the public good (Cancer Statistics registrations 2008).

In KSA, the National Cancer Registry (NCR) was developed in 1992 as a population based registry (Ministry Of Health 2001-2002). It was established under the authority of his Excellency the Minister of Health. The NCR, which based in the King Faisal Specialist Hospital and Research Centre (KFSH & RC), began reporting new cancer cases as of January 1, 1994. Each of the five main offices of the NCR is responsible for

gathering data from two to four regions. In the central region, the King Khalid University hospital in Riyadh covers Riyadh, Qassim, and Hail Health Regions. In the eastern region, the King Fahad University Hospital in Khobar covers Dammam, AlAhsa, and Hafr Al-Batin Health Regions. In the western area, the King Abdul-Aziz Hospital and Cancer Centre cover Jeddah, Makkah, Taif and Qunfudah Health Regions. In the southern region, the King Khalid University in Abha covers Asir, Baha, Najran, Jazan, and Bisha Health Regions. In the northern and Madinah region, the King Fahad Hospital covers Madinah, Tabuk, Jouf, and Northern Health Regions. In addition, there are offices in Oncology Departments to cover all new cases from different institutions, such as the Ministry of Defence and Aviation (Armed Forces Hospital in Riyadh), the National Guard (King Fahad Hospital in Riyadh covering KFNGH & KKNHG), and the Ministry of Interior (Security Forces Hospital, Riyadh). The main tasks for this registry are to collect data from all regions and offices, match all cases to ensure that each case is counted only once, verify diagnosis, conduct quality control reviews of all abstracts submitted, prepare regular reports and disseminate information to the medical community, government establishments, international organizations and the media. It is also responsible for training staff.

### **1.13 Screening services in the UK and Europe**

The Europe Against Cancer Programme simultaneously initiated a series of pilot screening programmes in several countries in Europe in order to develop expertise in planning and running high quality, population-based screening programmes before their incorporation into national policy (Commission of the European Communities 1996). In the early 1990s, national screening programmes were initiated in Australia and the UK; these were followed by organized programmes in several states of the USA, Israel and France. Germany and Switzerland were amongst the last western countries to join the international trend; they introduced their national screening at the beginning of the

Twenty-First Century. Experience in large-scale mammographic screening by the mid-1990s, and the availability of data on more recent follow-ups from the trials, led to discussion about the value of mammographic screening for women under the age of 50. Even on the basis of the same scientific evidence, few countries have established the same breast cancer screening policy. The policies differ according to the target age group that been screened, the frequency of screening, the number of mammographic views to be taken and the screening modalities. Until recently, the policy in Japan was based on clinical breast examination and later added mammography (IARC 2002).

### **1.13.1 Screening services of Breast cancer**

Cancer mortality can be avoided by early detection (IARC 2002). However, mortality rates from breast cancer have been dropping steadily since 1990. This was due to earlier detection and better treatment (Ferlay 2004). In the UK, the NHS provides screening for breast cancer as a free service in order to detect breast cancer at an early stage and thus to reduce the death rate from this condition (North East Yorkshire and The Humber 2002). All women over 50 years old are eligible for free breast cancer screening every three years.

Quinn and Babb (1999) found that the national call and recall system and incentive payments to general practitioners increased coverage to around 85% in England. This resulted in falls in incidence of invasive disease in all regions of England and in all age groups from 30 to 74. The fall in mortality in older women was largely unrelated to screening, but without screening there might have been 800 more deaths from cervical cancer in women under 55 in 1997 (Quinn 1999).

### **1.13.2 Screening services in cervical cancer**

Cervical screening has described as a process of methods to prevent, detect and treat cancer in its early stage. The first step is by taking a sample called Liquid Based Cytology (LBC). This sample is taken from the cervix for analysis. Most women consider this procedure as an uncomfortable process. A plan in the future is looking forward to detect the disease by computer-assisted techniques, and all women between the ages of 25 and 64 are eligible for free cervical screening services every five years. The cervical cancer programme started in the UK in 1964; unfortunately it did not cover women who were at greatest risk (Farmery 1994). By 1988 organized screening had been implemented at a recommended interval of 3 or 5 years for women aged from 20 years to 64 years. Until 2003, the interval in the UK varied between 3 and 5 years for different health authorities, with more than half of those in England issuing screening invitations every 3 years (Patnick 2000). The Department of Health issued a circular (Department of Health and Social Services 1988) requiring a computerized callrecall system to invite this age group to participate in cervical cancer screening every 3 to 5 years. The NHS Cervical Screening Programme now offers screening at different intervals, depending on age (Sasieni 2003). These new intervals divided into four invitations. The first invitation is for women who reach the age of 25 years. The second is a three years routine screening for those aged between 25-49 years. The third invitation is a five-year routine screening for women aged between 50-64 years, and the last invitation is for all women aged over 65 years who have not screened before or have had recent abnormal tests.

Since the 1960s, a significant reduction in the incidence of cervical cancer has been observed in countries with an organized screening programme (Bray 2002; Peto 2004). Nevertheless, some regions have presented an increasing incidence rate of cervical cancer, and rates in other regions have remained stable (Vizcaino 2000).

Cervical screening can prevent around 75% of new cancer cases in women who screen regularly (Sasieni 2003). The declines registered in cervical cancer mortality in young women were largely due to screening, and the persisting variations in mortality across Europe underline the importance of the adoption of organised screening programmes, with specific urgency in Eastern Europe (Levi 2000).

Regarding the socio-economic status has a generalized link to cancer. Few studies have examined the association between breast cancer screening and socioeconomic status (Rakowski 1995; Nelson 2003). Studies from the Centre for Disease Control (CDC) on metropolitan areas have shown that amongst 35 metropolitan areas in USA, women with annual household incomes of less than \$15,000, or without a high school education, were less likely to attend a mammogram clinic than those coming from high income area or with more education (Mickey 1995; Garbers 2003; CDC 2005). However, women in high-income countries such as the UK and the USA take advantage of early cancer screenings, drug therapies, and vaccines, which shifts the burden of breast and cervical cancer to low-income countries. A report from IHME, (Mohammad 2001), *The Challenge Ahead*, has shown that the growing burden of breast and cervical cancers amongst low resource countries in Africa, the Middle East, Latin America, and central Europe means that more attention should be directed toward cancer screening, treatment, and education a priority in the developing world.

### **1.14 Screening services in Saudi Arabia**

Compared to the UK screening services, which is organized by NHS (as described above), in Saudi Arabia, there is no specific plan or written system in place to direct women to the correct channels to satisfactorily detect cancer at an early stage. The KSA national health services do not offer invitation letters for any age group. One of the reasons is because the breast and cervical cancer data available from the Saudi National



Cancer Registry (NCR), launched in 1994, contains only numbers and percentages on the incidence of breast and cervical cancer. The health services in KSA provide a variety of free screening services for breast and cervical cancer. All women over 40 years old are eligible for breast and cervical cancer screening services. However, they usually do not know where to go if they have a problem. In 2004, health education in schools and hospitals started and was based on voluntary and individual effort. The health education program included the early detection of breast cancer but not cervical cancer. Further, the database does not contain information about the experience of women, or information on screening services.

### **1.15 Saudi women in the UK**

This section describes the Saudi population in the UK in order to present the current distribution among the British population. The total estimation of Saudi population living in the UK is around fourteen thousand, 3240 of whom are adult women (Al-Habib 2012). A small proportion settled in the UK permanently and there were few asylum claims. Only 670 Saudi born nationals have been granted British citizenship since 1980 (DoH 1993). A large number of Saudis make business-related trips to London or come to the UK to study. Thus, the Saudi community in the UK is characterized by the small permanent presence consisting largely of small businesses and middle-class professionals. See Figure 3 for the distribution of the Saudi population in the UK.

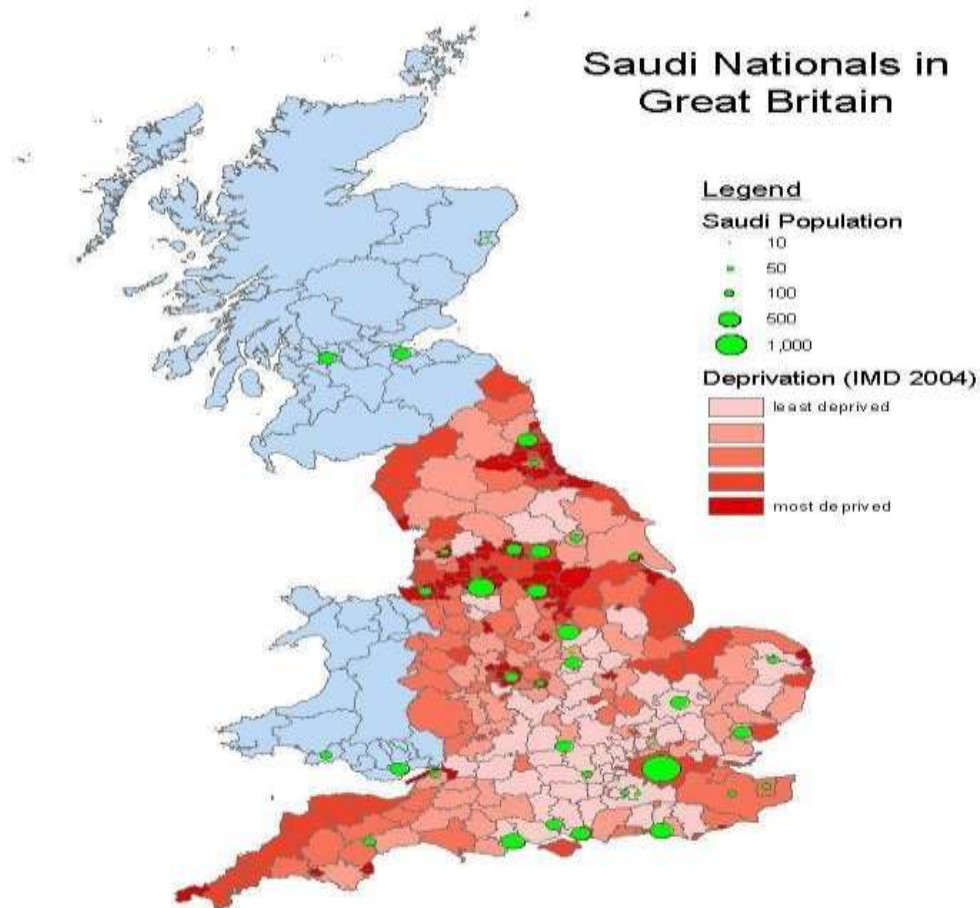


Figure 4: Distribution of Saudi population in the UK, Al-Habib, 2012

### 1.16 Rational of the thesis

The above background and perspectives made it clear that breast and cervical cancer are life threatening diseases and their morbidity and mortality could be avoided by early detection. In addition, lack of proper screening services in Saudi Arabia in contrast to the one in the UK motivated me to assess the facilitators and barriers Saudi women face when accessing breast and cervical screening services in the UK and Saudi Arabia. This thesis has relevance to the UK, as little is known about the process of accessing breast and cervical screening services by immigrant Saudi women. Access to cancer screening services has been studied in Europe, the US and some Arabic countries, such as Jordan and Palestine, however, up to my knowledge; the literature did not identify any studies on this topic in KSA. Moreover, locally advanced breast cancer is unusual in Western

countries where cancer screening is established, it constitutes more than 40% of all non-metastatic breast cancer in Saudi Arabia (Ezzat 1999).

Therefore, there is a need to explore the factors surrounding women's attendance at cancer screening services in Saudi Arabia.

Furthermore, it would be interesting to compare Saudi women experiences in both the UK and home country (KSA), this is because literatures highlighted the influence of migration status on women's attitude and experiences during accessing the screening services.

### **1.17 Aim and objectives of the thesis**

The main aim of this thesis is to explore the barriers and facilitators for breast and cervical cancer screening services among Saudi women living in the UK and KSA. To fulfil this aim, several objectives were set-up including the following:

- To explore Saudi women knowledge about screening services of breast and cervical cancer.
- To assess the barriers and facilitators women face when accessing screening services.
- To explore Saudi women's experiences when accessing screening services
- To look at the potential influence of migration on the uptake of and attitudes to screening services amongst Saudi women by comparing the findings between those living in the UK and those living in KSA.
- To address the potential solution of how to make screening of cancer more accessible.

### **1.18 Structure of the thesis**

The thesis is divided into seven chapters; this chapter (Chapter One) laid the background about the breast and cervical cancer. Chapter Two reviews the literature that is directly relevant to the research aim in order to get some insight about previous researchers' efforts in exploring barriers and facilitators women face when accessing breast and cervical cancer screening care.

Chapter Three discusses various theoretical models of health care access and utilization. Chapter Four describes the approach and methods selected to fulfil the thesis objectives. Chapters Five presents the quantitative findings of my thesis. Chapter Six presents findings of the focus groups of the thesis. Chapter Seven provides discussion and conclusion of the findings in view of the literature. The discussion and conclusion sections also address the findings of both quantitative and qualitative parts of my thesis in the light of the study objectives and connect these to literature review and finally potential recommendations for national health policy are presented.

## **Chapter 2 Literature Review**

### **2.1 Introduction**

Chapter one provided an overview of breast and cervical cancer, their risk factors, epidemiology, and development of screening services in the UK and KSA. Chapter Two is a review of the literature to understand and explore previous researchers' efforts in investigating the barriers and facilitators women facing when accessing breast and cervical cancer screening services. It provides a context for Chapter Three as it reviews the literature that forms the basis of the questionnaire and the topic guide. In addition, it is relevant to my thesis' aim, which is to explore the barriers and facilitators for breast and cervical cancer screening services among Saudi women living in the UK and KSA.

The review question is:

What are the barriers and facilitators that influence women when accessing breast and cervical cancer screening services?

### **2.2 Objective of the review**

The objectives of this literature review were:

- To understand how other researchers explore barriers and facilitators regarding cancer screening services
- Help to formulate the thesis questionnaire and the focus group guide and to give a context to the study findings regarding the barriers and facilitators for breast and cervical cancer screening services.

### **2.3 Method**

Medline, Web of Science (ISI), CINAHL, Cochrane library, and Google scholar were searched from 2000 until 2010. Specialized journals were also searched such as; Journal of Immigrant and Minority Health. Searches included MeSH and text words terms, with

combinations of 'and/or' Boolean operators. Terms used: breast, cervical, cancer, barriers, facilitators, screening, services, health, prevention, beliefs, experiences, views, immigrants, ethnic, minorities, culture, cross-culture, refugees, Muslim, Islam, and Arab. Hand searching the reference lists from the retrieved studies was done in order to locate any studies that might have been missed by the database searches. All citations were exported into End-Note software (Version X5).

### **2.3.1 Selection criteria**

Studies were included if they: (1) explored women's knowledge of breast and/or cervical cancer, (2) explored studies of women's experience of breast and cervical cancer, (3) explored the barriers that discouraged women from accessing screening services for breast and cervical cancers, (4) explored the facilitators that encouraged women to access screening services for breast and cervical cancers, and other female cancers, (5) used qualitative and/or quantitative components, and (6) were conducted with women aged 18 or older. I excluded studies of men's knowledge of cancer and studies with women under the age of 18 and the papers that did not report research studies but contained general comment on the topic.

### **2.3.2 Data extraction**

The data from the studies were used to compile a description of the studies and to summarize the evidence regarding the barriers and facilitators that women experienced when accessing breast and cervical cancer screening services internationally with a focus on the Arab women in particular and immigrants. The data extracted from the studies included: aims of the studies, description of methods, main findings, and conclusion of the authors. I decided not to report the scoring of the studies as there has been considerable debate amongst methodologists on the value and legitimacy of scoring as a means of judging qualitative research (William 2008).

As Kuper pointed out, the thorough assessment of qualitative research is an interpretive act and requires informed reflective thought rather than the simple application of a scoring system (Kuper 2008).

I am aware of the importance of having two reviewers to review the studies, to apply the predefined criteria, and to analyse data. However, one of my supervisors is an experienced qualitative researcher and I have had basic training in qualitative studies methods. These factors helped me to carry out this review sufficiently well to understand previous research efforts in exploring women's knowledge of breast and cervical cancer, experience with accessing cancer screening services and the barriers and facilitators related to their access to cancer screening services. The results of the studies were summarized in relation to the objective of this review.

Analysis of these studies was conducted and included: women's expression of their experiences, barriers, and facilitators when accessing screening services, the conclusions of the researchers of the study about the overall women's experiences, and my final interpretations about the included studies in this review. In addition, Islamic scholar's views and perceptions about the role of Islam and its values and concepts were discussed. This is because it might influence women's perception and understanding of the role of preventive medicine in general. Moreover, Islam as a religion plays a major part in every aspect of Muslim life.

The final search identified 357 articles. The articles were identified by reading the titles and abstracts to assess whether the contents were likely to be within the scope of the objective of this review. Although my review objective was to review Arab and non-Arab women's knowledge, I decided to include studies conducted with other European women as well because I had found only a few studies conducted in Arab and/or Saudi communities. An up-to-date literature search for the years 2010 to 2012 conducted with a similar strategy.

## 2.4 Results

The final search result retrieved 22 eligible references for this review (Appendix 2 for summary of studies and Fig 4 for the strategy of the literature review). Five primary studies were conducted in the US, four in Saudi Arabia, two in the UK, two in Jordan, one in Pakistan, one in Malaysia, one in Iran, one in Greece, one in London and Pakistan, and one in Chelsea. The last 3 references were: a literature review article, monograph article, and general article. Studies included varied in their objectives, approach, and method used to explore barriers, facilitators, and experiences of women about accessing breast and cervical cancer screening services. Twelve studies used a survey-based design, four studies used qualitative approach, three used a mixed method, one was a review article, and two were general articles that were written by a single author that addressed the Islamic medicine. All the primary studies aimed to explore the barriers, facilitators and/or knowledge of women during their experiences when accessing breast and/or cervical cancer services.

A study that was conducted in the US among Mexican American women showed that language was a barrier to access screening of breast and cervical cancer (Breen 2010), recommendation from this has included that understanding barriers specific to subgroups is key to developing appropriate policy and interventions to increase use of cancer screening exams. Another study also conducted in the US explored the relationship between patterns of health behaviours of women and the use of cancer screening tests while controlling for socio-demographic and health System factors (Meissner 2009). This study found that health behaviours, age, educational attainment, usual source of care, and health insurance were significantly associated with the use of breast and cervical cancer screening. This highlighted the role of intervention to modify behaviours in the health context if these barriers were tackled.



In the UK, Waller (2009) explored barriers to cervical screening attendance in a population based sample. This study found that embarrassment, fear of pain, worry about what the test might find, not being sexually active and not trusting the test were the main barriers to accessing cervical screening services. Authors of this study pointed out that practical barriers were more predictive of screening uptake than emotional factors such as embarrassment. This has clear implications for service provision and future intervention to increase cancer uptake as in another survey in the UK revealed that women who were older, in better health or had longer periods of formal education were less worried about cancer risk than those who had illness experiences, lower income, or who were smokers (Sach 2009). Additionally, the researchers highlighted that knowledge of cancer correlates with women's closer involvement with screening. This implies that educating women about their risk of cancer might improve their attitudes toward cancer screening uptake.

Moreover, in focus group discussions, Samoan American considered poor confidentiality as a barrier to accessing breast and cervical cancer screening services and expressed their beliefs in "God's will" for a cure of cancer if diagnosed (Wu 2010). Similarly, Iraqi women have addressed psychosocial barriers and culturally mediated beliefs impeded their ability to obtain breast cancer screening and pointed to reliance on God in preventing illness (Saadi 2012). Hence, culturally appropriate health education and outreach programmes are needed for this specific population to improve attendance. It, subsequently, would be needed for the design, implementation, and evaluation of specific and culturally sensitive interventions to promote breast cancer services. Findings from different studies may be used to develop interventions aimed at reducing perceived barriers, enhancing perceived benefits, and modifying negative emotional responses to breast cancer, in order to increase the likelihood of mammography utilization and motivate women to start undertaking mammography screening.

In a cross-sectional study, Asian American women identified several barriers to have mammogram such as; lack of time, scheduling, location, poor facility, pain, feeling uncomfortable, and lack of insurance (Wu 2008). In addition, they mentioned that fear of finding cancer and cultural barriers (such as male doing the screening) prevented them from attending breast screening services in the US.

However, another study addressed the factors that are barriers to breast cancer screening among Asian women; this study provided evidence supporting the importance of knowledge, perception and socioeconomic barriers in women's decision on uptake of such services (Parisa 2006). The author mentioned that other main barriers were: fear of treatment, and fear of the test itself, inability to act without husband's permission which needs to be addressed with tailored approaches that take into account culture and religion. Asian and Arab women have usually occupied a lower position; this position has subordinated their own needs including health care needs (Nissan 2004). In Greece, a population-based survey showed that perceived serious consequences of breast cancer, and strong beliefs about treatment control, were correlated with more benefits of mammography screening, fewer barriers to mammography screening, and higher self-efficacy (Anagnostopoulos 2012). In addition, the study found that a less coherent understanding of the disease was related to more perceived barriers to mammography uptake and less perceived benefits of mammography screening.

Additionally, it revealed that strong negative emotional representations were associated with higher self-efficacy and fewer barriers to mammography screening.

Furthermore, cultural beliefs continue to affect Jordanian and Palestinian immigrant women who live in the US (Kawar 2009). Among these women, more knowledge about screening of breast cancer was associated with both more fear and greater utility; negatively with cultural beliefs and conformity with patriarchal expectations (there was

less knowledge as cultural beliefs and conformity was greater); and positively with more general health habits.

Moreover, Jordanian women addressed in another study some barriers such as: embarrassment, too much time, pain, cost, and worrying about having breast cancer (PetroNustas 2001b). The study showed that educating women about the benefits and cost effectiveness of breast cancer screening programs might help in their understanding and enhance their uptake of the test.

In Jordan also, it was found that the major barriers to Pap smear screening included inadequate knowledge about the test, not being referred by a health professional and fear of having a bad result (Amarin 2008). This implies the need to increase awareness about Pap smear testing and to strengthen the existing health care infrastructure to be able to enhance uptake of Pap smear.

In Malaysia, female medical students were involved in focus group discussions to explore their perceptions regarding Pap smear test (Al-Naggar 2010). They expressed that barriers to such screening were: lack of awareness, shyness, and the cost of the test. Most of these women agreed that physician's gender would affect the women's decisions to uptake the test. The findings of this study suggest that it is important to provide information about the value of cervical smear test.

In Saudi Arabia, there are four studies (surveys) that addressed knowledge, attitudes, practice, and utilization of breast and/or cervical cancer screening services (Alam 2006; Jahan 2006; Amin 2009; Sait 2009). Lack of awareness and knowledge about the risk of cancer and benefits of screening were commonly prevalent among Saudi women. Researchers highlighted that traditions of conservative nature, which halt women from consulting providers regarding these sensitive issues, may be responsible for the knowledge defect and poor screening behaviours among Saudi women. Therefore, culturally sensitive health education messages should tailor to fulfil the knowledge gap

among these women with emphasis on role of prevention and guidelines for screening. Many studies investigated data on minority groups in the UK regarding the perception of breast health and factors that influence breast cancer screening practices. However, screening disparities exist and lack on the views of minorities, regarding breast cancer screening, such as Black women have identified by Banning study. This study showed that Black British women appear to be an underrepresented group. This was explained by several influential factors such as religion, educational awareness of breast cancer screening, breast health awareness (Banning 2011). Other studies investigated the awareness of breast health practices and the impact of culture and psychosocial issues on breast health among Muslim women, such as Pakistani women, in the UK. For example, a study compared between women who live in Lahore and London in regard to the breast cancer views. Findings revealed that women in Lahore were more inquisitive about breast cancer and held more developed views compared with British Pakistani Muslim women. Women concurred that concise and relevant breast health education is needed irrespective of faith to improve cultural sensitivity and awareness in both Pakistani communities (Banning and Hafeez 2010). Another study conducted in Pakistan used quantitative (survey) and qualitative approach (focus groups). They found that women generally were aware of the term breast cancer but were unsure of its aetiology. The survey revealed that women were aware of mammography (Banning and Hafeez 2009). The focus group discussions showed that there is strong cultural opinion that breasts are private organs that should not be discussed in public. Authors also highlighted that health beliefs and perception of risk can influence cancer screening behaviour among Pakistani women hindering access to such services.

Furthermore, Islamic scholars discussed the Q'uranic and Prophet Mohammad sayings(Sunnah) with regard to different aspects of health in the context of Islam (Nagamia 2003; Deuraseh 2006). Preventive medicine has been defined in Islam as the science of

maintaining individual and community health at its best. They explained that a target of preventive medicine is to protect the body from disease before they occur, to prevent the spread of infection, to maintain health to improve living conditions and to prevent accidents and causes of nervous tension. In general, Islam has put great emphasis on how people should keep their body in the well-being. For example, one of the verses in Q’uran stated:

"ولاتلقوا بايديكم الى التهلكة" البقرة، 591

*“Don’t push yourselves into perdition” Albaqara, 195*

Islamic Authors emphasized that Muslims should be fully aware of spiritual and physical medicine. In Islam, the breath and the body, the soul and matter, the faith and the world have been accorded equal importance.

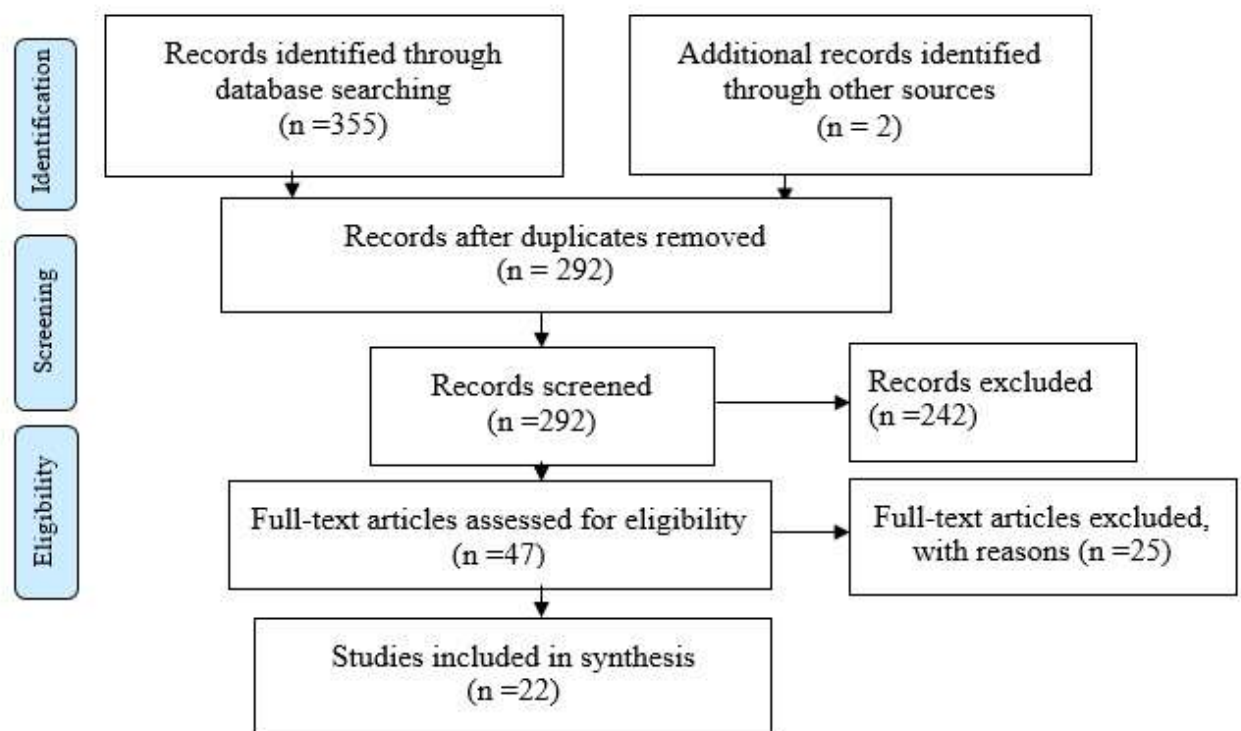


Figure 5; Flow chart of search strategy of the literature review

## 2.5 Conclusion

This literature review highlighted common and consistent evidence of lack of awareness and lack of knowledge regarding breast and/or cervical cancer screening services. This has

probably resulted in lower uptake of such services internationally and nationally (Saudi Arabia). International studies in the US, UK, and Asia focused on the barriers, as well as knowledge and attitudes of women towards the screening services, however, in Saudi Arabia, the focus was on the knowledge and attitudes rather than addressing the barriers to such services. Hence, further in-depth research needed in this sub-group population in order to improve access to screening of breast and cervical cancers.

This review highlighted also the role of culture, religion, and health beliefs in the understanding and attitudes in accessing screening services. This is particularly true in immigrant women where language was identified as barrier to attending breast and/or cervical cancer screening tests. Hence, many researchers endorsed the importance of addressing these issues in future research. Therefore, this literature review informed my approach to fulfil my thesis aim and objectives. It helped to design my method, questionnaire, and topic guide of the survey as well as the qualitative part. In particular, understanding previous researcher's findings of the barriers, facilitators and experiences of women, at the international and national level, helped in developing my questionnaires items. These items include : role of knowledge, role of emotional element in influencing women 'attitudes to attending screening services, fear of having cancer, pain during the test, embarrassment, role of cultural beliefs, religion influence, cost, and transportation issue.

Having addressed what previous researchers have done in investigating the facilitators and barriers women experienced when accessing the breast and/or cervical cancer screening services, the next chapter, I will describe my method that will fulfil my objectives.

## **Chapter 3: Theoretical Models of Health Care Access and Utilization**

### **3.1 Introduction**

This chapter discusses the various models and theories related to health care access suggested in the literature. This might help to understand women's attitudes, and behaviours, when accessing cancer screening services. In addition, this would help understanding the factors influencing preventive screening behaviours, particularly, among ethnic minority women. These theoretical models inform my methodology, topic guide of the focus groups, and explaining my findings. Models might not only facilitated the identification of barriers that can interfere with women' uptake of breast and cervical cancer screening services, they might also guide the approaches that could be designed to overcome them.

### **3.2 Behavioural Model**

This model has been widely used for assessing health service utilization among minority populations (Andersen 1995; Gelberg, Andersen et al. 2000). It has been applied in several studies to test access of care (Bazargan, Baker et al. 1998; Barkin, Balkrishnan et al. 2003; Bazargan, Johnson et al. 2003). This model conceptualizes health care utilization as an outcome of a multifaceted pattern of interactions among predisposing, enabling, and need for-care characteristics. Each component might be conceived of as making an independent contributor to predicting use of screening services. Predisposing characteristics present before the beginning of illness and comprise those characteristics that describe the propensity of individuals to use health care services. The predisposing vulnerable domain includes demographic characteristics, social structural characteristics, childhood

characteristics, living conditions, psychological status, and health belief variables (Gelberg, Andersen et al. 2000).

To use health care services, the individual should perceive some illness or need for preventive care. For example, a study that used this model found a strong association between obtaining a Pap smear test and continuity of care (enabling factor), even after all other predisposing, enabling, and need-for care factors were held constant (Bazargan, et al. 2004). They also showed that controlling for all other factors, women with health insurance were over two times more likely to report a recent test. The association of these enabling characteristics (affordability and continuity of care) with having a Pap smear test is an indication of how women will access screening test. This showed the impact of the enabling characteristics on the outcome variable, which is the cervical cancer-screening test.

### **3.3PRECEDE-PROCEED framework**

It was originally taken from Andersen's model of behavioural factors in health care utilization. PRECEDE stands for **P**redisposing, **R**einforcing and **E**nabling **C**onstructs in **E**ducational **D**iagnosis and **E**valuation. PRECEDE specifies that factors affecting behaviour can be broadly classified as predisposing, reinforcing, or enabling (Taylor, Schwartz et al. 1999). It suggests that health behaviour is regarded as being influenced by both individual and environmental factors. It is an educational and ecologic approach that has now been used in many of published studies to design interventions for planned change that account for the multiple determinants of behaviour (Green and Kreuter 1993). It suggests that factors affecting health choices are culturally determined and does not specify that the same variables such as perceived susceptibility to disease are determinants of behaviour across communities (Green and Kreuter 2005). For example, a study found that factors from all three of the PRECEDE constructs were independently associated with cervical cancer screening participation. Specifically, beliefs about karma, regular check-ups, the



prolongation of life, and the necessity of Pap testing (predisposing); prenatal care in the US and sex of provider (enabling); and physician recommendation (reinforcing) were all correlated with screening behaviour in one or both of the study's multivariate models (Taylor, Schwartz et al. 1999). In addition, the National Centre for Chronic Disease Prevention and Health Promotion at the Centers for Disease Control and Prevention recommended its use to plan and evaluate health promotion programs.

### **3.4 Health belief model**

Beliefs play a major role in explaining and determining behaviours. The Health Belief Model (HBM) is one such theory that, since its development in the 1950s, has served as one of the most widely used frameworks for understanding and explaining health related behaviour. The HBM is essentially a cognitive approach, which suggests that individuals will employ in preventive health behaviour if they believe themselves threatened by an illness or condition and believe that the benefits of taking preventive action outweigh the barriers to or costs of said action (Rosenstock 1974). The main domains of the HBM are perceived susceptibility, perceived severity, perceived benefits minus perceived barriers, and cues to action.

The HBM hypothesizes that feeling vulnerable to a health condition is a motivating factor to take action to avoid the condition. Perceived severity refers to how severe an individual views a condition to be. It is assumed that the more serious a health problem is, the more likely a person will take action against it. The HBM suggests that the likelihood of taking an action is influenced by beliefs that barriers to action are outweighed by the benefits of the action. Perceived benefits points to the perception that an action will end in a positive outcome or benefit to one's health. Perceived barriers are those costs or impediments that might put off an individual from undertaking an action or behaviour (Burak and Meyer 1997). Additionally, the model postulates that internal and external cues such as, body states and environmental factors, may also encourage or

inhibit health-enhancing behaviour. Moreover, self-efficacy, which is defined as the confidence that one can successfully practice the behaviour required to construct the outcome.

This model has been used in cancer research to understand screening participation. A study showed that among Hispanic women, using the HBM, the perceived barriers (e.g. fear of cancer, embarrassment, fatalistic views of cancer, and language), as well as perceived susceptibility (e.g. belief that screening tests are not necessary/needed) impede breast and cervical cancer screening (Austin, Ahmad et al. 2002). The authors emphasized that physician recommendations and community outreach programs are effective strategies to increase breast and cervical cancer screening uptake among Hispanic women. They indicated that cancer screening programs should use multi-sectorial approaches to address culture-specific issues and provide culturally sensitive and competent services.

Another study that used the HBM among Korean women when accessing cervical cancer screening found that there was misinformation and a lack of knowledge about cervical cancer (Lee 2000). These women therefore were confused about the causative factors and preventive strategies related to cervical cancer. The authors concluded that major structural barriers were economic and time factors along with language problems. Many participants were recent immigrants with no medical insurance and long work hours. They also identified the main psychosocial barriers such as fear/fatalism and denial.

Moreover, a study among African American women examined the predictors of acceptance and completion of mammogram (Burack and Liang 1989). Using multivariate analysis, authors demonstrated support for perceived benefits, perceived barriers and internal cues (presentation of a symptom of breast disease) in predicting both the acceptance and completion of mammography. Another study explored the predictors of mammography participation with 1,057 women over 35 years (Stein, Fox et al. 1992). They revealed cues to action (physicians Recommendation) was an influential predictor of prior

mammography, and perceived susceptibility predicted future intentions. Socioeconomic status (SES) significantly correlated with cue to action and perceived barriers.

The research using the HBM provides that the constructs (perceived susceptibility, severity, barriers and cue to action) is useful in explaining some important influences of breast cancer screening practices. The HBM model also overlooks cultural barriers to preventive behaviours, which may symbolize the social context in which women live.

### **3.5 The Trans-theoretical Model (TTM)**

The TTM uses and, according to many, greatly improves on HBM constructs in that, rather than specifying beliefs, the TTM allows for a range of positive and negative attitudes that may or may not include the HBM constructs of perceptions of benefit, severity, or susceptibility (Pasick and Burke 2008). It suggests that not all women face similar barriers or do they have the same degree of readiness to adopt a behaviour such as mammography or cervical cancer screening. Currently, the TTM is a major paradigm in health behaviour research including breast cancer screening (Ashing-Giwa 1999). The model progresses through these stages: (1) Pre-contemplation (status quo or no change); (2) Contemplation (initial thoughts of change); (3) Preparation (plans and initial steps towards behaviour change); (4) Action (the actual practice of the desired behaviour); and (5) Maintenance (maintaining the desired behaviour for a given time period) (Ashing-Giwa 1999).

The TTM embrace promise for identifying subgroups with different characteristics that may be important for intervention. In a study by Pearlman and colleagues examined within-group and between-group variation in stage of mammography adoption for African American, Latina, and white women (Pearlman, Rakowski et al. 1995). The authors found significant race/ethnic differences and concluded that the decision to get mammography is a complex process with different patterns observed within each race/ethnic group.

The TTM suggests that behaviour change is dynamic and non-linear. Hence, this model provides a framework for the process of change with women at varying levels of readiness

to change. It relies primarily on cognitive aspects associated with the decision making process.

The model postulates that an individual independently decides and practices the needed behaviour change. This individualistic perspective might not be relevant to diverse cultures.

### **3.6 Theory of Planned Behaviour (TPB)**

The TPB's central construct is intention, regarded by the theory as the most important and proximal predictor of behaviour (4). It emerged as a major framework for understanding, predicting, and changing human social behaviour (Ajzen 2011). The primary influences on intention are said to be normative beliefs, control beliefs, and behavioural beliefs (positive and negative attitudes). We are introspectively aware of the thoughts and feelings that lead up to our decisions and we find in these processes a convincing explanation for our behaviour. Empirical support for the theory comes from a host of correlational studies demonstrating its ability to predict intentions and behaviours. Montano and Taplin used the theory of reasoned action (predecessor to the TPB) and expanded it to include affect, the emotional response to getting a mammogram, and facilitators, external conditions that encourage or impede receipt of a mammogram in a multi-ethnic sample of women from a public health clinic (Montano and Taplin 1991). The authors found that only facilitators correlated with previous mammogram (the primary dependent variable).

Many factors, internal and external, could impair (or facilitate) performance of a given behaviour; the extent to which people possess the requisite information, mental and physical skills and abilities, the availability of social support, emotions, and compulsions, and absence or presence of external barriers and impediments. This model (TPB) provides valuable connections among beliefs, attitudes and behavioural intentions, reinforcements, beliefs, attitudes and intentions on influencing health behaviour. The model bears a resemblance to other models, but suggests the value of a new factor, namely subjective

norms. That is, women are more likely to participate in mammography screening if they have positive attitudes toward its benefits, believe that others like themselves participate in mammography, and perceive control over attaining the mammography.

In summary, the theories discussed above could be integrated in a variety of combinations. They commonly treat behaviour as a dynamic interplay between the person, the behaviour, and the environment. However, theories must reflect a more complex and nuanced approach to the socio-cultural and behavioural mechanisms involved. Culture has been regarded as a process of making sense of the world the complex concept of culture need not be defined nor scrutinized directly (KagawaSinger 2000).

Although it was not possible to cover all theory combinations and applications, it did appear that many studies have identified strategies for building on the strengths of individual theories by adding more or even new constructs or embedding theoretical approaches within other broader frameworks. Even in best possible combinations, the theories discussed have strengths and weaknesses. Limitations include abstraction from context, focus on cognition resulting in interventions primarily providing information, and little direction or insight into the progression by which behaviour might change or through which interventions can effect change. Furthermore, researching behaviour, beliefs and human intentions would be of limited methodology and conceptual problems including reliance on single item measures and a lack of standardized measures of known reliability and validity.

The issue of addressing the whole person that includes family relationships, socioeconomic status, and environmental factors (including social and political issues) is essential in assessing women behaviours when accessing breast and cervical cancer screening services. For the current thesis, I decided to keep an open mind rather than a adapting a single theory in order to explore the barriers, facilitators and experience of Saudi women when accessing breast and cervical cancer screening services in the UK and Saudi Arabia.

## **Chapter 4: Research Design and Methods**

### **4.1 Introduction**

The chapter describes the methods used to fulfil the thesis objectives. The objectives were to;

1. Explore Saudi women's knowledge about screening services of breast and cervical cancer.
2. Assess the barriers and facilitators women faced when accessing screening services.
3. Explore Saudi women's experiences when accessing screening services.
4. Look at the potential influence of migration on the uptake of and attitudes to screening services, amongst Saudi women, by comparing the findings between those living in the UK and those living in KSA.
5. Address the potential solution of how to make screening more accessible and appropriate to the needs of women.

Having multiple questions (objectives) means there is a need for more than one method to answer these questions. Hence, mixed method was used, a mixed method design was chosen for the study because the combination can provide more comprehensive answers for the study aims and objectives and can go beyond the limitations of using a single approach (Natasha 2005). The two approaches differ in their perspectives and means of data collection; however they share the same scientific aim (Atkin 2006). In combination, both methods can complement each other and provide a more complete picture of the topic under investigation (Adamson 2004). Researchers emphasized that using a mixed methods approach can greatly enhance our understanding as it expanded the dimensions of the research topic and findings in both methods could be checked for consistency (Chow, Quine et al. 2010).

Furthermore, the thesis methods were chosen on the basis of their ability to reveal the perspectives of Saudi women on breast and cervical cancer screening services. This choice has been informed by the literature review, where previous researchers' efforts explored and discussed in Chapter 2.

Making decision to use both qualitative and quantitative research approaches has based on three issues: 1. Quantify the variation between the two groups of participants, UK and Saudi, with respect to the different factors such as knowledge, experiences, barriers and facilitators. 2. Explore the association between these factors and 3. Describe the attitudes towards breast and cervical cancer screening services and experiences of the services by Saudi women living in the UK and KSA at the time of the study period.

The analytic objective of the qualitative section was a description, not quantification, of the variation between women's views regarding breast and cervical screening services. The qualitative method was used to describe and explain the relationships between the knowledge of breast and cervical cancer, the barriers to accessing the screening services, and the group cultural norms. Therefore, this method provides rich data that will help me to understand the experience of the participants.

The formatting of questions is an important difference between quantitative and qualitative approaches. In my thesis, the quantitative approach was supported by creating closed-ended questions for a self-administered questionnaire, whereas the qualitative approach was supported by creating open-ended questions for the topic guide used in the focus group discussions. The qualitative approach was applied in order to explore the same issues as the questionnaire, but to contextualise the topics within the social and cultural context of Saudi women living in the UK and KSA. This chapter includes: thesis instruments to collect data, thesis participants and sampling frame, recruitment and data collection process, safety and ethical considerations, and data analysis method.

#### **4.2 Thesis instruments to collect data**

Questions for both the questionnaire (survey part) and the topic guide (focus groups) were developed based on the literature review. A full-list of the literature used to inform the development of the questionnaire and the topic guide is shown in Appendix 1

#### **4.2.1 Survey instrument**

The self-administered questionnaire is shown in Appendix 3. The purpose of the self-administered questionnaire was to acquire the data to fulfil the study objectives by looking for the answers to specific questions. The questionnaire designed to; 1. Assess Saudi women's attitude towards breast and cervical cancer services in the UK and KSA.

2. Assess Saudi women's experiences in the process of attending breast and cervical cancer screening services. 3. Assess the knowledge that Saudi women have regarding breast and cervical cancer. 4. Assess the barriers and facilitators regarding Saudi women's access to breast and cervical cancer screening services. 5. Acquire the Saudi women's suggestions for improving breast and cervical cancer screening services in the UK and KSA.

The survey questionnaire consists of 43 items and is divided into five sections. Section one asks about socio-demographic factors including: age, city of residence, occupation, education, marital status, years of marriage, having children, and how many children a woman has. Section two involves women's perceptions of breast and cervical cancer, this includes: the role of lifestyle in the occurrence of breast and cervical cancer (smoking, lack of exercise, obesity, poor diet), women perception of their feelings of how they are informed about breast and cervical cancer (very well informed, reasonably well informed, not well informed), source of information women have about breast and cervical cancer (media, friend, school or work, health professionals), women's view of how common breast and cervical cancer are now compared to ten years ago (more common, less common, not changed, not sure), women's feelings evoked by the word cancer (pain, stigma, fear, anxiety, shame), women's perception whether cancer be treated, that people die from cancer, cancer can be cured, their views whether a benign breast lump; is not a cancer, is an early sign of cancer, can be treated easily, or whether people usually die of it.



Section three involves women's knowledge of breast and cervical cancer. This includes: their knowledge of signs and symptoms, risk factors, detection and treatment, source of information women held, role of hereditary factors in the occurrence of breast and cervical cancer.

Section Four explores women's experiences of breast and cervical cancer screening services. It asked whether women have ever received a letter to attend a mammogram or Pap smear test, whether they ever attended a mammogram or Pap smear test appointment, and whether they have to pay for such service. Then they were asked to describe their reflections concerning mammography and Pap smear test (Uncomfortable, anxiety provoking, painful, comfortable, reassuring, and painless). Women then were asked about what encouraged them to attend screening services. (Supportive health professionals, easy transportation, encouragement from husband, encouragement from family, available and convenient appointments, lack of importance of screening). What put them off from attending (taking off clothes, time consuming, lack of interest, long waiting list for appointments, cost, do not know where to go, presence of male staff, lack of transportation, lack of encouragement from husband, lack of encouragement from the family, hear of having it, lack of knowledge of screening).

Women were also asked about what they might advise when asked about screening (recommend it, do not know, do not recommend it).

Section five asks women of their suggestions to improve screening services. In particular, they were asked to choose from a list of options what could encourage them to attend breast and cervical screening services (governmental transportation, presence of female staff conducting the screening process, staff attitudes, use of different method such as MRI, the existence of specialized centres for screening, receiving an invitation letter, or attending an educational program). Then women were asked about the best way to spread the information about cancer (schools, media, mosques, shopping centres, and mobile messages).

For each question of the above sections, women were given the option of “other, specify” in order to express other factors, views, perceptions, or information that the questionnaire missed to explore.

In order to ensure the quality of the questionnaire, the questionnaire was written in Arabic and then was reviewed by Dr Kanaan, who is fluent in Arabic. The questionnaire was then translated into English so that it could be reviewed by my other two supervisors. The Arabic version was then piloted with Arabic-speaking friends and family members who matched the study inclusion criteria (30 women). This pilot study served as a pre-testing for the developed survey questionnaire. It was conducted to ensure the acceptability, the wording, and assessing the feasibility of the full-scale survey. It also helped to get women’s feedback to identify ambiguities and difficult questions and to discard all unnecessary questions. The questionnaire was then modified and refined according to women’s feedback. Finally, the questionnaire was submitted to the Ethics Committee at the University of York in order to obtain their approval.

#### **4.2.2 Focus group’s topic guides**

Individual interviews are a good choice if the range of opinion is useful and if the topic is sensitive. One-to-one in depth interviews provide information from a single perspective. Focus groups tend to suppress the outlying opinions because some participants hesitate to express a potentially unpopular view. In focus groups the participants act according to their personality; it is the risk that in some situations; those with a weak personality tend to follow those with a stronger personality (Milena, Dainora et al. 2008). The advantage of focus groups over individual interviews is that more information can be collected within a shorter period of time. Michael (2001) compared individual in depth interviews with focus group discussions and concluded that focus groups are helpful for exploring controversial topics. The social dynamics of focus groups may tend to encourage speculation about information under discussion. Furthermore, Gibbs (1997) showed that focus group research

can be an empowering process for participants. One important potential advantage of focus groups is that participants are able to bring to the fore issues that they deem to be important and significant. Issues that concern participants can be encouraged to surface, suggesting the potential for focus groups to address issues of power relations in the research process (Culley, Hudson et al. 2007).

In addition, previous researchers highlighted that problems can arise when researchers are not fluent in the language or knowledgeable about the culture of the groups with which they wish to work. Moreover, the perceived identity and the self-presentation of the researcher or facilitator might inhibit access to and/or recruitment of participants (Culley, Hudson et al. 2007). However, in the present thesis, these issues are not of concern as I as a principal investigator share the language, the culture, and probably the values that my participants have.

A topic guide (Appendix 4) was developed to facilitate a 'guided conversation' to ensure that similar ground was covered for all the focus groups. It was designed to be consistent with the domains of the survey questionnaire (Knowledge, experiences, facilitators, and barriers). The topic guide consisted of eight topics. The first topic involved an introduction that includes a welcoming statement, introduction of my-self and the organisation (University of York), and information about the study and its objectives. Then participants were given the option to leave the discussion without giving a reason for doing so. They were also reminded that their names will not appear in any document or publication when expressing their views and perceptions. The second topic guide was an ice-breaking event that allowed each woman to introduce herself, her background, occupation and other information that she would like to tell the group about herself. The third topic guide explored women's perception of breast and cervical cancers, meaning of cancer, feelings it provokes when the cancer word is heard, and rates of occurrence. The fourth topic guide involved discussion about risk factors of breast and cervical cancers. The fifth topic guide

involved the role of genetic and hereditary factors that might cause breast and cervical cancers and the relationship of family history to the chance of developing such types of cancers. The sixth explored women's thoughts concerning ways to detect and treat breast and cervical cancer, such as lifestyle, recognition of early symptoms and signs of breast and cervical cancers. The seventh topic guide probed into women's knowledge of screening services available in their area. The differences in screening delivered between the UK and Saudi Arabia, which has been discussed with UK participants only, their experiences when accessing screening services, what influence their decision to go and/or not to accept such services, their feelings about the services offered during the screening process, barriers they faced, and types of services they received (letter, self-attendance). The last topic guide was a discussion about the potential improvements women think might help others in enhancing the screening services of breast and cervical cancer in the UK and Saudi Arabia.

#### **4.3 Thesis participants and sampling frame**

In the survey part of the thesis, it was planned to recruit 200 participants from the UK and 200 from KSA. The choice of 400 participants was somewhat arbitrary. The study was not limited to a specific number of participants because it was an exploratory study and no specific hypotheses were being tested.

For the survey part, a convenience sample was selected. Convenience sampling is selecting a sample on the basis of convenience or availability. The benefits of convenience sampling are that it saves time and thus is a cost-effective method of gathering data. The rationale for using a non-random sample is that the thesis aim was meant to be an exploratory study and did not intend to prove a hypothesis. A previous researcher (Castillo 2009) noted that some researchers might use convenience sampling in exploratory studies if a fast and inexpensive method is needed to determine if further research is warranted. I am aware that such sampling method might lead to selection bias and data being misleading or failing to capture

the majority of Saudi women experiences and views about breast and cervical cancer screening services. However, I was limited by the time frame of my PhD and hence, selecting convenience sample would enable achieving the proposed sample size in a relatively fast way. Saudi participants living KSA were mainly come from Jeddah city, they were chosen as I live and work in. It is a multi-cultural city. In order to increase the likelihood of capturing Saudi women rather than non-Saudi women, a list of sites that Saudi women frequent visited was marked. The plan was to target centres attended by Saudi nationals and where they would be available to complete in the questionnaire and also possibly agree to take part in the focus groups. The site list consisted of 37 governmental, royal, and private hospitals in Jeddah, 16 departments in King Abdul-Aziz University, newly developed shopping centre (Al-Arab mall) and three charity organizations. Nine sites in Jeddah were selected from the list using Epi-Info. The selection consisted of three hospitals, three colleges, one event, one shopping centre and one women's voluntary organization. After the random selection of sites, the distribution of the questionnaires was conducted by convenience sampling.

Sampling in the UK took different approach. This is because in the UK it was difficult to reach Saudi women as they were scattered around the UK. The sampling technique used in the UK was also convenience sampling. A list of Saudi social and educational events that were to take place during the data collection period (from July 2009 to November 2010) was compiled. The sample consisted of the Saudi women who attended these events.

For the focus groups discussions, there was a lack of data about types of experiences, facilitators, barriers, attitudes and knowledge of Saudi women regarding breast and cancer screening, and therefore there was a limited basis for developing a sampling frame for the focus groups. Most authors supported the use of 4 to 6 focus groups to generate adequate data (Morgan 1996; Krueger 2000; John 2004). The literature suggested that an adequate focus group size is from 4 to 12 participants (Sim 1998; Beyea 2000; Krueger 2000).

However, for the current thesis there was no agreement about size of how many participants in each focus group, rather the focus was to be able to get a discussion going among participants. The plan was to recruit 20 participants in the UK and 20 in KSA. Women who were part of the convenience sample of the survey, and who had read the information sheet, had the option to take part in the focus groups, whether or not they had completed the self-administered questionnaire. They indicated their willingness to participate in the focus groups by ticking the appropriate box found in the questionnaire and providing contact information.

The distribution of the participants into the different focus groups was selected purposively, and based on recruiting participants who believed to have the information needed for the research aim and objectives their age and educational level were matched. The plan was to sort the participants according to two levels of education and two levels of age, creating four groups for each country. The categories of age and education were used to provide homogeneity amongst the group participants. The groups were constituted as follows: (1) women aged  $\geq 35$  years with a high school or less level of education, (2) women aged  $\geq 35$  who had attended university, (3) women aged  $< 35$  with a high school or less level of education, and (4) women aged  $< 35$  who had attended university.

#### **4.4 Inclusion and exclusion criteria of participants**

Participants for both the survey and focus groups discussion of the thesis were included if they had no previous diagnosis of any cancer, resided in Saudi Arabia or in the UK, and were 18 years old or older. For those living in the UK, one year's residence was the minimum, thus excluding students who are short term residents. The reason for choosing the minimum residency was to give women coming from Saudi the opportunity to get to know the health system in the UK. The exclusion of cancer patients was to avoid the distress that might come from answering questions about screening services if they had not used the screening services prior to diagnosis (Watson 1988). Also, women who have

or had cancer would likely to be more aware of the benefits of cancer screening than women without cancer and therefore, might be more inclined to participate, thus creating a self-selection bias. A sentence on the information sheet of the questionnaire under the title “Why you have been chosen” made it clear that woman who had been diagnosed with cancer were not eligible to participate. The rationale for choosing women age 18 or over and only focusing on breast and cervical cancer (see more details rational in the introduction), is because childhood cancers are unlike adult cancers in that they have different aetiologies, for example DNA changes prior to birth(American Cancer Society 2008; American Cancer Society2012). Children’s cancers, such as leukemia, nervous system tumours, neuroblastoma, Wilms tumour, lymphoma, rhabdomyo-sarcoma, retinoblastoma, and bone cancer are not strongly linked to environmental and lifestyle risk factors, which are important parts of the study. Finally, as breast and cervical cancer are very rare amongst children, children are not eligible for the screening services, and the screening services are the focus of the study.

#### **4.5 Recruitment and data collection process**

Before the data gathering process began in KSA, I applied and received permissions for collecting data from the various target sites: Dr.Samia Al-Almoudi of King Abdul-Aziz Hospital, the deputy of the Science and Art College in King Abdul-Aziz University (Appendix 9), and Amani AlWazer, secretary for the Al Faysalia charity institution.

I stood at the entrance of each department of King Abdul-Aziz University, King Abdul-Aziz Hospital, Al-Arab shopping centre and other selected places and distributed the questionnaires. If the questionnaire was completed at the recruitment site, women returned the questionnaire directly to me, and if not, they returned the completed questionnaires to a designated place (information desk at each Centre). I returned later to collect the questionnaires. The use of snowball sampling was created by the participants. I had not planned for it, but helpful participants distributed the questionnaires to their

relatives and friends. The additional completed questionnaires were attached to the initial questionnaire when they were returned to me.

One of difficulties during the distribution of the questionnaire in KSA was timing of the delivery of the survey to the University participants. The data collection time was at the end of the year and students were having their exams. Students were busy preparing to enter the exam or exhausted after the exam, and most of them were not willing to complete the questionnaires. The difficulty was overcome by increasing the visits to the university to capture more students.

For the UK participants, approaching Saudi women was also quite difficult because the only information that I had was from the Saudi Cultural Bureau, and that was the postal codes for Saudi family living in Newcastle upon Tyne. Therefore, mailing the questionnaires was not an option. I decided to attend all the events for the Saudi community, announced either by the Saudi Embassy or by the Saudi Cultural Bureau.

Attending the events allowed me to approach every Saudi woman who was present at the event. In Newcastle, I attended the regular monthly Saudi social meetings that took place at the Cow-gate Community Centre. Outside the city of Newcastle, I attended the Fourth Saudi Symposium in Manchester and the Family Violence Symposium in London. I approached women, explained the aim of my project, and invited them to participate. If they agreed, every woman was given the choice of having the questionnaire mailed to her home address, or being interviewed by telephone. Some women gave me their addresses to drop the questionnaire off at their homes because they first had to obtain permission from their husbands. In total, 1055 questionnaires were distributed, 600 in KSA and 455 in the UK.

Recruiting participants for the focus groups was developed according to the following plan: (1) decide on where and with what population to start, (2) recruit participants using a convenience sampling, (3) additional participants generated by relatives and friends of the



participants using snowball sampling, and (4) continue sampling for a period of three months. The focus group participants were selected based on a sampling frame obtained from two sources: (1) women who returned the survey and agreed to take part in the focus group, and (2) women who were relatives or friends of the participants and who were interested in taking part in the focus groups. The latter contacted me directly and indicated their interest in taking part in the focus group discussion.

Many studies of hard-to-reach populations have relied on a fairly simple and inexpensive convenience snowball sampling; it is a chain referral sampling method that relies on referrals from initial subjects to generate additional subjects. A main disadvantage of this sampling method is that it produces biased samples because respondents who have a large number of social connections are able to provide researchers with a higher proportion of other respondents who most likely have characteristics similar to that initial respondent (Johnston and Sabin 2010). Furthermore, snowballing sampling might be limited in terms of generalizability of the findings. In addition, it might be time consuming when following the referred respondent and might be difficult to find. Table 1 illustrates the bias generated from using snowballing sampling. The main reason for choosing snowballing method was feasibility and pragmatism, because there were no easily accessible sampling data bases to use.

**Table 1: Snowball sampling biases**

<b>Sampling</b>	<b>Bias Issue</b>
Respondents may refer to an unlimited number of peers	<ol style="list-style-type: none"> <li>1. Differential recruitment: Those with larger network sizes can recruit more peers, who are likely to have similar traits</li> <li>2. Clustering: leads to lower effective sample size</li> </ol>
Social network properties are ignored	<ol style="list-style-type: none"> <li>1. Clustering by network traits cannot be measured</li> <li>2. Size of social networks affect probability of selection</li> </ol>
Respondents refer, surveyors must find referred	Only members accessible to 'outsiders' participate
Convenience sample – analysis limited to proportions of sample, not generalizable	Probability of selection is unknown

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Table 2 shows the focus group protocol as it was planned and how the focus groups were conducted in reality. This allowed tracking of the process of conducting the focus group and identifying the obstacles and follow up of participants. Organizing a time and date for the focus group was done by telephone using the number provided by the participants on the information sheet. The focus group began with an introduction to explain the thesis aims and objectives and to assure participants that contribution was entirely voluntary. As some Saudi women prefer not to be heard by men, in order to respect the privacy and cultural values of the participants, the introduction included a statement that the transcription was going to be made by me, a woman, and no man will listen to their discussions. Before the focus groups were conducted, participants were asked again if they still like to take part in the group discussion. They were given the chance to stop and leave the focus group discussion at any time.

The first and second focus groups that took place in Newcastle upon Tyne were in the researcher own home in order to decrease the participants' transportation expenses, for which I was responsible, other reason was to provide a quiet area for recording. The third

focus group which was from the UK travelled to Jeddah at the planned time of the discussion. Therefore, for convenience it was conducted in Jeddah City. They were PhD students who live in different cities in the UK and were coming to visit their families in Saudi. The discussion took place in a coffee shop in Jeddah.

For the KSA participants, focus groups were conducted in different places according to the participants' availability and circumstances (venues were chosen according to participant's choice and ease of transportation).

**Table 2: Focus Group Implementation Protocol as planned and what was done in the UK and KSA**

<b>Focus Group Implementation Protocol</b>	<b>What was planned</b>	<b>What actually happened</b>
<b>Space</b>	A room where six to eight people can sit in a circle. No interruptions, no telephone calls Quiet enough for making tape recordings Nearby bathrooms	A room where six to eight people can sit in a circle There was interruptions from participants' telephone calls Not quite enough because participants' children were around There was a bathroom nearby
<b>Transportation money</b>	It's common in research focus groups to provide transportation	The researcher was responsible to pick and drop off the participants
<b>Sequence of Events</b>	1. Signing the informed consent 2. Moderator's Introduction. Be sure to tell participants that you are: recording, using their first or nick names only, using their data confidentially, not using their names in transcriptions only numbers, not identifying them individually in analysis	Here, participants were asked questions related to topic guide. All steps have been applied except stipends because the researcher used her own car (UK) and a driver in KSA to pick and drop most of
	Results, providing a stipend, providing a bathroom and food and drinks. Also, the participants may leave at any time.	participants who were not able to come by their own

#### **4.6 Safety and ethical considerations**

The questions in the self-administered questionnaire or in the focus groups could conceivably cause anxiety. For example, women might begin to worry about the causes and symptoms of cancer. Therefore, women were encouraged to contact us if they had any questions or anxieties. KSA participants with concerns regarding cancer-related medical issues and symptoms were referred to Dr. Al-Amoudi, Consultant Obstetrician Gynaecologist, IVF and the scientific chair for breast cancer at King Abdulaziz University. Dr. Al-Amoudi is a senior local supervisor in KSA, has extensive

experience with sensitive issues regarding cancer, and agreed to take any enquiries. Dr Al-Amoudi's *curriculum vita is* attached (Appendix 7). The contact details of Dr Al-Amoudi and mine were available at the bottom of the information sheet.

For those living in the UK, Dr. Rob Newton at the University of York agreed to take enquiries and his contact information was given also in the information sheet that was delivered to participants accompanying the questionnaire.

I submitted the ethics application form along with the relevant documents, such as the self-administered questionnaire (Appendix 6 English version and Appendix 7 for the Arabic version), invitation letter (Appendix 3), topic guide (Appendix 8), information sheet (Appendix 4) and consent form (Appendix 5), to the Health Sciences Research Governance Committee (HSRGC), University of York, on March 29, 2010. One month later, ethical approval was granted under some changes (such as removing the Breast Self-Examination part). The study took place between July 2009 and November 2010. Precautions were taken to ensure that participants were aware that they had the choice to participate or not. All participants were given the opportunity to opt out of completing the questionnaire or taking part in the focus group, at any point. Before the commencement of the focus group session, all participants were asked to sign the consent form (Appendix 5), and it was made clear to them that they would be able to withdraw from the study at any time. Therefore, the period of time between the completion of the questionnaire and giving formal consent, allowed participants the time to decide whether or not to participate.

All data was stored in accordance with the Data Protection Act. The following steps were taken to ensure confidentiality and anonymity of the participants: 1. Participants were assured that they would remain anonymous throughout the research and in any publications arising from the study. 2. Questionnaires only contained an identification code and respondents were not required to identify themselves. 3. All written

materials, such as questionnaires and transcribed interviews, were kept in secure locked cabinets on the University of York premises. 4. Other electronically recorded data were kept on a secure password protected by the University of York computer server. And 5. All of these data will be destroyed six months after the end of the study or within three years of its collection date.

#### **4.7 Data analysis plan**

The synthesis is the final analysis step in the integration of the findings of the qualitative and quantitative parts of the thesis. The combination of the two sets of findings provides a more holistic picture of women understanding of breast and cervical cancer services than does either of them alone. The combined synthesis provides a culturally sensitive understanding and possible explanations that elucidate the various dimensions of Saudi women's behaviours, perspectives, knowledge, experiences, and responses to breast and cervical cancer screening services.

Regarding the survey results, the data were labelled, coded and entered into the SPSS version 18 software, which was available via the University IT Services. Data were first cleaned then the different variables were analysed using frequencies and cross tabulations. The method of analysis was chosen to achieve the aim and objectives of the study, which involved the frequencies of followings variables: 1. Risk factors of the breast and cervical cancer among Saudi women. 2. Knowledge that Saudi women have relevant to cancer services available in their area. 3. Experiences that Saudi women have in accessing breast and cervical cancer services, and their reflections on these experiences, and 4. Potential influence of migration on uptake of/ and attitudes, to screening services among Saudi women. The objectives were obtained by examining the frequencies and percentages and making comparisons and cross-tabulations between the variables.

Descriptive frequencies and percentages were conducted first in order to summarize all of the participants' information and to describe the trend of responses with regard to barriers, facilitators, knowledge, and experiences when accessing screening services for breast and cervical cancer. Cross tabulations were then carried out to generate information about the relationships between demographic data, such as age, levels of education, occupation and marital status and the types of barriers, facilitators, knowledge, and experiences. Statistical significance between variables was explored using the t-test if variables were continuous and Chi-square if they were categorical.

Level of significance was expressed using the *P*-value with a cut of value of  $\leq 0.05$  as a significant value.

The focus groups discussions were conducted, audio-recorded and transcribed by me. I attempted to locate an organization or an agency that could transcribe the focus groups as it is difficult to find a word processing program in the UK that handles Arabic script.

Unfortunately, I could not locate such service to perform the work and to cover the cost. Therefore, the transcription, coding, and interpretation processes were performed manually by me under the supervision and review of my supervisors.

Table 3 describes the characteristics of different methods of qualitative analyses and is included to demonstrate the rationale for choosing content analysis for the study. This allowed me to select the most appropriate and feasible method to fulfil the thesis objectives. This technique and another three potential analysis techniques (grounded, narrative and triangulation methods) are illustrated in Table 3. Both grounded theory and narrative approaches yield complex themes and inter-relationships, which is not my area of interest. Grounded theory required two analysts or an analyst and a reviewer. Triangulation is usually used to establish validity rather than being an

analytic method *per se*. Triangulation also required two analysts. Therefore, although it is not the preferred technique for the focus group data, content analysis was the most suitable technique for this study. This study is a doctoral thesis and as such had a specific time limit with regard to completion. Thus, the choice of content analysis was also based on time considerations and ease of completion. The analysis aimed to identify ideas relevant to the thesis objectives.

Content analysis is mainly describing and grouping of concepts or ideas. Coffey and Atkinson pointed that:

*Coding can be thought about as a way of relating our data to our **ideas** about these data (p.27) (Coffey 1996)*

In the beginning, I read and re-read the transcripts of the focus groups in order to gain an overview of the data and become thoroughly familiar with the data set. In addition; it facilitated the process of identifying recurring initial *ideas*. This was carried out by writing preliminary notes in the left hand margins of the transcripts, initial thoughts, and comments. These ideas were listed in a table. Within every transcribed focus group, each phrase, sentence and paragraph was read in fine detail in order to decide 'what is this about'. This list process resulted in several numbers of ideas. Phrases or expressions were retained as much as possible from the participant's own terms when naming each idea. Although I had a set of prior objectives, I was aware that I should maintain an open mind and the data guided the labelling of these ideas. Categorization of the data involved also logical and intuitive thinking. It involves some judgments about meanings, about the importance and relevance of issues, and may be implicit linkages between ideas. Such categorization involved identification of the parts of the data that correspond with a particular idea.

Categories were classified to represent the thesis objectives: knowledge, barriers and facilitators, experiences, role of migration, suggestions to improve accessing breast



and cervical cancer screening. Findings (ideas) grouped under each category were written up with quotes to produce descriptive accounts of what was happening in that category. These quotes in the descriptive accounts were ordered with similar beliefs, views or experiences together. Using direct quotes from the focus groups data strengthened the face validity and credibility of the presented findings and demonstrated the integrity and competence of the results (Patton 1990). This was followed by the final stage, which was interpretation that provided associations between findings, explanations, and the nature of experiences women had when accessing breast and cervical cancer. This last step is called an explanatory account. Producing explanatory accounts involved finding links or connections between two or more categories. It was a process of exploring associations and particular patterns of behaviours or experiences, even contradictory ones, among Saudi women regarding their understanding, knowledge, and experiences when accessing breast and cervical cancer screening. This allowed systematic clustering of categories that are potentially related in a conceptually meaningful manner. Such correlations are the central part of content analysis in which various aspects of the relationship between two or more entities are analysed. The following is a description of the steps of the process. The first step in conducting correlation is to establish a focused question when reading the transcripts, such as what are the barriers and facilitators that keep Saudi women away from breast and cervical screening services. The first step sets the direction of the research findings. Without a focused question, the concepts and ideas are open to subjective interpretation and can be limitless, thus rendering the analysis difficult to complete.

The second step was to decide what and how the text will be conceptualized. For example, in my thesis, text relating to knowledge of breast and cervical cancer was being chosen, and once the knowledge category were chosen and gathered as an entity

for analysis, the relationships between the rests of the categories were examined. The groups of interrelated concepts are then examined for an overall meaning. Selected texts are then reviewed to determine the level of analysis. This step was used as a technique to simplify ideas for existence but not to simplify the results. It is important to retain the initial detailed labelling of ideas in order to preserve the greater amount for detail for the analysis. Ambiguous words such as “yalatif”, which means bad omen in the Saudi culture, that were discovered during the labelling process to hold different meanings in the text were an issue to be considered in the correlation process. Words such as “yalatif” mean that cancer could be a bad omen and sometimes means that it is a sad end.

The third step is to analyse the relationships between the labelled concepts and beliefs women held, by examining three aspects of the relationship: strength, sign and direction of the concepts. Measuring the strength of the relationship is analysed first. In my thesis, the strength of the relationship between the beliefs that might affect the participants’ access to breast and cervical cancer screening services was analysed. Another approach to labelling for strength entails the creation of separate categories for binary oppositions. For example, if a religious concept is in binary opposition to accessing breast and cervical screening services, then a separate theme is created for the negative impact of religion on access to cancer screening services. Following the analysis of the strength of the relationship, the relationship is evaluated by whether the concept and the belief are positively or negatively related, that is, the sign. The direction of the relationship between concepts and beliefs is useful for establishing types of directional relationships, for example assuming X (getting or calling the cancer) is the concept and Y (such as talking about cancer or pointing to the breast when talking about the cancer) is the attitude of the participants, then other aspects of the relationship can be analysed, such as "X occurs before Y" and "if X then Y". In

my thesis, concepts with bidirectional relationships are useful, but differ in focus. Classifying all categories as bidirectional is most useful for exploratory studies where pre-labelling may influence results. The fourth step is classifying the relationships after analysing the relationships. Findings from quantitative chapter will be combined with the finding from qualitative to highlight similarities and mutual differences beliefs, knowledge, experiences, and type of barriers and facilitators that affecting Saudi women both in the UK and Saudi Arabia. Transcripts were coded for topics that were consistent with the self-administered questionnaire to facilitate combining the quantitative and qualitative data.

Table 3: Summary of the different qualitative analysis in literature

Analysis Technique	Suitable Data	Advantages	Disadvantages
<b>Content Analysis</b>	Semi-structured interviews preferred technique Open-ended interviews: used but not preferred Cognitive testing: preferred technique Focus groups: used but not preferred Narratives: used but not preferred	Comfortable selftaught analysis can be completed quickly	Does not yield complex themes, relationships, inter-relationships or in depth insights
<b>Grounded Theory</b>	Open-ended interviews Focus groups: preferred technique Narratives	Yields complex themes, inter-relationships high reliability and validity	Steep learning curve requires two analysts or an analyst and a reviewer. Intensive work
<b>Narrative Summary Analysis</b>	Open-ended interviews narratives	Yields complex themes, relationships and sequences, very good for integration	Steep learning curve Intensive
<b>Triangulation</b>	Semi-structure interviews Open-ended interviews Cognitive testing Focus groups Narratives	Used to integrate quantitative and qualitative data, often to illustrate and explain Quantitative analysis results. High reliability and validity	Requires two analysts. Need both quantitative and qualitative analysis skills

[http://painconsortium.nih.gov/symptomresearch/chapter\\_7/sec3/table3.htm](http://painconsortium.nih.gov/symptomresearch/chapter_7/sec3/table3.htm)

## **Chapter 5: Results of the Survey**

### **5.1 Introduction**

This chapter provides the results of the survey part of the thesis. It is divided into three sections; the first section describes the socio-demographic characteristics of the participants. The second section presents the descriptive component of the survey results including the participants' knowledge, experiences, facilitators, barriers, and suggestion in both breast and cervical cancer screening services. The third section provides the inferential component of the survey results including the correlations between participants' knowledge, experience, barriers and facilitators with age, education, occupation and marital status regarding breast and cervical cancer screening services.

### **5.2 Socio-demographic Characteristics of the participants**

In Saudi Arabia, 285 participants completed the questionnaire (47 % response rate), and 218 participants from the UK (48 % response rate). The mean age of the respondents was between 31 in the UK and 33 in Saudi (SD=8 and 11 respectively). 43 % of participants from the UK were students, 33% were employed and 23.7 % were unemployed. 30 % of participants from Saudi Arabia were students, and 42 % were employed, and 30 % were unemployed.

83.6 % of participants (UK) were highly educated, 15.4 completed high school, and 1% was either non-educated or primary school graduates. In Saudi Arabia, 71.3 % were highly educated, 22 % completed high school, and 6.8 % were non-educated or had only primary school education.

71 % of participants were married (UK), and 51.6 % were from Saudi Arabia. 23.5 % were single (UK) and 38.7 % from Saudi Arabia. 5.6 % were either divorced or widow (UK), and 9.7 % from Saudi Arabia.

**Table 4: socio-demographic profiles of survey participants**

Socio-demographic profile	Saudi Women in the UK	Saudi women in SA
<b>Mean (SD)</b>		
Age	31 years ( $\pm 8$ )	33 years ( $\pm 11$ )
Years in the UK	3 years	-
<b>No (%)</b>		
Occupation *student		
*Employed	91 (43%)	83 (30%)
*Unemployed	70 (33%)	116 (42%)
	50 (23.7%)	77 (27.9%)
Education		
*Higher education	179 (83.6%)	199 (71.3%) <sup>61</sup>
*High school	33 (15.4%)	(21.9%)
* Primary, elementary or no formal education	2 (0.9%)	19 (6.8%)
Marital status		
*Married	151 (70.9%)	144. (51.6%) <sup>108</sup>
*Single	50 (23.5%)	(38.6%)
*Divorced or widow	12 (5.6%)	27 (9.7%)

UK participants had been in the UK for 1-12 years, with 90 % of the participants being in the UK for five years or less. Table 1 showed a slight difference in the characteristics of participants living in the UK and KSA. The mean age of the two groups was early thirties. 39.4% of the UK participants were from Newcastle upon Tyne, whereas Jeddah residents represented 96 % of KSA participants.

### **5.3 Knowledge, experience, facilitators, and barriers**

#### **5.3.1 Knowledge about *breast* cancer**

Participants expressed their knowledge regarding several lifestyle factors that might influence the occurrence of breast cancer. These included: smoking (47 % of

participants in the UK and 54.4 % of those who live in Saudi Arabia), exercise (26 % of participants in the UK and 33.7 % of those in Saudi), obesity (37 % of participants both in the UK and Saudi), and nutrition (60.5 % in the UK and 63.5 % in Saudi). However, 20.5 % of participants in the UK and 15.8 % of those in Saudi were not sure what factors might play a role in the occurrence of breast cancer, Figure 5. They also considered other risk factors that could have a role in increasing the prevalence of breast cancer. These involve the breast feeding (53.5 % of those in the UK and 50.2 % of participants in Saudi), hereditary (60 % of the UK and 58.9 % of those in Saudi), being old (38 % of the UK and 47 % of participants in Saudi), hormone replacement therapy (32 % from the UK and 43.2 % in Saudi Arabia), contraception (29 % of UK participants and 33.3 % in Saudi Arabia), fertility treatment (13.5 % of the UK participants and 18.6 % in Saudi Arabia), having no children (13 % of the UK participants and 18.6 % in Saudi Arabia), and being poor (2 % of the UK participants and 4.2 % in Saudi Arabia). Nevertheless, 20 % of Saudi women living in the UK and 16.8 % who live in Saudi were not sure about these factors increasing the prevalence of breast cancer.

Regarding participants' knowledge of various common symptoms of breast cancer, they provided their answers for each one with variable percentages. These symptoms included: underarm lump (78.5% in the UK and 70.9% in Saudi), change in breast size (53.5%/UK and 56.8%/Saudi Arabia), nipple discharge (53%/UK and 54.4%/Saudi Arabia), and breast pain (40%/UK and 46.3%/Saudi Arabia). On the other hand, 9% of participants who were in the UK and 12.65% who live in Saudi Arabia were not sure whether these symptoms are related to breast cancer.

83% of Saudi participants (UK) and 73% of those who live in Saudi considered mammogram as one of the detection method in breast cancer cases. 71.5% of those who live in the UK and 69% of participants living in Saudi Arabia believe also that

breast self-examination is another method of detecting breast cancer. However, 4.5% of the UK participants and 5.3% of those who live in Saudi Arabia were not sure whether these two methods can detect breast cancer.

Participants also expressed their knowledge regarding the different modalities of breast cancer treatment. These comprised of: surgery (60.5%/UK and 70.5%/Saudi Arabia), chemotherapy (57%/UK and 63.5%/Saudi Arabia), radio-therapy (29.5%/UK and 34.4%/Saudi Arabia), and pain killers (7.5%/UK and 18.6%/Saudi Arabia). Nevertheless, 21.5 % of all participants were not sure if these treatment modalities are really working curing breast cancer.

### **5.3.2 Knowledge about *cervical* cancer**

Similarly, participants expressed their knowledge regarding the influence of lifestyle aspects on the occurrence of cervical cancer. These include smoking (41 %UK and 45.3 %Saudi Arabia), exercise (34.5 %UK and 41.8 %Saudi Arabia), obesity (31 %UK and 36.5 %Saudi Arabia), and nutrition (18.5 %UK and 23.9 %Saudi Arabia). Yet, 37.5 % of Saudi participants living in the UK and 30.5 % of those who live in Saudi were not sure of the role of lifestyle issues in cervical cancer rate, Figure 6.

Participants also provided their opinion about the possible risk factors related to cervical cancer. These involve the multi-sexual partners (51.5 % UK and 50.5 % Saudi Arabia), hereditary (43.5 % UK and 36.5 % Saudi Arabia), being old (26 % UK and 28.8 % Saudi Arabia), hormone replacement therapy (23.5 % UK and 27.4 % Saudi Arabia), contraception (19.5 % UK and 30.9 % Saudi Arabia), fertility treatments (13 % UK and 22 % Saudi Arabia), having no children (8 % UK and 13.3 % Saudi Arabia), being poor (2.5 % UK and 4.2 % Saudi Arabia), and early sexual contact (12.5 % UK and 15.8 % Saudi Arabia). On the other hand 32 % of Saudi participants in the UK and 35.4 % of those who currently live in Saudi Arabia were not sure whether these factors would influence cervical cancer occurrence rate.



Participants expressed their views regarding several symptoms of cervical cancer. These consisted of; unexpected bleeding (33%/UK and 35.4%/Saudi Arabia), pain during intercourse (22.5%/UK and 22.8%/Saudi Arabia), and heavy periods (14%/UK and 24.9%/Saudi Arabia). However, 58% of those who live in the UK and 53.3% in Saudi Arabia were not sure whether these symptoms are part of cervical cancer.

84% of Saudi women in the UK and 77.5% of those who live in Saudi Arabia considered Pap smear as one of the detection method of cervical cancer. Nevertheless, 11.5% of those in the UK and 18.6% in Saudi Arabia were not sure of what detection methods available.

Moreover, participants provided their views regarding the treatment options existing for cervical cancer. These consisted of surgery (46.5%/UK and 58.2%/Saudi Arabia), chemotherapy (44%/UK and 49.8%/Saudi Arabia), radiotherapy (22%/UK and 27%/Saudi Arabia), and pain killers (6.5%/UK and 15.4%/Saudi Arabia). Yet, 37% of those who live in the UK and 28.8% of participants living in Saudi Arabia were not sure of these modalities in treating cervical cancer.

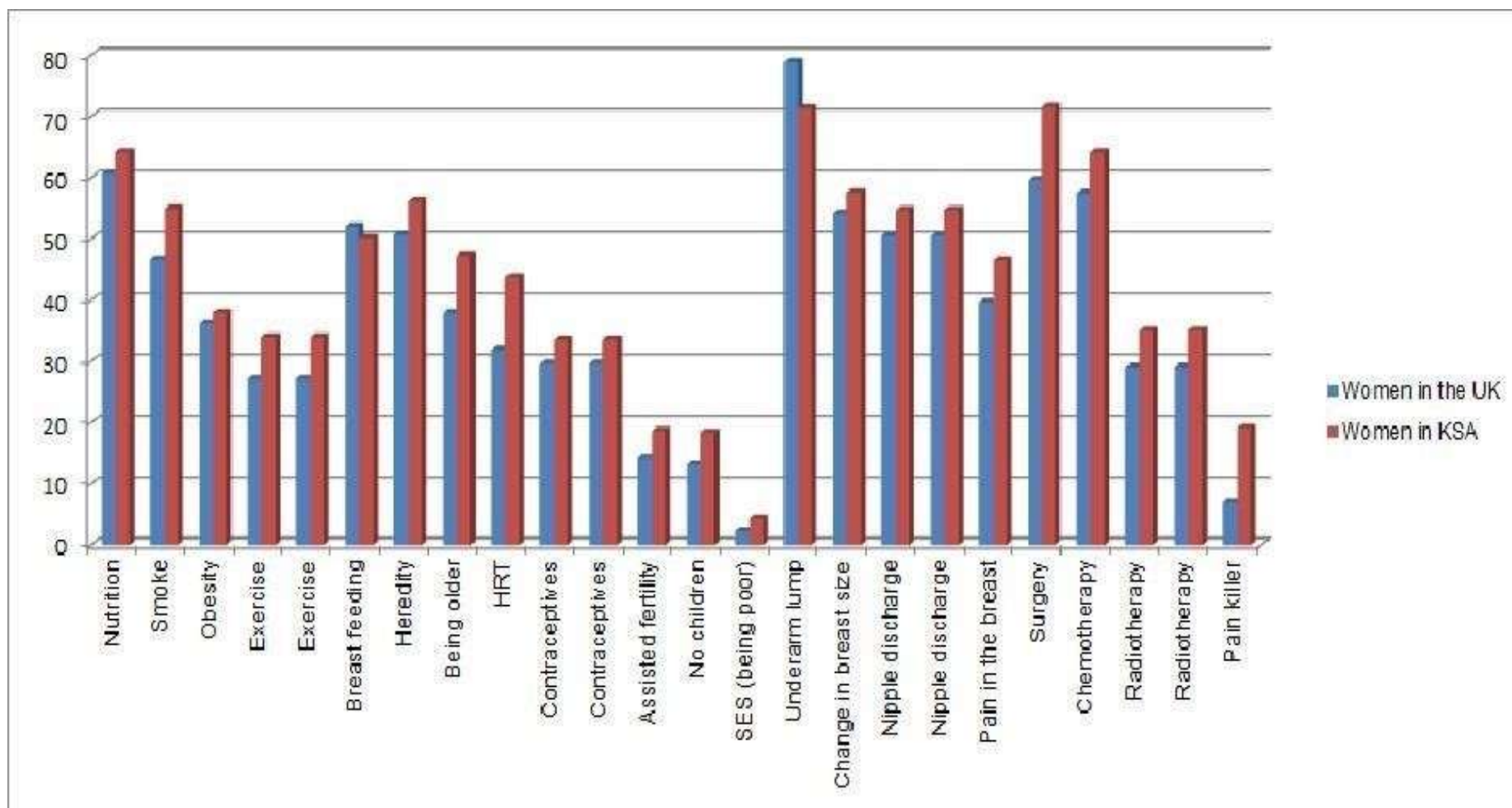


Figure 6: Participants' knowledge about breast cancer

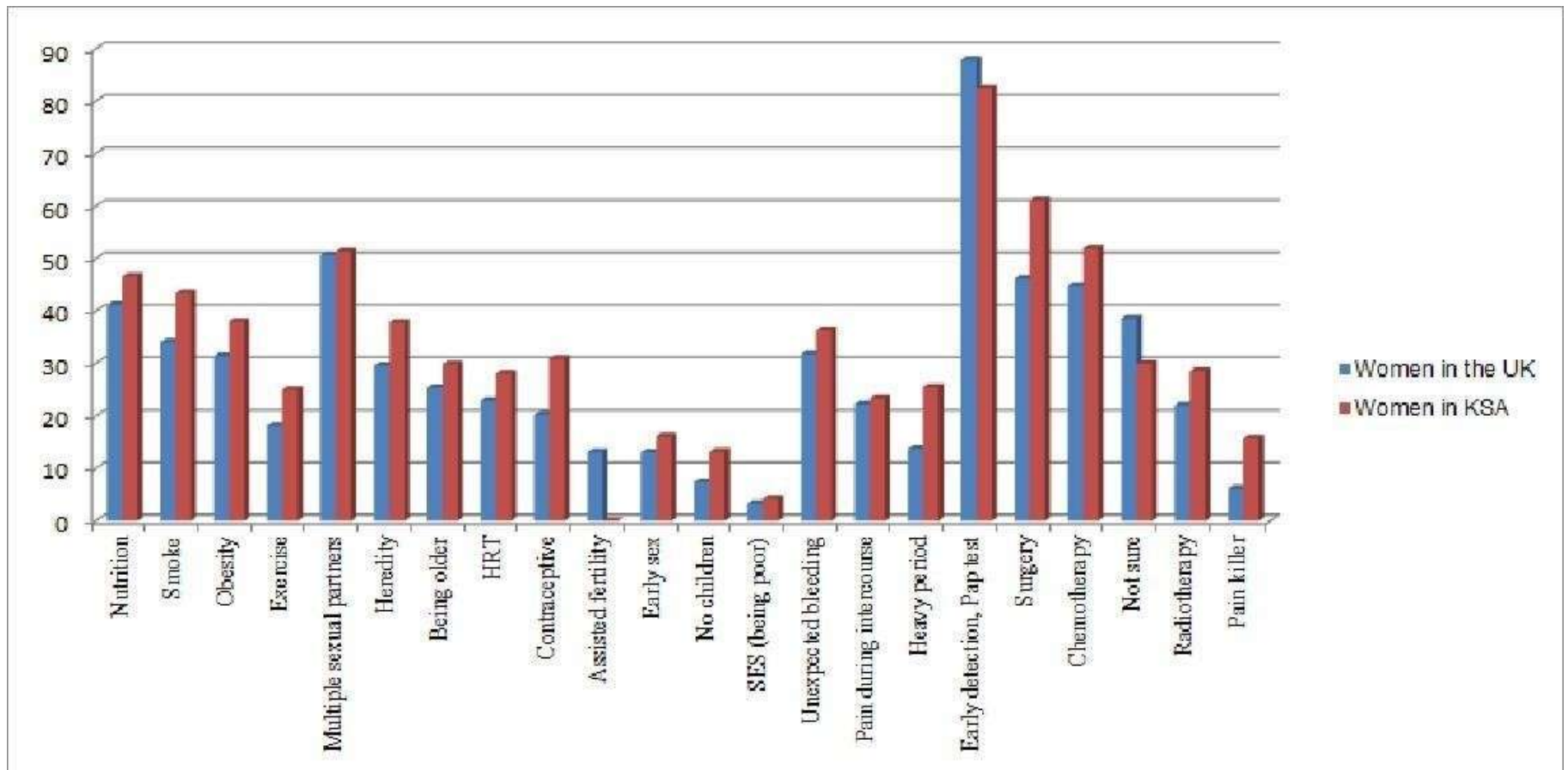


Figure 7: Participants' knowledge about cervical cancer

### 5.3.3 Experiences of breast cancer screening services

Participants provided their experiences when accessing breast cancer screening presenting variety and differences (percentages) in their encounter, feelings, and suffering (Figure 7). These include: receiving letter to attend for screening (27.6 % in the UK and 17.7% in the Saudi Arabia), attended screening (14.7 %in the UK and 15.7 % in the Saudi Arabia), had anxiety (29 % in the UK and 39.6 % in the Saudi Arabia), pain (26 % in the UK and 29.5 % in the Saudi Arabia), being uncomfortable (17.4 % in the UK and 16.8 %in the Saudi Arabia), had been reassured (30.9 % in the UK and 27.4 % in the Saudi Arabia), and being comfortable (15.9 % in the UK and 21.7 % in the Saudi Arabia). The frequency of Saudi women in the UK receiving letter for screening was higher than those who live in the Saudi Arabia. Moreover, women in the UK were less anxious and experienced less pain when attending breast cancer screening than women in Saudi Arabia.

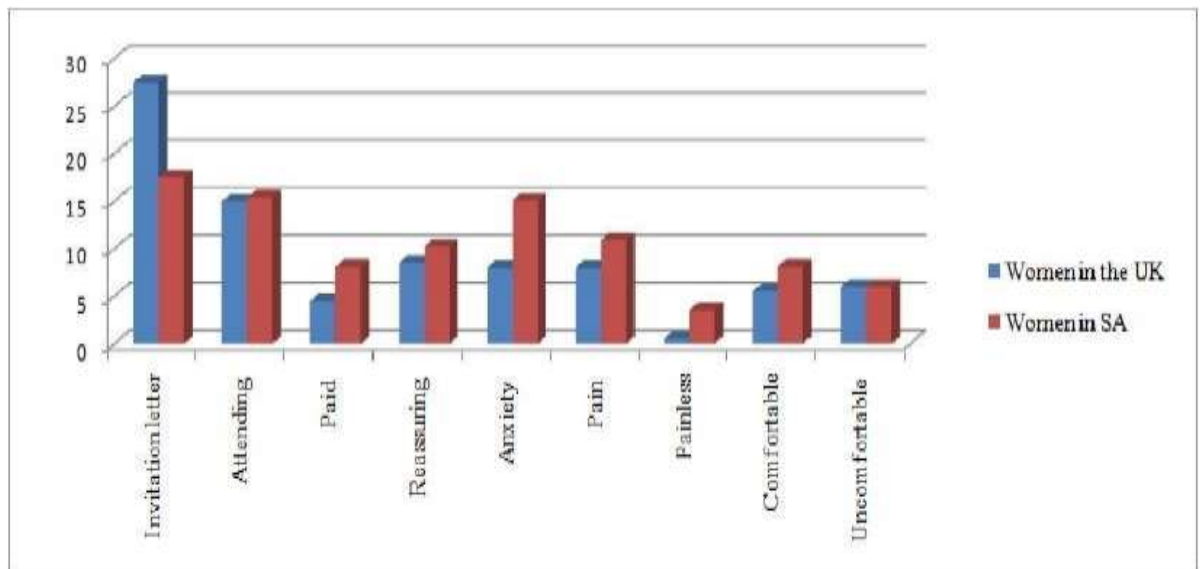


Figure 8: Participants' experience when accessing breast cancer screening services in the UK and Saudi Arabia

### 5.3.4 Experiences of cervical cancer screening services

In cervical cancer screening, Saudi women' experiences had a higher frequency of anxiety (Figure 8) when accessing services in Saudi Arabia (40.8 %) than those who live in the UK (29 %). In the UK, higher percentage of women received letter to attend screening (51.9 %) than women in Saudi (3.6 %). Hence, more women in the UK attended screening (31 %) than in Saudi (5.4 %). However, women in the UK experienced more pain (17.4 %) than those who live in Saudi (11.3 %) and were uncomfortable (25.8 % in the UK, 18.3 % in the Saudi Arabia). However, participants in the UK experienced more reassurance (36.6 %) than those in Saudi (21.4%).

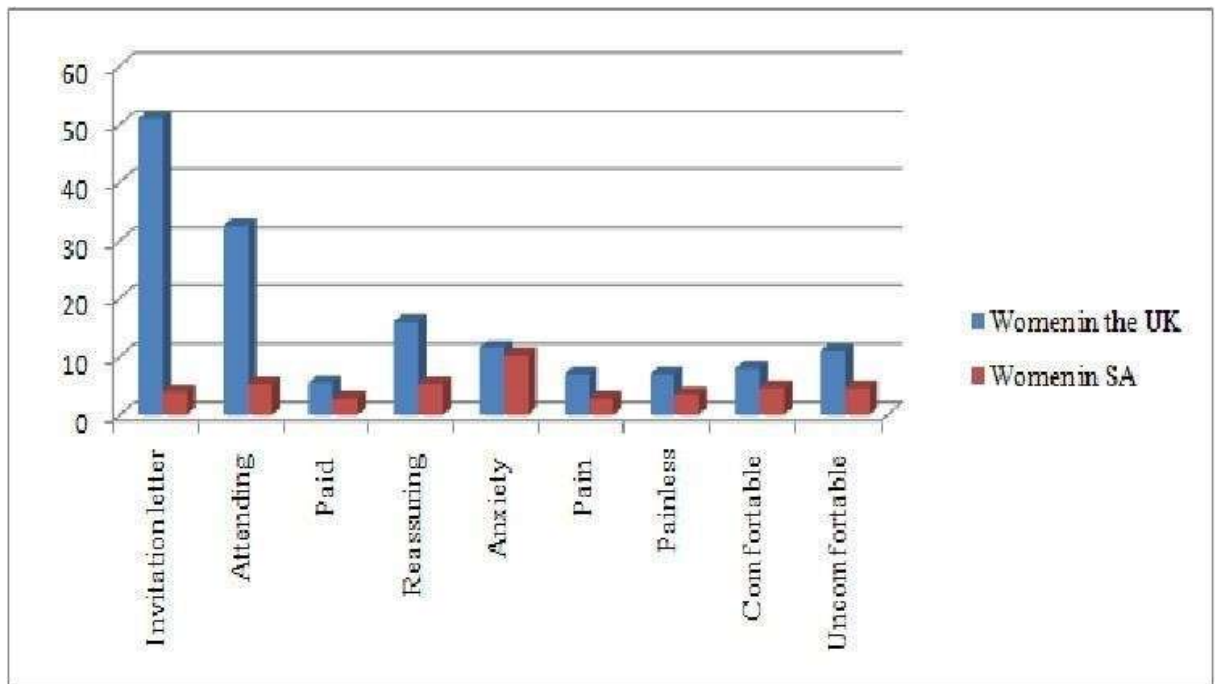


Figure 9: Participants' experience when accessing cervical cancer screening services in the UK and Saudi Arabia

### 5.3.5 Facilitators when accessing breast cancer screening services

Participants indicated that knowing the importance of the detection is the most important facilitator when accessing breast cancer screening (54.8% in the UK and

64.9% in the Saudi Arabia) (Figure 9). Other facilitators perceived less importance included: free screening (28.8 % in the UK and 33 % in the Saudi Arabia), having convenient appointment (21.9 % in the UK and 17 % in the Saudi Arabia), had a professional cooperation (20.5 % in the UK and 18 % in the Saudi Arabia), encouraged by their husband (12.3 % in the UK and 17 % in the Saudi Arabia), encouraged by the family (11.3 % in the UK and 21.3 % in the Saudi Arabia), and having easy transportation to reach the cancer screening services (8.3 % in the UK and 9.6 % in the Saudi Arabia).

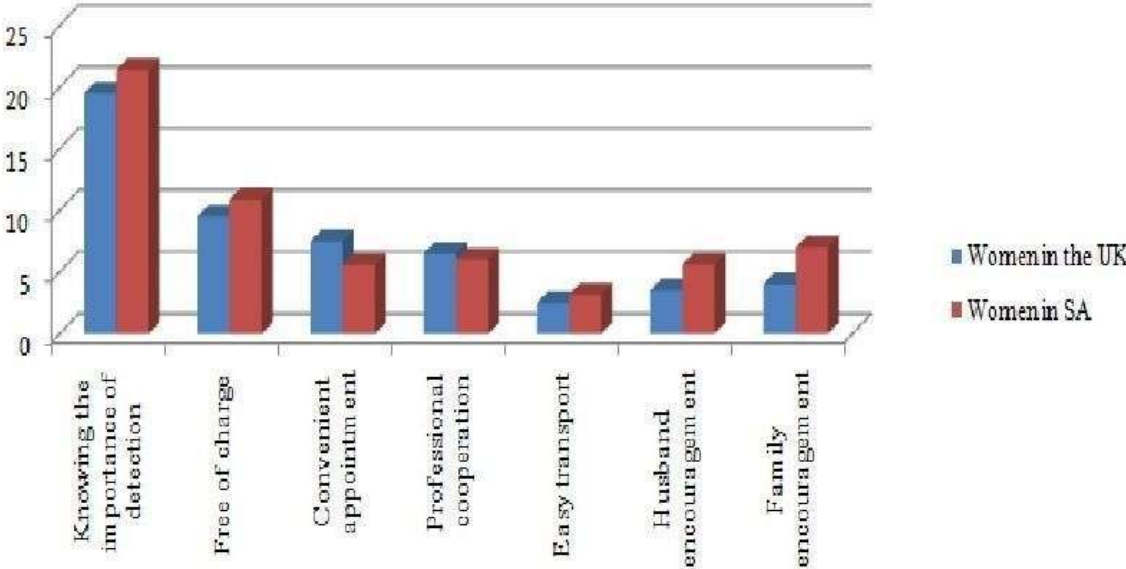


Figure 10: Facilitators when accessing breast cancer screening services among Saudi women in the UK and Saudi Arabia

**5.3.6 Barriers when accessing breast cancer screening services**

Participants signified their fear of having cancer as one of the most important barriers to accessing breast cancer screening services (36 % in the UK and 37.5 % in the Saudi Arabia). Other barriers included: lack of awareness of the importance of early detection (27.2 % in the UK and 22.5 % in the Saudi Arabia), not knowing where to go for screening (22.8 % in the UK and 30.2 % in the Saudi Arabia), lack of interest (20.9 % in

the UK and 26.5 % in the Saudi Arabia), presence of male at the screening service site (19 % in the UK and 21.2 % in the Saudi Arabia), need of taking off clothes (18.5 % in the UK and 25.9 % in the Saudi Arabia), and longer waiting time (10.7 % in the UK and 22.8 % in the Saudi Arabia). Some barriers were rated as less important such as lack of encouragement from the family, cost, transportation, lack of husband's support, and time (Figure 10).

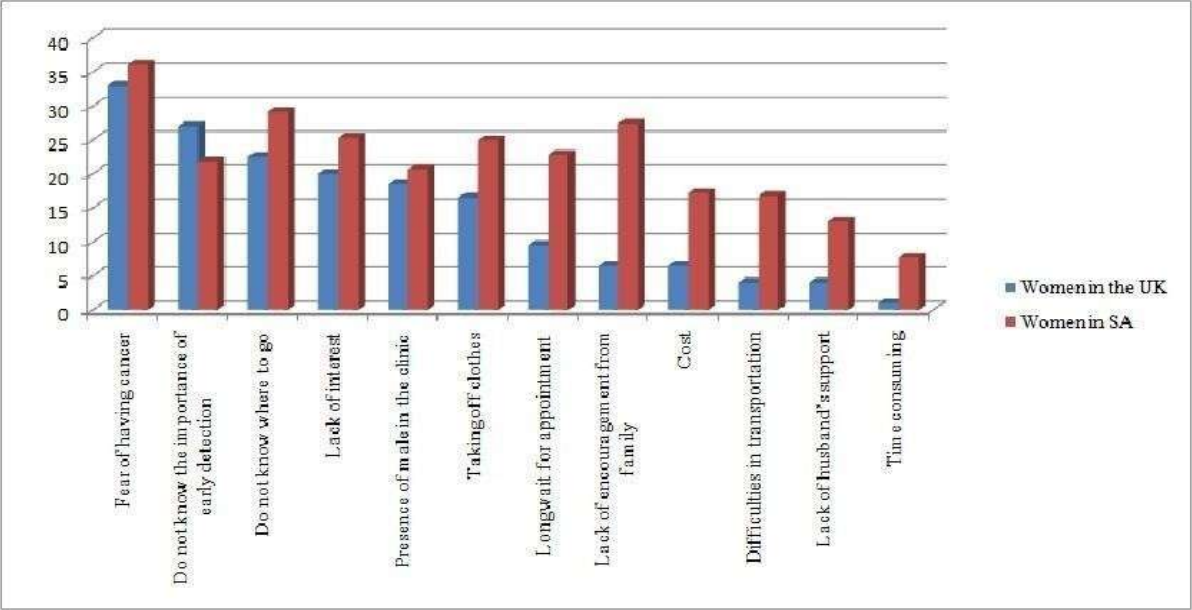


Figure 11: Barriers to breast cancer screening services among Saudi women in the UK and Saudi Arabia

### 5.3.7 Facilitators when accessing cervical cancer screening services

Knowing the importance of cervical cancer detection was one of the more important facilitators that encouraged women to access screening services (48.5% in the UK and 67.6% in the Saudi Arabia). Other facilitators women rated included: professional cooperation when accessing screening (36.6 % in the UK and 21.6 % in the Saudi Arabia), free screening (33.3 % in the UK and 27 % in the Saudi Arabia), having convenient appointment (29 % in the UK and 13.5 % in the Saudi Arabia), husbands encouragement (17.8 % in the UK and 16.2 % in the Saudi Arabia), family

encouragement (12.9 % in the UK and 13.5 % in the Saudi Arabia), and having easy transportation (13 % in the UK and 8.1 % in the Saudi Arabia). It is noticed that participants in the UK differ in their rating of the facilitators than those who live in Saudi Arabia, which might reflect the differences in the life style and the health services structure in each country (Figure 11).

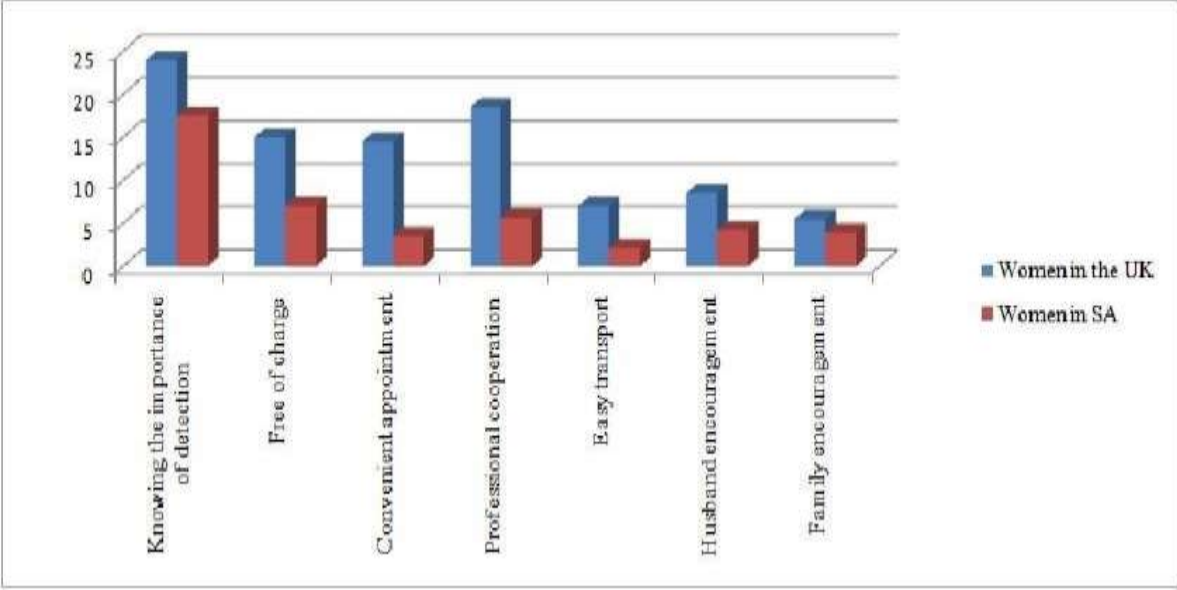


Figure 12: Facilitators of cervical cancer screening services among Saudi women in the UK and Saudi Arabia

**5.3.8 Barriers when accessing cervical cancer screening services**

One of the important barriers to cervical cancer screening services was participants’ fear of having cancer (29.9 % in the UK and 33.9 % in the Saudi Arabia). Other barriers participants thought might be of importance included lack of recognition of the importance of early detection (27.5 % UK and 28.8 % Saudi Arabia), taking off clothes (23.7 % in the UK and 30.7 % in the Saudi Arabia), lack of interest (21.2 % in the UK and 27.2 % in the Saudi Arabia), presence of male professionals in the clinic (20.3 % in the UK and 21.8 % in the Saudi Arabia), not knowing where to go for screening (17 % in the UK and 28.8 % in the Saudi Arabia), and a longer time to get an appointment (13.9 % in the UK and 21.8 % in the Saudi Arabia). Some barriers



were rated less important such as: the cost, lack of family encouragement, transportation, professional cooperation, and time (Figure 12).

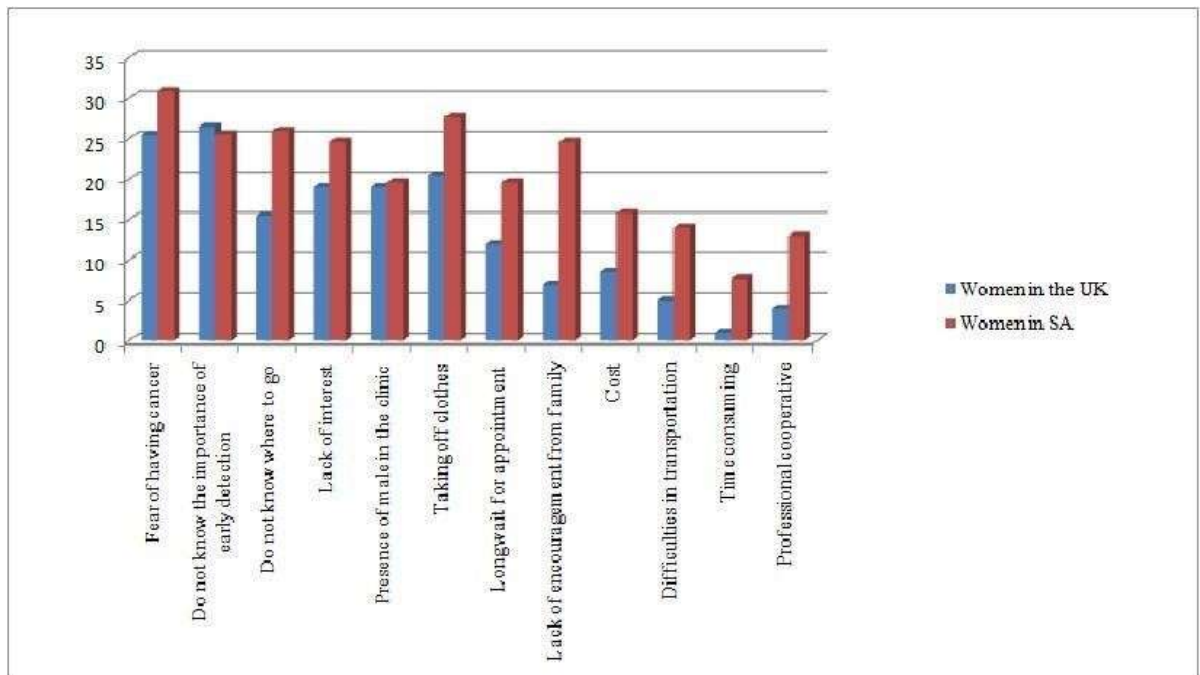


Figure 13: Barriers of cervical cancer screening services among Saudi women in the UK and Saudi Arabia

#### 5.4 Breast and cervical cancer: feelings evoked by the word cancer, opinions about the meaning of malignant and benign

Participants in the UK and Saudi rated fear, anxiety, and pain as feelings that could be evoked by the word cancer. These feelings were almost rated equally by Saudi women who live in either the UK or Saudi Arabia.

#### 5.5 Suggestions for improving access to breast and cervical cancer screening services

The most commonly reported suggestion from both UK and KSA participants was having female professionals when accessing screening services (61.8 % in the UK and 64 % in the Saudi Arabia). They also rated the importance of sending invitation letter as one suggestion to enhance attendance at screening services (56.3 % in the UK and

50.8 % in the Saudi Arabia). Moreover, 52.7 % of participants in the UK and 59.5 % those in Saudi Arabia indicated that having convenient appointment was important. Other suggestions were also ticked by participants as important to improve access to cancer screening services. These are: having a dedicated centre for screening (43.5 % in the UK and 54.5 % in the Saudi Arabia), having positive professional attitude (41.8 % in the UK and 41.7 % in the Saudi Arabia), attending educational activities (39.4 % in the UK and 47.7 % in the Saudi Arabia), availability of transportation (15 % in the UK and 24.6 % in the Saudi Arabia), and the suggestion of using MRI instead of mammogram (15 % in the UK and 23.5 % in the Saudi Arabia).

Furthermore, participants thought that media is an important tool that could help in disseminating information about breast and cervical cancer screening services (86 % in the UK and 80.4 % in the Saudi Arabia). Also, schools, hospitals, mobile messages, shopping centres, and mosques could be used to increase awareness of the availability cancer screening.

### **5.6 Correlations between participants' knowledge, experience, barriers and facilitators with age, education, occupation and marital status (breast cancer)**

Results revealed some correlations between participants' knowledge of perceived barriers and their knowledge and attitudes when accessing breast cancer screening services in both the UK and Saudi Arabia and their socio-demographic variables (Table 5). There was a significant correlation between lack of transportation with participant's age among women residing in Saudi Arabia ( $P= 0.04$ ); the older the participant was the more likely the presence of lack of transportation was conceived as a barrier to breast cancer screening services. Married Saudi women residing in

KSA found that lack of transportation is an important barrier compared to unmarried ones ( $P<0.01$ ).

Lack of family encouragement in Saudi Arabia was significantly correlated with participant's age; the older they were, the more likely was the presence of lack of encouragement reported as a barrier to breast cancer screening services ( $P=0.03$ ). There was also a significant correlation between appointment availability to access breast cancer screening services and age; the older a participant was the more likely appointment availability would be reported as a barrier ( $P<0.01$ ). In addition, there was also a significant correlation between appointment availability to access breast cancer screening services and education level, women with higher education were the more likely appointment availability would be reported as a barrier ( $P=0.01$ ).

Presence of male professional in delivering the breast cancer screening services was significant correlated with education; the higher level of education, the more likely presence of male professional perceived as barrier ( $P=0.03$ ).

It was also found that the younger Saudi participants, the more they identified pain during mammogram as a barrier when attending breast cancer screening services in the UK ( $P=0.05$ ). Additionally, they considered appointment availability is a significant barrier to such services ( $P<0.01$ ). However, older participants believed that lack of interest was a barrier for them ( $P=0.03$ ).

In Saudi Arabia, the younger the participants, the more their knowledge that chemotherapy is one of modalities in treating breast cancer ( $P=0.03$ ) and that hereditary factor could be a risk for such cancer ( $P=0.05$ ). This was the case as well among participants who live in the UK for knowledge of chemotherapy/radiotherapy ( $P<0.01$ ) and hereditary risk factor ( $P<0.01$ ). Highly educated participants in Saudi (not in the UK) were also found to be more knowledgeable of the role of nutrition as a

risk factor ( $P=0.02$ ) and presence of breast discharge as one of the symptoms ( $P=0.04$ ) of breast cancer occurrence.

Younger Saudi participants in the UK found to be aware that breast discharge is one of the symptoms for breast cancer than older women ( $P=0.03$ ), but not those who live in Saudi Arabia. It was also found that the more educated these women the more knowledgeable they are of the sign of pain in the breast ( $P=0.05$ ) and the fact that being old as a factor predisposing them to breast cancer ( $P=0.03$ ). However, the less education level participants attained, the more their beliefs that nutrition is a risk factor to develop breast cancer ( $P=0.04$ ).

Moreover, participants in the UK who attained less education considered hereditary factors ( $P=0.02$ ) and nutrition ( $P=0.04$ ) as less important factors in causing breast cancer. However, highly educated participants were more knowledgeable that pain in the breast ( $P=0.05$ ) and being old ( $P=0.03$ ) are important risks in the occurrence of such cancer.

Saudi participants in the UK who were married were found to be more knowledgeable of the role of the lack of exercise ( $P=0.03$ ) and contraceptive use ( $P<0.01$ ) in causing breast cancer than those who live in Saudi Arabia.

Furthermore, working participants in various occupations were found to be knowledgeable of the role of hereditary ( $P=0.02$ ), nutrition ( $P=0.03$ ), being old ( $P<0.01$ ), and childless ( $P=0.03$ ) as factors contributing to breast cancer than those who were un-employed.

Table 5: Correlation (P-values) between breast cancer's barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in Saudi Arabia and United Kingdom

Factors		Age (P-value)	Education (Pvalue)	Occupation (Pvalue)	Marital status (Pvalue)
Barriers					
SA	UK				
Lack of transportation		0.038			0.004
No family encouragement		0.025			
Appointment availability		0.006	0.013	0.002	0.002
Presence of male professional			0.028		
	Pain during mammogram	0.050			
	Lack of interest	0.033			
	Appointment availability	0.000			
Knowledge and attitude					
Chemotherapy as a treatment method		0.030			
Heredity as a risk factors		0.050			
Nutrition			0.020		
Breast feeding			0.043		
	Breast discharge	0.025			
	Heredity	0.000	0.018	0.021	
	Radiotherapy	0.002			
	Chemotherapy	0.009			
	Pain in the breast		0.046		
	Nutrition		0.041	0.032	
	Being old		0.030	0.002	
	Childless			0.029	
	Lack of exercise				0.030
	Contraceptive medicine				0.003

### **5.7 Correlations between participants' knowledge, experience, barriers and facilitators with age, education, occupation and marital status (Cervical cancer)**

Results provided several significant correlations between participants' knowledge of barriers and their knowledge and attitudes when accessing cervical cancer screening services in both the UK and Saudi Arabia and their socio-demographic variables (Table 6). Among participants living in Saudi, there was significant correlation between lack of family encouragement and participants' age; denoting that the older the women, the more they perceived the lack of family encouragement in Saudi Arabia ( $P=0.05$ ). It was also found that highly educated participants correlated significantly with the fact that lack of interest in screening ( $P=0.04$ ), lack of transportation ( $P<0.01$ ) and fear of having cancer ( $P<0.01$ ) were all barriers to attending cervical screening services. Being married was also significantly correlated with fear of having cancer as a barrier to such services ( $P=0.01$ ). Additionally, employed participants believed more that taking -off clothes ( $P<0.01$ ) and presence of male professionals when attending cervical screening ( $P=0.02$ ) were important barriers than un-employed women.

In Saudi Arabia, appointment availability as a facilitator was correlated positively significantly with age ( $P=0.02$ ), meaning the older the women, the more they perceived the appointment availability as a facilitator. Being highly educated was significantly correlated with husband's encouragement and knowing the importance of early detection ( $P=0.05$ ) as facilitators. Age was positively correlated with the knowledge that smoking ( $P=0.01$ ), chemotherapy ( $P<0.01$ ), and hereditary ( $P<0.01$ ) are risk factors for occurrence of cervical cancer. Additionally, it was found that being employed is highly correlated with the knowledge that assisted fertility could

contribute to the development of cervical cancer ( $P=0.05$ ) than in those who were un-employed.

In the UK, Saudi participants showed a significant correlation between being married and anxiety ( $P=0.03$ ). There were also a significant correlation between lack of transportation and participants' age; older women were more likely to face transportation problems when = attending cervical screening services ( $P=0.01$ ). Also the older the women, the more likely the lack of interest was in attending such services ( $P=0.04$ ). The correlation was significant also between the lack of interest in attending such services and being married ( $P<0.01$ ) and highly educated ( $P=0.05$ ). There is also a significant correlation between being older and the fact that these women do not know where to go for screening ( $P=0.03$ ).

Appointment availability was a facilitator in the UK and significantly correlated with age as older women were more likely to perceive appointment availability as a facilitator ( $P=0.04$ ). Knowing the importance of the early screening was also a facilitator in older women ( $P=0.04$ ) and highly educated ( $P<0.01$ ). Moreover, age was negatively correlated with the knowledge of unexpected bleeding, being older, role of hereditary, radiotherapy, and chemotherapy as factors the related to the development of cervical cancer ( $P<0.01$ ). Also, participants in employment were more knowledgeable of these factors than those who were un-employed. Additionally, being married was significantly correlated with the knowledge of unexpected bleeding ( $P<0.01$ ) and radiotherapy ( $P=0.02$ ) as predisposing factors to cervical cancer than those who were un-married.

Having described quantitatively the characteristics of the participants and the various correlations between some of their demographics and the facilitators, barriers, knowledge and attitudes about breast and cervical cancer screening services in Saudi

Arabia and the UK, in the next chapter, the participants' experiences and knowledge of the barriers and facilitators of such services will be explored qualitatively in-depth.



**Table 6; Correlation between (P-value) cervical cancer's barriers, facilitators, knowledge and attitude with age, education, occupation and marital status among Saudi participants living in Saudi Arabia and United Kingdom**

Factors		Age (P-value)	Education (Pvalue)	Occupation (Pvalue)	Marital status (Pvalue)
Barriers	UK				
SA	UK				
Lack of Family encouragement		0.050			
Lack of interest			0.043		
Lack of Transportation			0.008		
Fear of having cancer			0.000		0.014
Take off clothes				0.000	
Presence of male professional				0.017	
Husband encouragement					0.01
	Experience anxiety				0.027
	Presence of male professional		0.04		
	Lack of Family encouragement				0.022
	Not knowing the importance of early detection				0.042
Facilitators					
Appointment availability		0.016			0.039
Attending Pap test		0.041			0.012
Husband encouragement			0.055		0.008
Knowing the importance of early detection			0.048		
Smoking		0.013		0.050	
Chemotherapy		0.004			0.015
Heredity		0.006			0.033
Attending Pap test		0.041			
Assisted fertility				0.001	
	Reassurance after Pap smear				0.03

Continue; Table 6: Correlation between (P-value) cervical cancer's barriers, facilitators, knowledge and attitude with age, education, occupation and marital status among Saudi participants living in Saudi Arabia and United Kingdom

Factors		Age (P-value)	Education (P-value)	Occupation (P-value)	Marital status (P-value)
Facilitators					
	Appointment availability	0.04			0.01
	Don't know where to go	0.03			
	Lack of interest	0.04			
	Lack of transportation	0.01			
	Knowing the importance of early detection	0.04	0.01		
	Unexpected blood	0.003		0.029	0.003
	Being older	0.005		0.045	
	Heredity	0.005		0.043	
	Radiotherapy	0.000			0.024
	Chemotherapy	0.008			

## **Chapter 6: Focus Groups Results**

### **6.1 Introduction**

In the previous chapter, my participants completed a quantitative survey and the results were described above. In the present chapter, my participants expressed their beliefs, understanding, knowledge, and experiences in qualitative focus groups discussion about accessing breast and cervical cancer screening services. The results provided here were obtained from the descriptive content analysis of the transcripts of the focus groups discussion. Initially, the participants characteristics are described, then the main results presented reflecting the thesis objectives. Both sections are described together because participants in the focus groups mostly discussed cancer in general rather than pointing to a specific one. Quotes from participants in the UK would be labelled with as such and those from Saudi Arabia would be labelled as KSA.

### **6.2 Focus groups' characteristics**

Seven focus groups were conducted: three in the UK and four in KSA (see Table 7 and 8 below). Number of participants in each focus group ranged from 4-8 women and their age was between 18 years and 65 years old. They were heterogeneous in terms of their socio-demographic profiles (education and age). The majority was highly educated (Master and PhD holders), some completed the Bachelor degree, few were either high school graduate, completed primary school, and only two were illiterates. The majority of the participants were married and some were singles. The discussion time ranged between 28 minutes to 65 minutes.

Table 7: Socio-demographic characteristics of the focus groups in the UK

Name	Age	Education	Marital status	No of children
UK First focus group				
P1	21	Foundation	Married	1
P2	23	BSC	Single	-
P3	20	BSC	Single	-
P4	22	BSC	Single	-
P5	22	BSC	Single	-
P6	18	Foundation	Single	-
UK Second focus group				
P1	31	Master	Single	-
P2	30	Master	Married	1
P3	28	Master	Married	0
P4	26	Master	Married	1
UK Third focus group				
P1	39	PhD	Married	3
P2	43	PhD	Married	2
P3	35	Master	Married	3
P4	45	PhD	Married	3

**Table 8: Socio-demographic characteristics of the focus groups in Saudi Arabia**

Name	Age	Education	Marital status	No of children
KSA First focus group				
P1	49	PhD	Married	3
P2	50	PhD	Married	0
P3	51	PhD	Married	NA
P4	56	Master	Married	NA
P5	39	Master	Married	2
KSA Second focus group				
P1	45	High school	Married	5
P2	63	High school	Married	6
P3	59	Year 6	Married	13
P4	65	Illiterate	Married	4
P5	42	Illiterate	Married	4
KSA Third focus group				
P1	23	Bsc	Non-Married	0
P2	22	Bsc	Non-Married	0
P3	25	Bsc	Married	0
P4	29	Bsc	Married	2
P5	22	Bsc	Non-Married	0
P6	29	Bsc	Married	NA
KSA Fourth focus group				
P1	19	High school	Non-Married	0
P2	19	High school	Married	0
P3	20	High school	Married	0
P4	21	High school	Married	1
P5	21	High school	Non-Married	0
P6	22	High school	Non-Married	0

The focus groups discussion provided rich information about Saudi women's subjective experience and views of breast and cervical cancer screening services. The results of the focus groups discussion are provided here into two sections. The first section is descriptive accounts describing the participants' knowledge, barriers and facilitators, experiences, role of culture and religion,

and their suggestions to improve accessing breast and cervical cancer screening.

The second part represents the explanatory accounts linking the several components of the descriptive accounts in a meaningful pattern.

### **6.3 Descriptive accounts**

In this section, results discussed with regards to participants' knowledge of symptoms, risk factors, prevention and treatment of breast and cervical cancer.

Participants' perceptions, understanding and beliefs of the facilitators and barriers to cancer screening services are provided below.

#### **6.3.1 Knowledge of cancer symptoms**

Participants expressed several symptoms and signs that they thought are related to cancer. The majority of those in Saudi Arabia agreed that the presence of a lump in the breast or under the arm were symptoms of breast cancer. Although they were younger in age, they provided more details of breast cancer symptoms. Some, who were relatively older, gave less information about the breast cancer symptoms. They explained more knowledge about the lump such as its location, mobility, presence of pain and whether it malignant or benign:

*When applying breast self-examination you will find lump at the side of the breast (KSA4)*

*I have had a lump in my breast, I was afraid but the doctor told me that a breast cancer lump has no pain (KSA5)*

*Lump underarm...breast cancer lump...no pain, it is used to be moving lump (KSA7)*

*Breast cancer increased nowadays...it started by signs underarm (UK1)*

*I think breast cancer comes from the lymph nodes in the underarm (UK2)*

*I have the same view, it is a lump with pain...women might feel it in the late stage  
(UK3)*

Some described the lump in more details such as soft and hard. They indeed differentiated between malignant and benign lumps by defining a benign lump as an early stage of cancer whereas malignant lumps are the late stage:

*A moving lump indicates benign type in the early stage, where the lumps that are hard and fixed to the chest are malignant types and late stage  
(KSA7)*

*Blood from nipple, discharge is a sign but I think this happens in a late stage  
(KSA4)*

*I think malignant lump is abnormal with pain...in addition nipple discharge (KSA6)*

Some even described changes in colour in the skin as a sign of breast cancer:

*The most important symptoms...change in size and colour such as spots on the breast (KSA5)*

*Second symptoms of breast cancer after the lump is change in the breast colour  
(KSA7)*

They seemed to be knowledgeable about not only the presences of lump, but its characteristics and the associated symptoms and signs such as nipple discharge whether it is fixed or movable. In addition, Saudi participants who lived in the UK and Saudi Arabia had almost consistent knowledge of the breast cancer symptoms and signs.

Regarding cervical cancer symptoms, the majority of participants, who were in KSA explained that the absence of symptoms is problematic in cervical cancer. They thought that symptoms might include; irregular bleeding, pain during intercourse, discharge, cessation of menstrual period, and abdominal

and back pain. Those who mentioned irregular bleeding have added that this symptom could be confused with symptoms associated with the presence of the coil (loop). The UK focus groups did not mention symptoms for cervical cancer.

*I knew that cervical cancer has no symptoms; it appears when a Pap test is done (KSA4) I think unexpected bleeding for old women who are post-menopausal; bleeding is a symptom (KSA4)*

*Cessation of menstrual period or irregular menstruation period might be a symptom of cervical cancer (KSA4)*

*For married women, symptoms are easily detected because there is pain during intercourse (KSA6)*

*If I had irregular bleeding I would think this is because of the coil. I would not differentiate between symptoms of cervical cancer and the coil (KSA6)*

The last expressed views from participants living in Saudi might reflect their knowledge of cervical cancer, which was not expressed by those who were living in the UK. This might be explained by the observation during the focus groups that the discussion of breast cancer dominated their focus and many of them were single and concerned about breast cancer rather than cervical at this stage of their life.

### **6.3.2 Knowledge of risk factors, preventive measures and treatments for breast and cervical cancer**

The participants discussed health care level and differences in the UK and KSA mode of delivery. Some expressed the need to embrace and combine both the best of Western health care model and the teachings of the Qur'an. This might reflect the role of religion in the lives of Saudi women as a



distinctive conservative population. Moreover, it was noticed that when a specific risk factor discussed, it is often followed by a specific preventive system or treatment during the focus groups discussion. Thus, risk factors and options for treatment were discussed together. The risk factors and treatments were broadly explained in a comparative manner including three concepts: 1. the past as representing a natural and healthier lifestyle versus the present as representing a less healthy life style. 2. Internal risks that might be generated within the body (intrinsic) versus external ones, which could be generated by the environment And 3. Controllable versus uncontrollable factors. The concepts were seldom mutually exclusive, rather suggestive and inter-related. The concept of past versus present was expressed in terms of the past being the ideal state, whereas the present represented a departure from the ideal state, usually expressed as technological and behavioural changes. The “unnatural such as hormones” changes render the body vulnerable to cancer causing agents. The concepts of internal or external cancer-causing agents described the aetiology of cancer. Internal agents were generated within the body and external agents were originated outside the body. Risk factors were framed around the influence of modern technology and regarded most often as external. The concept of controllability and uncontrollability seemed to describe the nature of the cancer itself and whether or not treatment could control it.

The following quotes demonstrated the contrast of the unnatural tampering with the natural growth of plants, which results in changes to the body, which in turn results in cancer. The underlying idea was that the traditional ways of living were superior to the present in terms of health.

*Long time ago there was no medicine to take...people used to use herbs and this used to be active, away from factories and pollution (UK1)*

*Food contaminated by additives, the cancer increased because of polluted food. It changes our body. They use these additives even in the vegetables weren't left to grow naturally; they tampered with the growth process using hormones (KSA4)*

*We have bad food habits in Saudi...I think this is a factor (UK3)*

*Things like smokes, fumes, chips, coloured sweets and soft drinks are full of carcinogenic items especially children...also drinking water can decrease the risk (KSA7)*

Focus group participants from both the UK and KSA consistently mentioned that the use of natural food (no additives) and herbs in the past might have a positive influence on health and prevented cancer. Another comparison was about lifestyles as a risk factor for cancer. The following quotes explore the KSA point of view regarding the influence of food and exercise.

*Practicing exercise and food can affect cancer occurrence, but in different way because in the past days people were eating food full of fats but they were active, walking in the desert and cleaning their houses by themselves. We never heard about cancer before. (KSA5)*

*Cancer in general increased because of bad life style we've had nowadays. People become very busy with their jobs, working all the time, don't take care of their food and drinks (KSA6)*

*Food contaminated by addictive, the cancer increased because of polluted food, it changes our body...they used these additives even with vegetables that left to grow naturally...they tampered with the growth process using hormones (KSA4)*

*I don't think food has an effect, because men are taking the same food as women. It might be the air pollution, not the food (KSA4)*

*Exercise and healthy food are both main reasons for cure...we used to eat junk food, fast food, hydrogenated oil and saturated fat...also we do not know how many times they used it and whether it is clean or not (UK1)*

*The main task of exercise is to release negative charges in our bodies which act as cathodes attracting diseases (UK1)*

The above quotes explain the widespread beliefs of external and internal powers represented by the role of exercise as negative charges released from the body, which these women considered as contributing to occurrence of cancer.

However, some expressed that cancer has no reason at the first place:

*I do not think there is a specific factor that causes cancers...all cancers have no reasons (UK1)*

*As I know...I think there are no specific reasons...yes...but still no reasons (UK2)*

*I am not sure about the reason...some people have everything right...food and exercise, but still got cancer (UK3)*

Several participants explained that hereditary and genetically factors might contribute to the occurrence of cancer:

*Intermarriage...I mean relative marriage is a factor which spread cancer in the family especially in the third world...this happens when a risky person who is at risk...and I believe that person can get cancer at any time and any age...so when he get married to a lady with a high risk to get cancer...the cancer appear among their children (UK1)*

*I believe that hereditary transmits dangerous diseases, it can be explained by joining of two bad genes together to form new disease or worst form of a disease run in family*

*(UK2)*

*I think that the strongest factor is genetic (KSA4)*

*I think that genetic one of the factor that put you at risk...genetic has a strong role (KSA5)*

*I am not sure...genetic, may be...I heard that if cancer gets into your family, it will run to all the family...mostly 70% of people who gets specific cancer...the same run in the next generation...I think because of the same gene (KSA7)*

The discussion went further and several participants suggested different factors that might cause cancer such as X-ray, radioactive substances and technological advancement (mobiles). The quotes sometimes also incorporated the concept of the present as less healthy than the past in that modern technology was an interference with the natural and traditional, and hence detrimental to health.

*I think exposure to X-rays and the ozone layer are both causes of cancer (KSA4)*

*I think that the more technology, the more cancer. This is can be seen by knowing the difference of cases compared to developed countries. Technology has lots of rays which affect our body cells, for example, laptops. It has radiation, which could affect our body and cause cancer to the area near to the radiation. It is like positive and negative cathodes. If cancer is negative, for example, cells will act as positive cathodes. This is somehow the cause of cancer (KSA7)*

*I think the gulf war is the main reason for cancer cases in the Eastern area in Saudi because of the use of chemicals (UK3)*

*Things like fumes, radiation, chemicals and food pollution can be factors. I always watch science fiction films. It explains how radioactive materials hidden under the ground and can harm human life, children and adults (KSA7)*

*Mobiles can cause cancer because it becomes near to the body for long time with radiation (UK1)*

*All chemicals and rays such as microwaves are factors (KSA6)*

*I think the more technology, the more cancer...this can be seen by knowing the difference between cases in the developed countries...technology has a lot of rays which affect our body cells...for example laptops...it has radiation...it is like positive and negative cathodes (KSA7)*

Other external factors that were mentioned by some including contaminated water, use of some medications, and environmental pollution:

*Do you think... that toilet sprays (bidet) can cause infections to the area, especially when they get rusted and unhygienic? (UK1)*

*I remembered a place in Saudi, water pipes; they found a magnetic field, which could cause cancer...so they banned people from coming to this area (UK3)*

*I think taking medicines can affect...I mean...some medicines have side effects such as chills and increase in heartbeat...these types of medicines can convert cell in disease in human being (UK1)*

Another external factor specifically for breast cancer that mentioned was wearing tight clothing, particularly bras and particularly if the bras were underwired and dressed in at night.

*I have heard that tight clothes such as bra can cause cancer” (UK3)*

*Yes, tight bra and type of wire (KSA5)*

*I think sleeping with a bra... (Can) cause cancer (KSA5)*

Another external agent that was mentioned by some of the participants seemed to have a site specific association; this was deodorants and the relation of underarm and presence of underarm lymph-nodes in the women.

*Deodorants as well...and anything that prevents sweat from going out (KSA4)*

*Women are at high risk of getting breast cancer is because they have underarm lymph nodes (KSA5)*

A different set of exterior forces that were regarded as risk factors for cancer, were jinn and the evil eye. Jinn and evil eye are mentioned in the Qur'an.

Therefore, both the evil eye and jinn are forces sanctioned by time and tradition. Several participants mentioned that Jinn are supernatural beings with an independent will and can be good, bad or neutral. When jinn were described as cancer agents, they were regarded as an external force.

*Actually I believe in jinn and positive and negative spirits...Jinn can enter the body and distract cells which convert to cancer (KSA4)*

*In the view last period of time we heard a lot about cancer...they used to say "God protect us" ...cancer caused by evil eyes because it happened suddenly...silence...in religion it says that most of people in graves are from evil eye (UK1)*

*I think cancer caused by evil eye...I believe too (UK2)*

However few were not convinced by the idea of evil eye:

*I do not agree...I do not think evil eye develops cancer...women hanging every unexplained thing on black magic and evil eye...anything has no clear explanation always they refer to evil eye and black magic (UK3)*

*Logically evil eye has no explanation, especially if women protect herself by Roqya*

*(Special prayer)...Dr. Mustafa Mahmood said in his explanation to the evil that a specific ray launches from and caused the disease for the person (KSA4)*

*Evil eye has not been scientifically proven, it is a belief inherited, some people get the cancer and went for Shaikh for treatment and never treated by Qu'ran and that is because cancer cannot be affected by evil eye (KSA4)*

*It is known in Saudi culture that leukaemia is caused by the evil eye...I am sure that this true....but I never heard that evil eye causes breast cancer (KSA6)*

The evil eye is a widespread belief throughout the Mediterranean and the Middle East. The evil eye is an external force, but in as much as it is attracted by a person's behaviour or appearance, it can be regarded as both externally and internally generated. Excerpts from several participants demonstrate that the evil eye only becomes a threat if a woman does not protect herself by reading the Qur'an; therefore in that sense, the primary cause could be considered a moral failing and is thus internally generated.

In some explanations, biomedicine coexists with the Qur'an and the evil eye to enhance a cure (treatment's knowledge).

*I think the effect of the evil eye depends on the person's belief...and culture...some people think that any bad thing that happens is caused by the evil eye...where others know the fact of genetics...evil eye has a percentage (contributes as a risk factor) but (cancer is also) genetic...so people should use both medication and Qur'an (KSA6)*

*Yes I agree...both treatments should be used...we can't exclude the evil eye as a cause for cancer...but we consider other medical treatments and causes as well (KSA6)*

The following quote expresses the idea that the treatment must be consistent with the cause of the cancer. The rationale behind the statement is that the

Qur'an cures afflictions caused by the evil eye. If the cancer cannot be cured by the Qur'an, then it was not caused by the evil eye, this idea brought by the fourth focus group (KSA) who characterized by old in age with high education level.

*Evil eye has not been scientifically proven...it is a belief inherited (traditional belief).*

*Some people got cancer and went to a Shaikh for treatment and were not cured by the Qur'an...that's because cancer can't be affected by the evil eye (KSA4)*

The sixth focus group (KSA) has mentioned that having a member of the family with cancer can enhanced the evil eye belief. The implication of the next quote is that the evil eye is so prevalent that if it indeed was the cause of cancer (someone in her family would have cancer).

*I think because no one in my family got the cancer...so I can't believe in the evil eye (KSA6)*

Bad omen was another supernatural force which mentioned by KSA participants during discussion of breast cancer, it was brought up in three places; the first was pointing to the breast when talking about cancer, the second using mammogram to diagnose breast cancer and the third is related to the previous two omens which "thinking about cancer will call the cancer":

*Don't point to your breast (meaning that calling attention to the breast might bring the disease) (KSA4)*

*I'm afraid of machine (mammogram) itself...I feel women can get cancer by infection...it's not infection...I don't know what to say...bad omen (KSA5)*

*Fear of having it...bad omen (KSA7)*

Internal functioning was the umbrella for a number of risk factors, such as not breast feeding, hormones, and aging.



*I think having no babies...plus no breast feeding...hormones can also play a role (UK2)*

*I think a disorder in oestrogen can cause breast cancer (KSA4)*

*Women who did not feed their babies and age are factors (KSA5)*

*In our case because of the menstrual period, we have lots of hormone changes...we have to check on our health regularly (KSA6)*

Another factor that Saudi women think to be an effectively increase the risk of getting breast cancer is the psychological issues, this were discussed in most groups as risk factors. Women believe that external agents such as pharmaceuticals that cause toxins, being under stress, and a difficult family situation, result in an internal psychological disturbance that leaves the body vulnerable to cancer. The following quotes demonstrate possible psychological issues and stress discussed by participants from KSA (5&6) who were different in age and education qualifications.

*I think psychological status, taking lots of medicines, which could pass through our body causing toxins, being under stress such as shock or passing through a difficult time can all cause cancer. I know if a women has a bad husband and or ungrateful children and having lots of troubles, they usually easily get cancer (KSA5)*

*I believe always that psychological status is the main cause for cancer...some people put pressure on themselves...they like to live under stress, sadness and depression. They like to enlarge problems. This can convert healthy cells in human beings into chronic diseases such as cancer and heart problem (KSA6)*

In contrast, the following quotes demonstrate the idea of internally generated stress and depression as the risk factor by the UK (1) participants and KSA (6). These two participants are different in age but similar in education qualifications.

*Yes, the chance to get cancer increases when mother had it (cancer). It is because women become phobic about getting it, not heredity (UK1)*

*I think fear of cancer can put you at risk (UK1)*

*I believe always that psychological status is the main cause for cancer...some people put pressure on themselves...they like to live under stress, sadness and depression. They like to enlarge problems. This can convert healthy cells in human beings into chronic diseases such as cancer and heart problem (KSA6)*

Some of participants raised lack of moral such as internal risk factors for cervical cancer. For example, extramarital relationships and were mentioned by at least one person in each of the focus groups. Biomedical information on sexually transmitted diseases was frequently incorporated into the cultural norm framework of the participants. For example, the women specify that extramarital relationship is the risk factor; it is not any sexual relationship. In KSA, an extramarital relationship is perceived as both a legal and a religious offence.

*I think illegal relationship at an early age can affect the occurrence of cervical cancer (UK2)*

*Illegal relationships don't cause cancer directly...they cause a lot of infection which in turn causes cancer (UK3)*

*Transmission of cervical cancer is caused by illegal relationships...it is not important who are the transmitters; both male and female will be exposed to cancer if they had lots of illegal sexual interactions (KSA7)*

*Yes sure we have little illegal relationship that's why no cases of cervical cancer (KSA4)*

*I think women have more responsibility for developing cervical cancer. It is caused because she is involved in more than one relationship (KSA7)*

*I believe that this happen when women engaged in lot of sexual relationships...she gets viruses, fungus and bacterial infections...these recurrent infections can cause cervical cancer...I am sure in the future they will prove that illegal relationships are the only cause of cervical cancer (KSA7)*

*It might happen through men...he catches the disease from an infected woman and transfers it to the other one (KSA7)*

The final pair of concepts demonstrated by the participants in their discussions of cancer was the distinction between controllable and uncontrollable. The concept of controllability and uncontrollability was found in descriptions of causes of cancer and again in descriptions of treatments. Controllability was characterized as being within the control of the individual, such as behaviour, or within the control of health care professionals. Uncontrollable agents were most often described as environmental in nature such as air and the food. As demonstrated in the following excerpts, uncontrollable cancer-causing agents were usually described as external, and frequently incorporated the implication that the past was healthy and the present was characterized by uncontrolled modern technology. As may be seen by the quotes, the concept of uncontrollability and its association with the unhealthy present state is echoed across both countries and among age and education categories.

In the above quotes, the cause of cervical cancer was beyond the control of the individual in the sense that cancer-causing agents were all pervasive or resulted from the behaviour of another person.

Some participants believed that some surgical interference or chemotherapy could exacerbate the cancer:

*These two operations (mastectomy and hysterectomy) that cause the spread of cancer inside other organs of the body...for example if a women detected breast*

*cancer early...it will be so easy to cure ...but in the late stage...mastectomy can irritate other cells in the body and causes cancer to spread all over the body.... I meant...after the cancer spreads don't go for surgery (do not have surgery) (UK3)*

*I have heard of somebody who got a malignant tumour and...It was treated by chemotherapy...and even doctors proved that she was cured and stable...Awhile after...the cancer will be back...the cause is chemotherapy...it causes a different type of cancer (KSA6)*

The following section discusses cancer as controllable. The following quotes were in the context of cervical cancer and involved aspects of behaviour that were controllable. The UK (1) and KSA (4&7), both are having the similar idea regarding hygiene

*Carelessness in personal hygiene (can cause cancer) (UK1)*

*I am not sure...but...I never give birth before...I think when a woman gives birth, she should take care about the hygiene of her sensitive area by using herbs and antiseptic things (UK1)*

*I think recurrent infection and ignoring personal hygiene is a cause. (KSA7)*

Controllable factors were frequently expressed in terms of preventing cancer and included lifestyle choices, such as exercise and nutrition.

*Exercise and healthy food are both main reason for cure...we used to eat junk, fast food, hydrogenated oil and saturated fat. In addition we don't know how many times they use it (the oil or fat) and whether it is clean or not (UK1)*

*Exercise is a very important as a factor because fat affects the uterus (KSA4)*

*I believe that types of food play a role and exercise (KSA5)*

*Cancer in general...not only breast or cervical cancers...but all types of cancer can be affected by life style such as getting up early in the morning (KSA7)*

Another controllable factor was having information about cancer:

*I think there is no awareness...and no good screening services in Saudi...although we have a high level of personal hygiene (UK1)*

*My mum always advised us to check on our health...because she experienced the problem (KSA6)*

*I have three aunties, two of them discovered the cancer late and die of it, the third one discovered it early and survived...I believe that awareness is an important issue (KSA5)*

Controllability extended to treatments using either the Qur'an or conventional medical treatment:

*I have received lots of e-mails about the effectiveness of Sourat Yassine in curing all cancer forever (Sourat Yassine is a chapter in the Qur'an covers focusing primarily on arguments for the belief in God) (UK1)*

*The easiest cancer in treatment is breast cancer...because you can take away your breast...it is no essential part of the body like blood and colon...you can give it away...but if the cancer is aggressive...this won't be the end of the story (UK3)*

*Not true...chemotherapy is an effective treatment...my sister-in-law got the cancer five years ago...they remove the breast and treated by chemotherapy...she is ok now...following with her doctor...I believe breast cancer is the easiest cancer...especially if women detect it in early stage (UK3)*

*No...no...I don't agree...I believe that treatment by god's hands...I never saw a patient who died of cancer...one cured case...I think...enough for me...1% is equal to excellent...I saw one case who was treated by Sourat Al-baqara (the second and longest chapter of the Qur'an)...after doctors told her that they couldn't continue in chemotherapy...and told her she will die...she went to a Shaikh, he told her that this is a black magic and treated her with Albaqara...then she was cured (KSA7) I believe that a benign tumour is a male cancer which should be treated by surgery...while*

*malignant tumour is a female cancer and should be treated by drugs and surgery (KSA7)*

Psychological status was regarded by some as controllable factors and can help in the treatment of cancer:

*For example psychological status is very important for cancer patients...doctors should focus on patients' psychological states to improve their treatment and keep negative thinking away, even if the evil eye caused the cancer (KSA6)*

*In Saudi Arabia...we don't have, for example, special psychiatrists for cancer cases to help overcome the problem and increase their self-esteem...doctors focus on chemotherapy only...they ask patients and their families to take care and support each other but they never explain how...so families rarely help and patients keep feeling lonely (KSA6)*

*I think treatment should take three axes into account; psychological, medicinal (Biomedicine) and religious parts...honey...religious water, medicinal treatment and psychological status...these three axes will help to increase the cure rate (KSA7)*

In summary, the aetiology of cancer was associated with conceptualizations of past/present, internal/external and controllable/uncontrollable. Most of the cancer-causing agents were external factors and most frequently due to environmental factors. There was a notion that deviating from traditional social norms was detrimental to health. Although many of the causes were thought to be controllable, there was a sense of pessimism with regard to treatment. The same basic conceptualizations of past/present, internal/external and controllable/uncontrollable were present in both the UK and KSA and across different age groups and education level.

### **6.3.3 Facilitators and barriers to attending breast and cervical cancer screening services**

Facilitators, barriers and suggestions for improving attendance at screening services are interconnected and discussed together as they all address the overall women' motivation attendance at cancer screening services. Content analysis of the transcripts of the focus groups discussion revealed several concepts that participants expressed as facilitators, barriers and suggestions. These included: sources of encouragement; discouragement; or procedures that could be changed to improve attendance at cancer screening services. The concepts explained here lie within three domains: individual, institutional, and societal/cultural norms.

At the individuals' level, the responsibility of attending screening services or not suggest to lie or connected with the women' motivation and/or beliefs. Fear was a barrier and an overriding concept throughout all the discussions about accessing cancer screening services expressed by at least one individual in each focus group:

*To be honest...I received the invitation letter...it explained everything about the process...this has stopped me from attending...it looks painful (UK2)*

*Lots of people are scared of getting bad news (UK3)*

*The main reason for not attending was the fear...one of my friends reached the mammogram machine then she left the clinic before doing it (KSA4)*

*I'm afraid... even if my husband insisted...I will not go (KSA5)*

*I am afraid...if I have something bad...I don't want to discover it...I want it to be hidden (KSA7)*

*For me it is a scary step...pain...I do not know how the test is done (UK2)*

*Fear of heard bad news of having it (KSA6)*

*Fear can prevent women from attending screening services (KSA6)*

Having other priorities such as “no time” was expressed by some participants as a reason and barrier for not attending screening services:

*I am very busy...I have no time at all...I am studying and have kids (UK2)*

*I am in the first year of my PhD...I am scared to do it...I don't have time to visit doctors if something wrong appear...if I finished my upgrade I will do it (UK3)*

*Limited time...I have no time (KSA6)*

*Actually I do not have time to wait in hospital...waiting...horrible...it is not only waiting in the hospital...it is the process to get the appointment...it takes so long...in addition you have to run behind people to get the appointment date and time (KSA4)*

Other barriers were explained by some participants included cost and transportation to attend screening services:

*Having good transportation system...can ease the process...in Saudi Arabia, women should be allowed to drive to attend her appointment and husband is not always free (UK1)*

*Yes, I think cost will affect attendance...because in Saudi Arabia we have different socio-economic level (UK1)*

*Having no health insurance to pay for the cost...can obstacle women from attending (KSA4)*

*I belief that transportation and cost are the important barriers (KSA5)*

*There are a lot of people in rural places that cannot afford the price of transportation or communication and they do not know where to go (KSA7)*

The following excerpts do not place the responsibility with women themselves, but suggested that not understanding medical terms, knowing



someone in the medical field, or knowing someone who had cancer, and having a friend with whom to talk influenced whether or not an individual would attend screening services.

*Lots of Saudi living in the UK have difficulties in language of medical field...they will not understand terms regarding the disease (UK1)*

*If women have somebody close who suffers from cancer...this will increase awareness about the disease and attendance at screening services (UK2)*

*Having educated friend to talk with about the awareness will increase attendance (UK2)*

*My daughter is attending medical school...she told me about the free screening for breast early detection (KSA4)*

*I am obsessed with having the disease...because my mum died of cervical cancer and my auntie died of breast cancer...that's why I am doing BSE many times a day and checking on my health (KSA5)*

*I think a supportive friend is very important...if they decide to go together to the clinic...it is very important as a first step (KSA6)*

Ignorance was expressed by few as one reason for not bothering to go for screening services:

*I never check on my health...even when I had allergy in my hands...laziness (KSA4)*

*I think the reason is laziness and ignorance (KSA7)*

When participants asked about what could be the facilitators for them in order to attend cancer screening services. Some thought that having symptoms of cancer could encourage and motivate women to attend:

*One of the reasons to go to a screening clinic is to have some symptoms...I got lump in my breast... (KSA4)*

*I have had a lump...so I went to the screening clinic (KSA5)*

*I'm not anxious individual...that's why I didn't go to screening services...I think if I got it I will go even if don't have money and time(KSA6)*

*I went because I had pain in my breast...the result was negative...thanks to God (KSA7)*

Here, women without symptoms might not seek such service, and this would really delay their diagnosis, as breast and even cervical cancers are sometimes asymptomatic.

In some cases, knowledge about cancer and the importance of early screening was thought to be a key to attendance and women themselves were blamed responsible for acquiring the information.

*British people are more educated regarding diseases...they educate themselves...read about the treatment...unlike the Saudi public...they are scared to talk about it (UK1)*

*Women must know the factors that increase the risk...for example...if women over 30 years old...she should check on her health because it is better to know at early stage than late one (UK3)*

*If women know that early detection can increase your chances in life...I went because I was sure that if it was detected early...I will be cured KSA4)*

*I think it is important to have reliable information about statistics such as cure rate...not death rate...this will encourage women to attend (KSA6)*

*Having educated friends to talk with about the awareness will increase attendance (UK2)*

*The reason for not attending cervical cancer screening services...because we never heard about it...there is no awareness (KSA6)*

Peer influence and encouragement from friends and/or husband might be a facilitator to some participants:

*I think a supportive friend is very important...if they decide to go together to the clinic...it is very important as a first step (KSA6)*

*I think husband' encouragement...if my husband force me to go...I will go (KSA5)*

*I think husband encouragement will play a role...especially if he goes with her to support her (KSA6)*

It seems the influence of the husband' authority in the Saudi culture is very much controlling and unfortunately it is the norm and sometimes women do not have the will to decide for going to the screening services.

At the institutional level, factors that were mentioned as facilitators and barriers were the health care delivery system, such as hospitals, health care professionals, and the media. The focus group discussions indicated that a change in the health care delivery system would result in a greater attendance, or that the system was responsible in some way for facilitating women's attendance. The comments were related to appointments, whether or not the doctor contacted the women, characteristics of the clinics or hospitals, and dissemination of information. Furthermore, some participants compared between the cancer screening services in the UK and Saudi Arabia:

*I think in Saudi Arabia...it is very difficult to have an appointment...while in the UK, it is easier...sometimes in the same day...or the day after (UK1)*

*In Saudi Arabia we do not have enough female specialists in cancer treatment...they are very limited (UK1)*

*For appointment...in Saudi...two months' time for the appointment...cancer could developed and become worse (UK1)*

*In the UK...appointment for regular check may take two weeks...but if women have any concern about cancer symptoms, they will give an appointment within 24 hours (UK3)*

*In Saudi Arabia...GP cannot reach everyone in the area...so they cannot arrange an appointment...that's why it is better to announce about the availability of the test (UK3)*

*Nobody following up with women, no body reminds us...in the UK, they call you and remind you about the appointment (KSA5)*

*In the UK...women can ask for a translator...so this will encourage women to attend and break the language problem (UK2)*

*In the UK...they remind you about your appointment date...ask you to arrange an appointment...that's why women attend their appointments...nobody reminds me in Saudi Arabia (UK3)*

Here, participants throw the responsibility of caring about their health on the shoulder of health system in Saudi, which, I must highlight is very much different. This is especially true when it comes to incentives for general practitioners as in the UK, the more services you provide to your population, the more rewards you will receive, however, this is not happening in Saudi Arabia.

The health care system was also regarded as a being responsible for contacting women and reminding them that it is time for a screening.

*I think...it's easier to reach people at home and easier to motivate them by sending invitation letter...this is what happens in the UK...a GP can reach any registered person (UK3)*

*I think women should stick to one doctor...to monitor any health problem. For example my doctor in Saudi used to call me or send a text message to remind me that my check-up was due (UK3)*

*Nobody is following up with women, nobody reminds us...in UK they call you and remind you about the appointment...even if we asked for an appointment...we will get it in two to six months' time (KSA5)*

Information about cancers in general was suggested as a motivating factor for attending cancer screening services by most of the focus groups. Often the women thought that the institutional level should be responsible for and the best place to disseminate information.

*To be honest...women's awareness helps...women should be educated by health professionals (UK 1)*

*I have a brochure...I learned how to practice BSE...it is important to educate the public (UK2)*

*Women must know the risk factors that increase her risk to cancer...for example; if women over 30 years old, she should check on her health, because it is better to know at early stage than late... (UK3)*

*I think it is important to have reliable information about statistics such as cure rate...not death rate... this will encourage women to attend (KSA6)*

*In the UK...they have a hospital counselling line. When I was breastfeeding...I had a lump...I called them and they advised me to get the kit to practice BSE...and asked me to monitor the progress. After a while it disappeared (UK3)*

*In Saudi Arabia...a GP can't reach everyone in the area...so they can't arrange an appointment...that's why it is better to make an announcement about the availability of the test (UK3)*

The media was regarded as an important factor in the disseminating information about cancers and screening services:

*I think media have a strong effect on people...I remembered at the swine flu...they advertised in the TV about the importance of using mask...that's why, we should emphasise on media (UK2)*

*For cervical cancer...I don't have any idea about this cancer...I am not sure about the reason for no awareness regarding this cancer...no campaign...no events (KSA4)*

*My mum went to the screening services...because she saw an advertisement at the GP's about free breast screening (KSA6)*

Few participants expanded their thoughts and believed that knowing about others who already had cancer and knowing what they went through in their journey from diagnosis to treatment might be a facilitator and motivating to others to go for screening:

*Hearing about positive and happy endings for cancer survival encourages women to attend screening services...for example when Dr. Samia recounted her story on the TV...lots of women were talking about her survival...and attend screening services...especially because she was a gynaecologist (UK2)*

*I think the most important thing is spreading success story about survivals...this will influence attendance ...especially for breast cancer (UK3)*

A number of factors expressed by some that were related to specific facilities and procedures in the health delivery system:

*I don't like the hospital environment...I had an appointment for a blood test...I should do it...but I did not go...I hate the hospital environment (UK2)*

*Underdevelopment of governmental hospital can be a barrier. If governmental hospitals have new and technological machine...would be better (KSA6)*

*A governmental hospital is more reliable...unlike private hospitals who think about (their own) benefit only. The only barrier in governmental hospitals is distant appointments (KSA7)*

On the other hand, some participants still held some strong perceptions about health professionals and their experiences with them. These might act as positive and negative forces influencing their attendance for screening.

*My doctor always checks on my breast...I think because I am using contraceptive pills (UK3)*

*We have phobia from doctors...an appendectomy can kill you (UK3)*

*Medical mistakes could be one of the barriers...women don't want to experience any mistakes...if doctor misdiagnosed her case...doctors can make fatal mistakes (UK3)*

*I wish health professional would become more friendly and reassuring (KSA5)*

*It is essential to have health professionals with a positive attitude in this area (KSA5)*

*Nurses in Saudi are tough unlike the US, nurses there are friendlier (KSA7)*

At the societal and/or cultural level, participants discussed how influential the Saudi norms and values related to their decision to go or not to screening. Saudi cultural does not permit women to drive and contact unrelated strange men.

Gender segregation played a part in determining a woman's willingness to attend screening services.

The breast and cervical cancer screening procedures are related to very sensitive parts of women' body, in addition to the powerful influence of men controlling their choices, might all render them attending such services:

*Women don't like to go to male doctors...we need female doctors...it is easy to talk about it with her (UK1)*

*Some women afraid of their husband...she knows that he will refuse to take up the screening (UK1)*

*It is too embarrassing...I think even if I am married...I am not going to do it (UK2)*

*I feel shame...although I am married and have kids...but still feel shame...it is not like the emergency when you give birth...it is too embarrassing (UK2)*

*The problem is touching the sensitive are...this is what makes it embarrassing (UK3)*

*I've heard from my sister that cervical screening services are very embarrassing (KSA6)*

*For cervical cancer...My mum always asked me not to do it because I am virgin...it is embarrassing (KSA6)*

*If I had a choice...I will choose female...and will search for one with a good reputation (KSA7)*

*Husbands are busy...and some of them prevent women from going...and others don't care (UK1)*

*...if my husband forced me to go...I will go (KSA5)*

These women expressed clearly the influence of cultural and societal norms and values when accessing cancer-screening services.

#### **6.4 Explanatory accounts**

Participants of the focus groups expressed their views, beliefs and understanding of both cervical and breast cancer-screening services. However, discussion about breast cancer screening services seemed to be dominating than the cervical cancer. One reason might be the lower incidence of cervical cancer among Saudi women (more details in the introduction chapter). In addition, several participants were singles and most probably cannot have cervical screening, even breast screening might be of embarrassment to some. Participants provided various barriers, facilitators, and suggestions. Fear of cancer was a major barrier and having information was a major facilitator to screening services. The facilitators, barriers, and suggestions tended to be expressed as external to the individual and beyond the control of the individual. This might reflect the degree of control and oppression these women had either from their husband and/or society rendering them to decide going for screening or not.

The conceptualizations of past/present, internal/external, and Controllable /Uncontrollable that embedded in the discussion could be peculiar to Saudi women. Saudi women whether in the UK or in their home land might still



held some dominating values and culture that prevented some from taking care of their health and attend cancer screening services. Clearly, these values and attitudes travelled with them to the UK. This means that Saudi women might seem not to be influenced by their migration status in the UK or they did not have enough time to be acculturated to the British culture and their health system.

It seemed a necessity to re-examine the pervading sense of pessimism and passivity with regard to cancer screening and even treatment. The women in the UK and KSA mentioned that the reading of the Qur'an and obeying social norms such as not calling attention to oneself (modesty) and maintaining monogamous relationships were important facets of routine preventive health care. Therefore, the women's attitudes cannot really be characterized as passive, but values that need to be re-visited and used for their benefits.

Responsibility of health professionals towards women was a prominent concept expressed by many participants. Out-reach services was one option and advertising in health care settings was another one. This emphasized the shared responsibilities between the supplier of health and the consumers, especially in Saudi Arabia, where health services might still lack the recommended guidelines in delivering screening services in both breast and cervical cancers.

## **Chapter 7: Discussion**

### **7.1 Introduction**

This chapter summarized the findings of the thesis including those from the survey and the focus groups discussion. Findings were discussed and synthesized in relation to the literature. The survey and the focus groups discussion enabled me to reach the thesis' objectives. To accomplish the thesis objectives, of exploring Saudi women' experiences, knowledge, barriers, and facilitators when accessing breast and cervical cancer screening services, in the UK and Saudi Arabia. I linked the survey findings with the matching concepts that emerged from the focus groups discussion to triangulate the different types of data and provide a conceptual framework that could contribute to literature, especially Saudi women who have peculiar cultural/religious values that might influence their behaviour and attitude when accessing health services. The first section below is a brief summary of the thesis findings to remind the reader of the overall main findings. The second section addresses the link of participants' knowledge to their socio-demographic profiles. This might help in explaining some women' behaviour and attitudes towards breast and cervical cancer screening services and subsequently targeting them could assist in planning future strategies. The third section discusses the individuals' attitude and inner thoughts that drive their motives attending or not the breast and cervical cancer screening services. This would facilitate to focus the needed resources to those who held negative perceptions about such screening services. The fourth section expands the view to the health system in an attempt to realize participants'

perception of the health services provided to them and to some extent to ensure whether the existing screening programs are indeed meeting their expectation and were sensitive to their contexts. The fifth section elucidates the role of culture, religion, and societal values that might influence participants; attitude and explain barriers and facilitators to breast and cervical cancer screening services. The sixth section elaborates the strength and weakness of the thesis approach, methodology and analysis. The seventh section discusses the thesis implication to the literature, future research and planning of breast and cervical cancer screening programs. The last section concludes the thesis with an overall summary and highlights the main findings and future hopes in enhancing and improving the breast and cervical cancer screening services.

## **7.2 Summary of thesis' results**

Survey and focus groups discussion provided some consistent findings regarding Saudi women' perceptions, knowledge, beliefs of the barriers and facilitators in accessing both breast and cervical cancer screening services in the UK and Saudi Arabia. However, some issues were discussed in-depth and indeed raised new dimensions during the focus groups discussions, which enrich the understanding when encountering such services. They highlighted some cultural and health system variations that played a role in their attitudes, motivation and enthusiasm to attend screening. Fear of having cancer and lack of knowledge of the importance of early detection, particularly in cervical cancer were major findings with regard to barriers to attend screening services. However, being employed and highly educated was correlated with better

knowledge and awareness of the signs, symptoms, and treatment of both breast and cervical cancer. Participants shared their responsibilities with health professionals and the structure of the health system in the arrangement of early screening of breast and cervical cancers. Additionally, they suggested the role of media, education, and use of places such as mosques in disseminating information about the importance of early cancer detection.

### **7.3 Knowledge about breast and cervical cancer screening and socio-demographics**

In this section, participants' knowledge of different aspects of breast and cervical cancer was linked to some of their socio-demographic profiles (Table 4). This was done in an attempt to understand and explain a possible pattern in having such knowledge. This would help in targeting certain community groups when planning for strategies in enhancing their knowledge about breast and cervical cancer screening services.

Socio-demographic disparities appear to be strong predictors of underutilization of breast and cervical cancer screening services (George 2000). The results of the thesis suggested that older women are less knowledgeable of the symptoms and signs of breast cancer. Such observation might result in a delay in seeking help if they developed such symptoms and signs. This is consistent with previous research that showed older women were particularly poor at identifying symptoms of breast cancer, risk factors associated with breast cancer and their personal risk of developing the disease (Grinfeld, Ramirez et al. 2002). This study was conducted in the UK and researchers highlighted that these women had limited knowledge of their relative risk of developing breast cancer, of associated risk factors and of the

diversity of potential breast cancer related symptoms. The same authors found that over 70% of the surveyed women were able to identify painless breast lump, lump under the armpit and nipple discharge/bleeding as symptoms of breast cancer. Although their age group was older than my survey' participants (my study mean age is 31 years and Grunfeld' mean age is 47 years), women outside of the routine screening age group for both breast and cervical cancer will still need to be informed of the risks and symptoms of breast cancer. This is because evidence showed that 21% of cases occur in women under the age of 50 years (Grunfeld, Ramirez et al. 2002). Hence, this suggests that consideration should be given to the best way of communicating the need for continuing breast awareness among Saudi Women at earlier age of their life.

The survey also showed that participants with higher education and being employed were more likely to be aware of the importance of early cancer detection. This has been found in other studies, which similarly demonstrated that education appears to be one of the determinants of level of knowledge and health behaviour among some populations (Okobia, Bunker et al. 2006).

Majority of participants were aware of the detection methods of breast cancer (73%-83%). This is higher than those studies conducted in Middle Eastern countries such as Iran, where 61% of women knew about breast cancer screening methods (Montazeri, Vahdaninia et al. 2008). However, their mean age (43 years) was higher than my participants' age.

In my thesis, participants considered being old (60%), receiving hormonal contraceptives (29%-33.3%), and receiving hormone replacement therapy (32%-43%) as risk factors in the development of breast cancer. This is in comparison with a study that was conducted on healthy women in Europe

which showed that only 57% understood the age risk; 37% of women perceived hormonal contraceptive and 36% hormonal replacement therapy as risk of breast cancer (Pöhls, Renner et al. 2004). However, in the last study, the age of participants was more than 40 years, which is older than my study population. In the survey part, of the thesis, as well as the focus groups discussion, participants rated several factors as risk to breast cancer such as; hereditary susceptibility (60 %), nutrition (60 %), pollutants in air, plants and water (Several women in the focus groups raised these issues), being old (38 % - 47 %), smoking (47 % - 54 %), and not exercising (26 % -34 %) in both groups who live in the UK and Saudi Arabia. Almost similar findings in a study (US population) found that women endorsed the following causes of breast: heredity (84.4 %), diet or eating habits (46.4 %), pollution in the environment (57.6 %), aging (48.8%), smoking (58.3 %), and lack of exercise (35.7 %) (Wang, Miller et al. 2010). The different estimates found in the thesis might result from two main trends. First, awareness and acknowledgement of the role of these risk factors may have changed over time consistent with scientific advances. Secondly, different age groups with diverse socio-economic status might have different levels of knowledge. Women with high socio-economic status might have better access to information and possibly better understanding and intellectual ability to analyse and use information for their better health. This variety of conceptions about the causes of these cancers, are important targets for public education and risk communication efforts. Attention has turned to breast cancer prevention with researchers examining possible links between modifiable lifestyle factors and decreased risk of breast cancer (Atkinson, Lampe et al. 2004; Prentice, Caan et al. 2006).

Although no consistent evidence exists about diet and exercise, these lifestyle factors may affect breast cancer risk (Brody and Rudel 2003).

In a meta-analytical review that addressed the predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening, researchers found that women do not have accurate perceptions of their breast cancer risk (Katapodi, Lee et al. 2004), which is similar to some of my focus group participants. Katapodi' study found that they have an optimistic bias about their personal risk; however, having a positive family history, recruitment site, and measurement error confounded these results. Katapodi found that perceived risk is weakly influenced by age and education and is moderately affected by race/culture and worry. Younger women were more likely to perceive higher risk for developing breast cancer than were older women. In addition, there was an association between perceived risk and mammography screening. Studies that explored perceived breast cancer risk suggested that laywomen have a different set of beliefs about the causes, curability, and risk factors of breast cancer than health care experts (Facione, Giancarlo et al. 2000; Silverman, Woloshin et al. 2001). Such perceived risk is an important motivator for protective health-related behaviours such as accessing breast and cervical cancer screening services. However, as mention in my focus group sessions, personal experiences with mammography, especially negative experiences might influence how mammography is viewed and could control the magnitude of the relationship between mammography and perceived cancer risk. With regard to cervical cancer, majority of the participants of the focus groups centred their attention and discussion about breast rather than cervical cancer (more explanation is mentioned below). In addition, in the survey, 32%-35% were not sure of what are the risk factors for

cervical cancer. Moreover, participants' knowledge about cervical cancer, risk factors and cervical screening methods was lower than breast cancer. However, the majority identified the Pap smear test as one of the detection methods of cervical cancer (77.5 % - 84 %). This is in contrast to a similar population study, regarding age and education, conducted among women from Kuwait which showed that knowledge about the test was adequate in 147 (52.3 %) women (Al Sairafi and Mohamed 2009). The researchers also found that about 79 % of the respondents would prefer a female doctor to conduct the test, which is expected culturally and religiously among Muslim women as in other Gulf countries. Another study conducted among Arab Jordanian women showed that knowledge of cervical cancer and the Pap smear test was inadequate and 94.4% of their participants had only opportunistic testing (Amarin, Badria et al. 2008). Major barriers of Amarin's study to Pap smear test screening included inadequate knowledge about the test, not being referred by a health professional and fear of having a bad result.

Some of my participants expressed the role of husband's control and permission to go for screening and exposed her body parts to health professionals, especially male providers. This is similar to a study conducted in Serbia showing that gender roles and their overall subordinate position in the family and society influenced women's poor ability to access cervical cancer screening (Markovic, Kesic et al. 2005).

This relative lack of knowledge, risk factors and/or lower uptake of cervical screening services, might be explained by the lower prevalence of such type of cancer among Saudi female population due to environmental, cultural and genetic differences (Alsbeih, Al-Harbi et al. 2013). In comparison to the global view, the incidence of cervical cancer is very low in Saudi Arabia, rated



number 11 between all cancers in females and accounts only for 2.4% of all new cases (Al-Ahmadi, Al-Zahrani et al. 2013). HPV is widely acknowledged to be transmitted through sexual contact, which explains the epidemiological association between cervical cancer incidence and number of sexual partners (Waller, McCaffery et al. 2004), which was addressed by many of the participants during the focus groups discussion highlighting their awareness and knowledge of such risk factor of having multiple partners. This is consistent with the UK studies of women from ethnic minority groups' background found that women associated cervical cancer with promiscuity (McKie 1993; Box 1998). Moreover, in a systematic review, researchers showed that commonly held beliefs across several cultural groups emerged including the following: fatalistic attitudes, a lack of knowledge about cervical cancer, fear of Pap smear tests threatening one's virginity, as well as beliefs that a Pap smear test is unnecessary (Johnson, Mues et al. 2008).

#### **7.4 Individual and attendance of cancer screening services**

The participants were divided between those who assumed responsibility for prevention of cancer themselves (by initiating early detection screenings) and those who assigned this responsibility to doctors, to the health system, or to fate. The main facilitator to go for breast and cervical cancer screening among my participants was the fact of knowing the importance of screening. Other facilitators included: having a free screening, encouragement by their husband and family, and having easy transportation. This is in contrast to other studies, which showed that doctors' recommendation, encouragement from friends and families, presence of insurance coverage, and personal medical history such as the presence of symptoms are facilitators to attend breast and cervical

screening services (Ogedegbe, Cassells et al. 2005). In another study, among Chinese migrants in Canada, belief that Pap testing prevented cancer and general knowledge about the Pap test were associated with screening. Concern about pain/discomfort with the test, availability of time, culturally sensitive health care services and recommendation for Pap testing by a physician were also associated with screening uptake in both ways, as a facilitators and barriers (Hislop, Jackson et al. 2003). This is similar to my participants who rated lack of awareness of the importance of early detection, availability of time, taking off cloths and presence of male health professionals at the screening site as barriers that hindered them from accessing such services. This supports the need for public education and health providers' sensitivity to women's feelings and concerns prior and during the screening process.

Several participants mentioned that they would be further motivated to go for a Pap test or mammogram if a family member, husband or friend would go with them to the appointment. They stated that this would help them overcome their fears and encourage them to follow through with their appointments. Fear of having cancer was the main reason for not going for breast and cervical cancer screening services in the majority of participants in the focus groups discussion. Similarly, a study showed that severe levels of worry about getting breast cancer can act as a barrier for mammography (Andersen, Smith et al. 2003). Furthermore, it has been suggested that women of different ethnic backgrounds respond differently to breast and gynecologic cancer screening practices (Foxall, Barron et al. 2001). This was explained by differences in their body awareness, trait anxiety, and perceived risk. However, another study showed that cost, fear, and embarrassment were identified as the top barriers to breast and cervical cancer screening (Lyttle and Stadelman 2006). Hence, fear,

anxiety, and embarrassment across cultures are relatively similar. In addition, women from United Arab of Emirates (similar socio-cultural background to Saudi women) expressed similar fears and embarrassment as barrier to attend breast cancer screening program (Bener, Honein et al. 2002). Furthermore, another study conducted among Hispanic women in the US found that perceived benefits of screening were finding cancer early, and feeling good about taking care of one's health (Byrd, Chavez et al. 2007). They found also that personal barriers to having the test included embarrassment, fear, and pain. Facilitating factors fell into three categories: information/education, low cost or free tests, and supportive physicians and friends.

In an integrative review, researchers found that a major barrier in the majority of studies in the US was lack of physician recommendation. They also identified personal barriers related to knowledge and attitudes were significant in several studies (George 2000). Many women in George' study thought that mammography was not necessary if they were asymptomatic or had no personal or family history of cancer. Similarly, my participants perceive that having no family member with cancer, and lack of interest seemed to be barriers to seek for cancer early detection services. Another qualitative study in the UK, used multi-cultural samples including Arab women, showed that an individual is likely to take up screening if he/she is motivated highly about his/her health, believes he/she is susceptible to develop cancer, understands the seriousness of getting cancer, and believes the benefits of the taking time off work to take up screening far outweigh the cost of lost pay (Thomas, Saleem et al. 2005). They also identified that language could be a barrier. In addition, an interesting finding emerged among the young women within the cervical screening age range highlighted by the researchers, which might

provide one explanation of the low uptake of cervical screening. The need to subscribe to the culturally desired norm of young women entering marriage in the virginal state, and to keep up this appearance, was voiced strongly by both the Arabic and Muslim focus group participants. The authors suggested that these conditions need to be triggered by an internal (physical symptom) or external (health screening letter) cue to action.

Majority of my participants addressed the lack of knowledge of importance of cervical cancer screening test as one of the barriers to attend Pap test. Similarly, in a study conducted in Malaysia, participants mentioned that the main barriers for women to not perform Pap smear test is lack of awareness (70%), followed by shyness (52%) and the cost of the test (52%). Most agreed that the gender of the physician will affect the woman's decision to do Pap smear test (Al-Naggar and Isa 2010). Furthermore, another study among Iraqi women found that a lack of knowledge on cervical cancer (57.4%) and the Pap smear test was found among those did not have a clear understanding of the meaning of an abnormal cervical smear and the need for the early detection of cervical cancer (Osman, Al-Naggar et al. 2013). They also demonstrated that fear, pain and discomfort were barriers to Pap smear test.

Moreover, fatalistic attitudes may lead to a lack of participation in cancer screening as expressed by some of my participants during the focus groups discussion. This barrier has been expressed by women in a study that was conducted in Latin America indicating that women with the highest levels of cancer-related fatalism were less acculturated, less educated, and poorer than women who reported lower degrees of cancer-related fatalism (Otero-Sabogal, Stewart et al. 2003). Understanding of cancer-related fatalism has important

implications for the development of social marketing strategies and health education tools and for identifying specific populations to target.

In a study conducted among Iranian Muslim women, researchers found that facilitating factors for screening were self-care, fear, proactive coping, state of mind and advocacy. Barriers were negligence, cancer-related fear, low self-efficacy fatalism, misinformation, ineffective health communication and competing priorities (Lamyian, Hydarnia et al. 2007). This highlighted the differences in-between individuals and across various cultures. In recognition that not all individuals face the same barriers nor they do have the same degree of readiness to adopt behaviour such as mammogram or Pap test, some researchers adapted the trans-theoretical model, which differentiates the stages of readiness to adopt routine screening and allows for a range of positive and negative attitudes (Rakowski, Dube et al. 1992).

### **7.5 Health systems' structure and accessing breast and cervical cancer screening services**

Some participants in my study acknowledged the important role health care providers play in motivating them to get a Pap test and/or a mammogram. They noted that health care providers educating them on the examination and its purpose, along with recommending the test, would motivate them to attend screening services.

It was also noted that many participants preferred a female health professional over a male. This is particularly true in cervical cancer screening. Other motivating factors or facilitators to go for screening that are related to the health system structure were: having convenient appointment and professional cooperation when accessing screening. In addition, participants from the UK

differed in their rating of the facilitators, when completing the survey, than those who live in Saudi Arabia, which might be explained by the differences in their lifestyle and the health structure in each country. Participants in the focus groups also highlighted the advantages of National Health Services in the UK over the health system of Saudi, for example, the invitation letter, reminders to attend, and follow-up as strategies to enhance uptake of screening. However, these strategies are not yet in place in Saudi' health system. In the UK, one factor that encourages general practitioners to use different modalities to reach the target population is the payment they receive when they achieve the national target of screening in both breast and cervical cancer screening. This is not the case within the Saudi health care system. In KSA, doctors are not reimbursed and the care is left to their choice of assessment and prioritization at individual level rather than the national level. Assuring equitable treatment and care in the health and social care sector is a necessity for a world-class personalised service that the United Kingdom (UK) Government is aiming for, according to its latest policy strategies (Sallah 2011). In the UK, the practice of ethnic monitoring in health services intended to enable the provision of services without racial or ethnic discrimination (Psoinos, Hatzidimitriadou et al. 2011). National health services in the UK provide what is called ethnic monitoring that prompt the setting of targets and development of policies to address disadvantage, and eventually to improve service provision. This is obviously reflected by my participants of the focus groups who felt the quality and equity of such services in the UK with regard to breast and cervical cancer screening. Nevertheless, In the UK, the former Commission for Racial Equality (CRE), now part of the Equality and Human Rights Commission (EHRC), has been advocating ethnic monitoring since 1978 (Psoinos,

Hatzidimitriadou et al. 2011). In addition, there has been improvement of pathways to care for all ethnic groups, cultural competence training and community engagement and participation in healthcare services.

Women may also have believed that a woman's health care is her doctor's responsibility and felt no need to be proactive on her own behalf in between visits (Sadler, Dhanjal et al. 2001). This belief was interestingly also expressed from some of the focus groups participants who highlighted that the health care professionals are key factors and should advise them in doing their screening for breast and cervical cancer.

The health belief model might explain participants' understanding and knowledge of the role of various risk factors in the occurrence of breast and cervical cancers and their attitudes to screening services. Health belief model (HBM) is a social-cognitive model that has been used widely in the health literature to explain and predict behaviour (Chew, Palmer et al. 1998). The theory suggests that motivation to engage in a particular behaviour is based on three cognitive components: 1. Perceived susceptibility, 2. Perceived severity, and 3. Perceived efficacy. These three components combine to inspire an individual to change or maintain behaviour (Rosenstock 1974). Perceived susceptibility is the belief that one is vulnerable and likely to be affected by a particular health problem like breast cancer (Silk, Bigsby et al. 2006). A study suggested that women underestimate or overestimate their risk of breast cancer (Covello and Peters 2002). This could explain uncertainty about the risks for breast cancer and a desire to overcompensate for these factors by being overly optimistic or pessimistic about risks (Lipkus, Biradavolu et al. 2001). Some of the participants in the focus groups expressed their pessimistic feelings when having mammogram as if they are virtually calling the cancer to come to their

breast. Other participants, both in the survey and focus groups discussion addressed the role of hereditary factors in causing breast cancer. This was similar to a study showing that some women consider genetics to be more of a contributing risk factor towards breast cancer than lifestyle or dietary habits (Buxton, Bottorff et al. 2003). Consequently, women feel they cannot control their risk, which can result in fatalistic attitudes and decreased self-efficacy for screening as well as for treatment of cancer (Duncan 2001).

If a woman understands how critically cervical and breast cancers would affect her life, her perception of the diseases will motivate her to seek check-ups and periodic screening. When women perceive that they are all at risk of having breast or cervical cancer and that their risk of getting breast cancer is increased in the existence of family history, hormonal replacement treatment, and aging, they are more likely to be willing to undergo the screening, and act in accordance with the national health recommendations to prevent the disease occurrence. When the perception of susceptibility combines with perceived seriousness, it results in “perceived threat” (Hayden 2009). The perceived benefits demonstrate that women will adjust new behaviours when they believe that the new behaviour will protect them or lower their risk of developing a disease. If women believe that screening is important for early detection and prevention of cancer and that the chance of survival is higher if detected early, they would take part in secondary prevention practices. Women must believe there are benefits in adapting a healthy behaviour in order to change. The perceived barriers relate to women’s views of the obstacles they will face if they decide to go for the screening. In the present study, these



could be represented by, embarrassment, pain, anxiety, taking off clothes, lack of transportation, and lack of husbands' support.

Few of my participants believed that early detection of breast cancer would prevent devastating consequences, especially those who had relatives with breast cancer. A study used the HBM to measure Jordanian women's beliefs about mammography, and found that 79 % and 78 % of the women believed that mammograms would reduce chances of dying and having a radical surgery due to breast cancer, respectively (Petro-Nustas 2001). Other beliefs or even myths were expressed by some participants such as breast-feeding (or not) and having mother or relatives who had breast cancer can cause such cancer for them. This is similar to a study conducted in the US with young women, which showed many seem more concerned about the potential loss of the mother/daughter relationship. They describe their fears of recurrence of the disease as well as getting the disease themselves (Spira and Kenemore 2000). However, several of my participants perceived screening as bad omen, which might be linked to the perceived efficacy component of the HBM, which suggested the beliefs these women held that a health condition can be avoided or controlled, might be related to perceived benefits and barriers. Clarity regarding women's perceived susceptibility and severity, coupled with an understanding of how they perceive way of life and environment to be risk factors, can lead to opportunities for increasing efficacy of future screening programs. While scientists have found that the interaction of genetics, onset of puberty, eating, exercising, and lifestyle habits (e.g., tobacco use) impact the risk of breast cancer, there are still unknowns about the link between environmental agents and breast cancer (Mitra, Faruque et al. 2004). Hence, one must consider the perceptions of some women in light of the evidence and

certainty of the associations between cancers and the suggested risks. Moreover, further research is needed to confirm associations.

### **7.6 Society/culture, religion and attendance of breast and cervical cancer screening services**

Thesis results provided diversity in attitudes and beliefs, ranging from traditional to biomedical-modern, and reflecting the various ways of integration between these two belief systems. For example, some of the women believed that the evil eye might cause cancer, while others attributed cancer to the accepted modern causes such as genetic and some environmental factors. Several participants believed in individual responsibility for health; however, this was heavily stressed by the Quran. They cited this commandment in their interpretation that the body is a precious gift received from God, and the individual must take the best possible care of it. However, few deviant cases articulated a passive approach to taking care of their health. A possible explanation to this might be from the discrepancy that exists between religious precepts and traditional beliefs in Arab/Muslim society regarding health and illness. Haj-Yahia points out that despite the modernization processes in Arab society, the need to control one's world is not considered paramount by most Arabs, and many strongly believe that one's fate is controlled by God (HajYahia 1997). As few participants expressed, the perception of cancer as an unchangeable fate that cannot be prevented or cured is actually the result of ignorance of religion, and this mistaken view leads to greater passivity.

*“Islam is a way of life to live, a system to be followed, a code of ethics and a constitution to be applied in the daily life of every person” (Athar 1993) (p. 94).*

The Qur'an, the Holy book of Moslems, and the Sunnah, an account of the way of life of the Prophet Mohammed (peace be upon him), contain guidelines for a balanced lifestyle and include messages indicating that health promotion is a primary focus, while treatment of disease is a secondary focus (Rajaram and Rashidi 1999). Health is a central concern in Islam and members are encouraged to search for a cure through the teachings of the Prophet. Incorporating these Islamic health-related messages in breast and cervical cancer screening educational efforts is essential in increasing awareness and practice of breast cancer screening techniques among Islamic/Saudi women. The Prophet Mohammed stated:

*“An ounce of prevention is better than a ton of treatment” (Athar 1993) (p. 95)*

Many husbands inappropriately use Islam to defend their authority and dominance over their wives. This creates another barrier to breast as well as to cervical cancer screening practices. In traditional Arab society, with clear male dominance, the passive role of women has long been stressed and reinforced (El-Safty 2004), though this sharply depart from the principles of Islam (Rajaram and Rashidi 1999). Islam encourages the active role of women in the family and in the community. To my understanding, a process of integration is evident here too among my participants. The modern view, stressing the value of taking an active role in protecting health and encouraging women to discard their passive role, is now combined with the Islamic view on health promotion and the woman's right to take dynamic steps to promote her health. This integration was often expressed by the Saudi women in the focus groups. Most highlighted their belief that women should take responsibility for their health, although social and psychological barriers were mentioned. Hence, it was

suggested by several of the focus groups participants who explained the importance of linking the Islamic values and Qu'ranic instructions to the Western model of health care. This approach is culturally sensitive and would really help in establishing effective messages that target the Muslim/Arabs population that are always motivated and driven by their religious beliefs in every aspect of their life. In addition, some participants suggested that mosques are the preferred places where Muslims traditionally meet on daily basis (five times prayer) and on weekly basis for Friday group prayer, in order to deliver the preventive health measures such as the importance of breast and cervical cancer screening.

Furthermore, a study among Arab women in Israel expressed similar religious beliefs about breast and cervical cancer screening services (Azaiza and Cohen 2008). They highlighted their worries regarding the violation of religious and cultural requirements of modesty and a major theme on whom or what was responsible for one's health emerged. Scholars emphasized that cultures have a dynamic character with varied aspects within each cultural group, rather than a unified and fixed set of beliefs (Swidler 1986). Moreover, ethnic groups in Western countries (such as Saudi women) experience major processes of modernization, in which contemporary perceptions of health exist alongside with traditional beliefs (Angel 2000).

### **7.7 Strength and weakness of the thesis**

The main strength of my thesis is the combined approach of survey and focus groups discussion. Focus groups are an important strategy in formative research for identifying lay beliefs that are held by some females about breast and cervical cancer and the environment. They allowed for a wide range of

ideas regarding the screening services that may have not emerged through the survey data-collection techniques. In addition, the conceptual framework with its constructs (individual, institution, and culture/social) that emerged from the thesis findings might be a contribution to literature. These key constructs lay the groundwork for the improvement of health communication messages designed to increase awareness of preventative actions in breast and cervical cancer screening plans.

Strength of my thesis included also the proposed conceptual framework that composed of three ecological layers explaining the experiences, facilitators, and barriers that Saudi women believed and/or perceived when deciding to have breast and cervical screening. These levels of analysis included: the individuals beliefs, perception, knowledge and their family/husband influences, the second level explains the role of health structure and its responsibility and strategies in place that drive women's decision to go for screening, and lastly the wider cultural/religious power that underpins women' behaviour and might be the force that implicitly or even explicitly act as the decisive dynamic belief to access the screening services or not. This framework might inform future preventive and interventional strategies to enhance the uptake of breast and cervical screening and subsequently decrease overall women's morbidity and mortality.

One of the weaknesses of the survey tool was that it was developed based on the literature review and was self-administered. Although, this may limit comparability of my findings with that of other investigators, it is important to note that efforts were made to ensure some measure of validity by pre-testing the questionnaire on a convenient sample before commencement of the study (Pilot study).

These data are community-based and descriptive in nature. They cannot be considered representative of the larger Saudi female population and hence, have limited external validity. The generalizability of this study should be limited to some Saudi women; however, it might be useful to other countries with similar socio-cultural context such as Muslim/ Arab population. In addition, the fact that majority of the participants were highly educated could be perceived as a potential bias and limit the applicability of the findings to other Saudi women who are illiterate. Hence, additional studies using sampling methodology designed to result in comparable ethnic groups (in terms of age, socioeconomic status, and geographic location) are needed to distinguish between effects of ethnicity and demographic effects in multivariate analyses. Furthermore, the correlation between various variables of my thesis with the main outcome cannot be assumed to be of a cause/ effect relationship as they might be confounding factors affecting such relationships.

### **7.8 Thesis implications and recommendations**

Concerns over low uptake of cervical screening among minority ethnic women have urged much research to address the problem in an in-depth manner. However, research in this area has tended to focus on the communication insufficiency of women, without addressing the social and/or cultural contexts. This has not only hindered a wider theoretical understanding of the problem, but it has perpetuated ineffective health promotion practice in this area. Hence, there is an urgent need for promoting cervical screening to minority ethnic women in primary care in an attempt to tackle the problem by involving both health professionals and women from the communities.

Understanding the factors that influence women delay of screening services is a prerequisite for the development of strategies to shorten delays. Strong evidence suggests that older women are more likely to delay their presentation with breast cancer, although the strength of evidence for other risk factors for delay is inadequate to inform any intervention. Such factors are likely to relate to women's knowledge and beliefs about breast cancer and its management. It has been estimated that an effective screening programme may reduce mortality in the screening age group (50-64 years) by up to 25% (Blamey, Wilson et al. 2000). Women still need to be 'breast aware' and to accurately identify breast symptoms in order to receive treatment as quickly as possible. Many health professionals believe leaflets are often not read by the target audience (Murphy and Smith 1993). Therefore, any future campaign will need to make explicit the significant risk that breast cancer causes for women and join the more traditional leaflet approach to health education with other educational mediums such as television and radio broadcasts and individually tailored advice from health professionals. Health education should be also directed through women friendly organizations such as primary care clinics, hospital antenatal and postnatal clinics, and religious organizations as suggested by some participants from the focus groups. Furthermore, an ethical imperative for any health message is to include an efficacy element so that message receivers believe that they can reach the recommended behaviour, which is attending early detection clinic). Current research on useful health messages suggests risks should be described in a range of ways and shown in visual formats to complement interpersonal messages (Covello and Peters 2002). One strategy might be addressing stories of happy ending for those who had been screened and survived their cancers. This can be done by providing

brochures about the importance of early detection and happy ending stories are both needed to be spread in mosques, workplaces and media. The demand for knowledge, information and education from many of participants, in particularly of cervical cancer, had contributed to the solutions that they proposed to problems of poor communication and negative perceptions. Such information may be used to develop tailored breast and cervical cancer education programs for Saudi women. In addition to finding solutions to access barriers, the ultimate goal of research in order to increase cancer-screening efforts should focus on ways to decrease knowledge gaps for all women who are not screened, so they can advocate for themselves and make informed decisions about breast and cervical cancer screening.

Thesis results suggested that the focus should be to address the system and this would make more sense than trying to change the way women feel about breast and cervical cancer screening. If caregivers were better trained to put women at ease, to guard women's privacy, and to do a vaginal exam without causing unnecessary pain, then these very valid barriers would be easier to overcome. Intervention aimed at women themselves might encourage having a friend or husband go to the exam with them, or educate women to better communicate their fears and embarrassment to caregivers. Interventions should also be developed for men so that they can better understand and be insightful of what the screening tests are all about and the importance of finding early changes in order to prevent or even treat breast and cervical cancer. This could be done through media, men's workplace and mosques where men mostly go for five times a day for their prayers.



The ecological conceptual framework (Figure 13) abstracted from thesis results could be used to provide cues for action work at multiple levels to influence or enhance a woman's likelihood of accessing breast and cervical screening services. This is particularly an urgent imperative in Saudi Arabia rather than the UK, because literature showed that in the UK there are already effective and focused efforts to tackle low screening uptake among minority/migrants population. Moreover, one must carefully consider not only theory but evidence when planning for adoption, implementation, and maintenance of potential future efforts to enhance screening tests.

At the individual level, I suggest that health care providers' recommendation could be more effective if tailored to individual women's specific perceptions about the screening test and their cancer risk factors. Using conceptual approach to plan programs to enhance women's uptake of screening services aims to reduce barriers to access and increase delivery of these services by health care providers. For example, using reminders by mobile messages or in-print found to increase the median of completed mammogram by 14% (Baron, Rimer et al. 2008). However, individual reminders should be applicable across a range of settings and populations, provided they are adapted to target populations and delivery context that are sensitive to women's cultural values. Reminders should be framed to empower women addressing the need of them to take care of their own health.

Other methods that can be applied include mass media such as television, radio, newspapers, and magazines to communicate educational and motivational information in community or larger-scale intervention campaigns. At a lesser scale, small media including videos, brochures, pamphlets, flyers,

or newsletters can be distributed through community health care settings that communicate educational or motivational information to encourage cancer screening in Saudi population. Messages might describe screening tests and procedures and include indications for, benefits of, and ways to overcome barriers to screening. These messages also need to be tailored to address the unique cultural/religious characteristics of Saudi women relating the Islamic values of prevention of diseases and the responsibility of Muslims towards their health.

Health system-based interventions targeting women and health care providers or both could be developed based on this framework, however, this needs efficient resources, infrastructure, training, and support for health workers to ensure maintaining such services. Nevertheless, there is a need to evaluate and assess the effectiveness, applicability, economic efficiency, barriers to implementation, and other harms or benefits of such interventions to increase screening for breast and cervical cancer. Another strategy is the use of a mobile screening unit that has been proved to be a useful strategy (Mauad, Nicolau et al. 2009). In Saudi Arabia, Ministry of Health (MOH) is piloting such strategy currently in Riyadh (personal communication) using portable mammographic machine as an out-reach service screening for breast cancer.

At the society level, researchers have helped in explaining the process by which innovations, such as health promotion programs, are diffused through communities (Steckler 2002). However, a gap continues to exist in translating research findings into evidence-based public health practice. One suggestion is to use community-based agencies such as religious societies in Saudi Arabia who could work together with local public health officials and clinicians to increase use of primary and preventive health care services. This collaborative

agreement with these community agencies outside the traditional public health infrastructure opened new ground for public partnerships to improve access to women in need of breast and cervical cancer in Saudi Arabia. Such intervention need to be consistent with the economic, socio-cultural, and philosophical value system of the MOH.

The above proposed theoretical plan could be applied at a small scale to test its practicality and acceptability to the MOH. Yet, the potential benefits of such programs are limited by their adoption, implementation, and maintenance by the community, public health, and clinical practice settings. This needs funding, expert knowledge, and implementation protocol. In addition, training, technical assistance, and comprehensive instruction for each task are important activities that would help in the implementation process. Furthermore, evidence of the program success should include quantitative and qualitative assessment and evaluation to be conducted and submitted periodically to ensure its quality and continuous funding by MOH.

In a recent editorial in the British Medical Journal (BMJ), titled “too much mammogram”, the author highlighted that the rationale for screening by mammography should be urgently reassessed by policy makers. As time goes by we do indeed need more efficient mechanisms to reconsider priorities and recommendations for mammography screening and other medical interventions (Kalager, Adami et al. 2014). This is because new evidence showed that long term follow-up does not support screening women under 60 (Miller, Wall et al. 2014).The study revealed that no difference in breast cancer mortality was observed between the mammography and control arms, whereas a significant excess incidence of invasive breast cancer was observed in the mammography arm, resulting in 22% over-diagnosis. This means that

22% of screen detected invasive cancers would not have reduced a woman's life expectancy if left undetected. This study was conducted in Canada and might not be applicable to other populations with variable ethnic origin.

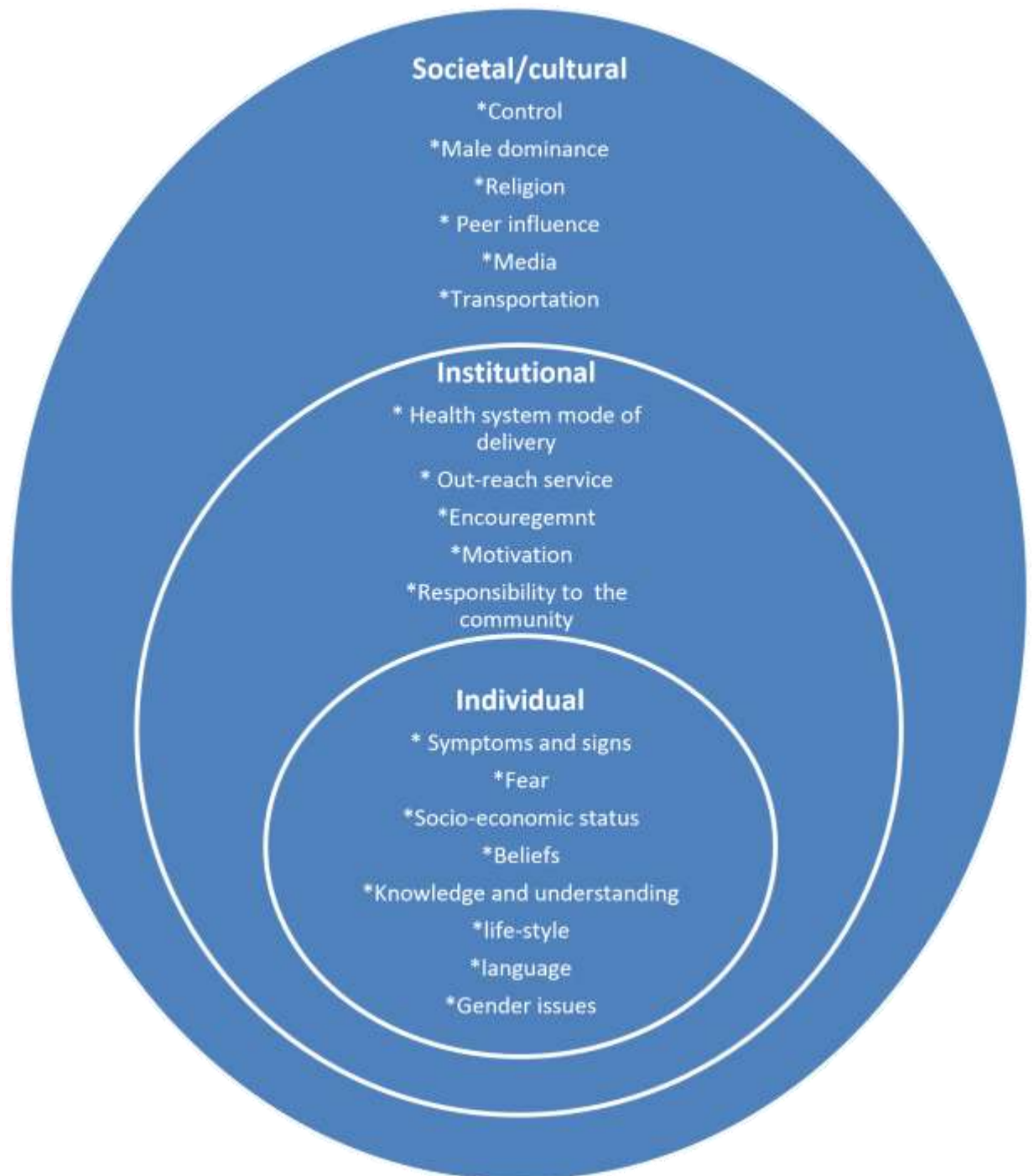


Figure 14: Ecological conceptual framework of facilitators and barriers when accessing breast and Cervical cancer screening services

## **7.9 Conclusion**

While the data reported in this thesis are encouraging, rich and diverse, conclusions must be drawn with caution. This was a self-selected, convenience sample, drawn from Saudi women living in the UK and Saudi Arabia. In fact, it might be overrepresentation of actual screening knowledge, beliefs, and behaviours since the impressions were that the more acculturated and better educated women might tend to consent to study participation.

Important barriers included health and cultural beliefs and attitudes, language and unsupportive attitudes of health professionals. A majority of Saudi participants believed educational programs would increase breast and cervical cancer awareness and knowledge and use of screening services. The health belief model was utilized to structure and explains the thesis findings and analysis.

Recommendations for the improvement of cancer prevention programmes include targeting understanding of lifetime risk of /survival from breast and cervical cancer, age as a risk factor for breast cancer, or hormonal factors. There is a need to separately address the perceptions of women depending on age, social status, cultural background, and educational levels. For policy makers who are interested in promoting education and intervention strategies to enhance breast and cervical cancer screening uptake, understanding the different ways in which the general public and health professionals perceive risks is imperative. Future research is fundamental to understanding audiences and identifying what activities and message content should be included in a screening campaign plan for breast and cervical cancers.

The very positive beliefs in informed decisions and personal choice must be integrated into the attitudes and practices of healthcare professionals through continuing professional development. The culture of the healthcare system should be developed to support these beliefs. The Saudi participants' strong personal faith in God and His actions through the provision of health care should be encouraged actively and supported by the healthcare system and health promotion programs, whereas any trend by the subjects to accept their fate passively must be sensitively modified through education. Health promotion messages must be personalized to the strong Muslim faith of these women and should support the Muslim concept that God wishes people to take responsibility for them-selves. Furthermore, the husband and family support felt by the majority of participants is a very positive aspect of their attitudes and should be supported by the screening program and healthcare system. Cooperation between researchers, community leaders, health care professionals, and policy makers is important to ensure the appropriateness and success of educational and outreach campaigns aimed at increasing screening uptake of both breast and cervical cancer.

After completing my thesis and achieving its objectives, I wish I could do it differently using different sampling approach. For example; I would select my participants randomly rather than conveniently, as this will increase the generalizability of the findings to the Saudi population. I would also hope to use a validated and reliable survey questionnaire that has been used in similar and Arabic culture. Moreover if I have the chance to do the study again, I might include breast and cervical cancer patients, although the process of ethics will be longer and more complicated, but I think this will add more strength to the outcome of the study, when publication is needed. In addition,

if I had the chance to continue with the work, I would like to have men's perspective and views about breast and cervical cancer screening, especially among Saudi women who are controlled and influenced by their men.

## Appendix

### Appendix 1: Summary of studies included in the introduction chapter as evidence to justify using risk factors

#### Evidence from literature of the risk factors of breast cancer

Factors	Literature
Being older	Office for National Statistics, 2010, ISD Online, Horner, MJ, 2006, Brian E. 2003 Statistical Information Team, Cancer Research UK, 2009
Being poor	ISD Online., 2004 American Cancer Society, 2005-2006 Mandelblatt et al, 2000 K E Heck, 1997
Not using breast feeding	Collaborative Group on Hormonal Factors in Breast Cancer, 2002Layde, PM. 1989
Assisted fertility	Venn, A. 1995 Ferlay J, Shin HR, Bray F, et al. GLOBOCAN 2008, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 10 [Internet]. Lyon, France: International Agency for Research on Cancer; 2010. Available from: <a href="http://globocan.iarc.fr">http://globocan.iarc.fr</a> . Accessed February 2013 Jemal. A, Bray. F, Melissa M, et al. Global cancer statistics. (2011) <b>61:(2),69-90</b>
Contraceptive pills or injection	Collaborative Group on Hormonal Factors in Breast Cancer, 1996 Jemal. A, Bray. F, Melissa M, et al. Global cancer statistics. (2011) <b>61:(2),69-90</b>
Use of hormone replacement treatment	<b>Ross</b> ,R, et al, (2000), effect of hormone replacement therapy on breast cancer risk: estrogens versus estrogens plus progestin. JNCI J Natl Cancer Inst; 92(4): 328-332. Anderson, G; Judd, H; Kaunitz, A and et al, (2003), effects of Estrogens Plus Progestin on Gynaecologic Cancers and Associated Diagnostic Procedures. The Women's Health Initiative Randomized Trial. JAMA; 290(13):1739-1748. Parazzini, F 1997, Atalah, E. 2001, Frisch, M. 1999 Collaborative Group on Hormonal Factors in Breast Cancer 1997
Hereditary factors	Key, T. (2003)
Not having children	Hajian-Tilaki KO,2010



Evidence from literature of the risk factors of cervical cancer

Factors	Literature
Being older	Ferlay, J. 2002 Press, L. 2004 Hemminki, K. 2001
Being poor	Cancer Research UK, 2008 Brown, 1997
Having sex at younger age	<u>Wang, X.</u> 2010
Assisted fertility	<u>Aust, T.</u> 2007
Contraceptive pills or injection	<u>Kiley, J.</u> 2007 <u>Merchant, RC.</u> 2007
More sexual partners	<u>Health Commun.</u> 2010 <u>Thompson, M.</u> 2010 <u>Levin, AO.</u> 2010
Use of hormone replacement treatment	Lacey, 2000; Parazzini, 1997, Atalah E, 2001, Frisch, M 1999, Netherlands, S. 1997
Hereditary factors	<b>Henry T.</b> 1998
Not having children	<u>Janssen, PG.</u> 2009 <u>Beijing.D.</u> 2010

Evidence from literature of the barriers of breast and cervical cancer

Barriers	Literature
Taking off clothes	<i>Waller, J.2009</i>
Religion issues, time consuming, laziness and neglect, lack of encouragement from family and husband and transportation	<i>Cohen, M. 2008Parsa, P. 2006</i>
Far appointment date and expensive charge	<i>Amarin, Z. 2008</i>
Fear to have it	<i>Szarewski A,2009</i>
Don't know where to go, lack of knowledge of the importance of medical investigation	<i>Maha S. 2008</i>

Evidence from literature review of the facilitators of breast and cervical cancers

Facilitators	Literature
Free of charge	<i>Amarin, Z. 2008</i>
Great health professionals, easy transportation, encouragement from family and husband and knowing the importance of the investigation	<i>Parsa, P. 2006</i>
Easy appointments	<i>Amarin, Z (2008)</i>

Appendix 2: Summary of studies included in literature review

Study ID	Aim/ country	Method	Findings	Conclusion
Breen 2010	Addresses whether differential access to care for immigrants and non-immigrants is associated with different cancer test rates. Mexican American	Survey	Language was a barrier to access screening of breast and cervical cancer	Understanding barriers specific to subgroups is key to developing appropriate policy and interventions to increase use of cancer screening exams
Anagnostopoulos 2012	To determine the factors that are associated with women's mammography behaviours, Greek	Survey	Perceived serious consequences of breast cancer, and strong beliefs about treatment control, were correlated with more benefits of mammography screening, fewer barriers to mammography screening, and higher self-efficacy. A less coherent understanding of the disease was related to more perceived barriers to mammography uptake and less perceived benefits of mammography screening. Strong negative emotional representations were associated with higher self-efficacy and fewer barriers to mammography screening.	Findings may be used to develop and implement interventions aimed at reducing perceived barriers, enhancing perceived benefits, and modifying negative emotional responses to breast cancer, in order to increase the likelihood of mammography utilization and motivate women to start undertaking mammography screening.
Meissner 2009	investigates the relationship between patterns of health behaviours and the use of cancer-screening tests while controlling for socio-demographic and health system factors, US	Cross-sectional	Health behaviour patterns, age, educational attainment, usual source of care, and health insurance were significantly associated with the use of breast, cervical, and colorectal cancer screening	This suggests potential for addressing cancer screening in the context of multiple behaviour change interventions once barriers to health care access are removed.

Continue; Appendix 2: Summary of studies included in literature review

Study ID	Aim/ country	Method	Findings	Conclusion
Saadi 2012	assess the perspectives of Iraqi women refugees on preventive care and perceived barriers to breast cancer screening, Iraqi refugees in Chelsea	Qualitative interview	Psychosocial barriers, culturally mediated beliefs, and health consequences of war impeded Iraqi refugee women's ability and motivation to obtain breast cancer screening, pointed to reliance on God in preventing illness, Preventing disease was seen as the function of nutrition and cleanliness, not doctors, fear of pain during mammography and fear associated with receiving a cancer diagnosis, their Muslim faith complemented rather than obscured their health-conscious efforts, System barriers such as insurance and transportation were the least commonly reported	To improve cancer prevention and decrease disparities in care in this most vulnerable population, culturally appropriate health education and outreach programs, as well as further community-level targeted studies, are needed
Wu 2010	To gain a better understanding of issues that may prevent women in American Samoa from using available cancer screening resources, Samoan American	4 Focus group discussion	Professional women were more aware and had higher utilization rates of age-specific screening services. Barriers to health care services included lack of awareness and fears regarding poor confidentiality, rely on "God's will" for a cure	Highlight the further need for outreach and education about female cancers.
Waller 2009a	To explore barriers to cervical screening attendance in a population-based sample, UK	Survey; face to face interview	barriers were embarrassment, fear of pain, worry about what the test might find, not being sexually active and not trusting the test	Practical barriers were more predictive of screening uptake than emotional factors such as embarrassment. This has clear implications for service provision and future interventions to increase uptake
Amarin 2008	To investigate attitudes and beliefs that affect a woman's decision to undergo cervical smear screening, Jordan	Survey	Knowledge of cervical cancer and the Pap smear test was inadequate in less-educated and older patients, Major barriers to Pap smear screening included inadequate knowledge about the test, not being referred by a health professional and fear of having a bad result.	There is need to increase awareness about Pap smear testing and to strengthen the existing health care infrastructure to be able to perform smears

Continue; Appendix 2: Summary of studies included in literature review

Study ID	Aim/ country	Method	Findings	Conclusion
Wu 2008	to identify and compare their differences in perceived barriers for mammography screening, Asian American	Cross-sectional self-administered questionnaires: closed and open-ended Qs quantitative and qualitative analysis :	Barriers: “lack of time,” “scheduling,” “location”   “poor facility,” pain, feeling uncomfortable, lack of insurance, Fear of finding cancer, culture a barriers (male doing the screening)	Recognizing similarities and differences in the barriers among demographic variables such as ethnicity, age, and length of U.S. residency among Asian subgroups can assist health professionals to address their needs when promoting adherence to mammography guidelines.
Parisa 2006	Literature search to identify factors that are barriers to breast cancer screening among Asian women./Iran/Asian literature review	Surveys and qualitative studies.	The findings provide evidence supporting the importance of knowledge, perception and socio-demographic barriers in women's decision on uptake of breast screening	Asian women’s participation in BCST needs to be empowered and motivated to actively participation by 1. Providing adequate information on BCST 2. Health care providers should consider a woman’s feelings about clinical breast exams and mammography to minimize their negative feeling and reduce anxiety 3. Government could raise the consciousness about the impact of patriarchal influence on women’s health/illness experience Increase cultural competences allow for effective communication and promote women’s participation in BCST
Al-Naggar 2010	to explore the   perceptions of medical students regarding the Pap smear test/ Medical student/ Malaysia	Qualitative/ three focus s group/ male and female	Main barriers for women to not perform Pap smear. Test is lack of awareness (70%), followed by shyness (52%) and the cost of the test (52%) Most agreed that the physician’ gender will affect the women decision. All mentioned that this advantage of a regular Pap smear test is to detect the early abnormality Some of the participant (39%) mentioned that the disadvantages are expense, possible injury in the vagina due to the test) procedures (35%), associated infection (30.4%) and pain (30.4%) The majority, (87% mentioned that the most effective prevention methods for cervical cancer are having sex only after getting married with the spouse only, HPV vaccination 15(65%) and Pap smear 14 (61%)	The main barriers for women to not perform Pap smear test is lack of awareness, shyness and the cost of the test. Gender of the physician will affect the women decision to do Pap smear test.

Continue; Appendix 2: Summary of studies included in literature review

Study ID	Aim/ country	Method	Findings	Conclusion
Sach 2009	to discover whether male and female perceptions of cancer and of screening differed/ UK	Postal survey (anonymous questionnaire)	Women were less likely to underestimate overall cancer incidence. Regarding risk factors women were more likely to rate excessive alcohol and family history as major risk factors. The majority of respondents believed the public health care system should provide cancer Screening, women reported having benefiting from the nationally provided screening services. Those who were older, in better health or had longer periods of formal education were less worried about cancer than those who had illness experiences, lower incomes, or who were smokers	Our results suggest that men's and women's differential knowledge of cancer correlates with women's closer involvement with screening. It is important to understand gender-related differences in knowledge and perceptions of cancer, if health promotion resources are to be allocated efficiently.
Sait 2009	To assess the knowledge, attitude, and practices related to cervical cancer screening, and its underlying aetiology and preventive measures among women living in the Kingdom of Saudi Arabia / KSA	Survey	The knowledge of the human papilloma virus (HPV) as an etiological agent for cervical cancer was expressed by (14.4%), and the HPV vaccine by (9.8%) of the respondents. Whereas, (67.6%) of the respondents were aware of the Pap smear, however, only (16.8%) had undergone the test. The main reason for not having a Pap smear was the lack of awareness.	The awareness on cervical cancer among women in Saudi Arabia is far behind that in the developed countries. There is a need to educate and promote awareness of cervical cancer in this population
Amin 2009	To assess level and determinants of knowledge about risk factors and utilization of screening methods used for breast cancer early detection among adult Saudi women in Al Hassa, KSA.	cross-sectional descriptive	Overall level of knowledge regarding risk factors and appropriate screening was low and dependent upon educational and occupational status. Early screening is underutilized among participants due to several perceived barriers. Clinical breast examinations were employed by less than 5% and mammography by only 3% of cases. A positive family history was found in 18% of cases among first and second degree relatives, and 2 % had a prior history of benign breast lesions.	Included women, irrespective of their educational status, had knowledge deficits regarding breast cancer risk factors and underutilization of the recommended breast cancer screening. Several barriers are contributing to such knowledge deficits and screening behaviour

Continue; Appendix 2: Summary of studies included in literature review

Study ID	Aim/ country	Method	Findings	Conclusion
Alam 2006	To assess knowledge of breast cancer and sources of information about breast cancer among women in Riyadh. We also analysed whether associations existed between demographic variables, knowledge of breast cancer, and the practice of breast self-examination and use of mammography Screening. KSA/Riyadh	survey	84% of participants were Saudi, 45% were married and 67.8% had a university level education. Eighty percent were between the ages of 20 to 50 years. Knowledge of breast self-examination (BSE) was high; 82% (95% CI: 79.2%-84.4%) knew about BSE, while 61% (95% CI: 57.9%-64.5%) knew about mammography, but only 41.2% (95% CI, 37.9%-44.5%) had performed BSE and 18.2% (95%CI, 15.5%-20.8%) had had mammography screening. Knowledge of breast cancer, risk factors and protective factors for breast cancer was moderate. There was a statistically significant association between the demographic characteristics (marital status, educational status and family history of breast cancer) and knowledge and practice of BSE	Though it has limitations, this study revealed an imbalance between the knowledge and practice of BSE among women. It also showed that there is only moderate knowledge of risk and protective factors for breast cancer and that knowledge and practice of BSE and mammograms vary according to marital and educational status. Hence, frequent community-based awareness programs are needed so that all women can know and practice BSE, which in turn helps to prevent breast cancer
Jahan 2006	to determine the knowledge, attitudes and practices of women in Qassim region regarding breast self-examination (BSE), and also to explore their level of knowledge regarding breast cancer. KSA/Qassim	Survey	The mean age of the participants was 36.2 +/- 10.2 years, and 70.7% of them were literate. Regarding the knowledge of risk factors, 76% of the respondents had 3 or more correct answers out of the total 7 questions. Twenty-six percent of the respondents did not know the presenting symptom of breast cancer. Whereas, 69.7% of the participants had never heard of BSE. The participants had a positive attitude towards learning BSE. Of the total respondents, 18.7% reported that they practice BSE, majority (57%) of whom had started performing it within the previous year. However, 74% of the respondents did not have access to breast health information	The level of awareness of the females of Qassim region regarding breast cancer and BSE is not adequate and a health education program for this subject should be introduced in the region.

Continue; Appendix 2: Summary of studies included in literature review

Study ID	Aim/ country	Method	Findings	Conclusion
Kawar 2009	to describe relationships among knowledge, affect, attitudes, including cultural beliefs, about breast cancer screening (BCS), and health habits to BCS/ USA/Jordan and Palestine	Survey	The study shows correlations among knowledge, affect, utility, general health habits, and participation in BCS consistent with previous research in non-Arab samples	Measures of the relationship of cultural factors to BCS participation need refinement. Future research related to BCS among Jordanian and Palestinian women can build on the results of this study
Petro-Nustas 2001b	assesses the beliefs held by a group of young Jordanian women toward mammography utilization as a screening procedure for breast cancer/Jordan	Survey/ The Health Belief Model (HBM) is the theoretical framework of this study	The overall results indicated favourable beliefs toward the use of mammography, coupled with the majority of women (76%) voicing their agreement with the overall benefits of mammography, and 24% were either not in agreement with or unsure about these benefits. Although about half of the sample (49%) perceived barriers to utilizing mammography, the vast majority (85%), reported an overall agreement with the statements of the health motivation subscale. There were no significant differences in women's beliefs as a function of their subgroups of age, education, or insurance status. Nevertheless, when compared with a group of older women who had undergone mammography, significant differences (in favour of the older group) were reported between the two samples, especially in terms of the responses given to selected preventive statements such as "wanting to discover health problems early" ( $t = 2.27, p = .024$ ) and "eating a well-balanced meal" ( $t = 1.92, p = .05$ )	Implications for nursing practice, such as recognizing culturally specific barriers and enhancing health education programs to trigger mammography utilization, were addressed



Continue; Appendix 2: Summary of studies included in literature review

Study ID	Aim/ country	Method	Findings	Conclusion
BANNING, M. 2011	This literature review aimed to explore Black women's perceptions of breast health and factors that influence breast cancer screening practices/UK-US	Review Article for the period 1994 to September 2009 Key words used included: breast cancer, breast health, African American women, Black British women, black women, breast cancer screening, qualitative studies.	Results: Black women hold a variety of views and perceptions on the risk that breast cancer poses. These perceptions are strongly related to existing knowledge, related stigmatization, spiritual and religious beliefs, all of which can adversely influence motivation to engage in self-breast examination and breast cancer screening.	US based studies identified several influential factors: religion, educational awareness of breast cancer screening, breast health awareness. Breast health interventions and research are needed to increase breast health awareness in Black British women
BANNING, M. & HAFEEZ, H. 2009	This study aimed to investigate the perceptions of Pakistani Muslim women in relation to the aetiology of breast cancer and impressions of breast health. The study took place in Lahore, Pakistan	Questionnaire and focus group interviews to investigate women's Perspectives on breast health. Data was collected over a period of six months, quantitative data was analysed using descriptive statistics and qualitative data was analysed using thematic analysis	Women generally were aware of the term breast cancer but were unsure of its aetiology. The questionnaire data revealed that women were aware of both mammography (55%) and breast self-examination (BSE) (77%). In comparison, the majority of women attending the focus group interviews had limited exposure to mammography. Although women had heard of mammograms they were unaware of breast cancer screening procedures	Even though there is a desire amongst women to engage in BSE by being taught the necessary technique and specific pathological changes to look for, there is a strong cultural opinion that breasts are private organs that should not be discussed publically. In view of this and the frequency of breast cancer in Pakistani Muslim women, it is essential that breast awareness campaigns are implemented by health care professionals such as breast cancer nurses, midwives and medical practitioners to explore the concept of BSE and breast cancer. Selective health education can educate women and lead to changes in health behaviour

Continue; Appendix 2: Summary of studies included in literature review

Study ID	Aim/Country	Method	Finding	Conclusion
BANNING, M. & HAFEEZ, H. 2010	Aim is to investigate the impact of culture and psychosocial issues on breast health awareness/ Lahore and London	Focus group interviews were used	Four themes emerged from the interviews: knowledge and factors associated with breast cancer, the image of the breast, knowledge of breast cancer screening, and measures that can be implemented to improve breast health awareness	Women based in Lahore were more inquisitive about breast cancer and held more developed views compared with British Pakistani Muslim women. Women concurred that concise and relevant breast health education is needed irrespective of faith to improve cultural sensitivity and awareness in both Pakistani
DEURASEH, N. 2006.	This article attempts to study the book of medicine ( <i>kitab al-tibb</i> ) in <i>Sahih al-Bukhari</i>	The book of medicine appears in the book 76 which consists of 58 chapters with 105 traditions (hadiths)	The book of Medicine ( <i>kitab al-tibb</i> ) gives primarily idea on the conditions of Muslims in the time of Prophet (s.a.w), how did they prevent and treat the disease. Preservation of health should be the primary object of medicine in which a physician has to give, and not the 'disease'.	It is found that most of <i>al-tibb al-nabawi</i> is preventive medicine ( <i>al-tibb al-wiqā'i</i> ) rather than therapeutic medicine ( <i>al-tibb al-`ilaji</i> ), and has been practiced in the time of the Prophet (s.a.w) and even after. Author highlighted that if we wish to have a complete account of Prophetic medicine, we shall not be satisfied by referring to the writing of traditionalist scholars in the past without referring to new discoveries made by the researchers after the demise of Prophet
Husain F.Nagamia	Examining the body of knowledge about Islamic Medicine mainly from its historical, scientific, therapeutic, and application view-points	Monograph	The definition of Islamic medicine depends on the perspective. The context can be historical, cultural, scientific, pharmacological, therapeutic, religious or even a geo-political	There is a challenge in adaptation of Islamic medicine to modern day needs. The roles of Islamic and Modern Medicines needs to be defined, each needs to be studied in depth and in light of each other progress, and each needs to be supplemented so that humanity can benefit from the good of each

### Appendix 3 participants' invitation letter

Barriers and facilitators to breast and cervical cancer screening services: a comparative study of Saudi women in the UK and Saudi Arabia.

#### **Invitation letter**

#### **Dear Participant**

We are writing to ask if you would like to take part in our study. We enclose an information sheet, with this letter, describing the study and what we hope to find out, and what we need you to do to help.

If you decide to take part, we would be grateful if you would sign the consent form and return it to us either with the questionnaire or at your focus group/interview session.

Our study team will be very happy to help you if you have any questions about this.

If you would like any further information regarding this study, please do not hesitate to ask and contact us at any time.

All information we collect about you will be treated in strictest confidence, and your privacy will be protected.

**Yours sincerely,**

**Mrs Nahid Batarfi**

## Appendix 4: Information sheet

### Barriers and facilitators to breast and cervical cancer screening services: A comparative study of Saudi women in the UK and Saudi Arabia Information sheet

We would like to invite you to take part in a new research project, before you decide whether to participate in this study, we would like to tell you why the research is being done and what it will involve, please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to contact us if there is anything that is not clear. Our contact details are at the end of this information sheet. **What is the study about?**

We would like to find out about the problems you may face in accessing Breast and Cervical cancer services provided by Ministry Of Health, by understanding any difficulties you may have, we hope to be able to help women manage services better in the future.

If you agree, we would like to spend some times with you either at the focus group discussion or by answering the question in the questionnaire attached, we will ask you about your response to the screening services, knowledge, awareness, barriers and facilitators to breast and cervical cancer screening services; this will take about 30-40 minutes in the focus group and 10-15 minutes for the questionnaire.

You are not being asked to attend for examination or have any test.

#### **Why I have been chosen?**

You have been approached because you are Saudi who have not diagnosed with cancer at any stage of your life, within the target age group-over 18 years old, living in Saudi Arabia or the UK.

#### **Do I have to take part?**

No, taking part in this study is entirely voluntary. It is up to you whether or not to take part. You are free to withdraw at any time and without giving any reasons.

#### **What will happen to me if I agree to take part?**

If you are happy to take part, firstly, you will be asked to fill the questionnaire attached, then kindly return it to the researcher. Focus group sessions will be scheduled in the future for the same objective and this is to digging more about difficulties you may face in accessing the screening services of breast and cervical cancer, if you would like to attend this focus group session you should contact us to pick the suitable date and time for you, before the focus group session you will sign a consent form.

The session will take between 30-40 minutes, it will include voice recording and the comments about your response will be written.

#### **Will my taking part in the study be kept confidential?**

All of the collected information will be kept strictly confidential. Analyses of the data you provide will be done anonymously, and any publication of our findings will not contain any information through which you or any other study member may be identified.

#### **Who has reviewed and fund the study?**

The study will be checked by the University of York, it is part of a doctoral research programme.

#### **How can I get the study result?**

You can contact one of investigators using the provided information; an e-copy of the abstract will be sent to you.

#### **In case you are not interested to participate**

If you are not interested to participate, you can help us by referring these documents to those you know could be interested in filling the questionnaire or attending a focus group sessions, if you don't know or don't want to take part by anyhow, don't worry all you can do is to return all documents to the researcher again including questionnaire and this information letter.

#### **Contact information**

Mrs.NahidBatarfi      [batarfina64@gmail.com](mailto:batarfina64@gmail.com)      00447748185171/00966503352771

Dr/ Samia Al-amoudi      [Dr.samia\\_amoudi@hotmail.com](mailto:Dr.samia_amoudi@hotmail.com)00966505626441/00966-26396812

## Consent Form

**Title of the project:** Barriers and facilitators to breast and cervical cancer screening services: a comparative study of Saudi women in the UK and Saudi Arabia.

**Name of lead Researcher:** Mrs Nahid Batarfi

**Supervisors:** Prof. Karl Atkin, Dr Mona Kanaan and Dr Rob Newton

I confirm that I have read and understand the information sheet given to me by the researcher Nahid Batarfi and have had the opportunity to ask questions for the above study

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason

I understand that relevant section of my demographic data and any data collection during the study may be looked at by responsible individuals from York University

I give permission for study team to have access to the information I gave in the questionnaire and information recorded during the focus group/interview session

I am happy to answer a questionnaire about my knowledge, opinion and attendance at the screening clinic of the breast and cervical cancer.

I know that my voice has been recorded during the focus group

Print your name;

Signature and date;

## **Barriers and facilitators to breast and cervical cancer screening services: a comparative study of Saudi women in the UK and Saudi Arabia.**

### **What is the study about?**

The study is asking women what they think about screening services for breast and cervical cancer. It wishes to compare the experiences of Saudi women living in UK and those living in Saudi Arabia. The research is as part of a doctoral programme.

### **Who will see my answers?**

Only the researcher will see your responses. These will not be revealed to anyone else, the information you give is totally confidential.

### **How long will it take?**

This questionnaire will take around 15 minutes to complete.

### **What is the topic of the questionnaire?**

The questionnaire is divided into five sections;

**Section 1:** An introductory section asks some background details about who you are. This information will enable us to compare the responses of different types of people.

**Section 2:** The next set of questions explores common perceptions about the cause of breast and cervical cancer.

**Section 3:** This section explores your knowledge of breast and cervical cancer services.

**Section 4:** These questions ask about your experience in accessing breast and cervical cancer services.

**Section 5:** The final sets of questions ask for your views on how to improve screening services. Each section is divided into two parts; one set of questions explore breast cancer, while the other explore cervical cancer. To help make it easier to complete the questions, questions on the different cancers are placed side by side.

### **How should I response?**

Please read each question carefully and tick the response, you most agree with. If you do not know the answer to any question please do not worry; simply tick the 'not sure' box. If you think that the question doesn't apply to you, please write "not applicable" in the "other please specify" box. In some questions you may enter more than one answer and you can add any other comments as you go along. Remember, there are no right and wrong answers,

### **What if I need further information?**

If you are still not sure what to do or have any questions or any worries, please refer to the information sheet again or contact Dr Al-amoudi, Dr Rob Newton or Mrs Batarfi, their contact details are listed at the end of the questionnaire and in the information sheet.

**Section (1); About You**

1. Age (in years)

2. City of Residence:

3. If you are living in the UK, how long have you been there?  
(Please state number of years)

**4. Occupation**

Government employer  Unemployed

Self-private employer  Student

Other (please specify) \_\_\_\_\_

**5. Education**

No formal education  High school

Primary school  University and above

Elementary school (middle)

**6. Marital status:**

Married  Divorced

Single  Widowed

Other (please specify) \_\_\_\_\_

7. How old were you when you got married? In years

**8. Do you have children?**

Yes  No  (go to Q 10)

9. How many children do you have?

**Section (2); Perceptions of breast and cervical cancer**

**(A). Lifestyle**

**10. Which of the following lifestyle issues may affect the occurrence of breast cancer?**  
(You can tick more than one box)

**Breast**

Smoking

Lack of exercise

Obesity

Poor diet

Not sure

**Cervical**

Smoking

Lack of exercise

Obesity

Poor diet

Not sure

Other (please specify) \_\_\_\_\_

**(B). General information about breast and cervical cancers**

**11. How well informed do you feel you are about the breast and cervical cancer?**

**Breast**

Very well informed

Reasonably well informed

Not well informed at all

**Cervical**

Very well informed

Reasonably well informed

Not well informed at all

**12. From where have you got the information about breast and cervical cancer?**

(You can tick more than one box)

**Breast**

Media

Family

Friends

School or work

Health Professionals

Other specify \_\_\_\_\_

**Cervical**

Media

Family

Friends

School or work

Health Professionals



**13. In your view is the breast and cervical cancer more or less common than ten years ago?**  
 (Please tick one box only)

**Breast**

More common

Less common

Not changed

Not sure

Other please specify \_\_\_\_\_

**Cervical**

More common

Less common

Not changed

Not sure

Other please specify \_\_\_\_\_

**14. Does the word cancer evoke any of the following feelings?**

(You can tick more than one box)

Pain

Anxiety

Stigma

Shame

Fear

Other (please specify) \_\_\_\_\_

**15. Please tick the answers you agree with**

(Please tick one only)

**a) Malignant cancer....**

Can't be treated

People usually die of it

Can be treated but not cured of it

Not Sure

Can be treated but with difficulty

Other specify \_\_\_\_\_

**b) A benign breast lump....**

Is not a cancer

Cannot be treated or cured

Is an early sign of cancer

People usually die of it

Can be treated easily

Not sure

Other specify \_\_\_\_\_

**Section (3); Knowledge of breast and cervical cancer**

**(A); signs and symptoms**

**Breast cancer signs and symptoms**

**16. What are the signs of possible breast cancer?**

(You can tick more than one box)

Changes in the shape of breast

Underarm lump

Pain

Discharge from nipple

Not Sure

Other (please specify) \_\_\_\_\_

**Cervical cancer signs and symptoms**

**17. What are the signs of possible cervical cancer?**

(You can tick more than one box)

Bleeding or pain during or after intercourse  Bleeding anytime

Unusual long periods  Not Sure

Bleeding between periods  Other (please specify) \_\_\_\_\_

**(B) Risk factors**

**Breast cancer risk factor's information**

**18. In your view which of the following are risk factors for breast cancer?**

(You can tick more than one box)

Being older  Use of hormone replacement treatment

Being poor  Hereditary factors

Not breast feeding  Not having children

Assisted fertility  Contraceptive pills or injection

Not sure  Other (please specify) \_\_\_\_\_

## Cervical cancer risk factor's information

**19. In your view which of the following are risk factors for cervical cancer?**

(You can tick more than one box)

Being older	<input type="checkbox"/>	More sexual partners	<input type="checkbox"/>
Being poor	<input type="checkbox"/>	Use of hormone replacement treatment	<input type="checkbox"/>
Having sex at younger age	<input type="checkbox"/>	Hereditary factors	<input type="checkbox"/>
Assisted fertility	<input type="checkbox"/>	Not having children	<input type="checkbox"/>
Contraceptive pills or injection	<input type="checkbox"/>	Not sure	<input type="checkbox"/>

Other (please specify) \_\_\_\_\_

### **(C) Detection and treatment:**

**20. What is the best way to detect breast and cervical cancer?**

(You can tick more than one box)

<u>Breast</u>		<u>Cervical</u>	
Attending a screening	<input type="checkbox"/>	Screening clinic	<input type="checkbox"/>
Breast self-examination	<input type="checkbox"/>	Pap test	<input type="checkbox"/>
Not sure	<input type="checkbox"/>	Not sure	<input type="checkbox"/>

Other (please state) \_\_\_\_\_ Other (please state) \_\_\_\_\_

**21. Which of the following do you consider to be effective treatments for breast and cervical cancer?**

(You can tick more than one box)

<u>Breast</u>		<u>Cervical</u>	
Surgery	<input type="checkbox"/>	Surgery	<input type="checkbox"/>
Chemotherapy	<input type="checkbox"/>	Chemotherapy	<input type="checkbox"/>
Radiotherapy	<input type="checkbox"/>	Radiotherapy	<input type="checkbox"/>
Pain killers	<input type="checkbox"/>	Pain killers	<input type="checkbox"/>
Not sure	<input type="checkbox"/>	Not sure	<input type="checkbox"/>

Other (please state) \_\_\_\_\_ Other (please state) \_\_\_\_\_

**22. Where have you got the medical information of breast and cervical cancer such as risk factor, detection and treatment?**

(You can tick more than one box)

**Breast**

Media

Family

Friends

School or work

Health Professionals

**Cervical**

Media

Family

Friends

School or work

Health Professionals

Other specify \_\_\_\_\_

**(D) Questions regarding family history information**

**23. Do you think that breast and cervical cancer are hereditary?**

**Breast**

Yes

No  (go Q 25)

I don't know

**Cervical**

Yes

No  (go to Q 25)

I don't know

**24. From whom do you think the cancer can be inherited?**

(You can tick more than one box)

Parents

Grandparents

Any other relatives

Don't know

**25. Do you think that your risk of getting cancer increases if one of the following relatives has had it? Please tick the answer you think is right (You can tick more than one box)**

Parents and siblings

Any other relatives

Grandparent, grandchild, uncle, auntie,

Friends

**26. If you know anyone has had breast or cervical cancer, please indicate who was this?** (Tick more than one if you have more than one diagnosed with cancer)

<u>Breast</u>		<u>Cervical</u>	
Parents and siblings	<input type="checkbox"/>	Parents and siblings	<input type="checkbox"/>
Grandparent, grandchild, uncle, aunt,	<input type="checkbox"/>	Grandparent, grandchild, uncle, aunt,	<input type="checkbox"/>
Any relatives apart from the above	<input type="checkbox"/>	Any relatives apart from the above	<input type="checkbox"/>
Friends	<input type="checkbox"/>	Friends	<input type="checkbox"/>
Other specify _____		Other specify _____	

**Section (4); Experience of breast and cervical cancer screening services**

**Experience of Breast cancer services**

**27. Have you ever received a letter to attend a mammogram?**

Yes  NO

**28. Have you ever attended a mammography appointment?**

Yes  (go to Q 29) NO  (go to Q 32)

**29. Have you paid to attend this mammogram appointment?**

Yes

**30. Could you describe your reflections concerning the mammography?**  
(Mammogram experiences) (You can tick more than one box)

Uncomfortable	<input type="checkbox"/>	Comfortable	<input type="checkbox"/>
Anxiety provoking	<input type="checkbox"/>	Reassuring	<input type="checkbox"/>
Painful	<input type="checkbox"/>	Painless	<input type="checkbox"/>

Other specify \_\_\_\_\_

**31. What encouraged you to attend the breast screening services?**

(You can tick more than one box)

- Free of charge
- Supportive health professionals
- Easy transportation
- Encouragement from husband
- Encouragement from other members of the family
- Available and convenient appointments
- Lack of the importance of the screening
- Other specify \_\_\_\_\_

**32. What would put you off from attending the breast screening Services?**

(You can tick more than one box)

- |  |  |
|--|--|
| Taking off clothes <input type="checkbox"/>                | Presence of male staff <input type="checkbox"/>                                |
| Time consuming <input type="checkbox"/>                    | Lack of transportation <input type="checkbox"/>                                |
| Lack of interest <input type="checkbox"/>                  | Lack of encouragement from husband <input type="checkbox"/>                    |
| Long waiting list for appointment <input type="checkbox"/> | Lack of encouragement from other member of the family <input type="checkbox"/> |
| Expensive <input type="checkbox"/>                         | Fear of having it <input type="checkbox"/>                                     |
| Don't know where to go <input type="checkbox"/>            | Lack of knowledge of Screening <input type="checkbox"/>                        |

Other specify \_\_\_\_\_

**33. If another woman asks your advice about the mammography, what would you say?**

(Please tick one box only)

- |  |   |
|--|---|
| Recommend it to her <input type="checkbox"/> | Don't recommend it <input type="checkbox"/> |
| Don't know <input type="checkbox"/>          | Other specify _____                         |

## Experience of cervical cancer services

**34. Have you ever received a letter to attend screening Pap test for cervical cancer?**

Yes  NO

**35. Have you ever attended this screening appointment?**

Yes  (go Q36) NO  (go Q39)

**36. Have you paid to attend this service?**

Yes  NO

**37. Could you describe your reflections concerning the Pap test?**

(You can tick more than one box)

Uncomfortable  Comfortable

Anxiety Provoking  Reassuring

Painful  Painless

Other specify \_\_\_\_\_

**38. What would encourage you to attend cervical screening services?**

(You can tick more than one box)

Free of charge

Supportive health professionals

Easy transportation

Encouragement from husband

Encouragement from other member of the family

Available e appointments

Lack of knowledge of the screening

Other specify \_\_\_\_\_

**39. What would put you off from attending the breast and cervical screening Services?**

(You can tick more than one box)

- |                                   |                          |   |                          |
|-----------------------------------|--------------------------|---|--------------------------|
| Taking off clothes                | <input type="checkbox"/> | Presence of male staff                                | <input type="checkbox"/> |
| Time consuming                    | <input type="checkbox"/> | Lack of transportation                                | <input type="checkbox"/> |
| Lack of interest                  | <input type="checkbox"/> | Lack of encouragement from husband                    | <input type="checkbox"/> |
| Long waiting list for appointment | <input type="checkbox"/> | Lack of encouragement from Other member of the family | <input type="checkbox"/> |
| Expensive                         | <input type="checkbox"/> | Fear of having it                                     | <input type="checkbox"/> |
| Don't know where to go            | <input type="checkbox"/> | Lack of knowledge of the of screening                 | <input type="checkbox"/> |
- Other specify \_\_\_\_\_

**40. If another woman asks your advice about the Pap test, what would you say?**

(Please tick one box only)

- |                     |                          |                     |                          |
|---------------------|--------------------------|---------------------|--------------------------|
| Recommend it to her | <input type="checkbox"/> | Don't recommend it  | <input type="checkbox"/> |
| Don't know          | <input type="checkbox"/> | Other specify _____ |                          |

**Section (5); Suggestions to improve screening services**

**41. What would encourage you to attend breast and cervical screening services?**

(You can tick more than one box)

- |  |                          |
|--|--------------------------|
| Governmental transportation  | <input type="checkbox"/> |
| Presence of female staff   | <input type="checkbox"/> |
| Staff attitudes  | <input type="checkbox"/> |
| Use a different method other than Mammogram such as MRI                  | <input type="checkbox"/> |
| The existence of a specialized centre for the detection                  | <input type="checkbox"/> |
| Receiving invitation letter from the relative health service authorities | <input type="checkbox"/> |
| Attending educational program such as seminars and events                | <input type="checkbox"/> |
- Other specify \_\_\_\_\_



**42. What is the best way that could spread the information about cancer?**

(You can tick more than one box)

Hospitals & clinics

Mosques

Schools

Shopping centres

Media

Mobile messages

Other specify \_\_\_\_\_

**43. Please use this space for anything else you would like to tell us about breast and Cervical cancer**

**Thank you for completing this questionnaire and adding this valuable information to our study. Please return the questionnaire to the same person hand it to you**

<b>Dr Rob Newton</b>	<b>Nahed Ali Batarfi</b>	<b>Dr Samia Al-amoudi</b>
<b>Department of Epidemiology</b>	<b>Department of Epidemiology</b>	<b>Associate Professor at KingAbdulazizUniversity in Jeddah (KAU) and a Consultant Obstetrician Gynecologist, IVF</b>
<b>University of York</b>	<b>University of York</b>	
<b>YO10 5DD</b>	<b>YO10 5DD</b>	
<b><u><a href="tel:01904321665">Tel:01904321665</a></u></b>	<b><u><a href="tel:00447748185171">Tel:00447748185171</a></u></b>	<b><u><a href="tel:0505626441">Tel:0505626441</a></u></b>
<b>Email:</b>	<b>Email:</b>	<b>E-mail</b>
<b>rob.newton@egu.y ork.ac.uk</b>	<b>Nahed.batarfi@ egu.york.ac.uk</b>	<b><u><a href="mailto:dr.samia_amoudi@hotmail.com">dr.samia_amoudi@hotmail.com</a></u></b>

## العوائق والدوافع التي تؤثر على المرأة السعودية لحضور عيادات الكشف المبكر لسرطان الثدي وسرطان عنق الرحم: دراسة مقارنة بين النساء السعوديات اللاتي يقطن في المملكة العربية السعودية والمملكة المتحدة

ماهي أسباب الدراسة؟

تعتمد الدراسة على عدة ركائز لمعرفة ماهي العوائق والدوافع التي تؤثر على معرفة المرأة بخدمات الفحص المبكر لسرطان الثدي وعنق الرحم سواءً كان في المملكة العربية السعودية او المملكة المتحدة، نتمنى أن تكشف الدراسة عن الفرق في تجارب المرأة السعودية في كلا الدولتين، هذه الدراسة هي جزء من برنامج الدكتوراة الخاص بالباحث.

من سيقراً الاجابات؟

فقط الباحثة هي من ستقرأ الاجابات، لن يتدخل أحد في قراءتها وستكون سرية للغاية.

ماهو الوقت الذي يستغرقه تعبئة الاستبيان؟

يستغرق تعبئة الاستبيان ما بين ال 8-10 دقائق.

ماهي المواضيع التي يبحثها الاستبيان؟

الاستبيان مؤلف من خمسة أقسام رئيسية:

**القسم الاول:** مقدمة بسيطة عن معلوماتك الشخصية كعمرك ومستواك الدراسي وغيرها والتي ستساعد في معرفة العلاقة بين مختلف الشخصيات.

**القسم الثاني:** أسئلة لإستعراض الوعي العام لدى المرأة السعودية فيما يتعلق بمسببات سرطان الثدي وعنق الرحم.

**القسم الثالث:** أسئلة لإستعراض المعرفة المنتشرة بين النساء السعوديات فيما يتعلق بسرطان الثدي وعنق الرحم.

**القسم الرابع:** أسئلة تتعلق بالخبرة التي واجهتك للوصول الى خدمات الكشف المبكر لسرطان الثدي او سرطان عنق الرحم.

**القسم الخامس:** المجموعة الأخيرة من الأسئلة تتركز في رأيك حول كيفية تحسين خدمات الفحص المبكر لسرطان الثدي وعنق الرحم.

لجعل الاجابة أكثر سهولة تم تقسيم هذه الأقسام الى جزئين: الأول يختص بسرطان الثدي والآخر بسرطان عنق الرحم وهما اما متوازيين

حيث يقابل احدهما الآخر او متتاليين حيث يتبع أحدهما الآخر

كيف تتم تعبئة الاستبيان

الرجاء قراءة الأسئلة جيداً، ثم أشيري على الإجابة الأقرب صحةً إليك والتي تناسب وضعك. لاتقلقي في حال لم تجدي الاجابة التي تناسبك.

ببساطة أشيري على لست متأكدة أو أكتبي ماتريدين في الخانة المعنونة بالأخرى الرجاء حدي. في بعض الأسئلة تستطيعين إختيار أكثر

من إجابة وتستطيعين إضافة أي تعليق او ملاحظة.

تذكري أن إجاباتك غير مبنية على أساس إجابات صحيحة او خاطئة.

ماذا في حال احتجت الى معلومات إضافية؟

إذا كنت مازلت بحاجة الى استفسار أو كنت غير واثقة مما ستكتبين أو ساورك بعض القلق والشكوك، رجاءاً قومي بالاتصال بالدكتور ه

سامية العمودي او الاستاذة ناهد باطرفي والتي تتوفر كافة معلومات الاتصال بهم في نهاية الاستبيان وصحيفة المعلومات.

ID Code

القسم الأول: معلومات شخصية

1. العمر (سنوات)

2. المدينة التي تعيشين فيها في بريطانيا والمدينة التي تعيشين فيها في المملكة

مثال (نيوكاسل-جده)

3. إذا كنت تعيشين في بريطانيا, كم عدد السنوات التي قضيتها في بريطانيا؟

4. الوظيفة

موظفة حكومية  غير موظفة

موظفة بشركة خاصة  طالبة

أخرى الرجاء التحديد

5. المستوى التعليمي

غير متعلم

ابتدائي

متوسطة

ثانوية

الجامعي وأعلى

6. الحالة الإجتماعية

متزوجة

عزباء

مطلقة

أرملة

أخرى الرجاء حدي

7. كم كان عمرك حينما تزوجتي لأول مره

(الرجاء ذكرها بالأعوام)

8. هل لديك أطفال؟

نعم  لا (انتقل الى سؤال 10)

9. كم عد الأطفال؟

## القسم الثاني: الوعي والادراك لمفهوم سرطان الثدي وسرطان عنق الرحم

### أ. النمط المعيشي

10. ماهي العادات في نظرك التي قد تؤثر على حدوث سرطان الثدي وعنق الرحم؟  
(يمكنك إختيار أكثر من إجابة)

#### سرطان الثديسرطان عنق الرحم

<input type="checkbox"/>	التدخين	<input type="checkbox"/>	التدخين
<input type="checkbox"/>	عدم ممارسة التمارين الرياضية	<input type="checkbox"/>	عدم ممارسة التمارين الرياضية
<input type="checkbox"/>	السمنة	<input type="checkbox"/>	السمنة
<input type="checkbox"/>	النظام الغذائي الغير صحي	<input type="checkbox"/>	النظام الغذائي الغير صحي
<input type="checkbox"/>	لست متأكدة	<input type="checkbox"/>	لست متأكدة

أخرى الرجاء حددي \_\_\_\_\_

أخرى الرجاء حددي \_\_\_\_\_

### ب. معلومات عامة عن سرطان الثدي وعنق الرحم

11. كيف تقيمين اطلاقك على المعلومات المتعلقة بسرطان الثدي وعنق الرحم؟

#### سرطان الثديسرطان عنق الرحم

<input type="checkbox"/>	مطلعة بشكل جيد	<input type="checkbox"/>	مطلعة بشكل جيد
<input type="checkbox"/>	مطلعة بشكل مقبول	<input type="checkbox"/>	مطلعة بشكل مقبول
<input type="checkbox"/>	غير مطلعة	<input type="checkbox"/>	غير مطلعة

12. ماهي مصادر هذه المعلومات؟ (يمكنك إختيار أكثر من إجابة)

#### سرطان الثدي سرطان عنق الرحم

<input type="checkbox"/>	الإعلام	<input type="checkbox"/>	الإعلام
<input type="checkbox"/>	العائلة	<input type="checkbox"/>	العائلة
<input type="checkbox"/>	الأصدقاء	<input type="checkbox"/>	الأصدقاء
<input type="checkbox"/>	العمل	<input type="checkbox"/>	العمل
<input type="checkbox"/>	أعضاء الطاقم الصحي	<input type="checkbox"/>	أعضاء الطاقم الصحي
<input type="checkbox"/>	لست متأكدة	<input type="checkbox"/>	لست متأكدة

أخرى الرجاء حددي \_\_\_\_\_

أخرى الرجاء حددي \_\_\_\_\_

13. من وجهة نظرك كيف تغير معدل انتشار سرطان الثدي وسرطان عنق الرحم في العشر سنوات

الأخيرة؟ (إختاري إجابة واحدة)

سرطان الثدي/سرطان عنق الرحم

- |                          |               |                          |               |
|--------------------------|---------------|--------------------------|---------------|
| <input type="checkbox"/> | أكثر إنتشاراً | <input type="checkbox"/> | أكثر إنتشاراً |
| <input type="checkbox"/> | أقل إنتشاراً  | <input type="checkbox"/> | أقل إنتشاراً  |
| <input type="checkbox"/> | لم يتغير      | <input type="checkbox"/> | لم يتغير      |
| <input type="checkbox"/> | لست متأكدة    | <input type="checkbox"/> | لست متأكدة    |

أخرى الرجاء حددي \_\_\_\_\_ أخرى الرجاء حددي \_\_\_\_\_

14. هل وقع كلمة سرطان يشعرك بالتالي؟ (يمكنك إختيار أكثر من إجابة)

- |                          |       |                          |          |
|--------------------------|-------|--------------------------|----------|
| <input type="checkbox"/> | القلق | <input type="checkbox"/> | الألم    |
| <input type="checkbox"/> | الخجل | <input type="checkbox"/> | وصمة عار |
|                          |       | <input type="checkbox"/> | الخوف    |

أخرى الرجاء حددي \_\_\_\_\_

15. الرجاء أشيري على الإجابة/الإجابات التي تتفقين معها

أ. كلمة ورم خبيث في نظرك؟ (يمكنك إختيار أكثر من إجابة)

- |                          |                                       |                          |                        |
|--------------------------|---------------------------------------|--------------------------|------------------------|
| <input type="checkbox"/> | مرض لا يمكن علاجه                     | <input type="checkbox"/> | عادة يموت المريض بسببه |
| <input type="checkbox"/> | مرض يمكن علاجه لكن لا يمكن الشفاء منه | <input type="checkbox"/> | لست متأكدة             |
| <input type="checkbox"/> | يمكن علاجه بصعوبة                     |                          | أخرى الرجاء حددي _____ |

ب. كلمة ورم حميد في نظرك؟ (يمكنك إختيار أكثر من إجابة)

- |                          |                           |                          |                             |
|--------------------------|---------------------------|--------------------------|-----------------------------|
| <input type="checkbox"/> | لا يعتبر سرطان            | <input type="checkbox"/> | مرض يمكن علاجه و الشفاء منه |
| <input type="checkbox"/> | علامة مبكرة لظهور السرطان | <input type="checkbox"/> | عادة لا يموت المصاب بسببه   |
| <input type="checkbox"/> | يمكن علاجه بسهولة         | <input type="checkbox"/> | لست متأكدة                  |

أخرى الرجاء حددي \_\_\_\_\_

**القسم الثالث: ماهي المعلومات التي تعرفينها عن أسباب. أعراض وعلاج مرض سرطان الثدي وعنق الرحم**

**أ. أعراض وعلامات سرطان الثدي وعنق الرحم**

**16. ماهي أعراض إحتمال وجود سرطان الثدي؟ (يمكنك إختيار أكثر من إجابة)**

<input type="checkbox"/>	بروز تحت الإبطن	<input type="checkbox"/>	تغير في حجم الصدر
<input type="checkbox"/>	إفرازات من حلمة الصدر	<input type="checkbox"/>	ألم
<input type="checkbox"/>	أخرى الرجاء حددي	<input type="checkbox"/>	لست متأكدة

**17. ماهي أعراض إحتمال وجود سرطان عنق الرحم؟ (يمكنك إختيار أكثر من إجابة)**

<input type="checkbox"/>	دم متقطع غزير غير متوقع	<input type="checkbox"/>	دورة شهرية غزيرة
<input type="checkbox"/>	لست متأكدة	<input type="checkbox"/>	الآلام أثناء أو بعد الجماع
<input type="checkbox"/>	أخرى الرجاء حددي		

**ب. العوامل التي تؤثر على حدوث سرطان الثدي وسرطان عنق الرحم (يمكنك إختيار أكثر من إجابة)**

**18. ماهي العوامل التي تؤثر على حدوث سرطان الثدي عند النساء؟**

<input type="checkbox"/>	إستخدام أدوية عوامل التكاثر الانجابية	<input type="checkbox"/>	كلما أزداد سن الشخص أصبح أكثر عرضة
<input type="checkbox"/>	استخدام ادوية الهرمونات البديلة	<input type="checkbox"/>	الفقر
<input type="checkbox"/>	عوامل وراثية	<input type="checkbox"/>	عدم استخدام الرضاعة الطبيعية
<input type="checkbox"/>	عدم الإنجاب	<input type="checkbox"/>	استخدام موانع الحمل المختلفة
<input type="checkbox"/>	أخرى الرجاء حددي	<input type="checkbox"/>	لست متأكدة

**19. ماهي العوامل التي تؤثر على حدوث سرطان عنق الرحم عند النساء؟**

<input type="checkbox"/>	الفقر	<input type="checkbox"/>	كلما أزداد سن الشخص أصبح أكثر عرضة
<input type="checkbox"/>	إستخدام أدوية عوامل التكاثر الانجابية	<input type="checkbox"/>	ممارسة الجنس في سن مبكر
<input type="checkbox"/>	تعدد العلاقات الجنسية	<input type="checkbox"/>	استخدام موانع الحمل المختلفة
<input type="checkbox"/>	عوامل وراثية	<input type="checkbox"/>	استخدام ادوية الهرمونات البديلة
<input type="checkbox"/>	لست متأكدة	<input type="checkbox"/>	عدم الإنجاب
<input type="checkbox"/>	أخرى الرجاء حددي		

ج.الكشف والعلاج (يمكنك اختيار أكثر من إجابة)

20). ماهي أفضل طريقة للكشف عن سرطان الثدي وسرطان عنق الرحم ؟

سرطان الثديسرطان عنق الرحم

<input type="checkbox"/>	حضور عيادات الكشف المبكر (كتحليل كمسحة المهبل)	<input type="checkbox"/>	حضور عيادات الكشف المبكر
<input type="checkbox"/>	لست متأكدة	<input type="checkbox"/>	الكشف الذاتي للصدر
<input type="checkbox"/>	أخرى الرجاء حددي	<input type="checkbox"/>	لست متأكدة
			أخرى الرجاء حددي

21. ماهي العلاجات الفعالة التي تعرفينها لعلاج سرطان الثدي وعنق الرحم ؟

سرطان الثديسرطان عنق الرحم

<input type="checkbox"/>	العملية	<input type="checkbox"/>	العملية
<input type="checkbox"/>	العلاج الكيميائي	<input type="checkbox"/>	العلاج الكيميائي
<input type="checkbox"/>	العلاج الاشعاعي	<input type="checkbox"/>	العلاج الاشعاعي
<input type="checkbox"/>	مسكنات الألم	<input type="checkbox"/>	مسكنات الألم
<input type="checkbox"/>	لست متأكدة	<input type="checkbox"/>	لست متأكدة
<input type="checkbox"/>	أخرى الرجاء حددي	<input type="checkbox"/>	أخرى الرجاء حددي

22). من اين حصلت على هذه المعلومات؟

سرطان الثديسرطان عنق الرحم

<input type="checkbox"/>	الإعلام	<input type="checkbox"/>	الإعلام
<input type="checkbox"/>	العائلة	<input type="checkbox"/>	العائلة
<input type="checkbox"/>	الأصدقاء	<input type="checkbox"/>	الأصدقاء
<input type="checkbox"/>	العمل	<input type="checkbox"/>	العمل
<input type="checkbox"/>	أعضاء الطاقم الصحي	<input type="checkbox"/>	أعضاء الطاقم الصحي
<input type="checkbox"/>	لست متأكدة	<input type="checkbox"/>	لست متأكدة
<input type="checkbox"/>	أخرى الرجاء حددي	<input type="checkbox"/>	أخرى الرجاء حددي



## د. التاريخ العائلي المرضي

23. هل تعتقد أن سرطان الثدي وسرطان عنق الرحم ممكن أن ينتقل وراثياً؟

### سرطان الثدي-سرطان عنق الرحم

- |                          |                        |                          |                        |
|--------------------------|------------------------|--------------------------|------------------------|
| <input type="checkbox"/> | نعم                    | <input type="checkbox"/> | نعم                    |
| <input type="checkbox"/> | لا (انتقل الى سؤال 25) | <input type="checkbox"/> | لا (انتقل الى سؤال 25) |
| <input type="checkbox"/> | لست أعلم               | <input type="checkbox"/> | لست أعلم               |

24. من من تعتقد يمكن وراثته مرض السرطان بشكل عام؟

- |                          |          |                          |               |
|--------------------------|----------|--------------------------|---------------|
| <input type="checkbox"/> | الأجداد  | <input type="checkbox"/> | الأباء        |
| <input type="checkbox"/> | لست أعلم | <input type="checkbox"/> | أي من الأقارب |

25. هل تعتقد أن مخاطر تعرضك للسرطان تزداد في حال أحد المقربين المذكورين أدناه أصيب به؟ (يمكنك اختيار أكثر من إجابة)

- |                          |   |                          |               |
|--------------------------|---|--------------------------|---------------|
| <input type="checkbox"/> | الأجداد/الأحفاد/الأعمام/العمات/الأخوال/الخالوات | <input type="checkbox"/> | الأبوة/الأخوة |
| <input type="checkbox"/> | لست أعلم  | <input type="checkbox"/> | أي من الأقارب |

26. إذا سبق أن أصيب أحد معارفك بمرض سرطان الثدي أو مرض سرطان عنق الرحم، الرجاء الإشارة إليهم (يمكنك اختيار أكثر من إجابة إذا كان لديك أكثر من مريض)

### سرطان الثديسرطان عنق الرحم

- |                          |   |                          |   |
|--------------------------|---|--------------------------|---|
| <input type="checkbox"/> | الأبوة/الأخوة                                   | <input type="checkbox"/> | الأبوة/الأخوة                                   |
| <input type="checkbox"/> | الأجداد/الأحفاد/الأعمام/العمات/الخالوات/الأخوال | <input type="checkbox"/> | الأجداد/الأحفاد/الأعمام/العمات/الخالوات/الأخوال |
| <input type="checkbox"/> | أي من الأقارب الغير المذكورين سابقاً            | <input type="checkbox"/> | أي من الأقارب الغير المذكورين سابقاً            |
| <input type="checkbox"/> | الأصدقاء  | <input type="checkbox"/> | الأصدقاء  |
| <input type="checkbox"/> | لست أعلم  | <input type="checkbox"/> | لست أعلم  |

القسم الرابع: تجاربك السابقة التي واجهتها للوصول الى خدمات الفحص المبكر لسرطان الثدي

### وسرطان عنق الرحم

### سرطان الثدي

27. هل سبق واستلمت من قبل خطاب دعوة لحضور الكشف المبكر لسرطان الثدي أو ما يسمى بالماموجرام؟

- |                          |    |                          |     |
|--------------------------|----|--------------------------|-----|
| <input type="checkbox"/> | لا | <input type="checkbox"/> | نعم |
|--------------------------|----|--------------------------|-----|

28. هل سبق أن ذهبت الى عيادة الكشف المبكر لسرطان الثدي أو ما يسمى بالماموجرام؟

نعم  (انتقلي الى سؤال 29) لا  (انتقلي الى سؤال 32)

29. هل سبق وأن دفعت مقابل حضورك للكشف المبكر عن سرطان الثدي؟

نعم  لا

30. أوصفي ماهو انطباعك عن الكشف المبكر أو ما يسمى بالماموجرام؟

غير مريح  مريح

مثير للقلق  مطمئن

مؤلم  غير مؤلم

أخرى الرجاء حددي \_\_\_\_\_

31. أي من الاسباب كان دافعا لذهابك الى عيادات الكشف المبكر عن السرطان؟

(يمكنك اختيار أكثر من إجابة)

مجانية الكشف  تعاون الطاقم الصحي

سهولة المواصلات  تشجيع الزوج

تشجيع أفراد عائلتي  توفر موعد مناسب

معرفة أهمية الكشف المبكر

أخرى حددي \_\_\_\_\_

32. ماهي الأسباب التي قد تعيق ذهابك الى عيادة الكشف المبكر لسرطان الثدي

وسرطان عنق الرحم؟ (يمكنك إختيار أكثر من إجابة)

خلع الملابس  مضيق للوقت

قلة الاهتمام  تعسر وجود مواعيد قريبة

تكلفة الكشف  وجود طاقم رجالي في غرفة الكشف

صعوبة المواصلات  قلة التشجيع من الزوج

قلة التشجيع من أفراد العائلة  الخوف من الاصابة به

قلة معرفة أهمية الفحص  لأعرف لمن أذهب

أخرى الرجاء حددي \_\_\_\_\_

33. اذا سألتك إحداهن عن نصيحة تتعلق بأشعة الماموجرام فماذا تقولين لها؟

(الرجاء اختيار اجابة واحدة فقط)

أنصحها بعمل الأشعة  لأنصحها بها

سرطان عنق الرحم

34. هل سبق واستلمت من قبل خطاب دعوة لحضور الكشف المبكر لسرطان عنق الرحم (المسحة المهبليّة)؟

نعم  لا

35. هل سبق أن ذهبت الى عيادة الكشف المبكر لسرطان عنق الرحم؟

نعم  (انتقل الى سؤال 36) لا  (انتقل الى سؤال 39)

36. هل سبق وأن دفعت مقابل حضورك للكشف المبكر عن سرطان عنق الرحم؟

نعم  لا

37. أوصفي ما هو انطباعك عن الكشف المبكر (المسحة المهبليّة)

غير مريح  مريح

مثير للقلق  مطمئن

مؤلم  غير مؤلم

أخرى الرجاء حددي

38. أيّ من الاسباب كان دافعا لذهابك الى عيادات الكشف المبكر عن السرطان؟

(يمكنك اختيار أكثر من إجابة)

مجانية الكشف  تعاون الطاقم الصحي

سهولة المواصلات  تشجيع الزوج

تشجيع أفراد عائلتي  توفر موعد مناسب

معرفة أهمية الكشف المبكر

أخرى حددي

39. ماهي الأسباب التي قد تعيق ذهابك الى عيادة الكشف المبكر لسرطان عنق الرحم؟

(يمكنك إختيار أكثر من إجابة)

- |                          |                               |                          |                              |
|--------------------------|-------------------------------|--------------------------|------------------------------|
| <input type="checkbox"/> | مضيعة للوقت                   | <input type="checkbox"/> | خلع الملابس                  |
| <input type="checkbox"/> | عدم الاهتمام                  | <input type="checkbox"/> | عسر وجود مواعيد قريبة        |
| <input type="checkbox"/> | وجود طاقم رجالي في غرفة الكشف | <input type="checkbox"/> | تكلفة الكشف                  |
| <input type="checkbox"/> | قلة التشجيع من الزوج          | <input type="checkbox"/> | صعوبة المواصلات              |
| <input type="checkbox"/> | الخوف من الاصابة به           | <input type="checkbox"/> | قلة التشجيع من أفراد العائلة |
| <input type="checkbox"/> | لأعرف لمن أذهب                | <input type="checkbox"/> | قلة معرفة أهمية الفحص        |

أخرى الرجاء حددي \_\_\_\_\_

40. اذا سألتك إحداهن عن نصيحة تتعلق بالمسحة المهبلية فماذا تقولين لها؟

(الرجاء اختيار اجابة واحدة فقط)

أنصحها بعملها  لأنصحها بها

لأعلم  أخرى الرجاء حددي \_\_\_\_\_

القسم الخامس: الإقتراحات لتحسين خدمات الكشف المبكر

41. ماهي العوامل التي تشجعك على حضور الكشف المبكر؟ (يمكنك اختيار أكثر من إجابة)

- |                          |   |
|--------------------------|---|
| <input type="checkbox"/> | وجود مواصلات حكومية   |
| <input type="checkbox"/> | وجود طاقم نسائي في غرفة الكشف                                 |
| <input type="checkbox"/> | معاملة الطاقم الصحي في مراكز الكشف                            |
| <input type="checkbox"/> | استخدام وسيلة أخرى غير الماموجرام مثل الرنين المغناطيسي       |
| <input type="checkbox"/> | وجود مراكز متخصصة للكشف                                       |
| <input type="checkbox"/> | تسهيل مواعيد الكشف المبكر                                     |
| <input type="checkbox"/> | إستلام خطابات دعوة من الجهة المعنية لعمل الكشف المبكر للسرطان |
| <input type="checkbox"/> | حضور المراءة ندوات تعليمية                                    |

أخرى حددي \_\_\_\_\_

42. ماهي الوسيلة الفضلى التي يمكن عن طريقها نشر الوعي الصحي الخاص بالكشف المبكر عن السرطان؟ (يمكنك اختيار أكثر من إجابة)

- |                          |                       |                          |                      |
|--------------------------|-----------------------|--------------------------|----------------------|
| <input type="checkbox"/> | المساجد               | <input type="checkbox"/> | المستشفيات والعيادات |
| <input type="checkbox"/> | المراكز التجارية      | <input type="checkbox"/> | المدارس              |
| <input type="checkbox"/> | رسائل نصية عبر الجوال | <input type="checkbox"/> | الإعلام              |
- أخرى حدي \_\_\_\_\_

43. الرجاء استخدام هذه المساحة لكتابة أي اضافات تودين اخبارنا بها فيما يتعلق بسرطان الثدي

وسرطان عنق الرحم؟

نشكر لك تعاونك في اتمام هذا الاستبيان وإضافة معلومات القيمة للدراسة

الرجاء إعادة الاستبيان الى العنوان التالي و عند وجود أي استفسار يمكنك الاتصال

على الدكتورة سامية العمودي او الاستاذة ناهد باطرفي المرفق ببياناتهم أدناه

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**University in Jeddah (KAU) and a**

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**IVF**

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شكراً لإستكمال الاستبيان

## Barriers and facilitators to breast and cervical cancer screening services: A comparative study of Saudi women in the UK and Saudi Arabia

### Topic Guide

<b>Introduction</b>	<ul style="list-style-type: none"> <li>• Welcome and thanks for agreeing to take part in the study</li> <li>• Introduce self and organisation e.g. University of York</li> <li>• Give background about the objective of the study: for example looking at the access to breast and cervical cancer screening services for Saudi women who are living in the UK and Saudi Arabia.</li> <li>• The aim of the research is to identify the barriers to accessing breast and cervical screening services in the UK and Saudi Arabia and make recommendations for improving screening services.</li> <li>• I am talking to Saudi women in the UK and Saudi Arabia.</li> <li>• Funding from the project is from the University of York</li> <li>• Give the participants some information about the confidentiality, consent procedure, tape recording, format of the focus group (importance of one person talking at a time) length of the discussion (not more than 30 minutes) Then ask them if they would like to ask about anything before starting the interview.</li> <li>• Consent forms should be signed in this time</li> </ul>
<b>About You</b>	<p><i>I would like to distribute a small piece of paper asking a few questions about your background:</i></p> <p>How long have you been in the UK (<b>probe for the entrance date</b>)?  City of residence in UK/Saudi (<b>probe for length of time in UK/Saudi</b>)?  Marital status (<b>probe for length of time married</b>)?  Age (<b>probe for age when married</b>)?  Occupation/job (<b>probe for husband job</b>)?  Education level (<b>probe to where she spent her first years of life</b>)?</p>
<b>Perceptions of breast and cervical cancer</b>	<p><i>I would like you to think about breast and cervical cancer:</i></p> <p>What do you know about breast and cervical cancer (<b>probe if heard about breast and cervical cancer, for the source of the information, where from e.g. family, friends, people in the community, schools, internet, workplace, media-national campaigns</b>)?  Do you think that rates of cancer have changed over the last ten years (<b>probe for increases and decreases in rates of breast and cervical cancer and national and international geographical variations</b>)?  How do you feel when somebody talks about/mentions the word cancer (<b>probe for issues around anxiety, fear, lack of knowledge about breast and cervical cancer</b>)?</p>
<b>Risk factors</b>	<p><i>Let's talk about some of the things that might cause breast and cervical cancer:</i></p> <p><b>In your view why are some women more likely to get breast or/and cervical cancer</b> (probe, for some types of clothes like specific type of bra, heredity psychological status, food, life style and breast feeding and surgery, sex with a</p>

	<p>Number of partners/ early sexual activity (HPV debate), use of the contraceptive pill, lifestyle e.g. poor diet, lack of exercise, poverty...etc).</p> <p><b>Do you know anyone who has had breast or cervical cancer</b> (probe for who this was i.e. mother, sister etc. What was their experience and how this has affected respondent perceptions of breast and cervical cancer)</p>
<b>Family History</b>	<b>In your opinion do you think there is a link between breast and cervical cancer and genetics</b> (i.e. family history of breast and cervical cancer e.g. mother, sister, auntie).
<b>Detection and Treatment</b>	<p><b>What are your thoughts concerning breast cancer prevention and precautions</b> (probe for views on changing lifestyle e.g. exercise, diet etc and views on screening for breast and cervical cancer).</p> <p><b>What are your views specifically about breast self-examination</b> (probe to identify if women know how to carry out a self-examination, how many women carry out self-examinations, where they get information on how to self-examine, if they are confident about their self-examination/doubt over ability to self-examine)?</p> <p>What are the signs of breast and cervical cancer (<b>probe for knowledge on symptoms e.g. breast-changes in shape, underarm lesions, pain/cervical abnormal bleeding (after sex), heavy periods, and long periods</b>).</p> <p>What do the terms malignant and benign mean in relation to breast and cervical cancer (<b>probe understanding if breast and cervical cancer can be treated, perceptions of survival rates</b>).</p>



<p><b>Knowledge about breast and cervical screening services</b></p>	<p><i>I would now like to discuss what you know about breast and cervical screening services in the UK and Saudi:</i></p> <p>What have you heard about breast and cervical screening services in UK/Saudi (<b>probe for if they have ever used any of these services/know anyone who has used these services e.g. members of the family, friends, colleagues etc</b>).</p> <p>What are the differences between the health services in UK and Saudi (<b>probe way the services are organised e.g. private or state run. Issues around access to available services e.g. letter of invitation vs. self-attendance</b>)?</p> <p>Are you aware of what happens when you go for breast or cervical screening (<b>probe to the process of mammography and pap smear test</b>)?</p> <p><b><u>Women who have used breast and/or cervical screening services</u></b>  <i>I would like to ask you about your experience of using breast and cervical screening services.</i></p> <p>How did you decide to use the breast/cervical screening service (<b>probe GP/hospital invitation letter, during pregnancy, own imitative after public campaign, media/TV etc</b>)?</p>
	<p>What did you feel about the service you received (<b>probe for views on health professionals e.g. gender issues, friendly, their communication skills, language, cost of screening (Saudi only)</b>).</p> <p><b><u>Women who haven't used breast and/or cervical screening services</u></b> <i>would like to ask you a little bit about why you haven't used breast and cervical screening services.</i></p> <p>What have been your reasons for <b>not</b> using breast and cervical screening services (<b>probe to fear, male health professionals, GP/hospital staff personalities, time, transport, cost, language barriers, don't know about that services/lack of information</b>)?</p> <p>In your view what factors would improve your uptake of breast and cervical screening services (<b>probe cultural and religious sensitivity e.g. female health professionals, transport, flexible appointment system, availability of interpreters</b>).</p>

<p><b>Improvements to breast and cervical screening programmes</b></p>	<p><i>I want to ask all of you your opinions on how breast and cervical screening programmes in UK and Saudi can be improved:</i></p> <p>In your view how could breast and cervical screening services be improved <b>(Probe for opinions on more information on risk factors/symptoms, service availability (community based services) screening procedures, self-examination)?</b></p> <p>Would you be willing to attend an information evening on breast and cervical cancer screening <b>(e.g. how to self-examine, information about service availability in your area).</b></p> <p>Would you be willing to teach other women how to carry out breast self-examinations <b>(e.g. in the community).</b></p> <p>Is there anything you would like to talk about (probe anything else that they?)</p> <p>Thanks for taking part in the focus group <b>(explain that their views are very important, repeat confidentiality and participants will be sent summary of research findings).</b></p>
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## Appendix 9: CV of Dr.Samia Al-Amoudi

### **CV Brief for Dr.Samia Al-Amoudi**

Dr.Samia Al-Amoudi is an Associate Professor at King Abdulaziz University in Jeddah ( KAU) and a Consultant Obstetrician Gynaecologist, IVF. She is head of scientific chair for breast cancer at KAU. Previously she has worked as Vice Dean of the College of Medicine and Allied Sciences at King Abdulaziz University; a Temporary Advisor for a 1995 Inter-country workshop on Reproductive Health and Research Methodology at the World Health Organization; and Director of the Dr.Samia Al-Amoudi Medical Centre.

In 1981, she was among the first group of female medical graduate from King Abdulaziz University. She is a single parent and mother of one son, Abdullah 16 years of age, and one daughter, Esraa 12 years of age. On April, 2006 she was diagnosed with breast cancer and is still on treatment. She was the first Saudi to share her personal battle with the disease, breaking the silence to speak out about its impact.

Dr.Samia Al-Amoudi is the author of 13 books. Her publications include *Break the Silence*, 2<sup>nd</sup> edition (in English) and *My Journey with Breast Cancer* (in Arabic) and Breast cancer survivors in Saudi Arabia in English. Her children wrote 2 books about breast cancer. She has participated in several print, radio, and television programs, including CNN and ABC Good Morning America. She prepared and Presented 15 television episodes as part of a program entitled "Messages of Love" about breast cancer on the IQRAA TV channel. She also has a weekly column in Al Madina Newspaper she wrote 31 article about her personal experience with breast cancer.

### **Dr. Al-Amoudi has received a number of awards.**

In March 2007, the U.S Department of State awarded her the first International Women of Courage Award in recognition of her breast cancer awareness campaign and for sharing her personal battle with breast cancer to raise awareness across the Kingdom and throughout the Middle East.

MBC TV named her one of 4 women in the Middle East who has contributed to change in their societies.

In October 24 she was the facilitator of the first lady of USA Laura Bush during her meeting with breast cancer survivors in Jeddah during her visit to Saudi Arabia.

On 15<sup>th</sup> January 2008 she had been invited to Riyadh to meet the President of USA during his visit to Saudi Arabia where he showed his and his wife appreciation and support to her work. She was honoured by Susan G Komen for the cure in March 2008 in Washington DC. In 2008 she was nominated by King Abdulaziz University, Jeddah (Collage of Medicine) for the Islamic Development Bank prize for Women's contribution in development 1429-2008. On 23<sup>rd</sup> of Aug 2008 she was honoured and received award ALMIFTAHA from prince Faisal bin Khaled of Asir region in recognition of her work and efforts to raise public awareness in breast cancer.

Her story is included in the secondary schools English curriculum in 2008 (people who made a difference).

In Jan 2009 she was interviewed on CNN vital signs.

She received numerous appointments, Sayidatymagazine.Dec, 2008 Sayidatys Top 70 Arab Women of 2008.

She was honoured by British Council on women's international day in 10<sup>th</sup> march 2009 and by Jeddah cultural club on 14<sup>th</sup> of march2009.

Nashwa show from Dubai honoured her on mother day 2009.

A Doc film about her story with breast cancer (break the silence) was aired by Al-Arabia news TV channel on 29<sup>th</sup> of March 2009.

Appendix 10: Correlation (P-value) between breast cancer's barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in Saudi Arabia

Factors	Age		Education		Occupation		Marital status	
<b>Knowledge</b>								
<b>Lifestyle</b>	<b>T-test</b>	<b>P-value</b>	<b>Value</b>	<b>P-value</b>	<b>Value</b>	<b>P-value</b>	<b>Value</b>	<b>P-value</b>
Smoking	0.516	0.607	0.749	0.720	3.492	0.171	0.439	0.801
Lack of exercise	0.810	0.419	1.389	0.566	1.115	0.562	2.276	0.329
Obesity	-0.179	0.858	0.184	0.962	1.589	0.452	0.481	0.777
Nutrition	0.276	0.783	7.229	0.020	3.347	0.187	3.602	0.176
Not sure	-1.438	0.157	5.786	0.050	0.357	0.872	2.801	0.250
<b>Symptoms</b>								
Change in shape	0.319	0.750	0.110	1.000	0.571	0.770	1.122	0.564
Underarm lump	1.409	0.160	4.850	0.072	1.512	0.470	4.304	0.113
Pain	0.296	0.768	2.685	0.248	1.009	0.610	2.854	0.249
Breast discharge	-1.613	0.108	6.080	0.043	0.990	0.606	3.324	0.199
Not sure	0.561	0.578	4.878	0.074	0.904	0.664	3.466	0.194
<b>Risk factors</b>								
Being older	1.812	0.071	1.193	0.616	2.286	0.323	1.107	0.602
Being poor	1.017	0.331	4.991	0.082	0.542	0.866	2.650	0.239
No breast feeding	-0.390	0.697	0.309	0.966	1.137	0.567	4.932	0.091
Assisted fertility	-0.15	0.988	0.222	1.000	0.587	0.771	0.467	0.843
Contraceptive	-0.881	0.380	2.747	0.243	0.257	0.888	2.637	0.275

Continue: Correlation (P-value) between *breast cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in Saudi Arabia

Factors	Age		Education		Occupation		Marital status	
<b>Risk factors</b>								
Heredity	-1.483	0.139	1.296	0.529	0.123	0.952	5.404	0.075
Childless	0.949	0.346	0.635	0.748	0.394	0.872	1.296	0.549
Use of hormone replacement treatment	-1.143	0.256	0.397	0.891	0.498	0.792	0.741	0.693
Not sure	-0.283	0.778	10.287	<b>0.005</b>	1.196	0.567	1.213	0.553
<b>Treatment</b>								
Surgery	-0.551	0.583	2.462	0.295	2.581	0.275	0.371	0.832
<b>Chemotherapy</b>	-2.180	<b>0.030</b>	2.673	0.263	0.246	0.892	5.345	0.072
Radiotherapy	-1.890	0.060	0.206	1.000	3.690	0.158	4.599	0.097
Pain killer	-0.963	0.339	2.269	0.249	1.105	0.589	3.946	0.138
Not sure	0.181	0.857	0.728	0.672	0.348	0.846	0.166	0.939
<b>Heredity as a separate question</b>	-1.977	<b>0.050</b>	4.046	0.102	2.795	0.593	7.903	0.093

Continue: Correlation (P-value) between *breast cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in Saudi Arabia

<b>Factors</b>	<b>Age</b>		<b>Education</b>		<b>Occupation</b>		<b>Marital status</b>	
<b>Experience</b>								
Receive letter	0.559	0.578	5.839	0.261	8.431	<b>0.015</b>	2.214	0.876
<b>Attend services</b>	-2.608	<b>0.012</b>	0.890	0.561	6.127	<b>0.046</b>	2.293	0.329
Paying	-0.160	0.874	1.492	0.222	4.975	0.086	1.292	0.511
Uncomfortable	-1.124	0.272	1.260	0.262	1.411	0.535	2.194	0.327
Anxiety	0.496	0.621	2.218	0.136	0.806	0.686	0.519	0.799
<b>Pain</b>	-2.197	<b>0.033</b>	0.292	0.589	1.168	0.566	2.807	0.265
Comfortable	1.643	0.110	0.020	0.887	2.080	0.403	2.759	0.256
Reassure	0.933	0.355	1.412	0.235	1.340	0.545	1.767	0.446
Painless	0.401	0.698	0.456	0.499	0.478	0.838	0.869	0.790
<b>Facilitators</b>								
Free charge	0.127	0.900	0.135	0.713	0.222	0.919	0.910	0.723
Easy transport	-0.104	0.920	0.272	0.602	0.552	0.891	1.353	0.543
Family encouragement	0.737	0.467	0.330	0.566	3.347	0.179	3.694	0.185
Knowing the importance of early detection	-0.819	0.416	0.306	0.580	1.467	0.472	2.780	0.256

Continue: Correlation (P-value) between *breast cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in Saudi Arabia

Factors	Age		Education		Occupation		Marital status	
Professional cooperative	0.881	0.387	0.301	0.583	0.937	0.662	1.498	0.544
Husband cooperative	-1.050	0.300	0.020	0.888	1.811	0.436	6.833	<b>0.019</b>
<b>Appointment availability</b>	-2.273	<b>0.033</b>	0.548	0.59	4.035	0.124	2.881	0.276
<b>Barriers</b>								
Take off clothes	-0.914	0.363	2.209	0.314	3.631	0.165	1.948	0.388
Lack of interest	0.413	0.681	11.528	<b>0.003</b>	3.082	0.218	5.372	0.068
Cost	-1.317	0.193	0.608	0.774	0.406	0.841	11.813	<b>0.002</b>
<b>Transportation</b>	-2.116	<b>0.038</b>	4.991	0.083	4.302	0.116	10.583	<b>0.004</b>
<b>Family encouragement</b>	2.263	<b>0.025</b>	1.977	0.393	2.955	0.224	3.307	0.202
Knowing the importance of early detection	0.832	0.407	2.771	0.205	1.870	0.398	4.752	0.091
Time waste	-0.652	0.521	5.978	<b>0.042</b>	3.599	0.153	2.605	0.275
<b>No appointment available</b>	-3.015	<b>0.006</b>	8.073	<b>0.013</b>	3.147	0.202	12.221	<b>0.002</b>
Presence of male professional	-1.339	0.184	1.454	0.481	2.691	0.255	0.443	0.793
Husband encouragement	-1.586	0.120	2.737	0.259	1.771	0.414	15.872	<b>0.000</b>
Fear of having it	-0.959	0.339	4.843	0.068	1.550	0.486	5.929	<b>0.048</b>
Don't know where to go	-0.704	0.483	0.977	0.632	4.283	0.126	0.220	0.888
Advice mammogram	1.751	0.082	13.972	<b>0.005</b>	6.174	0.180	16.309	<b>0.002</b>

Correlation (P-value) between *Breast cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in the UK

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Smoking	-0.303	0.762	0.096	0.756	1.068	0.600	2.465	0.282
Lack of exercise	-1.569	0.120	1.008	0.315	0.452	0.803	6.687	<b>0.030</b>
Obesity	-1.307	0.193	0.300	0.584	2.260	0.316	0.886	0.686
Nutrition	-0.202	0.840	4.167	<b>0.041</b>	6.906	0.032	2.491	0.303
Not sure	0.999	0.321	1.720	0.190	0.971	0.605	2.454	0.302
<b>Symptoms</b>								
Change in shape	-1.300	0.195	1.720	0.190	2.206	0.337	0.593	0.783
Underarm lump	-0.623	0.536	0.026	0.872	2.965	0.227	0.468	0.808
Pain	0.348	0.729	3.984	<b>0.046</b>	0.537	0.809	3.293	0.208
<b>Breast discharge</b>	-2.256	<b>0.025</b>	0.151	0.697	2.669	0.260	1.452	0.503
Not sure	1.832	0.081	0.243	0.622	5.268	0.071	3.415	0.156
<b>Risk factors</b>								
Being older	-1.362	0.175	4.690	<b>0.030</b>	12.085	<b>0.002</b>	0.219	0.965
Being poor	-1.930	0.148	0.350	0.554	0.977	0.695	1.021	0.651
No breast feeding	-1.930	0.055	0.287	0.592	4.758	0.091	4.141	0.134
Assisted fertility	-0.369	0.714	1.333	0.248	0.840	0.669	1.503	0.440
Contraceptive	-0.199	0.842	2.333	0.127	2.174	0.339	11.112	<b>0.003</b>
<b>Heredity</b>	-4.310	<b>0.000</b>	3.326	0.068	7.604	<b>0.021</b>	5.177	0.070



Continue; Correlation (P-value) between *Breast cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in the UK

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Childless	-1.526	0.136	1.221	0.380	7.136	<b>0.029</b>	0.120	1.000
Use of hormone replacement treatment	-1.143	0.256	0.026	0.872	0.012	1.000	2.700	0.251
Not sure	2.120	<b>0.038</b>	0.002	0.967	5.026	0.083	4.322	0.101
<b>Treatment</b>								
Surgery	-0.711	0.478	2.638	0.104	5.976	0.055	1.158	0.595
<b>Chemotherapy</b>	-2.643	<b>0.009</b>	0.831	0.362	3.696	0.154	1.444	0.499
<b>Radiotherapy</b>	-3.107	<b>0.002</b>	3.218	0.073	3.526	0.180	3.414	0.174
Pain killer	-0.010	0.992	0.241	0.623	0.302	0.945	0.239	1.000
Not sure	1.433	0.157	0.382	0.536	3.745	0.152	0.206	0.947
Heredity as a separate question	-1.889	0.061	8.056	<b>0.018</b>	3.349	0.510	2.563	0.654
<b>Experience</b>								
<b>Receive letter</b>	-2.068	<b>0.042</b>	0.950	0.330	1.664	0.414	1.902	0.389
<b>Attend services</b>	-3.134	<b>0.004</b>	0.051	0.822	7.135	<b>0.027</b>	9.366	<b>0.008</b>
Paying	-1.870	0.094	0.688	0.407	3.309	0.239	12.201	<b>0.003</b>

Continue; Correlation (P-value) between *Breast cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in the UK

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Uncomfortable	-1.393	0.187	0.085	0.770	2.209	0.345	1.817	0.398
Anxiety	0.298	0.768	0.012	0.914	2.479	0.339	1.920	0.431
<b>Pain</b>	-2.065	<b>0.050</b>	0.390	0.533	1.946	0.434	2.209	0.313
Comfortable	1.977	0.060	0.019	0.891	0.434	0.827	2.290	0.272
Reassure	-0.118	0.907	1.313	0.525	6.834	<b>0.035</b>	1.181	0.662
Painless	1.193	0.238	0.249	0.618	1.921	0.324	1.696	1.000
<b>Facilitators</b>								
Free charge	-0.189	0.852	0.003	0.953	0.380	0.946	0.983	0.624
Easy transport	-0.477	0.665	0.003	0.959	0.759	0.736	0.537	1.000
Family encouragement	1.442	0.181	0.413	0.520	1.248	0.688	1.036	0.647
Knowing the importance of early detection	-1.022	0.311	0.346	0.556	0.176	0.956	1.212	0.623
Professional cooperative	0.088	0.931	0.061	0.805	0.130	1.000	0.633	0.863
Husband cooperative	0.260	0.802	0.304	0.581	1.447	0.505	1.148	0.766

Continue; Correlation (P-value) between *Breast cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in the UK

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Appointment availability	-1.258	0.224	0.435	0.510	0.560	0.806	0.181	1.000
<b>Barriers</b>								
Take off clothes	0.816	0.419	0.263	0.608	0.307	0.884	1.029	0.631
<b>Lack of interest</b>	2.148	<b>0.033</b>	1.085	0.298	1.531	0.496	1.386	0.513
Cost	-1.001	0.335	0.618	0.432	0.362	0.876	3.838	0.166
Transportation	-1.736	0.084	0.587	0.444	1.813	0.467	0.395	0.788
Family encouragement	-0.154	0.880	2.530	0.112	1.244	0.533	3.388	0.160
Knowing the importance of early detection	1.198	0.234	0.618	0.432	6.841	<b>0.030</b>	2.827	0.247
Time waste	1.283	0.412	0.364	0.546	2.656	0.167	2.014	0.474
<b>No appointment available</b>	-3.750	<b>0.000</b>	0.547	0.460	10.486	<b>0.004</b>	2.118	0.336
Presence of male professional	-0.060	0.953	4.834	<b>0.028</b>	0.307	0.841	4.169	0.106
Husband encouragement	1.084	0.307	0.052	0.820	1.242	0.586	2.285	0.288
Fear of having it	-0.884	0.378	0.228	0.633	0.798	0.671	0.068	1.000
Don't know where to go	-1.427	0.158	0.004	0.950	0.331	0.862	0.895	0.638
Advice mammogram	1.087	0.354	4.060	0.109	5.150	0.093	1.412	0.864

Correlation (P-value) between *cervical cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status, among Saudi participants living in Saudi Arabia

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
<b>Lifestyle</b>								
Smoking	2.501	<b>0.013</b>	2.146	0.351	12.689	<b>0.001</b>	1.603	0.437
Lack of exercise	-0.161	0.873	3.492	0.150	1.185	0.557	2.309	0.322
Obesity	0.366	0.715	1.170	0.605	0.077	0.974	0.791	0.686
Nutrition	-0.658	0.511	2.448	0.274	0.452	0.802	2.763	0.265
Not sure	-1.245	0.215	3.415	0.157	1.401	0.507	0.010	1.000
<b>Symptoms</b>								
Heavy blood	-1.401	0.164	2.967	0.228	0.982	0.613	4.509	0.099
Pain during intercourse	-0.540	0.590	3.637	0.134	2.878	0.242	3.576	0.178
Unexpected blood	-0.094	0.925	0.634	0.758	1.553	0.448	2.444	0.311
Not sure	1.233	0.219	1.024	0.668	0.214	0.898	9.811	<b>0.008</b>
<b>Risk factors</b>								
Being older	0.496	0.621	0.805	0.666	3.246	0.201	1.589	0.455
Being poor	0.848	0.414	5.120	0.079	1.030	0.606	0.926	0.671
Multi sexual relationship	0.365	0.715	1.229	0.589	0.925	0.646	0.558	0.782
Assisted fertility	1.737	0.085	4.878	0.058	6.081	<b>0.050</b>	2.402	0.321
Contraceptive	0.024	0.981	0.275	0.958	1.589	0.440	1.739	0.437
Early sex	-0.547	0.587	1.302	0.478	3.232	0.202	0.776	0.702
Heredity	-1.166	0.245	0.881	0.702	1.888	0.406	3.315	0.201

Correlation (P-value) between *cervical cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status, among Saudi participants living in Saudi Arabia

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Childless	0.881	0.382	5.149	0.056	0.850	0.681	3.875	0.152
Use of hormone replacement treatment	-0.151	0.880	0.320	0.911	0.059	0.986	1.468	0.486
<b>Not sure</b>	1.990	<b>0.048</b>	1.461	0.520	4.569	0.098	4.938	0.089
<b>Treatment</b>								
Surgery	-0.781	0.436	0.251	0.921	1.516	0.461	3.842	0.156
<b>Chemotherapy</b>	-2.924	<b>0.004</b>	4.465	0.111	1.565	0.447	8.384	<b>0.015</b>
Radiotherapy	-1.636	0.104	0.684	0.758	4.742	0.095	3.299	0.210
Pain killer	-1.149	0.256	3.320	0.157	1.045	0.633	4.934	0.085
Not sure	1.899	0.059	1.639	0.477	0.828	0.659	4.586	0.110
<b>Heredity as a separate question</b>	-2.788	<b>0.006</b>	1.069	0.628	3.667	0.462	10.487	<b>0.033</b>
<b>Experience</b>								
Receive letter	-1.192	0.257	0.211	0.900	0.946	0.680	2.207	0.299
<b>Attend services</b>	-2.240	<b>0.041</b>	1.545	0.435	1.292	0.568	8.024	<b>0.012</b>
Paying	-0.107	0.917	1.193	0.275	0.270	1.000	2.666	0.248

Continue: Correlation (P-value) between *cervical cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in Saudi Arabia

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Uncomfortable	-0.154	0.880	2.413	0.120	1.533	0.497	1.686	0.457
Anxiety	0.816	0.417	0.373	0.541	0.989	0.656	1.425	0.544
Pain	0.078	0.939	1.322	0.250	1.908	0.421	4.393	0.085
Comfortable	-1.241	0.224	1.085	0.298	2.364	0.320	1.128	0.657
Reassure	-0.366	0.718	1.729	0.189	2.230	0.322	2.337	0.362
Painless	-0.814	0.434	0.075	0.784	2.758	0.232	3.442	0.162
<b>Facilitators</b>								
Free charge	1.556	0.129	0.857	0.355	0.835	0.683	0.110	1.000
Easy transport	-0.481	0.648	0.515	0.473	0.590	0.844	0.584	1.000
Family encouragement	0.330	0.747	0.448	0.503	0.828	0.748	3.930	0.116
Knowing the importance of early detection	-1.089	0.281	3.921	<b>0.048</b>	3.386	0.188	0.525	0.820
Professional cooperative	-0.177	0.861	1.609	0.205	1.934	0.419	3.379	0.178
Husband cooperative	0.511	0.618	0.815	0.367	1.410	0.523	0.264	1.000
Appointment availability	0.637	0.535	0.210	0.647	1.010	0.613	1.083	0.759

Continue: Correlation (P-value) between *cervical cancer*'s barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in Saudi Arabia

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Take off clothes	1.028	0.306	4.371	0.097	16.944	<b>0.000</b>	1.423	0.506
Lack of interest	0.771	0.442	6.040	<b>0.043</b>	2.625	0.276	4.232	0.128
Cost	-1.138	0.260	1.993	0.375	0.100	0.954	5.442	0.055
Transportation	-1.795	0.079	9.386	<b>0.008</b>	3.509	0.170	4.056	0.121
<b>Family encouragement</b>	1.981	<b>0.050</b>	0.934	0.672	0.693	0.705	2.851	0.234
Knowing the importance of early detection	1.925	0.055	0.999	0.643	0.335	0.839	1.905	0.390
Time waste	-0.906	0.374	7.595	<b>0.025</b>	4.729	0.099	2.650	0.228
<b>No appointment available</b>	-2.457	<b>0.016</b>	1.606	0.402	0.829	0.668	6.354	0.039
Presence of male professional	0.143	0.887	1.645	0.401	7.863	<b>0.017</b>	1.016	0.649
Husband encouragement	-1.616	0.113	5.437	0.055	1.257	0.543	8.770	<b>0.008</b>
Fear of having it	-0.764	0.446	15.884	<b>0.000</b>	1.349	0.491	8.123	<b>0.014</b>
Don't know where to go	-0.088	0.930	2.982	0.184	1.615	0.443	0.084	0.959
Advice mammogram	2.472	0.130	8.624	0.068	8.649	<b>0.039</b>	47.749	<b>0.000</b>

Correlation (P-value) between *cervical cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in the UK

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Smoking	-1.258	0.211	0.000	0.990	3.357	0.194	1.798	0.436
Lack of exercise	-1.068	0.289	0.001	0.977	0.208	0.921	1.431	0.529
Obesity	-0.501	0.617	0.002	0.969	0.138	0.958	4.738	0.109
Nutrition	-0.509	0.612	1.451	0.228	1.437	0.516	0.940	0.620
Not sure	1.460	0.146	0.188	0.665	3.773	0.157	0.588	0.796
<b>Symptoms</b>								
Heavy blood	0.161	0.873	0.353	0.552	4.305	0.109	3.405	0.141
Pain during intercourse	0.334	0.739	0.043	0.835	1.833	0.423	3.351	0.193
<b>Unexpected blood</b>	-3.037	<b>0.003</b>	1.100	0.294	7.068	<b>0.029</b>	11.325	<b>0.003</b>
Not sure	1.673	0.096	0.312	0.576	5.637	0.063	9.339	<b>0.008</b>



Correlation (P-value) between *cervical cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in the UK

<b>Risk factors</b>								
<b>Risk factors</b>	<b>T-test</b>	<b>P-value</b>	<b>Value</b>	<b>P-value</b>	<b>Value</b>	<b>P-value</b>	<b>Value</b>	<b>P-value</b>
<b>Being older</b>	-2.881	<b>0.005</b>	1.428	0.232	6.224	<b>0.043</b>	2.231	0.320
Being poor	-0.736	0.502	0.114	0.736	2.371	0.353	3.201	0.202
Multi sexual relationship	-1.391	0.166	0.593	0.441	1.621	0.460	4.328	0.118
Assisted fertility	-0.732	0.470	0.485	0.486	3.592	0.167	0.860	0.721
Contraceptive	-1.471	0.146	1.299	0.254	1.364	0.530	2.345	0.303
Early sex	0.322	0.749	2.002	0.157	1.137	0.617	2.698	0.243
<b>Heredity</b>	-2.842	<b>0.005</b>	1.164	0.281	4.231	0.123	0.786	0.699
Childless	0.025	0.980	0.225	0.635	3.018	0.211	1.233	0.462
Use of hormone replacement treatment	-0.503	0.616	0.174	0.676	0.801	0.661	2.244	0.380
<b>Not sure</b>	2.639	<b>0.009</b>	0.397	0.528	9.317	<b>0.010</b>	12.524	<b>0.002</b>
<b>Treatment</b>								
Surgery	-2.499	<b>0.013</b>	0.860	0.354	2.852	0.230	0.317	0.896
Chemotherapy	-2.681	<b>0.008</b>	0.529	0.467	4.858	0.088	0.958	0.646
Radiotherapy	-3.513	<b>0.001</b>	5.477	<b>0.019</b>	6.080	<b>0.045</b>	6.705	<b>0.024</b>

Correlation (P-value) between *cervical cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in the UK

Pain killer	-0.422	0.680	0.001	0.971	0.878	0.660	0.441	0.863
Not sure	3.079	<b>0.002</b>	0.068	0.795	6.417	0.042	5.383	0.070
Hereditiy as a separate question	-2.548	<b>0.012</b>	6.221	0.046	4.711	0.320	2.725	0.625
<b>Experience</b>								
Receive letter	-3.915	<b>0.000</b>	1.550	0.213	1.664	0.417	12.559	<b>0.001</b>
Attend services	-6.239	<b>0.000</b>	0.059	0.808	7.135	<b>0.026</b>	38.193	<b>0.000</b>
Paying	-1.272	0.231	0.283	0.595	3.462	0.212	6.454	<b>0.031</b>
<b>Experience</b>								
Uncomfortable	-1.693	0.100	0.515	0.473	2.209	0.342	3.651	0.173
Anxiety	1.177	0.247	0.645	0.422	2.479	0.338	6.596	<b>0.027</b>
Pain	1.239	0.231	0.003	0.953	1.946	0.431	0.632	0.824
Comfortable	-0.057	0.955	2.144	0.143	0.434	0.833	0.799	0.604
Reassure	1.215	0.228	0.055	0.814	6.834	<b>0.036</b>	3.428	0.181
Painless	-1.390	0.182	3.153	0.076	1.921	0.325	2.181	0.357
<b>Facilitators</b>								
Free charge	-1.128	0.265	0.226	0.634	2.026	0.381	3.082	0.168
Easy transport	-1.246	0.231	0.003	0.959	0.148	1.000	0.215	1.000
Family encouragement	-0.936	0.352	8.385	<b>0.004</b>	1.945	0.360	1.483	0.572
Knowing the importance of early detection	0.279	0.781	0.711	0.399	3.447	0.190	3.016	0.228
Professional cooperative	1.030	0.306	0.204	0.652	1.077	0.642	0.405	0.898
Husband cooperative	0.173	0.864	0.064	0.800	3.520	0.204	1.616	0.408
Appointment availability	-0.069	0.945	4.369	0.037	6.449	<b>0.040</b>	1.617	0.498

Correlation (P-value) between *cervical cancer's* barriers, knowledge and attitude with the age, education, occupation and marital status among Saudi participants living in the UK

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Take off clothes	0.944	0.348	0.028	0.866	0.595	0.734	1.851	0.426
<b>Lack of interest</b>	2.522	<b>0.040</b>	0.211	0.646	0.296	0.835	1.971	0.370
Cost	-0.542	0.594	0.197	0.657	1.608	0.443	2.767	0.253
<b>Transportation</b>	-2.483	<b>0.014</b>	0.242	0.623	1.205	0.534	0.121	1.000
Family encouragement	-0.433	0.672	0.016	0.899	1.687	0.472	7.106	<b>0.022</b>
Knowing the importance of early detection	0.790	0.431	0.627	0.428	4.873	0.084	5.897	<b>0.042</b>
Time waste	1.029	0.484	0.370	0.543	2.609	0.162	2.019	0.478
<b>No appointment available</b>	2.124	<b>0.043</b>	6.752	<b>0.009</b>	4.230	0.124	1.827	0.345
Presence of male professional	-0.593	0.556	4.165	<b>0.041</b>	0.897	0.631	0.722	0.739
Husband encouragement	-0.615	0.557	1.553	0.213	0.412	0.903	0.494	0.781
Fear of having it	0.227	0.821	1.743	0.187	1.406	0.484	0.915	0.650
<b>Don't know where to go</b>	2.227	<b>0.030</b>	0.412	0.521	1.351	0.529	2.798	0.193
Advice Pap test	1.708	0.090	1.372	0.514	12.390	<b>0.005</b>	19.049	<b>0.000</b>

*Correlation (P-value) between cancer's suggestion and socio-demographic factors among Saudi participants living in Saudi Arabia*

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Governmental transport	0.317	0.752	7.631	<b>0.016</b>	1.655	0.450	6.618	<b>0.032</b>
Female professional	-0.219	0.827	0.497	0.808	1.336	0.512	0.679	0.718
Professional attitude	-0.338	0.736	2.306	0.318	0.513	0.827	0.862	0.668
Use MRI	-1.548	0.125	4.421	0.077	0.756	0.702	0.105	0.977
Build detection centre	-1.405	0.161	1.174	0.625	1.372	0.496	4.926	0.084
Easy appointment	-0.522	0.603	0.116	1.000	6.558	<b>0.038</b>	0.502	0.801
Invitation letter	1.585	0.115	3.648	0.151	5.905	<b>0.051</b>	3.261	0.194
Event attending	1.187	0.237	0.247	0.963	4.459	0.108	4.302	0.111
Hospital	0.939	0.349	1.026	0.632	3.224	0.189	3.686	0.172
School	-0.280	0.780	7.418	<b>0.022</b>	1.556	0.470	1.478	0.464
Media	0.497	0.621	8.171	<b>0.015</b>	0.866	0.659	0.380	0.849
Mosque	-1.298	0.199	1.704	0.426	1.357	0.493	9.157	<b>0.008</b>
Shopping centre	1.129	0.260	3.294	0.227	2.088	0.353	2.644	0.279
Texting messages	1.229	0.221	2.017	0.414	2.851	0.231	1.754	0.435

Correlation (P-value) between *cancer's* suggestion and socio-demographic factors among Saudi participants living in the UK

Factors	Age		Education		Occupation		Marital status	
	T-test	P-value	Value	P-value	Value	P-value	Value	P-value
Governmental transport	-1.094	0.283	1.066	0.302	0.744	0.712	4.123	0.092
Female professional	0.223	0.824	3.090	0.079	1.568	0.475	0.921	0.640
Professional attitude	0.438	0.662	0.033	0.856	3.022	0.220	2.009	0.358
Use MRI	-1.907	0.058	1.789	0.181	2.785	0.245	7.854	<b>0.013</b>
Build detection centre	1.831	0.069	0.182	0.670	0.915	0.657	0.359	0.894
Easy appointment	0.534	0.594	0.155	0.693	1.323	0.532	0.394	0.859
Receiving invitation letter	-1.585	0.115	0.306	0.580	2.590	0.271	2.118	0.367
Event attending	0.027	0.978	0.036	0.849	3.184	0.212	7.373	<b>0.020</b>
Hospital	-0.144	0.886	0.631	0.427	5.953	<b>0.050</b>	4.564	0.095
School	0.137	0.891	2.395	0.122	8.796	<b>0.010</b>	6.776	<b>0.024</b>
Media	0.119	0.906	0.367	0.545	0.051	1.000	2.834	0.236
Mosque	-0.907	0.365	0.434	0.510	0.824	0.642	12.603	<b>0.001</b>
Shopping centre	0.237	0.813	1.055	0.304	0.980	0.622	7.924	<b>0.013</b>
Texting messages	-0.086	0.932	1.420	0.233	4.950	0.085	0.431	0.835

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