Immigrant Arab Women: Knowledge, Beliefs and Attitudes towards Breast Cancer and Cancer Awareness Practice

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Abstract

Background: Breast cancer is the most common cancer among women of all ethnic groups. Breast cancer awareness reduces mortality and improves survival rates, but low levels of awareness have been attributed to various factors. To date, little is known about what factors influence breast cancer awareness among immigrant Arab women in the UK. The aim of this research was to explore the knowledge, attitudes and beliefs related to breast cancer awareness practices with Arab women living in England. Methodology: A qualitatively driven mixed methods approach was adopted. The first phase used semi-structured one-to-one interviews with 10 women. The second phase comprised two focus groups with 34 women from Portsmouth and London. A quantitative approach using the Breast Cancer Awareness Measurement questionnaire was also administered to describe first and second generation women’s knowledge, perceived risk factors and barriers to seeking medical help, compare and contrast data from these two paradigms.

Findings: A lack of knowledge about breast cancer awareness, among Arab women of both generations, was evident across two phases. Revealing that socio-cultural, religious beliefs and health services barriers play an important role in shaping Arab women’s experiences and practices. Comparisons across generations showed trends towards increased knowledge for second generation women, but the findings were not statistically significant except anticipated delay in seeking help (p<0.001).

The second phase, focus group discussions, revealed both strengths and weakness of current breast cancer educational leaflets with suggestions to improve format, layout, content and availability. The qualitative data provided
contextual data on additional barriers which were, not revealed in the B-Cam measurements and descriptors.

**Conclusion:** Low levels of knowledge and lack of confidence among Arab women indicate a strong need to increase relevant breast cancer awareness such as mass media and community health campaigns, together with an enhanced participation of health care providers.
Declaration

‘Whilst registered as a candidate for the above degree, I have not been registered for any other research award. The results and conclusions embodied in this thesis are the work of the named candidate and have not been submitted for any other academic award.’

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## Abbreviations

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<tbody>
<tr>
<td>BC</td>
<td>Breast Cancer</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>GP</td>
<td>General Practice/General Practitioner</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>NCEI</td>
<td>National Cancer Equality Initiative</td>
</tr>
<tr>
<td>TTT</td>
<td>Train The Trainer programmes</td>
</tr>
<tr>
<td>ERIC</td>
<td>Education Resources Information Centre</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
</tr>
<tr>
<td>ASSIA</td>
<td>Applied Social Sciences Index &amp; Abstracts</td>
</tr>
<tr>
<td>IBSS</td>
<td>International Bibliography of Social Sciences</td>
</tr>
<tr>
<td>BNI</td>
<td>British Nursing Index</td>
</tr>
<tr>
<td>ECO</td>
<td>European Multidisciplinary cancer congress</td>
</tr>
<tr>
<td>EORTC</td>
<td>European Organization for research &amp; treatment of cancer</td>
</tr>
<tr>
<td>B-CAM</td>
<td>Breast Cancer Awareness Measure</td>
</tr>
<tr>
<td>ACS</td>
<td>American Cancer Society</td>
</tr>
<tr>
<td>CSAMI</td>
<td>Centre for Studies of Arab and Muslim Issues</td>
</tr>
</tbody>
</table>
Acknowledgment

The years spent in completion of this thesis have been filled with trials and challenges, most of which have required a great deal of patience from myself and those who have struggled on this path alongside me. The most valuable possession humans hold is time; some people take very good advantage of their time, they use their time to do good, and when this opportunity is taken, the natural consequence is for the next opportunity to present itself. When the good opportunity of time is not taken, we don’t waste time, time wastes us, therefore this thesis has become a part of a lifelong commitment to learning and developing in order to serve society. The rewards I have attained from my past years as a PhD student have been immeasurable. I have gained a great deal which will aid my personal and professional life, both now and in the future.

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Dissemination

To date the findings have been disseminated in the following ways:


Oral Presentations:
- Arab community centre/ University of Southampton (June 2009)
- Muslim Community/Portsmouth (August 2010)
- Iraqi community association/London (September 2011)
- Arab community organization/London (November 2012)
- Chandlers Ford Muslim conference (January 2014)
Dedication

This thesis is dedicated in the loving memory of my father Nimaa M. Redha, who taught me one of the vital lessons this life has to offer; opportunities are privileges we should strive and work beyond our boundaries to attain. By providing me with various opportunities, to the best of his abilities, he inspired me to become the best version of myself and to struggle for what I believe in. This has led me to become eternally grateful for the sacrifices he has had to endure in order to pave the way for the many blessings I have received throughout my years.

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To my brothers and sisters, who have been my heroes, they have always been the inspiration towards my life’s achievements.
Outline of the Thesis

**Chapter 1.** This chapter is divided into 3 parts 1) General background 2) Review of the current breast cancer literature, 3) The process of literature review. Part one will provide a background of two important areas: ethnicity and health, breast cancer in ethnic minority women, Arab population, cultural competence in healthcare delivery of services and implications for healthcare professionals. This provides a clear rationale for conducting this research. The second part discusses breast cancer in Arab women as general and in the UK, breast cancer epidemiology, risk factors and early detection. The third part provides an overview and discussion of the literature most relevant to the current research. The first section provides an Introduction and general overview of the literature review, which is followed by a thorough description of the literature search process and an evaluation of the pertinent literature which makes a significant contribution to the understanding of the research topic. The next section describes the key findings and contributions of the primary research to the field. Finally, the Implications for the current research programme is introduced.

**Chapter 2.** This chapter will discuss the methodology used in the first qualitative research study in Phase One. This discussion will include the description of the recruitment, data collection methods, approach to data analysis, findings and discussion. Data were collected from 10 immigrant Arab women by semi-structured audio taped one to one in-depth interview. The rich data sets were managed using thematic analysis. Analysis across the data sets highlighted four
main themes: Poor/Lack of knowledge, Socio-cultural beliefs and attitudes, Religious beliefs and attitudes, and Health services barriers.

**Chapter 3.** Describes the methodological approach adopted for Phase Two, including data collection process for the quantitative measurement using the validated Breast Cancer awareness Measurement (B-CAM) questionnaires and sampling. This is followed by rationale for focus group design, reflections on Phase two and process of audio recording. Part 2 describes the approach to quantitative data analysis results for all 6 domains of the B-CAM questionnaire and the final part which describes the focus group qualitative analysis, findings and discussion.

**Chapter 4.** Discussion of overall research, conclusion and implications of this research, limitations of the study and includes the researcher's reflections on the appropriateness of using mixed methods to research this phenomena.
Chapter One

Introduction/Background
Part 1
1.1 Introduction

The United Kingdom (UK) consists of a population derived from a diverse range of ethnic backgrounds, thus making it a multicultural society (Mayer et al., 2000). According to a census conducted in 2011 by the Office for National Statistics (ONS), more than 9 million people living in the UK are from ethnic minority groups (Office for National Statistics, 2011). The Arab population forms 11% of the ethnic minority communities in the UK. This population is known to be at a heightened risk of a range of chronic illnesses in comparison to the white population (i.e. cardiac disease diabetics and others such as breast cancer (El-Sayed, Tracy, Scarborough & Galea, 2011). Due to perceived cultural barriers it has been suggested that the majority of the Arab community residing in the UK, have deemed it challenging to approach health care services which may not have the capacity to address their issues with cultural sensitivity (Aljalili, 2004). According to the ‘white norm’, there is a fundamental assumption that the current strategies and health care services are suitable for the majority (Robinson, 2002); practices such as these fail to recognise the vast range of varying health care needs of ethnic minority communities (Mason, 2000). Communication between the patient and the health care professional is vital within any health care system. Ethnic minority groups may differ in their communication approach, which includes their understanding of illnesses, which can be influenced by their own cultural norms and attitudes.

The National Health Service (NHS) strives to provide high quality care, which is focused on the patient and meets the health needs of individual patients,
(Department of Health, 2005). Therefore healthcare professionals need to be responsive of the UK’s increasingly diverse multi-ethnic society and focus on delivering culturally competent care which has the potential to bridge the health inequalities gap (Department of Health [DoH], 2007; Pesquera, Yoder & Lynk, 2006; Szczepura et al., 2005).

“Mixed methods research is a methodology for conducting research that involves collecting, analyzing, and integrating (or mixing) quantitative and qualitative research (and data) in a single study or a longitudinal program of inquiry” (Cresswell, 2003, p. 6). Mixed methods research emerged around the 1950s adopted by researchers known as pragmatists (Cresswell, 2007; Tashakkori & Teddlie, 2003). Pragmatists believe that multiple paradigms can be used to research under-researched topics (Creswell & Plano Clark, 2007; Giddings, 2006). This approach has generated a great deal of interest, within the last decade, resulting in a mixed methods paradigm of its own (Creswell, 2003; Gilbert, 2006; Haerkamp, Morrow, & Ponterotto, 2005; Johnson & Onwuegbuzie, 2004; Johnson, Onwuegbuzie & Turner, 2007).

For this reason, mixed method approaches have been well received in applied research settings and have progressively become popular in health research (O’Cathain, Murphy & Nicholl, 2007; O’Cathain, 2009; Tashakkori & Teddlie, 2003), including areas such as cancer (Bertero, 2008; Dubois & Loiselle, 2009; Kubon et al, 2012; Tsai, Morisky, Kagawa-Singer & Ashing-Giwa, 2011).

There are a number of approaches to conducting mixed methods research, for which it is important for the researcher to consider carefully both research design in relation to time ordering (whether qualitative and quantitative research are
carried out sequentially or concurrently) and whether equal status is given to both the qualitative or quantitative paradigm or dominance of one approach to another (Johnson & Onwuegbuzie, 2004).

For this research study, an exploratory sequential design was adopted, whereby the research dominance was that given to the qualitative paradigm. This design was adopted due to the limited research conducted in the area of breast cancer and breast awareness among Arab population in England. Qualitative research has been found to be a valid method, for exploration psycho-social research questions in areas where little is known (Liamputtong & Ezzy, 2005). Therefore, it was deemed appropriate to start with and continue with an exploratory qualitative approach to gain a deeper understanding of immigrant Arab women’s knowledge, beliefs and attitudes toward breast cancer and breast awareness. However, following Major Review (a key stage progression assessment at 18 months doctoral training) peer review feedback suggested that at Phase Two, measuring knowledge and perceived barriers by using a validated measure, such as the Breast Cancer Awareness Measurement (BCAM) questionnaire, would be useful to fully describe the characteristics of the population in order to compare levels of knowledge and perceived barriers with those of native UK women described in current literature. It was also postulated that there would be a difference between first and second generation Arab immigrant women’s knowledge and practice of breast care and breast awareness behaviour which could be measured using the BCAM questionnaire. Therefore, at Phase II, concurrent data collection, dominated by qualitative research, but including the validated BCAM quantitative measure, were adopted.
Before reviewing attitudes, beliefs and practices of women toward breast cancer and breast cancer awareness, it is important to understand and define key terminology and classifications of ethnicity and the target population (immigrant Arab women) under study.

1.2 Definitions

1.2.1 Defining Race and Ethnicity

Various settings within society utilise the concept of ethnicity to a broad extent; these structures include research, medicinal services, education, politics and in daily dialogue. The healthcare setting within the UK aims to lessen the disparities people with distinctive ethnic backgrounds face in terms of health (House of Commons, 2009). However, race, ethnicity and culture are terms which have been under debate and discussion for many years.

Researchers have also struggled to distinguish these concepts as a result of disagreements in terms of established or shared definitions; there are presently no broadly acknowledged meanings of race and ethnicity, which has caused much complexity. This results in the use of such terms in compound multiple forms or as independent labels, i.e. race/ethnicity, race and ethnicity, race-ethnicity (Comstock, Castillo & Lindsay, 2004; Pfeffer & Moynihan, 1996). Lack of clarity may potentially raise problems in research investigating health amongst ethnic minority populations. An example of this might be that, instead of the analysing relevant variation or health differences likely to influence (such as cultural beliefs towards certain diseases, poor education, racism or limited healthcare access), researchers may be lead to believe that health differences
are due to a person’s race and ethnicity (Comstock, Castillo & Lindsay., 2004; Jones, 2000).

1.2.2 Race

Race is often seen as a combination of physical components that make up a group of people with similar features reflecting inherited origin (Bhopal, 2007). During the beginning of the 19th century, it was widely believed that race is defined as the genetic makeup between varying groups of people (Szczepura et al., 2005); however this comprehension has been undermined by various scientists and epidemiologists. Populations throughout the world share the same 99% of genetic makeup; diseases with genetic causes are also not constrained to any particular race (Bhopal, 1999; Pfeffer & Moynihan, 1996; Szczepura et al., 2005).

Race is a concept, which has currently been advanced from the perspective of social productivity whereas emphasis is put on its roots (Kaplan & Bennett, 2003). In social epidemiology, the distinguished element of race based on physical features is greatly understated; it is often viewed as politically incorrect by various researchers to utilise the term “race” as there are both social and historical affiliations that demoralise specific races, such as the Black African slave trade or the ethnic cleansing by the Nazi program (Bhopal, 2004; Pfeffer & Moynihan, 1996).

Race is also widely associated with the terms “Black” and “White”; social perceptions define a person who does not categorically fit the criteria to be “white” or of another skin colour to be defined as belonging to the “Black” race (Bhopal & Donaldson, 1998). This issue can prove to be problematic when referring to
those who do not fall within the ‘White’ subdivision as ‘Black’ implies that their origins belong to a similar group; this concept is invalid as ethnic minority populations are by no means similar. However, in other contexts such as the study of racism, the concept of race is important and needs to be emphasised. Thus the term ‘race’ is context dependent and while some areas of research may not consider it an appropriate term, other fields (e.g. epidemiologic research) may find it highly relevant. For the reasons highlighted above the following section will aim to define the term “ethnicity”.

1.2.3 Ethnicity

The definition of ethnicity differs to that of race; it is progressively becoming a more frequently used term in health research and increasingly preferred to race (Afshari & Bhopal, 2002; Bhopal, 2007; Smaje, 1995). Ethnicity is a varied concept making it complex; the identification of an individual’s social group is recognised as ethnicity, which comprises shared aspects such as religion, language, dietary habits, physical features and origin (Gill, Kai, Bhopal & Wild, 2004; Bhopal, 2007); these are features which have previously been ascribed with race (Bhopal, 2007). Some people prefer to identify themselves with a certain culture rather than an ethnicity which is; however both culture and ethnicity are terms which can be utilised in place of each other (Szczepura et al., 2005). Although both terms are similar, culture covers broader aspects that depicts a group of people; these surround areas such as common practices and faith systems, attitudes and rituals (Pfeffer & Moynihan, 1996).

Culture includes the characteristics and knowledge of a particular group of people, usually defined by language, religion and social habits (Zimmermann,
In a similar way, Arabs are defined largely by speaking a common language (Arabic) and a shared sense of geographic, historical, and cultural identity. The Arab culture is defined by its essential twin constituents of Arabism and Islam (Sulaiman, 2007). To most, although not all, Arabs, Islam is the indigenous religion as well as their indigenous civilization. Therefore, it could be argued that although an Arab may be born and live in different geographical locations they may be considered homogeneous in terms of dominant culture (Arabism), language and religious beliefs (Sulaiman, 2007).

1.2.4 Acculturation

Acculturation is a word used to describe the extent to which individual has both accepted and adapted to the customs and standards of the new country (Ahmed & Lemkau, 2000). When migrating to a new country, immigrants carry their native countries beliefs and cultural attitudes; the entire process of migration can be an extremely difficult one, as the new place of residence possesses an entirely new culture and lifestyle. The adaptations that occur with the move which includes the familiarisation of the country’s laws, health care systems and accustoming oneself to the altered lifestyle can be a source of discouragement and worry for the individual (Dasgupta, 1998). This difficulty can be particularly true for individuals who wish to confirm their ethnicity by grasping on to their cultural practices (Bhattacharya & Schoppelrey, 2004). There are various levels of acculturation, which can be subject to modification over the generations and time (Phinney, 2003). The four categories of acculturation include the following (Farver, Narang & Bhadha, 2002):
• Assimilation – It is exclusive identification to the new culture, where a minority group gradually adapts to the customs and attitudes of the prevailing culture and customs

• Integration – This is also identified as bi-cultural, the individual is able to relate themselves to both cultures.

• Marginalization – the rejection of both the individual’s native and new culture

• Separation – The singular identification of their native culture whilst completely rejecting the culture of their new settlement

During the progression of adjustment period in both first and second-generation immigrants, acculturation becomes a significant part of this process. Anderson, Scrimshaw and Fullilove (2003) have demonstrated that the level of acculturation an individual undergoes has an impact on their involvement with health care and their interaction with the health care professionals. Other factors which have an impact includes the communication that takes from within the families and generations (Ahmed & Lemkau, 2000).

Elder generations find it challenging to accept and integrate with the culture of the new settlement, they are more inclined to grasp on to their own cultures (Dasgupta, 1998). First generation immigrants tend to restrict the majority of their integration with people from within their own circle, their lack of keenness to associate with the new culture may be due to the amount of difficult they face when interacting due to cultural and linguistic barriers; this in turn increases their difficulty in accessing health care services (Ahmed & Lemkau, 2000).

On the other hand, if the majority of the life of an immigrant having migrated before the age of 12, was spent in the new country; this might lead to an
experience of alienation between the conflicting cultures experienced which, in turn, may cause inter-generational strains (Ahmed & Lemkau, 2000). Second generation immigrants may also find this concept applicable to them; the reason for this might be that these individuals exposure to westernised customs are in contrast with family and own cultural beliefs, attitudes, values, which are being maintained by the older generation. This becomes particularly challenging when the conflicting cultures clash.

The varying grades of acculturation and distinctions between first and second generations described may have an impact on the individual’s perception of health, health care experiences and interaction with health care professionals (Anderson, et al., 2003). Less acculturated and first generation immigrants are increasingly liable to assume and accept myths regarding cancer, which may lead to the inaccurate belief that it’s a contagious condition. This group of immigrants might then be less inclined to seeking medical advice and support due to their lack of understanding towards any illness; the adaptation of these cultural taboos could potentially lead to these individuals hiding their illness from society. (Ashing-Giwa, et al., 2004).

The knowledge, beliefs and attitudes towards cancer vary greatly between the two generations; unlike the first generation immigrants, second generation groups are more acculturated, thus realising the importance of actively seeking health care. This group of individuals may feel more comfortable in discussing their illness, they may also attempt to inform and encourage the first generation of the significance of speaking of their illness to a healthcare professional (Deepak, 2004). Due to the various stages of acculturation first and second generation individuals acquire, it is imperative that no assumptions are made by
health care professionals regarding their cultural background and the form of care and support needed by these patients.

Furthermore, Deepak (2004) defined migrants to the United Kingdom belonging to two categories; one known as ‘first generation’ immigrants and another group, which included two or more generations. First generation immigrants include those who migrated independently or with a companion, whilst second generation involved those who came as a family with two or more generations. But, the author be unsuccessful to express whether the second group would also be categorised as first generation immigrants or the generation status would depend on how many generations moved. For instance, if two generations were to move to the United Kingdom (i.e. father and son), the first generation (i.e. the father) would be defined as a first generation immigrant, whereas the second generation (i.e. the son) would be known as a second generation immigrant. The classifications of the generations would be dependent on how the term generation is defined. Moreover, Stedman described a generation as a group on individuals belonging to a specific time category (Stedman, 2004); this definition would mean first generation Arab immigrants are the combination of generations migrating at the same time. Further complexity is added when attempting to define people according to their generation and immigrant status in terms of second and third generations. The status of a second-generation immigrant is for those for have parents born in a country other than the country they have obtained a citizenship in (Macmillan Dictionary, 2009). A more accurate method of identifying an individual belonging to second generation would be to state their generation followed by their nationality (e.g. second generation British born), this method prevents the individual from being identified as a second generation immigrant
when they do not fit the criteria of an immigrant (Suinn, Ahuna & Khoo, 1992; Ours & Veenman, 2003).

The third generation individuals belong to parents who were born in the UK but whose grandparents were born abroad (Suinn et al., 1992). Research identifying the variances between generations often explain the interpretation of the author when mentioning immigrants belonging to either first or second generation; however the selection of this terminology works on the assumption that the reader can comprehend it in a similar way to the author, with a limited amount of rationalisation. An example of this is the determination of both the status of generation and immigration on the basis of the individual’s age; a study by Inman (2006) categorised first generation immigrants to those who migrated to the USA after the age of 20 and those who migrated before the age of 12 were defined as second-generation immigrants. Another definition of second generation immigrants by Ours and Veenman (2002) claims they are those who were born in a country from at least one immigrant parent, or immigrated to the country at or under 6 years of age. In order to provide clarity, first generation immigrants/elder generation will be denoted as those who migrated to the United Kingdom either independently or with their families consisting of two or more generations; and second generation immigrants/younger generation are those who are citizens of the UK with parents born abroad (Deepak, 2004).

1.3 Cultural Competence in Health Care

Various research projects have suggested that immigrants face more difficult encounters in the access of health care; these barriers have the potential to result in late diagnosis, decreased health screening uptake and a lowered confidence
in utilising health care services. Barriers which may trigger these outcomes
include the individual’s lack of familiarity of healthcare, language difficulties and
cultural attitudes (Deepak, 2004; Johnson et al, 2004; Lodge, 2001;
Papadopoulos & Lees, 2004; Watts, Merrell, Murphy & Williams, 2004)

Some health care services can sometimes make the incorrect assumption that
the decreased uptake of patients belonging to various ethnic minority groups are
due to their lack of concern towards the services provided (Vernon, 2002).
Research has shown that linguistic barriers between the patient and the
healthcare professional plays a significant role in the delivery of good quality care;
health care professionals have often been challenged by the vast difference in in
linguistic factors, including a lack of knowledge of their patient’s culture
(Hammoud, White & Fetters, 2005). These existing barriers have impacted both
the capacity and the confidence for immigrants, in particular those of the first
generation, to actively participate in seeking appropriate health care (Cox, Kelly,
Talman, & Coutts, 2007; Szczepura et al, 2005; Thalassis & Taha, 2006). The
broadly recognised barriers outlined highlight the vital implications of providing
culturally competent health care by health care professionals; these will be further
outlined in the following section.

1.3.1 Cultural Barriers

The health beliefs an individual possesses is greatly dependent on their cultural
values and customs; these factors establish the way in which the symptoms of
the disease is understood and the kind of information necessary to aid in this
understanding (Szczepura, 2005). An example of this is the way in which breast
cancer is perceived in a way of culture; such as the concept that it is a disease
derived from the “white woman” or a contagious disease (Balneaves et al., 2007; Watts, et al., 2004). Identification of illnesses such as cancer can be an experience which is isolating for an Arab woman due to the cultural standard of keeping such issues private and concealed for the favour of prevention of stigmatisation and the maintenance of a good standard within their communities. Spiritual and religious practices have often proved to be an effective method of dealing with health concerns for the ethnic groups including Arab women, however such attitudes may impact the individual’s treatment compliance or result in an unwillingness to utilise health services (Ashing-Giwa et al., 2004; Szczepura, 2005).

Openly discussing or examining one’s body parts is considered highly inappropriate and these are broadly accepted concepts and standards maintained within the Arab culture (Taha, et al., 2010). Issues such as these increases the difficulty for many Arab women to access health care services as aspects such as modesty and reputation are both under questions, these are factors which have high regards within their culture. A prevention factor for a majority of Arab women is the emphasis placed on her modesty as it may involve the examination by a male physician or health care professional (Amin, Mulhim & Meqihwi, 2009; Akhtar, Nadrah & Gabbani, 2010) and therefore reluctance in accessing health care services and ignorance that treatment by female health care professionals exists (Mamdouh et al., 2014).

Additional preventative factors concerning culture, including family dynamics, may suggest that seeking health care without the support of the family becomes very difficult, which may lead to obtaining help at later stages. This may be especially the case in cultures where prioritising family needs before their own is
of great importance (Szczepura, 2005). On the other hand, health care professionals should often practice cultural and religious awareness as they have the possibility of conveying an impact of either positive or negative nature on the patient’s views and experiences relating to health care. This in turn aids the health care professional in providing appropriate, culturally sensitive and health care.

An awareness of the religion (Islam) that exists in the Arab culture is also essential and respectively, assumptions concerning Arab women based on cultural and religious beliefs should be prevented by health care professionals. To enable and improve the level of comfort and confidence in accessing health care amongst women of various cultures and ethnicities, it is imperative for health care professionals to have an awareness of their varying cultural and religious needs. For example, the dietary needs of a Muslim patient is different from that of a non-Muslim as they only consume Halal meat, and religious practices such a prayer where Islamic traditions require 5 daily prayers (Ahmed & Lemkau, 2000).

1.3.2 Linguistic Barriers

As well as being aware of the cultural beliefs and attitudes of immigrant Arab women, linguistic competence is also important as language barriers have been known to hinder communication between the patients and health care professionals, making it difficult for immigrant Arab women to access health care services. Ethnic communities such as those originating from South Asia and China, have shown evidence of limited English proficiency, in particular those belonging to the first generation (Ryan, 2013; Brach & Fraserirector, 2000; Brenner, 2002; Gill, et al., 2004). The ability to understand English may also have
its differences and challenges. An individual may struggle with confidence in reading or speaking the English language despite having a fair understanding of it (Szczepura et al., 2005); due to this the materials available in promoting health awareness may not always reach the ethnic populations as the materials may not cover the message in their native tongue.

Individuals who are overwhelmed by the language barriers can have the health care needs met by being supplied with translated material and interpreters; these methods further enhance the understanding the individual has of health related matters and encourages the communication between them and the health care professionals (Dunckley, Hughes, Addington-Hall & Higginson, 2003; Szczepura, et al., 2005). It is important to take into consideration that not everyone who is provided information in their mother tongue will be able to read or write in their own language, this is particularly applicable to immigrants of the first generation. Previous investigations have demonstrated a total of 40% women of Arab origin lack literacy in their own language (Maamouri, 1999).

Research has shown that additional sources of delivering health related information including visual or auditory mediums, may demonstrate in aiding to overcoming language barriers (Szczepura, 2005; Watts, et al., 2004). Another method of overcoming language barriers for patients with limited English proficiency is through the use of interpreters or bilingual health care professionals; this will aid communication between the health care professional and the patient (Szczepura, 2005).
1.4 Implications for Health Care Professionals
On the basis of the above highlighted barriers, it is imperative that health care meets the cultural needs of all people accessing health care services. Campinha-Bacote (2002) created a model as an outline for providing culturally competent care that can aid health care professionals to deliver efficient care. This model displays cultural competence and continues the process for health care professionals in order to attain competent health care within the cultural context. This model displays cultural competence and continues the process for health care professionals to achieve culturally competent health care. There are five components, which form this model:

- The procedure involved in investigating culture and being understanding towards the dissimilarities involved in culture (Cultural awareness)
- The advancement of the knowledge regarding cultural beliefs, attitudes and practices (Cultural knowledge)
- The application of cultural skill and knowledge when providing care for patients (Cultural Skill)
- The continuous development of knowledge and skills in order to appropriately deal with people from various cultures (Cultural encounters)
- The attempt to provide culturally competent health care and the motivation to improve upon cultural awareness and knowledge, and developing the skills required to engage with people from various cultural origins. (Cultural desire)

Ensuring all people are delivered culturally competent health care can diminish inequalities in health care. A qualitative study conducted by Chevannes (2002) relating to the knowledge of health care professional of black minority ethnic
groups related to issues of health, both before and after participating in a cultural diversity training program. Prior to training, health care professionals recognised their limited knowledge of the cultural beliefs and attitudes related to black minority ethnic. Specific education and training surround the issue of the BME culture was inadequate and health care professionals reported that they required appropriate training which is able to meet the cultural needs of BME people. In addition, their capability to deliver care of a high standard was largely impacted by the language barriers; they also found it challenging to select appropriate interpreters for the consultations as they had limited language awareness. Following the training program, there was a reported increase in awareness of BME group’s health care needs in health care professionals; comments were also added on how some of the health care professionals transferred this training in to their practice.

Recommendations were made regarding this area by various researchers for policy makers, health care professionals and researchers (Ahmed & Lemkau 2000; Anderson et al., 2003; Bhopal, 2007; Chin, 2015); these include the following:

- Stipulate specific training in cultural competence aimed at health care professionals in favor of developing the knowledge, awareness and sensitivity regarding the cultural attitudes and beliefs of various ethnicities.

- Support for staff in the health profession by providing continuous education on the provision of culturally competent care.

- Efficiently utilising linguistic interpreters for those lacking English proficiency.
- Effectively utilising educational materials which is both linguistically and culturally appropriate.

- Not approving of use of knowledge without confirmation.

- Plan aimed at programs for recruiting and retaining members of staff who reflect cultural diversity of the community.

1.5 Arab Population

The classification of the term Arab is largely based on the use of the n Arabic language as a first language along with a shared sense of historic and cultural identity. Arabs are associated with a specific region of the world, which extends from the Atlantic coast of Northern Africa to the Arabian Gulf (Hourani, 1991).

In addition, the term Arab is not a racial classification; rather that Arabs comprise people with a wide variety of physical features. With a total population of 230 million across 22 nations as follows: Africa consisting of 10 Arab states (Morocco, Mauritania, Algeria, Tunisia, Libya, Sudan, Somalia, Eritrea, Djibouti and Egypt), in addition to 12 Arab states in Asia (Iraq, Jordan, Lebanon, Syria, Kuwait, Bahrain, Qatar, Oman, United Arab Emirates, Saudi Arabia, Yemen, and Palestine(United nation development program (UNDP, 1993)).

The large majority of Arabs are Muslim, equating to 92%, therefore they are not all the same in respect of religious belief. Other faiths include Christianity and Judaism, among other minorities. In spite of a large number of Muslim Arabs, overall they enclose only around 17% of the
Islamic population global (with other large residents in Indonesia, Malaysia, South Asia, Iran, Central Asia, Turkey, and Sub-Saharan Africa). The close association between the religion of Islam and Arab identity stems from historical origin of the faith in the Arabian peninsula and the original Arabic language of their sacred book; the Holy Qur’an.

Part 2 Breast Cancer in Arab Women

2.1 Breast Cancer Epidemiology and Risk Factors

Globally the most diagnosed form of female cancer, is that of breast cancer; it accounts for 31% of all female cancer sufferers in the UK. It has been estimated that the risk of developing breast cancer for a woman in the UK is one in eight. In 2011, there were 50,285 new cases of breast cancer in the UK, 49,936 (99%) in women and 349 (less than 1%) in men (ONS, 2013). Although the incidence of the disease is on the increase, since the establishment of breast cancer screening services in the UK, the mortality rates of the disease have been decreasing.

Breast cancer currently has one of the highest survival rates in five years; this is due to the advances in treatments in case of early detection over the last 30 years. Between 2001 and 2006 these rates reached 82% for women diagnosed with breast cancer, in comparison to the years between 1971 and 1975, where the rate was down at 52% of women diagnosed (Cancer Research UK, 2011).

There are various factors that play a role in the incidence of cancer; these include certain influences including environmental, lifestyle risk and hereditary
components factors (American Cancer Society (ACS), 2011). Risk factors can also be modified over time, due to factors such as age or lifestyle change. For instance, there is a strong link between the increase of the woman's age and breast cancer; 81% of cases arise in women aged 50 years and over, and almost 50% of cases appear in women between the ages of 50 and 69 (ACS, 2011). For instance, there is a strong link between the increase of the woman's age and breast cancer; a large number of cases rise in women over the age of 50 (81%), with 50% of cases appearing in women aged range 50-69 (ACS, 2011).

A family history of cancer is known to be amongst the risk factors, diagnoses of breast cancer in a biological family member can almost double the risk of the disease in a woman (ACS, 2011). On the contrary, a large number of women who suffer from breast cancer have no family link to the disease (85%); an equal amount of women who have had family members diagnosed with the disease never develop this condition. Macmillan cancer support (2011) has stated that an increased exposure to oestrogen is connected to a higher risk of developing breast cancer; for example a late menopause or late first pregnancy. Other risk factors linked with cancer have included lifestyle factors such as obesity and alcohol consumption. However the presence of risk factors does not necessarily signify a conclusive risk of having breast cancer; many individuals with a diagnosis of breast cancer have not been exposed to related risk factors.

### 2.2 Breast Cancer in the Arab World

Breast cancer has posed a major health threat amongst Arab women in Arabic countries (Berner, Ayub, Kakil & Ibrahim, 2007; El Saghir et al., 2007; Salem, Kamal & Helal, 2008). Despite the low incidence rate of breast cancer in Arab
countries in comparison to Western countries, they are rapidly increasing (Berner et al., 2007; Azaiza & Cohen, 2006; WHO, 2011).

It has been found that breast cancer is the most common type of cancer among Arab women, forming 14-48% of the entirety of female cancers. In comparison to the age range of female breast cancer sufferers in Western countries, breast cancer in Arab countries is present in a female population that is almost 10 years younger (Berner et al., 2007; Al Saad, Al-Shinnawi, Mahmood Shamsi, 2009; Salim, Kamal, R., & Helal, 2008; Najjar and Easson, 2010). The median age of female breast cancer sufferers in Arab countries is between 48-42 years, with 50% of all cases below 50 years; however in Western countries the median age of female breast cancer sufferers is 63 years with only 25% shown to be below the age of 50 (Saadat, 2008; El Saghir et al., 2007).

Arab women are often diagnosed at advanced stages of breast cancer, (Harirchi, Karbakhsh, Kashefi & Momtahen, 2004; WHO EMRO, 2006; Berner et al., 2007; El Saghir, 2008; Baron-Epel, Friedman & Lernau, 2009; Salim et al., 2009; Harirchi et al., 2004) which means they have less of a chance of responding successfully to treatment (Tarabeia et al., 2007; Petro-Nustas, 2001).

2.3 Breast Cancer amongst Arab Immigrants in the UK

Between 2001 and 2009, the ethnic minority population in the UK increased by 4% (ONC, 2011). According to the latest census data (2011), there are approximately 9.1 million (12.1%) ethnic minority men and women in the UK (compared to 6.6 million in 2001); with half the minority ethnic population describing themselves as British Asian (Indian, Pakistani, Bangladeshi or other Asian) and a quarter describing themselves as Black (Black Caribbean, Black
African or other Black) (ONC, 2011). In spite the growing of ethnic minority in the UK, there is insufficient knowledge regarding their breast cancer experiences, incidence and survival rates within this community.

As mentioned previously, breast cancer is one of the most common forms of cancer in the UK. With so many women developing breast cancer, it is the most common form of cancer in women of all ethnic groups (Breast Cancer Care, 2005; Lodge, 2001). The competency of care services is considerably dependent on the receipt and assessment of accurate data concerning the racial and ethnic origins and the mother tongue of the patients. Furthermore, research suggests that the collection of this information encourages organisations to develop and implement significant improvements (Marshall, Shekelle, Leatherman & Brook, 2000).

In the UK, the availability of data on breast cancer incidence, survival and mortality rates is limited for the minority groups. This is due to the fact that patients' ethnicity is not routinely recorded within all NHS Trusts (Jack et al, 2006). Recording patients' ethnicity (using the classifications provided by the Office of National Censuses) has been mandatory since 1995, as part of the ‘admitted patient contract minimum dataset’ (National Cancer Alliance, 2001). However, even with this, data regarding ethnicity is still very poor quality or mostly incomplete (Department of Health, 2007). This has implications for NHS Trusts to strive towards collecting such data to allow for more accurate analyses. This information would then help to identify where inequalities exist, and as a result, appropriate measures can be taken to reduce this.
Ethnic classification data from the 1991 to 2001 census provides limited insight into the size of the Arab population living in the UK via classification using ‘other’ category. Lack of recognition of Arabs as a separate ethnic category led to the National Association of British Arabs, in conjunction with the British Arabs Forum, recommending an additional, separate category box for ‘Arab’ for ethnic profile grouping for governmental and non-governmental statistics in the Census of Population 2011 (Centre for Studies of Arab and Muslim Issues (CSAMI), 2011).

ONS 2011 guidance was subsequently adapted to introduce a separate ‘Other’ category for ‘Arab’. Unfortunately this additional separate category for Arab ethnic profiling has not been adopted by the NHS which still complies with the categories set out in the 2001 Census (Health and Social Care Information Centre, 2015) (see Appendix 3.2). It is, therefore, highly likely that current Arab ethnicity data collected by the NHS is limited which, in turn, may also reflect inaccurate records within the Cancer Research UK and National Cancer Intelligence Network (NCIN) data. This limitation means that major future health care planning and development issues may not include an accurate representation of the Arab community; for example, planning of health education needs. Increasingly medical research looks at the health needs of particular groups within the community from which to plan future health requirements. As with many other ethnic groups health needs have been identified, immigrant Arab women have health needs and problems which are particular to them and unless there is a reasonably accurate guide to the statistical incidence of breast cancer on which to base research, these health needs may go unheard.

At present, in UK there is a gap in ethnicity data being reported and recorded. There are currently no studies in the UK that have explored breast cancer
incidence rates and experiences among Arab women in the UK. Cancer Research UK and NCIN have gathered data from various sources and aim to present an accurate account of cancer amongst some of ethnic communities, in the hope to raise awareness and early detection in communities where incidence rates of cancers are the highest, for example South Asian women and black minority ethnicity. These studies suggests that the women tend to be diagnosed at a younger age and are more likely to be diagnosed at a progressive stage than White women (Farooq & Coleman, 2005; Velikova, Booth, Johnston, Form & Selby, 2004). In other research conducted in the UK among South Asians community, it is proclaimed that breast cancer among south Asian women has a lower occurrence and higher survival rate compared to non-south Asian women (Farooq & Coleman, 2005; Zaman & Mangtani, 2007). However in the UK there is a higher rate of breast cancer among south Asian women compared to those living in their native country. (Jain, Mills & Parikh-Patel, 2005) and has been recognised as being the most common cancer among first generation immigrant women from minority ethnic groups (Cancer Research Campaign, 1997).

In the absence of recorded ethnicity data, different measures were used in these studies by categorising their first name and last name using a computer based name recognition algorithms (Barker & Barker, 1990; Farooq & Coleman, 2005). However, this method can be difficult for three reasons. Firstly, what makes this process complicated is not all ethnic names are the same in terms of character, also some of them having westernised names and different spelling which could not be picked up and causes negative data. Secondly, Westernised names are common among the Christian ethnic group as they share similar names with the western population, and thirdly, marrying into different societies leads into taking
their partners last name (Bhopal, 2007). The challenges stated is what makes the process difficult as it results in the specific ethnic group to be misidentified or a confusion regarding their identity. With all the limitations identified, these name algorithms are still being used and is considered the unsurpassed applied method in regards to collecting such data (Farooq & Coleman, 2005).

At present, ethnic data is commonly gathered through the Hospital Episode Statistics (HES) dataset. This is heavily dependent on patients self-reporting their ethnicity at registration/hospital appointment. The National Cancer Data Repository (NCDR) is the first national analysis database that administers quality cancer statistics that allows analyses of epidemiology of cancer, identifying ethnic patients in England from 2002 to 2006. This database was compiled when the National Cancer Intelligence Network (NCIN), shared their cancer statistics with the national cancer registry data, establishing the NCDR (NCIN, 2009).

Unlike the UK, the health system in the USA routinely records patients’ demographic information, including ethnicity via cancer registries such as the Surveillance Epidemiology and End Results (SEER) cancer registry, allowing analyses of cancer incidence, mortality and survival rates to be produced with ease (Ward et al, 2004). However, there is no one single database. Instead, different hospitals in different parts of America use different programs of data collection to record information (e.g. programs such as the National Centre for Health Statistics, National Cancer Data Base and SEER). Nonetheless, a study conducted in USA using these databases demonstrated that Arab-American women are more likely to become diagnosed with advanced stage breast cancer in comparison to White women (Darwish-Yassine & Wing, 2005). The lack of figures on breast cancer incidence amongst immigrant Arab women and the
differences in the incidence, survival and mortality rates between them and White women is worrying and needs to be further explored. It would be inappropriate to assume that Arab women’s experiences are the same as the experiences lived by White women, especially in groups where mastectomy rates are higher or cancer is presented at later stages. Therefore, further research is warranted. Additionally, incidence rates of breast cancer among ethnic communities, including Arabs, are on the increase (Hensley Alford et al., 2008). These communities construct the largest non-White population in the UK. Therefore, it is fundamental to focus research on these communities in order to comprehend their needs and experiences in order to provide appropriate health care.

2.4 Early Detection

Early detection is absolutely crucial for successful treatment and recovery (Saadi, Bond & Percac-Lima, 2011), therefore it is essential that women are extremely familiar with the physiognomy of their breasts, both in appearance and to touch, and are able to recognise and report any noted changes immediately. While the detection of a change does not necessarily indicate cancer, Initial indications of the development of breast cancer are usually manifest in alterations in the skin or tissue of the breast and the detection of a lump.

The most accurate method early detection to date, is still breast cancer screening using mammography (Lerner, 2001). The National Health Service Breast Screening Program (NHSBSP) has been routinely inviting women aged range 47-73 for mammographic screening once every three years since it began in 1988. The screening is open to all healthy women with no symptoms and whether
or not they have a clinically relevant family history of breast cancer. Within the ethnic community the application of breast screening is comparatively low among ethnic minorities, compared to the White population (Caplan et al. 1996). This is especially true for those who did not have access to such services in their home country (Bottoroff et al., 2007).

Part 3: Literature Review

3.1 Introduction of Literature Review

The goal of the literature reviews is to find and take all evidence acquired from the relevant and specific researches and make an appropriate assessment and summary with the view to rendering this information more conducive to decision-making. Literature reviews based on a different scientific design that should be clear, pre-specified and use various methods (Oxman, 1993). To obtain a reliable assessment of the effectiveness of the intervention and defensible conclusions, the researcher should carry out good literature reviews. Furthermore, a specific intervention may be used as a launch pad to assist the researcher in drawing attention to those areas where knowledge is deficient (Petticrew & Roberts, 2006) and therefore enabling it to be used as a guide for further investigation (Brown et al., 2006).

The literature review's principle aim is to equate the reader up to date with existing literature on a subject and provide the rationale for further research needed in the same area. A good structured literature review is characterised by a sensible flow of thoughts, present and relevant references, good use of terminology and a
thorough view of the earlier research on the subject. The results from a literature review can be structured in two ways depending on the nature of the literature, it may be structured descriptively or quantitatively. Descriptive structures are considerations of the review findings based on the quality and content of the available literature. While quantitative structures, for example; meta-analysis, depend on the use of statistical approaches by integrating the results of two or more researches to provide a summary that will contribute to new knowledge and understanding. (Fink, 2010).

Before I commenced with this research, a primary exploration of the literature indicated that there was very little primary research within the field of immigrant Arab women’s beliefs about and attitudes toward breast cancer in UK. Moreover, a significant amount of the literature was quantitative in nature. All high-standard literature review results relating to a particular focus question was, therefore identified, assessed, selected and combined by the researcher into a well-organized appraisal of the literature (Petticrew & Roberts, 2006).

It was evident in the initial stage that a systematic review and meta-analysis in response to issues of effectiveness would be impossible owing to a deficit of quantitative research evidence concerning the Arab community. Alternatively, the literature was broadly assessed for the evidence to generate a summary of the research. Nevertheless, a comprehensive search using systematic methods to the literature assessment was implemented, as represented in the sections which follow.
Knowledge, beliefs, attitudes toward breast cancer and breast cancer awareness were the main search terms of this research as follows:

<table>
<thead>
<tr>
<th>Term and definition</th>
<th>Usage within this study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>Facts, information, or skills acquired through experience or education to provide theoretical and/practical understanding of breast cancer and breast cancer awareness.</td>
</tr>
<tr>
<td>Beliefs</td>
<td>Used here to reflect immigrant Arab women beliefs about health, sickness, illness including breast cancer, treatment options and expectation, roles and responsibilities, prognosis and cultural “truths” which might influence subsequent behaviour regarding breast cancer awareness</td>
</tr>
<tr>
<td>Attitudes</td>
<td>Used here to explore the way in which the immigrant Arab women felt about, or expressed an opinion of breast cancer and breast cancer awareness</td>
</tr>
</tbody>
</table>
3.2 The Objectives of the Literature Review

To ensure the need for the current programme of research a thorough search of the literature was carried out in order to reach and respond to the following objectives:

- To collate all available research literature broadly relevant to immigrant Arab women beliefs, attitudes and practices in breast cancer and breast awareness, to include both published and grey literature.
- To appraise the relevant primary, research-relating, breast cancer and breast awareness knowledge, beliefs, attitudes and practices among immigrant Arab women.
- To identify the current gap in literature and to inform the direction of the primary research study to follow.

As my primary interest is that of the individual’s perception, belief and knowledge of breast cancer and breast awareness practice, I sought to ask the following psycho-social questions:

1. What is the knowledge and understanding of Immigrant Arab woman towards breast cancer and breast cancer awareness?
2. How does breast cancer knowledge and experiences of immigrant Arab women affect their practices towards breast cancer awareness?
3. What are the knowledge of immigrant Arab women towards breast cancer warning signs and symptoms, risk factors and perceived barriers to seeking medical help?
4. What is the usefulness of current educational material (NHS and Breast Cancer care Charities produced leaflets) relevant to Arab immigrant women in England?

5. Which factors could motivate the immigrant Arab women to be more aware of breast cancer?

Qualitative research seeks to describe, understand and explain a particular phenomenon to make visible the experiences and perceptions of the research subjects. This is achieved by exploring the data (usually consisting of words or actions of research participants) for conceptual definitions on how people perceive situations to provide explanations of why something happens in a particular way as well as looking for typologies or classifications of grouping of people (or situations) that tend to have common characteristics, opinions and experience (Marshall & Rossman, 1995, Strauss and Corbin, 1990). The importance of qualitative research in evidence-based health care is that it is oriented towards the humanistic aspects and experiences of the patients. Rather than educate about the usefulness of health care, it aims to provide context specific data concerning the suitability of it and the impact of illness (Evans, 2002).

3.3 Complexities of Searching and Reviewing Qualitative Literature

Ritchie & Lewis (2003) stated that providing a proper definition of qualitative research is not an easy accomplishment. The term is used as a comprehensive category comprising a broad spectrum of formulations and techniques found within diverse research disciplines. Even so, primary qualitative research studies
have specific aims, often based on a particular philosophical or theoretical position (Ring, Ritchie, Mandava, & Jepson, 2010).

Evans (2002) have discussed the complexities in reviewing qualitative literature as currently, the prevailing methods employed in the acquisition of quantitative research are not fully developed and do not readily transfer well into qualitative research. Therefore, the determination of qualitative research in Information Technology (IT) databases is often hard. Difficulties occur because of the descriptive and often lexical style chosen for the titles which do not fully describe the methodology used, the variable data provided in abstracts form and the numerous methods used for indexing throughout different databases reflecting these complexities within the field of immigrant Arab women’s beliefs, attitudes and practices concerning breast cancer, these are further complicated by the absence of accurate information about immigrant Arab women in UK, as previously described which can make them less visible within the British society as an ethnic group (Aljalili, 2004).

Furthermore, there are substantial indications that searches restricted to key words in titles within databases often pass by relevant qualitative publications. One way of overcoming this difficulty is to always search using title and abstract together. However, index terms is an alternative technique for identifying appropriate research in computer databases. Index terms are used to define both the topic and the approach of research methodology. Regarding the accuracy of qualitative research indexing; there is scant information, presenting the danger that potentially relevant work might be left out in the research process owing to the possible use of erroneous or inappropriate index terms, in which the content does not precisely reflect its title. Acknowledging the risk of relevant qualitative
publications being overlooked and omitted in the current research, necessary counter measures were taken by including a number of strategies, such as searching for both title and abstract, thesaurus mapping and cited literature searches, as described in the following sections.

3.3.1 Search Process

In the following section, the pre-planned, step-by-step search process is defined. Initial and comprehensive approaches were agreed to ensure that the review was reliable and reproducible. Although I carried out this review on my own, my first academic supervisor together with highly skilled librarians from the University of Portsmouth reviewed each stage to support the reliability of the search process. The initial literature search was carried out between January and April 2008. During this three-month period, the researcher identified the articles relevant to the research by reading all of the abstracts found throughout the broad search. The articles which seemed to qualify for inclusion were obtained, fully read through in detail and summarised using data extraction sheets for later analysis. The comprehensive review of the literature was then repeated in 2014 with some amendments as detailed in the following section.

3.3.2 Initial Search Term

Search terms for the original literature review in the 2008 research questions relating to the ‘what’ (knowledge, beliefs attitudes and practices), the ‘who’ (first and second generation of Immigrant Arab women) and the ‘why’ (ability to access the breast cancer and breast awareness information) were all covered with the
identified search terms. Therefore three main categories were originally identified:

- Knowledge, beliefs and attitudes
- Immigrant Arab women
- Ability to access the breast cancer and breast awareness information

Knowledge, beliefs and attitudes is the main concept of this research and as it is commonly related to immigrant Arab women; this was the key population to search within. Accessing the breast cancer and breast cancer awareness information was the main outcome of interest. This was the judgment of the researcher, and it is recognised that others may have selected different terms. Each of the three original search terms were expanded to take into account the definition of the Arab women. The initial search terms are illustrated in Figure 1 below.
In consultation with the experienced university librarian and my first academic supervisor, all of these three terms were expanded based on advance search knowledge and different approaches. For example; for the first term, cultural, social and religious beliefs and attitudes was also included, as these terms appear to dominate main aspects of Arab life.

Under the second term immigrant Arab women, there were four additional terms added. These terms reflect the definition of the Arab community in Britain, as they are diverse with its members hailing from 22 different countries with the majority identifying themselves as Muslim (CSAMI 2011). Therefore, the following additional terms; Muslim women, Asian women, African women and all individual 22 Arab countries were listed and included in the search.

In addition, the terms breast cancer and breast awareness were expanded by four additional terms to represent different terms for breast cancer and breast cancer awareness e.g. breast neoplasms, breast neoplasms/prevention & control, mass screening, breast cancer screening and breast health promotion.

Finally, one more search term was added to the previous terms. The new term; breast cancer and breast awareness leaflet (NHS and breast cancer charity) was added. The expanding of the search terms was decided in collaboration with the experienced university librarian and my first academic supervisor. Figure 2 illustrates the search terms used for the second expanded search of the literature.
3.3.3 Electronic Databases

To identify all available literature, it was essential that a range of relevant electronic databases were used. Six databases were originally identified to be relevant to this study. However, due to the replication in some of the electronic databases and minimal results, it was also recommended by the university librarian that not all of the original databases were searched again for the second review of the literature. For instance, the librarian advised that in the British Nursing Index (BNI) it was possible to find information corresponding to the Cumulative Index to Nursing and Allied Health Literature (CINAHL). In the second review only five databases were used. The three categories, together with named databases within each category are illustrated in Figure 3 below:
In addition to these selected electronic databases, the ‘Database of Theses and Dissertation’ was also used to extend the research of ‘grey' or unpublished literature during the original literature review. The search process also drew on manual searches of other grey literature sources, such as written records from government archives; reports, newsletters, fact sheets, working papers, conference minutes as well as personal contact with the Breast Cancer Care Charity based in Central London.
3.3.4 Thesaurus Mapping and Cited Search

After the identification of the applicable databases and the expanded search terms, the thesaurus mapping terms for each of the databases were identified. Due to the differing mapping terms used within each separate database, this process had to be repeated several times for each of the electronic databases. For the thesaurus mapping cross-referencing, each set of mapped terms and identified terms that were meaningfully related to the expanded search terms were considered. These were then compared within each of the expanded terms under the original search terms e.g. breast cancer was mapped to breast carcinoma, breast tumor etc. To ensure the reliability of the cross-referencing, the results were checked by an experienced university librarian. The librarian advised on narrowing certain terms to avoid repetition within the individual searches.

During the search some problems were encountered with the following two databases:

- Education Resource Information Centre (ERIC)
- Applied Social Sciences Index & Abstracts (ASSIA)

The combination of the original search terms did not identify any studies. Following discussion with the university librarian, it was suggested that the search terms and thesaurus mapping were too specific, therefore limiting the articles indexed under the search terms. A number of variations were attempted, but it was apparent that the broad terms ‘information’ and ‘breast cancer’ needed to be searched and then combined with breast awareness. Whilst this was very basic
categorisation, it was the only combination that identified articles within these databases.

Even with the comprehensive measures described above, there was still a risk that some key literature might have been missed in the search, given the limitations previously described. To safeguard against this situation, an additional search measure was taken in the form of a cited search of the relevant primary research. Web of Science (Web of Knowledge) is a journal article database which indexes periodicals throughout the fields of science, arts and humanities, enabling the discovery of what this particular literature field holds on a specific subject which also covers ‘Cited Reference Search’. In this type of search it is possible to enter brief details of a known journal article, conference paper, book, etc. and the ‘Web of Science’ search engine then finds more recent references which have cited that earlier known work. It was hoped that the cited reference search would uncover additional literature relevant to the field of current research subject that may otherwise be missed in the search through the electronic databases. In addition to searching for potentially uncovered literature, the cited reference search proved useful in exploring the influence of the relevant primary research within the field.

The search strategy in the form of a search statement was developed from the research question to define the elements of the search strategy for the systematic review of the literature. The search strategy used included both free text words and phrases as well as MeSH terms. Search terms were also combined by using the Boolean operators which included: (OR, AND). By shortening the word down to its first few letters and using the truncation symbol (asterisk, dollar sign) it
enabled me to pick up all the possible endings for a word and allowed for different spelling variants to ensure maximum recall of all possible articles.

3.3.5 Data Extraction Sheets

Due to the nature of the research topic and the importance of gathering any available good quality relevant research studies in a poorly researched area, all relevant literature that had been located was critically appraised and included in this review of the literature.

Data extraction sheets provide a useful implement in the critical appraisal process, particularly when faced with a large volume of data (Petticrew & Roberts, 2006). It can be overwhelming and difficult to extract data systematically and consistently across studies. The use of data extraction sheets allowed each article to be critiqued in the same fashion. The design of the data extraction sheets used within this literature review was influenced by Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP, 2014) to help one make sense of qualitative research. The information reported within the data extraction sheets is attached in (Appendix 3.1). Information extracted included:

1. Title, author and year of publication

2. Characteristics of the study (Design, Method, Reliability and validity)

3. Participants (Inclusion and Exclusion Criteria, Number Enrolled, Number of Withdrawals, Source of Participants)

4. Methodology (Setting, Duration, Analysis Methods)

5. Outcome description
3.4 Evaluation of the Literature Search Findings
Within this section, the literature search findings are explored in terms of:

- The range of the literature found
- Critical appraisal of the primary research that makes a significant contribution to the research subject.

3.4.1 The Range of the Literature Found

Due to the broad search terms used in the initial search, more articles than originally anticipated were identified. Each abstract was read in full and the key relevant articles that appeared to meet the inclusion standard were obtained. The search results from the individual database are shown in Table 1.

Table 1: Number of Articles Found within Each Database

<table>
<thead>
<tr>
<th>Database</th>
<th>Total found</th>
<th>Number of relevant Articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Nursing Index(BNI)</td>
<td>65</td>
<td>8</td>
</tr>
<tr>
<td>Cumulative Index to Nursing and Allied Health Literature (CINAHL)</td>
<td>205</td>
<td>15</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>192</td>
<td>25</td>
</tr>
<tr>
<td>International Bibliography of Social Sciences (IBSS)</td>
<td>104</td>
<td>27</td>
</tr>
<tr>
<td>SIGLE</td>
<td>47</td>
<td>12</td>
</tr>
<tr>
<td>Applied Social Sciences Index &amp; Abstracts (ASSIA)</td>
<td>39</td>
<td>10</td>
</tr>
<tr>
<td>Education Resource Information Centre (ERIC)</td>
<td>41</td>
<td>15</td>
</tr>
</tbody>
</table>
Of great importance to observe is the fact that the quantity of appropriate articles within each database, as listed in the table above, does not take duplication into consideration, of which there was a considerable amount (as illustrated in Figure 4 below). Following the identification of the key relevant abstracts that appeared to meet the inclusion criterion, the full articles were retrieved for review.

In 2008 a total of 88 articles were identified as being appropriate to be reviewed in full and in 2012/2014 there were 14 additional articles. This makes a total of 102 articles which were read in full and basic data extraction sheets were completed for each article. Figure 4 describes the studies found and included in the review. Of these 102 articles, only 28 were judged to be relevant to the research program based on the broad inclusion criterion: direct or indirect relevance to Arab women's knowledge, beliefs and attitudes toward breast cancer and breast cancer awareness.

Following the review, 74 articles were excluded (i.e.70% of the total literature found), as they were judged to be irrelevant to the research subject. The reason that the electronic database search found so many excluded articles is explained by the broad search terms used in the initial search. A significant volume of this literature was Irrelevant to breast cancer in immigrant Arab women, for example male breast cancer, another type of cancer. Another volume focused on topics such as health issues specifically related to the Arab population and information about cervical cancer treatment measures, rather than the knowledge, beliefs and attitudes toward breast cancer and breast awareness.
Figure 4: Description of Studies Located and Included in the Literature Review

The 28 relevant articles were further categorised in terms of primary research and secondary articles. The primary research involved the collection of primary research data; whereas secondary articles comprised anecdotal reports, expert opinions and review articles. There were 20 secondary articles. A number of the titles are presented below to illustrate the characteristics of some of these articles:
These five examples provide a typical selection of the nature of the relevant secondary articles found within the review. Broadly speaking, the secondary literature consisted of expert opinion reflecting the improvement in the quality of written information about breast cancer, common breast cancer and breast screening issues from the perspective of women with breast cancer. Whilst the secondary articles do not lend themselves to being critically appraised, information contained within them adds to the richness and vibrancy of the research subject. Relevant qualitative primary research articles were critically appraised using the qualitative framework produced by the Critical Appraisal Skills Programme (CASP) while the quantitative primary research articles were appraised using the questions derived from a notable series titled “Users’ Guides to the Medical Literature,” which appeared in the Journal of the American Medical Association (JAMA) from 1993 through 2000 (Guyatt GH, 1997; Guyatt GH, 2000). The cited reference search generated 16 results in total; 8 of which
were duplicates within the literature review and the other 8 were excluded as irrelevant to the research, as illustrated in Figure 4.

3.4.2 Analysis and Interpretation of the Primary Research

For ease of reference, an example of the overview of the eight relevant primary research studies is presented in Table 2. There were three quantitative studies and five qualitative design studies.
Table 2: An Overview of the Relevant Primary Research Studies

<table>
<thead>
<tr>
<th>Author(s) &amp; Date:</th>
<th>Baron, Granot, Badarna Avrami, 2004</th>
<th>Berner, Alwash, Miller, Denic, &amp; Dunn, 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country of Origin:</td>
<td>Israel</td>
<td>United Arab Emirates (UAE)</td>
</tr>
<tr>
<td>Title:</td>
<td>Perception of breast cancer among Arab Israeli women</td>
<td>Knowledge, attitudes, and practices related to breast cancer screening: a survey of Arabic women</td>
</tr>
<tr>
<td>Objective(s):</td>
<td>To identify social and cultural aspects of the Arab Israeli woman's life that may reduce screening attendance for early detection of breast cancer.</td>
<td>To explore the knowledge, attitudes, barriers, and practices related to breast cancer screening among Arabic women of United Arab Emirates (UAE)</td>
</tr>
<tr>
<td>Sampling/Participants</td>
<td>Sampling: Snowball Inclusion criteria. Over 50 years old with no history of cancer. Participants: 68 women attended six focus groups in 4 villages and one town. Majority Muslim with 8 Christian Arab women attendees. All women were married with children; majority did not work outside the home. Both Muslim and Christian, religious and less religious women attended the same focus groups.</td>
<td>Sampling: Convenience. Inclusion criteria: Aged 40-65 years, attending health care clinics (for any reason) in the city of Al-Ain and its outskirts. Participants: Of 1750 invited women, 1445 agreed to participate and completed questionnaires. Of these, 78 had histories of breast cancer and were excluded from analysis, leaving 1367 women (78%) for the study. Mean age = 46.5 years. All women exclusively Muslim.</td>
</tr>
<tr>
<td>Design &amp; Methodology:</td>
<td>Qualitative study/Focus groups</td>
<td>Quantitative/cross sectional, community-based survey</td>
</tr>
<tr>
<td>Main Findings/Themes:</td>
<td>The major themes which emerged were:</td>
<td>The results of the survey showed:</td>
</tr>
<tr>
<td></td>
<td>• Impact the disease can have on the role of a woman as mother and wife,</td>
<td>Breast Screening Examination (BSE) practiced =13% Clinical Breast Examination (CBE) = 13.8% clinical breast Mammography = 10.3%. BSE was more commonly practiced by younger women, more educated, employed, living in semi urban areas, and had visited their health clinics &lt; 10 times per year. 80% of women preferred breast examinations carried out by a physician. 97% preferring a female doctor to perform clinical examination. 16% of women reported being invited for breast screening,</td>
</tr>
<tr>
<td></td>
<td>• Impact on femininity,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Problems with coping with the disease,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Finding religious meaning in the disease, and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Problems of privacy and confidentiality in the Arab society.</td>
<td></td>
</tr>
</tbody>
</table>
but only 10% had experienced the procedure at least once. Knowledge about breast cancer screening was low in the study population with 50% of women aware that over 50 years of age should be screened every 2 years.

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weakness</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The study design was appropriate to answer the psycho-social question posed.</td>
<td>• Ethically approved</td>
</tr>
<tr>
<td>• Although dominated by Muslin women included non-practicing Muslin women and some Christians.</td>
<td>• Large sample. The setting for data collection was justified</td>
</tr>
<tr>
<td></td>
<td>• Content validity, face reliability of the questionnaire tested to reduce bias.</td>
</tr>
<tr>
<td></td>
<td>• Findings clearly presented and data analysis sufficiently rigorous.</td>
</tr>
<tr>
<td></td>
<td>• Satisfactory response rate not reported.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weakness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• The sample was large but restricted to the Muslim women who visited the primary health care clinics. Restricted to Muslin women who visited selected primary health care clinics. Non-Muslin women and those not attending primary health care clinics unrepresented.</td>
</tr>
<tr>
<td></td>
<td>• Views of &lt; 40 years old women excluded.</td>
</tr>
<tr>
<td>Author(s) &amp; Date:</td>
<td>Donnelly et al., 2013</td>
</tr>
<tr>
<td>-----------------------------------</td>
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</tr>
<tr>
<td>Country of Origin:</td>
<td>Qatar</td>
</tr>
<tr>
<td>Title:</td>
<td>Beliefs and attitudes about breast cancer and screening practices among Arab women living in Qatar: a cross-sectional study</td>
</tr>
<tr>
<td>Objective(s):</td>
<td>To investigates beliefs, attitudes, and breast cancer screening practices of Arabic-speaking women in Qatar.</td>
</tr>
<tr>
<td>Sampling/Participants:</td>
<td>Sampling: Nonprobability convenience Inclusion Criteria 35 years or older, ability to speak Arabic, Minimum 10 years residence in Qatar, attending one of seven designated hospitals and community health clinics in capital of Qatar, south of Qatar, and north of Qatar Participants: 1,044 women participated (1044 Muslim &amp; 19 Christian) in 30-minute face-to-face administered questionnaire. Participants’ ages ranged from 35–82 years (M = 44.9), 52% were Qatari nationals, 47.9% were non-Qatari residents (from the Levant, North Africa, neighbouring Arab peninsular countries, or other countries in the greater Middle East).</td>
</tr>
<tr>
<td>Design &amp; Methodology:</td>
<td>Quantitative/ a structured survey questionnaire. Data collection was using a structured face to face administered survey questionnaire. Interviews were conducted in Arabic by seven female nurses fluent in Arabic and English.</td>
</tr>
</tbody>
</table>
**Main Findings/Results:**

The majority of participants (76.2%) stated health status was “good” or “excellent.” When asked why people get cancer, participants responded “fate,” “having an unhealthy lifestyle,” “not breastfeeding one’s baby,” or “hereditary factors.

Most participants wanted to know if diagnosed with cancer (86.6%), and preferred to consult female doctors (72.4%) and other female HCPs (90.8%); only 2.1% preferred examination by a nurse rather than a doctor. Approximately half of the participants had no preference for their HCPs’ language (48.6%).

Further analyses on age and education differences indicated that older participants (50+ years) and those with lower education levels were more likely to have no preference for the status of HCP (doctor or nurse) examination; did not want to know if they had cancer, and attributed cancer resulted from not breastfeeding (p < 0.05).

Data analysis revealed that multiple negative influences appeared to affect Jordanian women’s participation in breast screening. The following four themes were identified:

1) Participants’ lacked accurate breast cancer knowledge.
2) Inaccessibility of equipped breast cancer screening facilities
3) Health insurance and financial concerns, and
4) Negative socio-cultural influences influenced non-participation in BCS, including social stigma.

Summary: Knowledge about breast cancer was inadequate. The decision to participate in BCS was influenced by cultural negative influences and by clinicians’ advice. Findings indicated insufficient knowledge and cultural misconceptions about BC and screening.

**Strengths**

- Ethical approval obtained.
- The study address a clearly research question and the population of the study by recruited them from hospital and health clinic settings in the north and south Qatar to represent the participants living in various populated regions in Qatar.
- Good size sample; High response rate was achieved 87.5%;
- The researcher has justified the methods chosen.
- Data analysis was sufficiently rigorous with clear results presented.
- There is an in-depth description of the analysis process & sufficient data are presented to support the findings.

- The research method (study design) was appropriate for answering the research question
- All data checked for accuracy against the original taped data.
- Sample characteristics described to enable transferability of findings to similar group.
<table>
<thead>
<tr>
<th>Weakness</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• There is adequate discussion of the evidence both for and against the researchers’ arguments</td>
<td></td>
</tr>
<tr>
<td>• It is difficult to generalize the results of this study to all women living in Qatar because of the non-probability convenience sampling.</td>
<td></td>
</tr>
<tr>
<td>• Ethical approval not reported.</td>
<td></td>
</tr>
<tr>
<td>• No details were reported about data analysis.</td>
<td></td>
</tr>
<tr>
<td>• Content analysis in this pilot study described the findings, which might not explore the underpinnings of the phenomena. It is possible that, unknowingly, the investigator recruited only women who were more open and willing to talk about their feelings about BC and BCS.</td>
<td></td>
</tr>
<tr>
<td>• Caution in interpreting the findings regarding these women is required since this was a small sample designed for a qualitative pilot study and might not be representative/transferable to a wider target population.</td>
<td></td>
</tr>
<tr>
<td>Author(s) &amp; Date:</td>
<td>Mellon et al. 2013</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Country of Origin:</td>
<td>USA/ Detroit</td>
</tr>
<tr>
<td>Title:</td>
<td>Knowledge, Attitudes, and Beliefs of Arab-American Women Regarding Inherited Cancer Risk</td>
</tr>
</tbody>
</table>
| Objective(s): | To explore attitudes, knowledge and beliefs regarding hereditary breast cancer in the Arab-American community in metropolitan Detroit. | • To describe the levels of breast cancer awareness among Saudi females.  
• To correlate the levels of breast cancer awareness with demographic variables of Saudi females. and  
• To assess differences in the levels of breast cancer awareness by demographic variables |
| Sampling/participants: | Sampling: Convenience. Recruited from an existing south eastern Michigan breast cancer outreach project at an Arab-American community centre by a trusted outreach worker at the centre  
Inclusion Criteria: (1)18 years or older, (2) a personal or family history of cancer, (3) ability to speak English, and (4) ability to provide written informed consent to participate in the focus group. No restrictions were placed with family members attending the focus group. 18 were invited to participate in the focus group; 13 took part. | Sampling: Non-probability Convenience; Inclusion criteria: i) Adult Saudi females, 20 years & older. ii) Living in Jeddah city. iii) No personal history of any type of cancer. iv) Not working in the medical field. Participants: 200 Saudi female living in Jeddah. The participants were predominantly young, their mean age was 32.3±10.9, single, had college level education/unemployed and without family history of breast cancer. Recruited from shopping malls in Jeddah city, Saudi Arabia. |
| Design & Methodology: | Qualitative/ A semi-structured interview guide with open-ended questions was utilized to conduct the focus group. | An exploratory study / A self-administered questionnaire; Breast Cancer Awareness Measure (Breast CAM) version 2. |
| Main Findings/Results: | The results of the focus group analysis revealed four major thematic categories and their sub-themes:  
• Cultural knowledge Cancer as a shame and stigma  
➢ Beliefs regarding causes of cancer  
➢ Myths and misconceptions | Participants had poor knowledge about breast cancer warning signs and risk factors with only 50.5% aware of breast lump, 47% knew about bleeding or discharge from the nipple, 38.5% had knowledge of dimpling of the breast skin, 37.5% were aware of changes in the size of breast or nipple, 36% knew about pulling in the nipple. Relevant breast |
Cancer as a test from God
- Fear of cancer treatment
- Accepting and being strong in surviving cancer
- Feelings and beliefs about cancer
  - Cancer as “the most kept secret”
  - Keeping cancer a secret from the patient
- Communication patterns
- Cancer as “the most kept secret”
- Keeping cancer a secret from the patient
- Influence of the family, and experience with the healthcare system and community.
- Worry for children
- Receiving support from family
- Experience with the Healthcare System and Community
- Barriers to screening
- Interactions with healthcare providers
- Education as empowerment

Results indicated that cultural beliefs and personal experiences with cancer influenced the women’s perspectives on hereditary cancer risk. A high level of secrecy about cancer within Arab-American families was present, which may prevent accurate risk assessment and referral for genetic services. Other identified barriers that may influence hereditary risk assessment included stigma, fears and misconceptions of cancer.

cancer risk factors: 57.5% correctly identified family history/having a close relative with breast cancer were risk factors, 41% aware of risk of alcohol consumption and 35.5% aware of hormone replacement therapy risk.

Participants’ knowledge about breast cancer screening program, participants showed some/inadequate knowledge about breast cancer screening program and BSE. The majority (71.5%) were aware of the availability of breast screening program, while only 27.0% were invited for breast screening program and 20.5% had undergone breast screening on breast screening program. Knowledge about BSE, the majority (79%) knew of BSE, but less than one half (47.5%) of participants had knowledge of how to perform BSE, while only minority (17.5%) correctly identified frequency of performing BSE as monthly, or menstruation was appropriate time to perform BSE by 29.0% of participants. Analysed by demographic variables showed that Saudi females’ knowledge about breast cancer warning signs differed significantly by their level of education; highly educated females had more knowledge about breast cancer warning signs than others.

Strengths:
The interview guide was initially developed with the help of expert peers comprising open-ended questions to allow respondents to explain their own views and experiences as fully as possible

- Ethical approval reported.
- The study addressed clearly the research objectives.
- The strength of the study was the employed of validated Cancer Awareness Measure (B CAM2).
- Participant details collected on age, marital status educational level, occupation and family history of breast cancer. The setting for data collection was justified & it is clear how data were collected.
- The data analysis was sufficiently rigorous.
<table>
<thead>
<tr>
<th>Weakness</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Pilot study of only one focus group included English-speaking Arab-American women with most of the women from one Arab country (Lebanon). Only one focus group conducted through convenience sampling method. Large focus group (N=13) could have made hearing all voices difficult, inhibited some participation and raised concerns about confidentiality Some of the women attended with their family member which may have affected their responses</td>
<td></td>
</tr>
</tbody>
</table>
| • A clear findings and adequate discussion of the evidence both for and against the researchers’ arguments   | • Random sampling method rather than convenience would provide better generalisability  
• Recruitment strategy was not clearly explained  
• The sample was limited by mainly young women (mean age was 32.3) taking part;  
• Religion was not reported |
<table>
<thead>
<tr>
<th>Author(s) &amp; Date:</th>
<th>Saadi, Bond &amp; Percac-Lima, 2011</th>
<th>Scanlon, 2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country of Origin:</td>
<td>USA</td>
<td>UK</td>
</tr>
<tr>
<td>Title:</td>
<td>Perspectives on Preventive Health Care and Barriers to Breast Cancer Screening Among Iraqi Women Refugees</td>
<td>An investigation into breast cancer related knowledge, beliefs and attitudes among women from minority ethnic groups living in London and Sheffield: A qualitative study</td>
</tr>
<tr>
<td>Objective(s):</td>
<td>To obtain in-depth information about their perspectives on preventative health, and explore potential barriers to breast cancer screening.</td>
<td>Investigation into the breast cancer related knowledge, beliefs and attitudes among women from minority ethnic groups living in Britain, and identify methods of dissemination that are likely to be successfully among these groups.</td>
</tr>
<tr>
<td>Sampling/participants:</td>
<td>Sample: Convenience. The participants were Iraqi refugees receiving care at Massachusetts General Hospital Chelsea HealthCare Centre Chelsea (MGH Chelsea). Participants: 20 one to one interviews were conducted in Arabic at MGH Chelsea or at the patient’s home. Average age 41.25 years (range 23–55 years)</td>
<td>Sampling: Convenience and snowballing sampling strategy. Participants: Comprised 78 minority ethnic women (57 south Asian, 2 black and 19 Arab) and 10 white British participants. This was facilitated by liaising and working in partnership with Macmillan Cancer Information Workers in London and key workers/representatives from local community groups. The white British socially disadvantaged group were recruited from a ‘fit club’ in a leisure centre in a disadvantaged area of Sheffield. Age range: 20-70+.</td>
</tr>
<tr>
<td>Design &amp; Methodology:</td>
<td>Qualitative/ semi-structured interview</td>
<td>Qualitative/ Seven focus groups (3 in Sheffield and 4 in London)</td>
</tr>
</tbody>
</table>
## Main Findings/Results:

Three major themes emerged:

1. Culturally mediated beliefs about illness and preventive care. The majority of women defined illness as symptomatic and did not talk about preventive care.

2. Knowledge about breast cancer screening. The majority of women knew about mammograms. Many mentioned that screening for disease was not the norm in their home countries and because screening centres were typically far away, testing was done only when breast cancer was suspected.

3. The women faced many barriers to obtaining mammography screening such as psychological barriers, health consequences of war and religiously influenced concerns.

## Strengths & Limitations:

The study design appropriate to explore the barriers to Breast Cancer Screening among Iraqi women refugees.

Ethical considerations included voluntary participation explained, confidentiality and secure storage of data, written consent obtained. Interview guide provided

Thematic analysis, two researchers analysing data independently, inter-rater reliability 90%, third reviewer combined transcripts, confirming coding of themes, relevant quotes used to illustrate themes.

The main themes were

- Poor knowledge
- Pessimistic Attitudes to cancer
- Beliefs about prevention and Cure
- Breast Cancer Awareness Campaigns not reaching women from minority ethnic groups
- Barriers to accessing information, Suggestions for promoting breast cancer awareness

The findings suggest that Asian and Arab women share much in common with the white British socially disadvantaged women, in terms of poor level of knowledge about breast cancer, personal susceptibility and pessimism about prevention, but that distinct differences were observed between these groups. For the Asian and Arab women their frame of reference, unlike British women, was firmly embedded in a specific socio-cultural-economic context, which contributed to the development of cultural constraints over the discussion of cancers, engagement with preventative behaviours and with health care services.

Good size sample and balanced age profile & partnership approach were very successful in recruiting participants for the focus groups and has also created more outreach opportunities for breast Cancer Care to conduct breast awareness education.
| Weakness | Convenience sample through a health centre in Massachusetts, may result in underestimating the financial challenges faced by Iraqi refugee women elsewhere in the US, because of Massachusetts’s universal health care provision.  
Dominated by women > 40 years with only 7 < 40 years old.  
Women’s socioeconomic status not obtained, with no explicit educational data collected, which could influence whether or not these women had knowledge of mammography. | Validity and reliability of the analysis weakened because by many of the recordings not transcribed and reliant on field notes for analysis and interpreter not briefed fully beforehand, no health background.  
No details on data analysis approach, audit trail of themes, validity of themes, independent analysis.  
Size of groups varied and this affected how much people participated in the discussion - smaller groups had more in-depth discussions.  
Only 1 socially disadvantaged white British group included. |
3.4.3 Conclusion of Literature Review

In illustration, conclusions from the analysis and explanations of the relevant literature, the review the primary objective of this literature review were carried out as listed below:

- To collate and critique all research literature broadly relating to immigrant Arab women's beliefs, attitudes and practices toward breast cancer and breast awareness, to include both published and grey literature.

- To map and appraise the relevant primary research relating to breast cancer and to breast awareness knowledge, beliefs, attitudes and practices among immigrant Arab women.

The first objective was adequately achieved through the comprehensive search strategy that was adopted to safeguard against overlooking any literature, particularly qualitative research. The literature review was systematic in its approach, explicit and reproducible. In total, 105 articles were identified as corresponding with the criteria for inclusion and were studied in depth, of which there were only eight relevant primary research studies. All relevant primary research took place between 1998 and 2014. Whilst some studies had similar themes, they all had a different focus on participants' beliefs and attitudes towards breast cancer. The second objective was to map and appraise the qualitative and quantitative evidence relating to the knowledge, beliefs, attitudes and practices regarding breast cancer and breast awareness among immigrant Arab women.

The primary research that has been undertaken provides limited evidence of the knowledge, beliefs and attitudes of immigrant Arab women regarding breast cancer.
cancer and breast cancer in England. Furthermore, there is no evidence exists for the usefulness of leaflets concerning breast cancer and breast awareness (NHS and breast cancer care charity) as the research has been deeply focused on these issues.

3.5: Key Findings and Contributions of the Primary Research that Makes a Significant Contribution to the Field

There have been a number of key findings and contributions that have been identified through reviewing the literature relating to knowledge, beliefs and attitudes towards breast cancer and breast awareness among immigrant Arab women in England/UK which are explored in turn below. The results of the comprehensive literature review highlighted that there is little robust evidence on the level of knowledge, beliefs, attitudes and practices of breast cancer and breast awareness among Arab immigrant women in UK. The primary research that has been reviewed provides strong evidence of generally poor knowledge about breast cancer amongst Arab women in USA and in other countries and the source/s of any knowledge were strongly rooted in social and cultural beliefs and attitudes, adding to the growth and strength of cultural restrictions and taboos effecting the ability to discuss breast cancer. The major gaps in the research literature have been summarised below:

- The majority of the research toward breast cancer and early detection occurred in America, Canada and other countries which have their own distinctive health care systems with different cultures and lifestyle patterns than in UK.
Publications of research carried out on Arab women in the UK as a minority group were somewhat scarce. The research has concentrated on other ethnic minority populations (South Asia, Black ethnic minority, Caribbean) Kathryn A Robb, et al. (2008), and excluded the Arab population as a minority ethnic group, most likely because this group is less visible and more difficult to access.

- The search of the literature concurs with findings from 2011, namely that research conducted with Arab women in the UK remains scarce (CSAMI, 2011). To date there is only one UK-based study that has investigated the factual knowledge of breast cancer and the concurrent beliefs and attitudes surrounding it among Arab women, as well as other ethnic minorities resident in London and Sheffield. Research was carried out by Scanlon et al. (2004) with 88 women in Sheffield and in London of which two groups of 19 Arab women in Sheffield; one focus group consisting of 13 women from socially-disadvantaged backgrounds, two focus groups of 22 Asian-Bengali women and two further focus groups of 34 South Asian women. Scanlon’s study shared findings that raised concerns about Asian and Arab women generally having poor level of knowledge about breast cancer, poor awareness of own personal susceptibility to it and their pessimism and faithlessness about its prevention. Similar findings have also been shared amongst white British socially disadvantaged women. However, whether there are different social and cultural constraints contributory factors has yet to be fully explored.

While Scanlon’s research delivers valuable information on the experiences of Arab women, it is not without its limitations. Firstly, insufficient detail is
given for the two focus groups of 19 Arab women who were from Sheffield. No information is given regarding the content of the focus group questions and insufficient detail is provided regarding the background of the discussion. The researcher does not clearly state what level of training the focus group moderators were given. The possible lack of cultural sensitivity to the questions raised in discussion is a drawback in this study which might affect how much findings were related to the Arab culture which is not yet clear.

Scanlon conceded that the analysis was lacking in validity and reliability. Several factors were apparently responsible for this; failure in much of the recordings were not transcribed, thereby resulting in the analysis being largely dependent on original interview notes, the use of interpreters with little or no health education background and their preliminary briefings being somewhat inadequate. Additionally, she stated that because group sizes had been unequal, that had affected the numbers who actually took part in the discourse. Further to this, it was reported that despite the significant efforts of key workers to get the women in the group to talk, the extent to which their overall contribution affected the results is ill-defined. Difficulty in ascertaining the extent of knowledge in individuals was problematic owing to the frequently vague responses, for instance an agreeing response was often only explicit by a general murmuring or nodding of heads, which cannot be taken as an accurate gauge for pre-existing knowledge of a particular point raised by another participant. Scanlon, 2004, postulates that the language may be a barrier in a mixed ethnic group for Arab women to involve themselves in focus group
discussions and one-to-one interviews could explore more cultural issues in detail. The current proposed research study will consider the age range, educational level, period of residency in the UK and whether the women interviewed are first generation or second generation, which are factors not included in the other studies. In this research, the researcher will assume the role of the interviewer being fluent in Arabic and English, as well as being part of the same culture, I will also act as mediator for the focus groups and interviews, this should minimise misinterpretation which may occur through differences in language and meaning. In addition, the research will explore current educational materials. There is no information regarding assessing the usefulness of current educational material (NHS and charity produced leaflets) relevant to this population.

- Recommendations set out by the Government in the White Paper reported that the goal of the New NHS’ (DoH, 1998) is to guarantee that those groups who have been difficult to access before may be fully alerted to screening services and encouraged to make use of them. If ethnic minority women are to be represented in these targets, it is important to address why and how relevant health promotion material should and can be tailored to the needs of these minority women.

3.6 Implications for the Current Research Programme

The results from the literature review have been essential in the design of this PhD study. The overall form and character of this PhD thesis has been balanced on the results of the literature appraisal. The literature review findings showed
that there is a dearth in the literature regarding the knowledge, beliefs and attitudes of immigrant Arab women toward breast cancer and breast awareness in UK. In addition there is a dearth in the literature to explore in detail the current knowledge of breast awareness and to inform practice and gaps in knowledge regarding breast cancer and breast awareness educational materials throughout the female Arab population in England.

The plan of research reported in this thesis aims to explore the knowledge, beliefs and attitudes of immigrant Arab women towards breast cancer and breast cancer awareness. Furthermore, to explore the usefulness of current educational materials (NHS and Breast Cancer Care leaflets), as neither of these subjects has been previously researched.

**Chapter two/phase one:** A qualitative study using one-to-one interviews to explore the immigrant Arab women’s knowledge, beliefs, attitudes, and practice towards breast cancer which may affect breast awareness practices.

**Chapter three/Phase two:** First part; to assess the knowledge of immigrant Arab women's awareness of breast cancer, warning signs and symptoms, risk factors and perceived barriers to seeking medical help. Using quantitative data from an Arab, women-based survey, which was based on a validated tool breast cancer awareness measure B-CAM version 3, in order to compare and contrast the immigrant Arab women with other populations. In addition through triangulation between qualitative and quantitative data to contrast findings from two different sources to identify similarities and differences in data gathered. Second part; to explore the usefulness of current educational material (NHS and Breast Cancer...
Care Charities produced leaflets) relevant to Arab immigrant women in England through qualitative focus group discussions

I anticipate that by expanding and deepening our comprehension of Arab women’s knowledge, beliefs and attitudes towards breast cancer and breast health awareness in this research, it will greatly endow the current literature on the subject. What is more, breast health awareness practices are influenced by the socio-cultural context (Berner et al., 2002 & Azaiza & Cohen, 2006) and it is my sincere hope that the outcome of this study will be drawn upon by health professionals to create breast health promotion interventions that are both culturally sensitive and specifically designed to surmount all obstacles and to revolutionise the England/UK facilitators.
Chapter Two

Phase One Qualitative Study
2.1 Introduction

This chapter will discuss the rational for the methodology used in the first phase of this research study. It will include a description of the study population, data collection methods, data analysis, findings and discussion. The aim of phase one was to explore the knowledge, attitudes and beliefs related to breast cancer and breast awareness practices of immigrant Arab women in England recruited from a privately funded Arabic school in the South of England.

The following objectives were set to meet this aim:

1. To explore knowledge and understanding of breast cancer and breast awareness practice among immigrant Arab women in England.

2. To explore immigrant Arab women’s attitudes, behaviours and beliefs towards breast cancer which may affect breast awareness practices.

For the purpose of meeting the two objectives outlined before, qualitative research methodology was employed in this first phase of the research study. Qualitative research is both an increasingly popular and appropriate methodology that is widely used to explore health beliefs and attitude since it is often preoccupied with investigating the perception of people have about their world (i.e. their experiences, beliefs and attitudes) to explore and think about them in ways that are both useful and substantive.

This approach has been selected to answer the psycho-social question “What is the Arab immigrant women’s knowledge, beliefs and attitudes regarding breast cancer as well as breast awareness practices for those resident in England?”
A number of qualitative approaches to collecting and analysing data were considered for this study. Whilst grounded theory and ethnography are two commonly used philosophical approaches used in qualitative research, after careful consideration, these were not selected in favour of a non-philosophical approach. Grounded theory approach is a commonly used qualitative method in the social sciences to inductively generate or discover a theory out of the data (Creswell, 2007). It was felt that, since the immigrant Arab women were considered a hard to reach population, it would be difficult to complete the “data dance” and provide saturation of categories through continual sampling to “test out emerging theory” as well as validate the statements due to the paucity of current literature (Kelsey, 2003), It was for this reason, grounded theory was rejected. Ethnography, with its roots in anthropology, allows the researcher to study the structure and function of a group of people to describe and interpret cultural meaning (Savin-Baden & Major, 2013, p.196). However, since ethnography relies on multiple data collection methods, including that of participant observation as its primary method it was not practical or feasible to explore this particular phenomena using this approach and hence it too was also, subsequently rejected. Instead, thematic analysis was selected as a practical, systematic approach that provide a rich and detailed, yet not restrictive approach to data collection and analysis (Braun and Clarke, 2006).

2.2 Plan of Investigation for Qualitative Research

The following sections describe the research approach as well as presenting and discussing the findings.
2.2.1 Ethical Issues

A favorable opinion for Phase One of this research was acquired from the University of Portsmouth, School of Health Science and Social Work Ethical Committee in May 2008, application no: 08-02. The principle ethical concern taken into consideration for this research were: informed consent and confidentially of participation. A copy of the ethical committee letter of the final approval can be found in Appendix 3.3.

2.2.2 Written Information

Firstly, I made sure that all participants had received written information and understood the purpose and consequence of taking part. Included in the research pack given to all potential participants was an introductory letter, written information sheet and an informed consent form in both English and Arabic together with a stamped addressed envelope, which included a tear off reply slip. Within the written information sheet were details of the research study's purpose; what taking part would involve, that such participation entirely self-imposed and that they were free to end it when so ever they wished and with no obligation to explain why. The information sheet also outlined the anticipated time required for being interviewed (estimated to be between 1-2 hours) and that the conversation would be digitally recorded, that I would be personally transcribing all audio-recorded interviews and analysing the data, removing all names from subsequent publications. The written information also informed the immigrant Arab women that, prior to interview, they would require to provide information in response to a set of demographic questions such as their age, occupation, marital status, period
of residence in England, educational level and whether first or second generation.
It was explained that this demographic information would be collated and used to
describe characteristics (without naming) of those who took part.
Immediately before starting the interview, I also checked that each participant
understood and been given an opportunity to ask questions in order to ensure
that they fully understood what taking part involved. It was emphasised to each
participant that there were no correct or incorrect responses and that they were
encouraged to answer the questions entirely at their own liberty and in their own
way. It was also emphasised that the participant could stop the digital recording
at any time and only start again, if they wanted to and were ready to do so.

2.2.3 Informed Consent

I gave the participants time to consider taking part. Each potential participant
having received and had an opportunity to read the comprehensive written
information concerning the interview and the reasons for undertaking the
research. The research packs were received approximately 10 days in advance
of organising the interview date and time. Having read the written information and
discussed any queries, each participant, who agreed to participate, gave their
personal consent with their signature on the written consent form.
The signed consent form was retained and stored in a locked drawer at my home
while a facsimile was given to the participant. A copy of the invitation letter,
Information sheet and consents forms in both languages (English and Arabic) can
be found in Appendix 1.1.
2.2.4 Anonymity and Confidentiality

Protection of personal privacy in term of anonymity and confidentially, such as home address, contact details etc., was guaranteed to all individuals involved by making sure any personal information had these details removed so that the final documents did not contain any person’s name. To identify each transcript, I gave each Arab woman a unique number; this helped me to differentiate between the women and help maintain confidentiality.

A further ethical consideration was that of ownership of data. In order to check understanding and ensure that each participant was willing to allow the data to be used, each participant was sent their verbatim interview transcription for validation and they were allowed to edit out anything they did not wish to be included in the analysis. All transcriptions and digital recordings entered in the computer and stored on flash disks were kept securely in a locked place at my home. I was the only one with immediate access to this information, it was stored in my personal computer, which was password protected.

2.3 Sampling Framework

Two approaches of recruitment were adopted to reach this particular population. Firstly, a purposive non-randomised sampling framework was the first technique applied. In a purposive non-random sample, how many people are interviewed is rather less important than the criteria employed for the actual selection. The characteristics of individuals are used as the basis of selection, most often chosen to reflect the diversity and breadth of the sample population (Bryman, 2008). Here, the aim was to produce sufficiently rich data and an in-depth understanding to provide a broad description of cultural processes and
experiences that might influence the knowledge and attitudes of these women towards breast cancer and breast awareness.

Snowballing sampling was adopted which is considered to be a type of purposive sampling. In this method persons already taking part in the research are requested to forward further possible volunteers who may add to the work via their social networks. Snowball sampling is frequently employed to locate and enlist “hidden populations”, or those sectors of society who are less accessible to researchers using alternative sampling methods (Thomas & Brenda, 1995).

Arab immigrant women are thought to be an example of such a “hidden population”. In terms of recruitment, the researcher did not recruit Arab immigrant women via the NHS health care system due to the lack of accurate recording of the “Arab” ethnicity group. The absence of a specific “Arab” ethnicity box to tick means that Arabs are most likely to tick the “other” box. Consequently, combining recruitment via community groups (for example, through Arabic schools and Arab associations), as well as identification through recommendation from existing participants or contacts were seen as appropriate methods of recruiting these Arab women.

2.3.1 Recruitment

The study was conducted in a privately funded Arabic School in the south of England. One hundred and fifty students, females and males, attend from the ages of 6-16 years old. Initial contact with the head teacher of the school indicated support for the research and permission was granted to send out an introductory letter inviting women (teachers and mothers of students attending the school) to
take part in the study. Accompanying the introductory letter was a written information sheet and a stamped addressed envelope for returning the tear off reply slip. A one-off follow-up phone call was made approximately 10 days after receiving the letter. No further follow-up contact was made if participants declined to take part.

I sent a total of fifty letter invitations through the Arabic school in the south of England and twenty-eight women responded to the invitation (ten women working in the Arabic school and eighteen women who were the mothers of the students studying in the school). From these twenty-eight women, nine women did not subsequently take part. Seven declined to participate in the research, following the invitation. Two women who were interested in being interviewed, however on further investigation did not meet the inclusion criteria of being of Arab origin. Finally, ten of the women out of 19 were interviewed. Data collection was terminated due to a lack of any fresh subject matter being produced (data saturation) and informational repetitiousness (Strauss & Corbin, 1998). This was achieved through the ten interviews conducted. Six women were recruited via the Arabic school and four woman were recruited through recommendation by some of the women who had already agreed to take part (a process described as snowball sampling).

**2.4 Data Collection**

Data collection were conducted with semi-structured, audio-taped, one-to-one, in-depth interview. Face to face interviews afford the possibility of adjusting successive questions to those particular answers the interviewees give as well as providing an opportunity to further examine answers with secondary questions
where suitable to explore issues that interviewees raise (Cohen, Phillips & Palos, 2001). The data obtained, particularly from one-to-one interviews can carry a much richer and more instructive content than information derived from alternative approaches. The semi-structured interviews were guided by an interview schedule based on previous literature and adapted with information that emerged from the research questions.

The interviews were conducted over a period of seven months between 12th June and 14th January 2009. All interviews were audio recorded. The goal of the digital sound recording was to confront the criticism of qualitative research which claims it is ‘prone to systematic biases’ (May 1991; 198).

2.4.1 Interview Schedule

The semi-structured interviews were guided by an interview schedule based on previous literature and adapted with information that emerged from the research questions. I was able to explore and attempt to explain the themes that caused most areas of concern. The topics in the interview schedule provided were broad with prompts were given. This provided an opportunity for the participants to elicit their thoughts and viewpoints on the subject matter under focus instead of draw them towards my preconceived choices. Hence, the flexibleness of the interview process was preserved all through the data collection process, enabling women to feel more at ease about sharing their experiences without concern about being judged.

2.4.2 Practice Interview

Before conducting the interviews, I initially contacted three women (who were associates of mine). These women who took part in practice interviews were not
from the original sample and their data was not used in the final analysis. However, they were from a similar background to the study sample; Arab immigrant women resident in the UK without a previous history of breast cancer. I felt it was important to pilot the interview schedule and practicing the interview process.

The interviewees were encouraged to be as candid and forth-coming as possible. The time taken for the interview ranged from 30 to 60 minutes, so I was able to gauge how long the study interviews might take. I thanked them for taking part in the practice interviews. After the practice interviews, I listened to each of these three interviews and analysed them to see whether the interviewees appeared to have understood the questions posed. Some useful feedback from these interviews reminded me to adapt the interview style to ensure the language used was very simple English for easy comprehension or to use Arabic language where there were difficulties. It was also a reminder to me to ensure in the future, that I asked each interviewee if they preferred to carry on in Arabic. This was particularly important for those who were struggling to find English words to express themselves. I adapted the interview schedule to include a few more topic area prompts by, for example, the use of alternative wording that appeared more suitable. Below is an example of topic area prompts:
The final interview schedule was based on four main topic areas:

1) Topic one focused on the immigrant Arab women's general knowledge of breast cancer and breast awareness. It was hoped to explore the level of knowledge towards breast cancer and breast awareness.

2) **Topic Two** focused on the cultural beliefs and practices of Immigrant Arab women as to the causes of breast cancer and subsequent treatment options.

3) **Topic Three** focused on the cultural attitudes and behaviour of Immigrant Arab women to breast awareness.

4) Topic Four: focused on the usefulness of current educational material (NHS and Breast Cancer Care charity produced leaflets) relevant to this population. It was hoped that this would inform practice and gaps in knowledge regarding educational materials relevant to this population by assessing the usefulness of current educational material.

### Attitudes, awareness and knowledge about breast cancer

- What concerns women in your culture about their health?
- What are some things that come to mind when I mention the word cancer?
- What types of regular check-ups or exams are recommended for women to prevent diseases and protection their health?
- How important is it for women to get a mammogram or clinical breast exam?

### Probe: frequency of exam, prevention measures

- What do you know about breast cancer?
- Does the risk of breast cancer reduce as we age?
- What changes in your breasts will make you more aware?
- Are you familiar with your breast health and the changes they go throughout your life?
- Do you know how your breasts look and feel normally so that you can recognize any abnormal changes?
The sequence of topics, as well as new topic development occurred as the interview progressed and was determined by responses (Interview schedule: Appendix 1.2).

The interview schedule was used in all of the interviews to make certain that the scope of topics were discussed at each while still providing the flexibility for participant led topic areas to be raised and permitting subjects/questions to be rearranged according to the natural course of the discussion.

Immigrant Arab women were encouraged to talk about their knowledge, attitudes, beliefs and practices towards breast cancer and breast awareness through open ended questions, reflection and probing. Open-ended questions permit the interviewee speaking in their own way, using terminology about anything that concerns them and do not permit the interviewer to “pull” the interviewee down a particular path. They also assist in creating a rapport in addition to garnering information and deepening comprehension, whereas closed-ended questions normally require a mere straightforward, mono-syllabic, “yes” or “no” answer. Prompts were used to access areas which did not emerge naturally. Arab immigrant women were encouraged to develop and enrich their responses with the use of probes and bi-lingual question repetition (English and Arabic) as methods to induce a more relaxed and comfortable sensation.

Whilst topic areas were put to every participant, but it was inconsequential that they were asked in the same order. This method and the use of probes can aid in achieving a more profound investigation of the subjects in focus through encouraging a freer and more laid-back and candid interview situation.

Further assurance were given to the participant that their responses would remain confidential throughout the research with all names removed. It was explained
that the study's purpose was to explore their knowledge and attitude to breast cancer and breast cancer awareness, and that those enlisted to take part would be perfectly at liberty to terminate their participation in the research whenever they wished. My being of Arabic descent and an active member of the Arab women's community, along with my having developed the knowledge and skills to communicate with immigrant Arab women in a culturally sensitive manner, served to minimize risks during the study. There were no identified participants in distress during all the interviews.

Conducting community based research requires the researchers to give something back to the researched group, so that the findings from the research can change their position in the society (Bulmer, 2001). With this in mind, the researcher gave Arab immigrant women a clear explanation of the multiple purposes of the research. Additionally I informed them I would take these findings to the health providers by publishing, where possible, in relevant journals and would disseminate the research findings to the Arab communities by presenting the findings at Arab social gatherings, such as mosques, Arabic schools, community halls, Arab association clubs etc.

Cassidy (2001), discusses the concept of the interviewer's 'invisibility' to the interviewee. The idea was to try and produce a 'rapport' and to generate a more natural environment for open and honest communication. To ensure the success of the interview, I tried to achieve a balance “between the warmth required to create ‘rapport’ and the detachment necessary not to affect the data being collected” (Oakley, 1981, p.33). Nonetheless, building a rapport with the interviewee without weakening that neutrality is absolutely crucial; the interviewee must be able to feel that they can impart any information they wish
without inducing the interviewer's favor or displeasure concerning the details of their response. I attempted to communicate a sincere respect to the participants and stress the immense importance of sharing all their thoughts, emotions, attitudes and knowledge on the focus subject in a completely impartial way without any prior judgment or bias. Therefore, my approach was quite passive and neutral; listening and giving the participants as much chance as possible to speak on their own volition, without any pressuring, advising, guiding or correcting.

At the same time, I tried to remain active in encouraging listeners; to ensure the women felt comfortable with sharing and elaborating their stories. By maintaining eye contact, avoiding interrupting the women as they shared their stories, nodding my head, leaning toward the speaker, I tried to achieve active listening at each interview.

2.4.3 Venue

The venue for the interview was taken into consideration since the setting chosen, (if the participant does not feel at ease) can impact upon the participant’s emotions which, in turn, influence how they respond during the discussion. The location should be one where participants feel comfortable and secure, as well as being convenient. Furthermore privacy is also a vital part of this decision and yet, if at all possible, the surroundings should be familiar to the participant, for example their own home. Inconvenient locations can possibly discourage participants; limiting their choice of interview venues affects the participant’s keenness to take part in this research.
Each woman was invited to be interviewed with an appointment time and venue most suitable for them. The women were asked to choose where the interview took place, either in their own home, at an office in the University of Portsmouth, or in the Saudi Arabia School, where I was given permission to use a quiet room. Written consent to participate was obtained immediately before the interview. Five women chose to be interviewed in their own home and five wished to be interviewed in the Saudi Arabia School, in a separate room from the teaching class rooms.

The interview was conducted in the language preferred by the women. As I am fluent in Arabic I was able to conduct the entire interviews in Arabic (where preferred), but also to engage more directly with participants. This aided in the comfort level of the women and eased the flow of discussion. In addition, I took field notes which was crucial for all interviews to summarize nonverbal communication. The notes were taken straight away after the interview had ended; this is because during the interview, concentration has to be maintained, however only important observations were written down, such as the women’s emotions expressed, any interruptions, initial thoughts. Finally, towards the end of each interview I offered some direction as to useful relevant websites/addresses and support in the form of breast cancer and breast cancer awareness brochures (NHS & Breast Cancer Care Charity) to all participants. I thanked each participant for taking part in the study. The majority of immigrant Arab women found the interview to be interesting and enjoyable.

2.4.4 Audio Recording

With the permission of the participants, I recorded the interviews for data collection with an audio-tape. A Philips Digital phone recording model PDR3 was
used to record the interviews verbatim. A digital phone recorder has a number of advantages and useful functions than using a cassette recorder. Before choosing to use a digital phone recorder I constructed a comparison Table (3) of the digital recorder versus cassette recorder highlighting these differences in terms of usefulness.
Table 3: Comparing Usefulness of the Digital Recorder versus Cassette Recorder

<table>
<thead>
<tr>
<th>Digital Phone Recorder</th>
<th>Cassette Recorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Digital Phone Recorders Provide More Space (With a digital phone recorder you can record more hours of conversations than you can on a tape call recorder).</td>
<td>Provide less space with limited time of recording. If the interview went overdue then the tape would not record the conversation over that time.</td>
</tr>
<tr>
<td>Digital Phone Recorders Can Be Used Easier With Modern Technology (If you need to email a telephone recording it is much simpler because the files are already in WAV format).</td>
<td>With cassette recordings it could not be sent over a technological medium such as email and can only be sent through the post. This is time consuming.</td>
</tr>
<tr>
<td>Digital Phone Recorders Are Smaller If size is a factor then digital phone recorders win hands down. They’re very small and compact in comparison to tape phone recorders.</td>
<td>Cassette recorders are very big in size and in some cases heavy, which may be difficult to carry from place to place.</td>
</tr>
<tr>
<td>Sound quality Digital voice recorders offer better audio record quality. This is in part because digital voice recorders have a higher signal-to-noise ratio which means there is less noise.</td>
<td>Cassette recorders have poor audio and playback quality. This is mainly due to the lower signal-to-noise. A low signal-to-noise ratio means that the device or file has lots of hiss and static, while a high rating means clear-sounding audio.</td>
</tr>
<tr>
<td>Features Digital Voice Recorders offer a wide range of features for greater functionality and efficiency. Enhanced features include the ability to save hundreds of recordings as files in folders on the recorder. This method of storing audio files is similar to the way files are saved on a PC.</td>
<td>Efficiency is not a point when it comes to cassette recorders. The functions available are limited with no storing options compared to digital.</td>
</tr>
<tr>
<td>Record Time While there are many variations of storage depending on the manufacture and the model, most units use removable memory cards and allow for storage capacities of 512MB or greater.</td>
<td>With cassette recording the size of memory available is dependable on the tape. The maximum capacity on a tape is 120 minutes.</td>
</tr>
</tbody>
</table>
To conduct my interviews I decided to use a digital recorder for the many advantages it holds. The first reason being is that recording by digital sound devises gives superior audio-sound quality, which is essential for good reproduction, as it allows for less background noise and clear understanding of what the participants are saying. Secondly, digital voice recorders offer greater functionality and efficiency. Firstly, the memory and storage space of a digital recorder is an important feature, as it allows the researcher to record for a long time due to digital recorders having higher storage capacity. Finally it has capacity to store a very large volume of recording files.

2.5 Reflexivity within the First Phase of the Study

Reflexivity is a critical reflection by researchers of how their own values or preconceived idea may influence the process of data collection and analysis. The researcher needs to reflect on, consider and assess the research process and findings to provide new understanding, new data collection framework or new theory (Boud, Keogh & Walker, 1985). Reflection prepares the researcher for new skills development, ideas and even intellectual maps in research process (Mezirow, 1991; Seibert & Daudelin, 1999; Schon, 1983). I found reflection an important part of adapting and developing my study skills. Possessing a relatively strong and clear idea of what I wished to explore placed me in an advantageous spot on commencing my PhD research journey. Deciding on a topic in which you have an earnest interest in is what I had been advised and had read numerous times in the process of choosing my topic. The topic has to be motivated by curiosity rather than method, as well as holding your interest.
and focus for the entire duration of your candidacy (Munhall, 2007; Polit & Beck, 2004; Ross and Morrison, 1992).

I understood that this topic could develop from various sources: relevance to work, interest, gaps in literature and personal experience (Roberts, 2007). At the beginning of my PhD, I was worried that my personal interest and experience of the topic may be looked upon as an unsuitable starting point; nevertheless, the more I read, the more I realised that this was not the case, and that it was a suitable place to begin (Etherington, 2005; Gilbert, 2001; Lowe, 2007; Roberts, 2007). I am investigating a topic in which I am not merely the researcher, but may well also be one of the participants. I was raised within the framework of breast cancer; members of my family have been diagnosed with the disease.

I have had family members diagnosed with the breast cancer, but none more important than my auntie who raised me. The possible loss of my auntie made me more familiar with this hidden and serious illness at a very early age. Two years later, my worst fear became a reality when I unfortunately lost my auntie to the disease. As such, I understood that doing research in this field would require sensitivity due to the taboo status of this topic amongst Arab immigrant women. Nonetheless, I had a strong conviction that this research was imperative, that it needed to be done, and that my research experience could present an important perspective and make up for the gaps in the literature about the knowledge, attitudes and beliefs of immigrant Arab women towards breast cancer and breast awareness.

In this study, I decided to follow in the footsteps of previous researchers and utilise my experiences of conducting this research: in acknowledging and framing the focus subject and while gathering the data (Clingerman, 2007; Warr, 2004). It
is precisely in this way that researchers nurture perceptivity and add depth of meaning to their analysis of their research topic, as well as learning about the behaviour of those who being interviewed, which develops a widely intuitive insight in the researcher (Holland, 2007; Hubbard, Backett-Milburn & Kemmer, 2001; (Perry, Thurston & Green, 2004; Rager, 2005). ‘Knowledge is not something objective and removed from our bodies, but is created through our experiences of the world as a sensuous and affective activity’ (Hubbard et al., 2001, p. 126).

Being an Arab immigrant woman, living in UK, who may have similar experiences with breast cancer and breast awareness, I felt I had part insight into the Arab culture and a general understanding of Arab immigrant women’s experiences. Even though my interview questions were designed in a manner to be more understandable to Arab women, they were not leading or biased towards an answer that I was expecting them to say. I made sure of this by making neutrality a factor and not emphasising a certain point during questioning.

However, I firmly believe that the research process was by the knowledge I had acquired concerning the suitability of experiences, because it had rendered me in state of heightened aware of the subject. I knew that my subject choice and the method I had chosen for the carrying out the research was able to be informed by my existing, background knowledge and experiences. Most people in most places today will inevitably acquire some awareness, knowledge and experience of at least some parts of the wide social-economic, ethnic and cultural spectrum that is the modern world and this can serve us very well in preparing and equipping us for the process of research into our subject elect (Brannick and
Coghlan, 2007; Simmons, 2007). This is precisely the personal approach I decided to take.

I am certain that my own personal experiences could form a substantial and advantageous contribution to my research, as well as adding breadth and depth to my comprehension. Although I was aware of a number of choices in ways to commence the research work, I was of the firm conviction that a qualitative approach to data collection and analysis allowed me greater immersion into the world of Arab immigrant women and thereby allowing me first-hand experience and deeper access into their knowledge, beliefs and attitudes towards breast cancer and breast awareness.

I discovered that this predilection, this concept was firmly tied up with the qualitative design method. In electing to interview the participants directly and personally in a one-to-one interview I was endeavoring to achieve a more profound investigation of their knowledge, beliefs and attitudes of breast cancer and breast cancer awareness. While using this approach, if comprehension is diminished to an impersonal view, eliminating all our previous experiences, then in the end the significance of the experience we are attempting to investigate is thoroughly negated, as we de-experience our experiences and de-world the world we encounter (Safranski, 1998; Frede, 1998).

I believe, I therefore, managed to balance the power structure between my role as researcher as opposed to female member of the Arab immigrant population to ensure I created an ambiance in which those who took part perceived me to be entirely on equal ground (not superior) and maximize the opportunity for the immigrant Arab women to openly share their views, without fear of judgment.
2.5.1 Reflection on the Interview Process

This was the first interview study I have carried out consequently I was nervous in meeting the first women to be interviewed. However, when interview started, the conversations were so natural and I discovered that many of the Arab women were open and keen to share their stories. Throughout the interviewing process my confidence increased with the advancement of the interviews, making it easier to develop a rapport with them. Setting a comfortable foundation and cordial communications with the interviewee is essential to the successful outcome of the interview, as it can greatly affect the extent of candidness and the interviewee's ability to share their thoughts and experiences (Liamputtong & Ezzy, 2005). Even though the willingness to share stories flowed naturally there were moments where encouragement was needed to expand on specific experiences, overall all the women who participated and took part provided me with, I believe, insightful and rich data.

After the first interview had been conducted I took time to listen to the audio-taped interview, not with the purpose of formal data analysis of its content, but instead to reflect on the interview style. My academic supervisor also listened to my initial interviews and gave me some feedback. Minor adjustments were advised after these first interviews. At each interview, I took field notes as to whether I thought the interview had appeared relaxed, too directive or whether there had been any distractions or interruptions.

2.6 Transcripts of Interview Recording

I transcribed verbatim all of the interviews myself to provide precise 'word-for-word' reproduction of the verbal conversation's audio-recording (Poland, 1995).

There is an on-going debate as to whether non-auditory communications such as
body language (posturing and gestures) and emotive signals like coughs, sighs, grunts, laughs, cries etc, as well as silences ought to be transcribed into the text, when the definition of transcription is narrowly that of standard, communicable, spoken language (Wellard & McKenna, 2001). Poland (1995, p. 292) asserted that "the very notion of accuracy of transcription is problematic given the inter-subjective nature of human communication, and transcription as an interpretative activity". The manner in which the transcriber both perceives and construes the interview conversation is pivotal to the form and accuracy of final transcription (MacLean, Meyer, & Estable, 2004). I decided to transcribe the data myself in order to be totally immersed within the data. (Dearnley, 2005).

In addition, I took field notes which was crucial for all interviews to summarize non-verbal communication as some participants' communication methods may have been non-verbal, such as signaling and facial expression (sadness, anger and fear), therefore this would not have been detected by audio alone. Whether to continue the exploration of the subject, switch to another area or terminate the interview may be deduced in response to signs or prompts from the interviewee communicated through their body language. Verbatim transcription coupled with the interviewers' written observances of the participant's physical behaviours has been mentioned as being key to the credibility and dependability, of qualitative data collection (MacLean, et al. 2004; Seale, 1997; Wengraf, 2001). I took steps to ensure that names were removed and that confidentiality was maintained throughout by adopting a numerical coding system on all the audio recording files and, verbatim transcriptions which were securely stored, password protected, on my home computer only.
After I finished each transcript, I carefully listened to the original audio-taped interview and compared the recording with every transcript to check for accuracy. Auditing transcripts recognises that qualitative data analysis, starts immediately after interview and proceeds by listening closely, reading, revising and ending with a ‘preliminary thematic identification (memoing)’ of the text written-up from the audio-recording (Miles & Huberman, 1994: 56). This method of accounting for the audio-record was deemed crucial for getting to know the all information well, hence the faithfulness (Boyatzis, 1998), but it was a time-consuming process although one that I felt to be of the utmost importance in guaranteeing the accuracy of the transcription.

Furthermore, during the course of checking the recordings I made notes in the margins of the pages. Comments were added in the right-hand margin, while special codes relating to them were inserted on the left (Miles & Huberman, 1994). An example of the initial coding and marginal remarks on a hard copy of one of the interview transcripts shown below in Figure 5.
Figure 5: An Example of the Initial Coding and Margin Remarks of One of the Interview Transcripts

The process of coding the comments included producing annotations depicting all my responses and thoughts as they happened and which were essential to the exploratory process. Examining these annotations could suggest new interpretations in addition to links with other data. Furthermore, it was imperative
for me to be careful to ensure what actually emerged came from within the data. However, my notes often raised further questions and areas to examine as I continued gathering and coding more information. These notes included remarks, built-in ideas about ideas (hypothesising) and instructions to remind me to seek clarification in subsequent interviews and make painstaking checks with the information in the same record or references to information in other transcripts (Perakyla, 1997).

In summary, making remarks during the transcript reading can not only provide signposts for later reflection but also decrease the tediousness of coding (Miles & Huberman, 1994). It can also guard against or at least help to diminish mistakes and muddiness caused by the researcher's personal mood and disposition (Boyatzis, 1998). I found the marginal comments particularly useful when I stopped analysis and then returning back to the coding some time later (due to busy family interruption or need), these remarks helped refresh my thoughts and helped me focus again more quickly.

### 2.7 Participation Validation of Interviews

Researchers from many fields across the board habitually invite their participants to review the records of their interviews as a part of the qualitative research process (Goeman, et al., 2008; Cappleman, 2004; Reimer & Furrow, 2001; Sinacore, Healy & Justin, 2002). In the course of these personalised reviews, the participants themselves determine and rectify faults and omissions in the transcript and possibly clarify or add further information including embellishing the researchers' insights related to interviewees' responses in the interview. I made the decision to concentrate on interviewee transcript review as a
methodical approach for testing the veracity and accuracy of the information prior to any formal analysing and coding was begun.

Additionally, participants were consulted as to whether they wished to read the records of their interview and they would receive a two versions of the transcript; one in English and the other in Arabic, in order to review the content and make any necessary corrections as well as any desired alterations, additions or deletions to any part if the text. Most women had a negative response, while a few showed interests in the transcripts and a few in the final written report. I compared each interview transcript with the digital interview recording before sending to each interviewee with a request to “please make a critically revaluation, comment, delete or correct any aspect of this transcription.” feedback comments of any kind were invited in the return the document within a two week deadline.

I had anticipated that some women might dread reading the contents of their own interview; sometimes interviews written out can seem repetitive or superficial. I tried to anticipate this reluctance to review the transcription by assuring them I valued the content of the interview. Nobody appeared to be distressed by the return of the transcripts and apart from minor alterations (such as misheard words or phrases), they were returned without many changes.

2.8 Qualitative Data Analysis

In-depth qualitative analysis can be, quite difficult to attain owing to the omission of much of the finer detail. It may be problematic to choose quotations that are representative of the categories as well as persuasive to the reader.
There are many different approaches to analysing qualitative data and after careful consideration I decided to choose one specific approach that of thematic analysis. Thematic analysis is a method of determining, investigating and presenting repeating and relating themes throughout the research data. Both the definition and methodology of thematic analysis are by no means clear or certain and there appears to be a tendency for subjectivity as well as vagueness regarding the interpretation process (Braun & Clarke, 2006; Tuckett, 2005). Braun and Clarke (2006) define this type of analysis as a fundamental approach to qualitative analysis. I decided to adopt the decision process outlined by (Braun & Clarke, 2006) to guarantee the reliability of the structure and the product, by making certain that the analytical process was transparent by clearly reporting on each step and the decisions made.

Throughout my study it was my earnest wish to work within a structure that permitted less rigidity and offered a chance to honor the prospect of likenesses along with divergences in the view of immigrant Arab women. After careful consideration of my personal aims in the study, I was convinced of the greater degree of suitability that thematic analysis would have as a device in facilitating a deeper comprehension of my data and because it has been defined as a somewhat less rigid approach (Braun & Clarke; 2006; Cassell & Symon, 2004). Employing thematic analysis permitted negotiability of the reality that I was co-constructing by interpretation of the immigrant Arab women’s stories. Furthermore, the ease of access to presented results rendered it easy for those who had contributed, as well as for other readers, to understand it. Being new and inexperienced to the practice of field research, this kind of analysis appeared
advantageous as a flexible, but structured approach that looked relatively simple to use.

It has been defined as a somewhat less rigid approach (Braun & Clarke; 2006; Cassell & Symon, 2004), this being one rational for its employment in my study. Conversely, it is possible to use thematic analysis in various theoretical intentions for which it permits a substantial degree of flexibility. Employing thematic analysis mean that there was a negotiability to the reality that I was cooperating with immigrant Arab women and that what was reaped from the research were comparatively simple to share with them. Furthermore, the ease of access to presented results rendered it easy for those who had contributed, as well as for the readers, to understand it and also retained room to investigate the intricacies of further central subjects.

Disregarding the reality that it is possible to view the skills employed in this process as non-proprietary compared with other qualitative analysis tools, Braun and Clarke (2006) protested that the approach does not hold much “Kudos” in relation to other analytic processes, such as grounded theory, Interpretative Phenomenological Analysis (IPA) or discourse Analysis. There are few directions and regulations for the use of this approach (Attride-Stirling, 2001) and it is this that makes it so flexible, although it may also result in the view that it is also somewhat untrustworthy. For the purpose of increasing comprehensibility and uniformity in its utilization, Braun and Clarke (2006) created a guide for the various stages of the thematic analysis procedure, while simultaneously retaining its best advantage as a tool; its flexibility.
In thematic analysis it is necessary to explore those subjects and patterns related to qualitative research (Braun & Clark, 2006). It is not grounded in any particular theoretical and epistemic framework and can therefore be applied across a wide range of qualitative research approaches (Braun & Clark, 2006).

Thematic analysis is used for organizing and describing data in rich detail and thus is considered most appropriate for any study that seeks to interpret findings. Furthermore, thematic analysis can be an essentialist or realist method, which reports experiences, meanings and the reality of participants, or it can be a constructionist method, which examines the ways in which events, realities, meanings, practises and so on are the effects of a range of discourses operating within society (Braun & Clarke, 2006).

Additionally, thematic analysis is one of the few methods of analysis that is epistemologically free and is thus compatible with a range of theories and paradigms and, as such, is an analytic approach that can be applied across a wide range of theoretical and epistemological settings to provide a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data (Attride-Stirling, 2001, Braun & Clarke, 2006).

While there are differences in terms of how a thematic analysis might proceed...
Braun and Clarke (2006) outlined a six-stage model as guidelines to conducting thematic analysis in a theoretically and methodologically sound manner. The researcher can adopt either an inductive, deductive or hybrid (combination) approach in the data analysis. For this study, an inductive approach was adopted in terms of the themes were generated directly from the data set or elements (Braun & Clarke, 2006). In essence, the coding and themes development throughout the analysis phase were directed by the content of the data set. The present study included all six of Braun and Clarke proposed steps in the data analysis process. This approach to data analysis, together with the aims and description of each stage are set out in Table 4 below:

Table 4: Stages of Thematic Analysis (from Braun & Clarke. 2006, p.87)

<table>
<thead>
<tr>
<th>No</th>
<th>Stage</th>
<th>Description of the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Familiarizing with the research data</td>
<td>Transcribing data, reading and re-reading the data, noting down initial ideas.</td>
</tr>
<tr>
<td>2</td>
<td>Generating initial codes</td>
<td>Production of initial codes from the data in a systematic way across the entire data set and collating data relevant to each code, giving full and equal attention to each data item, and identify interesting aspects in the data items that may form the basis of repeated patterns (themes) across the data set.</td>
</tr>
<tr>
<td>3</td>
<td>Searching for themes</td>
<td>Collating codes into potential themes, gathering all data relevant to each potential theme, it might use a table or mind map to generate the initial thematic map at this early stage.</td>
</tr>
<tr>
<td>4</td>
<td>Reviewing themes</td>
<td>Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a final thematic 'map' of the analysis</td>
</tr>
<tr>
<td>5</td>
<td>Defining and naming themes</td>
<td>Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.</td>
</tr>
<tr>
<td>6</td>
<td>Producing the report</td>
<td>The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.</td>
</tr>
</tbody>
</table>
2.8.1 Stage 1: Familiarizing with Research Data

To obtain a sense of each individual interview in its integrity prior to fragmenting it into various sections, it is essential that the researcher immerse themselves in all the research data to the point where they know it 'inside out' and 'back to front'. I collected all the research data myself, which enabled me to start data analysis in earnest, being aware, in advance, of the purposeful and environmental setting in which the information was gathered. I also wrote my field notes immediately following each interview making notes of some initial analytic interests and thoughts. I then transcribed the audio data into a written form which was an excellent way to re-familiarise myself with the content of each interview before starting the thematic analysis. Once the final version of the interviews transcription had been finished, “active” reading of transcriptions took place by repeat reading of transcriptions to search for meanings and patterns alongside listening to the interview audio recordings.

2.8.2 Stage 2: Generating Initial Codes

This phase involves the stage which includes producing initial coding from the research data. Initial coding has been described by Braun and Clarke (2006) as the procedure of determining characteristics in the information which attract the researcher’s interest. More explicitly, coding is the process of probing the basic qualitative data which has been transcribed, pulling out text excerpts (vocabulary, phrases, sentences or paragraphs) and giving them their own codes or labels in order to facilitate their later retrieval for analysis, comparing and determining any patterns.
Whilst coding can be performed either manually or through a software program, I used manual coding (rather than working with computer software), because I did not have the opportunity to train on such programs. Instead, after all the transcripts were read thoroughly in the first phase, I then went back to each transcript to read again and make notes in the margin of the transcripts (previously described under section 2.6 and shown in Figure 5).

The initial coding operation consisting of an open coding process. I carefully reviewed each interview and elaborated it with side notes wholly interview transcript. The transcribed texts were amalgamated and notable ideas were emphasised with clear highlight labels throughout this stage. Scanning for themes within the texts normally “involves pawing through texts and marking them up with different coloured pens” (Sandelowski, 1995, p. 373). See Figure 6 for an example of initial codes applied to a short segment of the present study data.
Figure 6: Example of Initial Codes for Short Segment of Interview Data

I used underlining and highlighting with different coloured pens to represent different units of text or topic areas that I thought were about the same topic, concept or idea, (for example red was used for the initial theme of “No Knowledge, green for the initial theme “Arab culture beliefs and pink for unawareness of breast health” and so on). After classifying the passages of text that appeared to be ‘about’ the same thing, I gave it an initial code or label subsequently written on the transcript. I coded all extracted data and then collated them together within each code. This involved copying the extracted data from each transcript and photocopying extracts of printed data. I then collated each code together in separate computer files. Furthermore, I re-read all the notes for each transcript and revised them to acquire a broad outline of repeated codes.
and how they associated with the theme or category. (See Figure 7 for an example of initial codes and category)

Figure 7: Example of Initial Codes and Theme Category

The coding categories in the present study were initially constructed in the light of the research questions, as well as the interview guides and in relation to pertinent literature and overall theoretical and methodological perspectives. Moreover, I derived the initial codes on the basis of the main study objectives (a) The knowledge, attitudes and beliefs of immigrant Arab women toward breast cancer, and (b) The knowledge, attitudes and beliefs of immigrant Arab women to breast cancer awareness. These two factors were divided and, by revisiting the transcriptions, the most essential ideas in the interviews were determined and
molded into a significant group of codes. The transcriptions were then disintegrated, categorised and structured according to these codes. (See Figure 8 for an example of initial codes and text segment)

For example, the initial code “breast cancer knowledge” included text segments such as, “no idea about breast cancer sign and symptom, I never heard about risk factor”, “Very hard pain is the most sign for the breast cancer and the pain started around the nipple then it will radiated to the whole breast”, ”the causes may be is heredity or genetic problems”, “the only thing that I know is lump and redness like a rash on the area of the breast”.

The code “breast awareness knowledge” included text segments such as, “I never think about my breasts”, “I never draw my attention to my breasts”, “I don’t know if there is special health awareness for breast”, “I never heard of it before from the doctor or nurse”, “I use to check my breast when I got a time but not regularly”, “I am not sure about the way of breast exam”, “Are there normal and abnormal breast? I am never heard about breast awareness”.

Figure 8: Example of Initial Code and Text Segment

Furthermore, I made a continuous comparison to check the texts against existing codes (sometimes I had already made a particular code and did not need to repeat but instead, sub-divided this initial code into subcategories (See Figure 9 below for an example of initial code which was subsequently broken down into a number of sub-categories.)
2.8.3 Stage 3: Searching for Themes

In the pursuit of generic themes matter, I organised codified examples of excerpts. Owing to the very great number of excerpts across and within interviews, I chose to select verbatim quotes which I felt to be most representative of the code. The root of this decision was a selection of quotations that illustrated the foremost link to the code or that provided the best description to demonstrate its importance. To illustrate this, in one of the interviews, a first generation immigrant Arab woman asserted that “the unfamiliarity with the existing health care system in England represents the reason for the lack breast cancer awareness, which is reflected in the immigrant Arab women's lack of knowledge about the importance of breast cancer screening (mammography) as a valuable procedure for them”. This illustrated that this woman was keen to be aware of breast cancer, but “unfamiliar with the existing health care system” This quotation was therefore picked out from this interview as one example to demonstrate the codes “unfamiliarity with health system” as well as “lack of breast cancer awareness knowledge”.

Figure 9: Example of One Code and Its Subcategories
The system of ordering the codified excerpts most often included choosing two or more extracts of each interview to exemplify the individual codes that had been specially created. Each excerpt was highlighted with its context intact, meaning that related text both leading up to it and following on from it was kept intact together with reference to the particular question it was in response. A note was made alongside with information indicating its place in the original transcription, specifically; its line number and a number of other codes relating to that excerpt. During my progress through the thematic analysis, a repetition of codes across and within interviews became apparent and this led to a more ‘automatic’ creation of natural groupings or themes. The system of collapsing was executed and an itemisation of all the final codes (for phase one) within the entire data set as evident in (Appendix 1.3).

By keeping this list of codes on post-it notes as a convenient visual reference, I was able to determine potential topics as categories, moving the post-it notes around to achieve best “fit”. Once I felt I had logically categorised, I consulted with my first supervisor for input. At first the data was grouped in 6 initial themes and 23 sub-themes, which when condensed and summarised represented the data more concisely. However, both the substantial quantity of data and the considerable number of categories caused it be a very slow and lengthy task. However, this was necessary to lead to the creation and refinement of further themes and sub-themes as well as the conceptualisation of an initial thematic map, illustrated in Figure 10. A number of “potential links” were determined from execution of the initial analysis and which arose out of requiring further consideration in the upcoming phases of analysis.
Figure 10: Developed Thematic Map, Showing Five Main Themes
2.8.4 Stages 4 and 5: Reviewing, Defining and Naming Themes:

Phase 4 consisted of two distinct and consecutive sections of reviewing. First, it was essential here to think about what warranted a “theme” as I made reference to the Braun and Clarke (2006) article. Here it was recommended that:

A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set

(Braun and Clarke 2006, p.82).

The operation of determining whether there were obvious “themes” consequently entailed revision of particular interviews and the mulling over of whether a “theme” actually existed there. This frequently resulted in an addition of extracts to the information already in my possession and also to the removal of sub-themes and codes which were absent in other interviews. For instance, “difficulties in transportation” was removed as a preliminary code because it failed to conform to any lucid themes and was only apparent in a single interview.

In addition, I had an overlapping theme “social and cultural beliefs and attitudes”, I noticed their sub-themes had many similarities; therefore I combined it into one theme, which is the “socio-cultural beliefs and attitudes”. The origin of this socio-cultural concurrence is the concept that society and culture forge one's knowledge. Social and cultural customs, beliefs, attitudes, values and language concurrently create a person's individuality and experience (Lisa, Farrah, & Raymond, 2009). This approach promulgates that the basis of an individual’s
thoughts is his or her socio-cultural heritage. Therefore, in adherence to this approach, what an Arab woman thinks is based on her socio-cultural background. A sociocultural approach considers more than the individual in endeavoring to comprehend cognitive activities.

I also overlapped three categories (fear of death, gossip and stigma) under one sub-theme, which is taboos and fears surrounding breast cancer. The reason I overlapped these categories under one sub-theme was due to the shared subject of taboo (gossip and stigma) and fear (inclusive of morbidity; death) surrounding breast cancer. The outcome and the revised themes are shown in Figure 11 below.
Figure 11: Final Thematic Map, Showing Final Four Main Themes with 17 Sub-Themes
Figure 11 indicates the highly complicated nature of the review process in the thematic analysis and the involution of my own thought processes. This facet of the procedure was difficult in respect of the need to discern the most appropriate places for the sub-themes to be able to make a significant representation of the findings and it entailed a lot of revising and reconsideration of distinct themes. As part of the refinement, I identified that all four final main themes contained their sub-themes (defined as basically themes within a theme useful for defining composition in an especially big and convoluted theme, in addition to showing an order of significance within the data (Braun & Clarke 2006).

On achieving satisfaction about the provision of adequate examples in support of each theme, the second phase of revising commenced. This involved the rereading' of the entire research data in order to ascertain whether the themes were clearly defined, named and in an appropriate position within the collection of data as a whole. It was necessary for the final theme name to be succinct, catchy and instantly convey the subject matter to the reader (Braun and Clarke, 2006). This procedure resulted in giving one of the main themes a new title. (Phase 5). For instance, after reading over the complete collection of data, it appeared that the Main Theme; “Systematic Barriers” would be more suitably labeled as “Health Care Services Barriers”. Likewise, following the completion of this process of revising sub-themes and making an all-encompassing appreciation of the data set in its entirety, “Feels neglected and misunderstood” seemed better represented as “Feelings of being targets of racism and discrimination”. It was necessary for the final theme name to be succinct, catchy and instantly convey the subject matter to the reader (Braun and Clarke, 2006).
A final thematic map in response to the first phase of the study is shown in Figure 11.

2.8.5 Stage 6: Producing the Report

The sixth and final stage of the analysis involved producing the report; this was considered as the final stage for analysis. The purpose of writing up the thematic analysis was to supply a brief, tidy, rational, non-repetitious and engaging discourse of the data content. It is possible to achieve this, for instance, by supplying an adequate number of data excerpts to show and reinforce the theme being defined. These excerpts obviously determined other topics and presented a clear example of the point being asserted. The excerpts were submersed within the discourse of the analysis and powerfully depict the narrative I was relaying about the information concerning each main theme and its sub-themes. It is necessary that the transcription contain enough evidence of the topics within the information to sum up:

"excerpts need to be embedded within an analytic narrative that compellingly illustrates the story you are telling about your data, and your analytic narrative needs to go beyond description of the data, and make an argument in relation to your research question"

(Braun and Clarke, 2006:93)

In the next section I will present a report and discussion of my findings. This thematic analysis will include an overview of the main themes and sub-themes. I present these in turn providing a concise, coherent, logical and non-repetitive account that identifies and integrates the themes derived from the analysis (Braun and Clarke 2006). Evidence for each theme is presented in the form of data extracts from the original transcripts in order to strengthen Attestation for each
theme is conferred in the form of extract of the data from the original write-ups for the purpose of fortifying the transparency and validity of my report. Verbatim examples of genuine data of the interviews were used to clarify a variety of findings and provide useful descriptive material. Verbatim quotes from the interviews were chosen on the basis that they provided a real exemplar of the theme being described.

Using verbatim quotations or extracts from the original data, to provide accuracy, richness and elegance, will best help the reader to form a judgment about how well the explanations are grounded in the data (Corden, & Sainsbury, 2005). The findings were also linked to the literature on the topic where appropriate, to make a comparison with those findings of previous works. The whole process of data collection, analysis and final write-up is presented in Figure (12) below:
To begin with, all tiers of the analytic procedure were executed by me, followed by a conference with first and second supervisors, as categories, themes and sub-themes were processed and sorted throughout the data analysis stage.

2.9 Validity of Thematic Analysis

Internal validity is a pertinent issue, as thematic analysis can only be as good as the coding system that is developed from the data. However, checking the reliability of the findings is possible and a competent thematic analysis will have validity built into the research process. Nonetheless, a necessary stage in the
growth of a useful framework for analysis is to ascertain the pertinence of the code to the basic, raw data (Boyatzis, 1998).

To examine the reliability of the coding system, a second independent researcher (S. A.) read through all the interview transcripts and briefly wrote some notes and initial ideas and then read through these transcripts to generate initial codes, collating codes into potential themes independently without seeing my codes and themes list. The findings were compared and discussed. It was, however, named under different categories and although these categories shared similar meaning; after discussion a decision was made between us as to what final categories should be named.

Braun and Clarke (2006, p.96) additionally created a 15–point checklist of criteria for competent and effective thematic analysis, as illustrated in Table 5. I have added a third column to this checklist to show how I feel I have achieved each criterion.
<table>
<thead>
<tr>
<th>Process</th>
<th>No</th>
<th>Criteria</th>
<th>How I achieved criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transcription</td>
<td>1</td>
<td>The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.</td>
<td>I transcribed all the interviews myself. I listened to the tapes alongside the transcriptions, changing inaccuracies, adding in intonation of voice, pauses, etc.</td>
</tr>
<tr>
<td>Coding</td>
<td>2</td>
<td>Each data item has been given equal attention in the coding process.</td>
<td>I gave each data equal attention by reading and re reading the transcripts for each interview carefully and noted down initial ideas.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.</td>
<td>After the coded process I thoroughly generated the themes through the consideration of every single example as everything is important.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>All relevant extracts for all each theme have been collated.</td>
<td>I collated all relevant extracts by sorting them out into initial groups relevant to their theme</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Themes have been checked against each theme have been collated.</td>
<td>I reviewed all the collated themes by checking their relevancy to the theme</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Themes are internally coherent, consistent, and distinctive.</td>
<td>I made sure that all themes were coherent, consistent and distinctive by reviewing them numerous times</td>
</tr>
<tr>
<td>Analysis</td>
<td>7</td>
<td>Data have been analysis – interpreted, made sense of – rather than just paraphrased or described.</td>
<td>I identified the story that each theme told rather than just paraphrasing it or describing it</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>Analysis and data match each other- the extracts illustrate the analytic claims.</td>
<td>I carefully made sure that the analysis and the data reflected each other by thoroughly reading the evidence for each theme</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>Analysis tells a convincing and well-organized story about the data and topic.</td>
<td>When writing each theme story I made sure it was easy for the reader to understand the whole story.</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>A good balance between analytic narrative and illustrative extracts is provided.</td>
<td>I selected quotes that more clearly identified and support the themes and sub themes.</td>
</tr>
<tr>
<td>Overall</td>
<td>11</td>
<td>Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.</td>
<td>I did not rush on any phase of analysis, giving adequate time over all.</td>
</tr>
<tr>
<td>Written report</td>
<td>12</td>
<td>The assumptions about, and specific approach to, thematic analysis are clearly explicated.</td>
<td>My assumptions were clearly explicated because I followed the thematic analysis step by step</td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>There is a good fit between what you claim you do and what you show you have done- i.e, described method and reported analysis are consistent.</td>
<td>I described clearly the method of analysis I used in the research when i was writing up the report</td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>The language and concepts used in the report are consistent with the epistemological position of the analysis.</td>
<td>The language I used was chosen so as to be easily understood by the reader and to easily identify the concept of the analysis</td>
</tr>
</tbody>
</table>
The 15-point checklist was extremely useful in terms of helping me ensure rigour in the process of data analysis. With each analysis step broken down into detailed criteria, I believe this has made the research process taken more transparent and easier to follow.

2.10 Findings

2.10.1 Introduction

Braun and Clarke (2006) report in detail how the sixth phase of a thematic analysis starts at the point that the researchers have a collection of fully-developed themes and includes the closing analysis and transcription of the study report; a process demonstrated in this and the concluding chapter. Data generated through in-depth interviews were organized, analysed and interpreted in light of the research questions. This chapter will begin by a description of research participants, followed by a presentation of the themes that emerged during the qualitative interviews. I discuss the research outcomes analytically, emphasising the most apt findings relating to the research aims of this phase of the research study whilst making links to the pertinent literature presented in the previous literature review chapter. This move from the descriptive to the analytic is what Braun and Clarke (2006) identify as a key feature of a rigorous thematic analysis.

Thematic diagrams were employed to exhibit the findings with reference to a thematic map made in the process of the thematic analysis (figure 9); statements quoted verbatim by immigrant Arab women are included to evidence each theme and sub-theme. Particular quotes have been selected because they best represent the theme being described and in some cases, were the only data available. This method was selected in order to relate the story told from within the data in a brief and clear manner, both within and across the themes. This
work however, is not devoid of some limitations, which will be pointed out in the next section. I will then reflect on the possibilities of future research in this area, as well as on the broader theoretical, methodological and practical implications of the current research. The chapter, as well as the thesis, ends with some suggestions for improving immigrant Arab women equitable access to breast cancer and other breast awareness health care services in England.

**Participants Characteristics:**

The selection process for included participants was made on the basis of the following criteria a) the women participants were of Arab origin, born outside England (first generation), and Arab women born in England (second generation), b) the women were selected to represent an age range between 18-70 years inclusive c) women were excluded if they had a personal history of breast cancer. It was anticipated that women with a personal history of breast cancer would be more aware and educated about breast cancer compared to women with no personal experience of breast cancer.

**2.10.2 Participant Biographical Data**

A total of ten Arab immigrant women were interviewed. Five women chose to be interviewed at their home, three women chose to be interviewed in the Saudi Arabia School and two women requested an interview at the researcher's home. Overall, five interviews were conducted in Arabic and five were conducted in a combination of Arabic and English. The individual characteristics of the study participants are presented in Table 6 to show the number of women in each age group, occupation, marital status, level of education, country of birth, length of residence in England number of children, religion and whether first or second generation.
### Table 6: Biographical Characteristics of the Participants

<table>
<thead>
<tr>
<th>Demography</th>
<th>Immigrant Arab Women N=10</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>2</td>
</tr>
<tr>
<td>30-39</td>
<td>3</td>
</tr>
<tr>
<td>40-49</td>
<td>2</td>
</tr>
<tr>
<td>50-59</td>
<td>3</td>
</tr>
<tr>
<td>60-70</td>
<td>0</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>1</td>
</tr>
<tr>
<td>Self employed</td>
<td>3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5</td>
</tr>
<tr>
<td>Student</td>
<td>1</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
</tr>
<tr>
<td>Married</td>
<td>9</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
</tr>
<tr>
<td>University Degree</td>
<td>6</td>
</tr>
<tr>
<td>Secondary School</td>
<td>3</td>
</tr>
<tr>
<td>Illiterate</td>
<td>1</td>
</tr>
<tr>
<td><strong>Country of Birth</strong></td>
<td></td>
</tr>
<tr>
<td>Saudi Arabia</td>
<td>2</td>
</tr>
<tr>
<td>Iraq</td>
<td>1</td>
</tr>
<tr>
<td>Egypt</td>
<td>1</td>
</tr>
<tr>
<td>Yemen</td>
<td>1</td>
</tr>
<tr>
<td>Libya</td>
<td>1</td>
</tr>
<tr>
<td>Kuwait</td>
<td>1</td>
</tr>
<tr>
<td>UK</td>
<td>3</td>
</tr>
<tr>
<td><strong>Length of residence in UK</strong></td>
<td></td>
</tr>
<tr>
<td>1-2 year</td>
<td>2</td>
</tr>
<tr>
<td>3-4 year</td>
<td>1</td>
</tr>
<tr>
<td>5-6 year</td>
<td>2</td>
</tr>
<tr>
<td>7-8 Year</td>
<td>2</td>
</tr>
<tr>
<td>9-10 Year</td>
<td>2</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>1</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
</tr>
<tr>
<td>Having children</td>
<td>7</td>
</tr>
<tr>
<td>No Children</td>
<td>3</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
</tr>
<tr>
<td>Muslim</td>
<td>10</td>
</tr>
<tr>
<td>Others</td>
<td></td>
</tr>
<tr>
<td><strong>Generation</strong></td>
<td></td>
</tr>
<tr>
<td>First</td>
<td>7</td>
</tr>
<tr>
<td>Second</td>
<td>3*</td>
</tr>
</tbody>
</table>
Three women were second generation (UK born) but only one woman had been in the UK consistently for over 10 years. Two of the three second generation women had been resident in the UK for less than 10 years because despite being born in the UK they had left for extended periods of time joining parents working in other European countries.

The average age of the ten Arab immigrant women was 40.3; ages ranging from 20 to 59 years. They had been living in the UK for periods of at minimum one year up to more than ten years, with an average of 6.8 years residency. Of these, nine women were married, one was unmarried. Seven women were first generation with three women from the second generation. Participants were from 6 different countries: 2 from Saudi Arabia, 1 from Egypt, 1 from Kuwait, 1 from Iraq, 1 from Yemen and 1 from Libya. The parents of the three second generation women were 1 from Egypt, 1 from Yemen and the last one from Saudi Arabia. Additionally, these ten interviewees had completed information sheet relating to the participants’ highest level of education; most of them (6 women) had an undergraduate degree and 3 had A-level qualification. Among the others, one was illiterate (not able to read and write in Arabic and English). The religion of all the participants was given as Muslim. The themes presented in this chapter have been inductively abstracted using the stages of thematic analysis described (See Table 5), and address the research aim and objectives outlined at the beginning of this chapter, presented again below for ease of reference:
Thematic analysis of the data brought to light four main themes with sub-themes arising from each. The four main themes were: poverty / lack of knowledge, socio-cultural beliefs and attitudes, religious beliefs and attitudes and health care services barriers. These themes are related to the knowledge, beliefs and attitudes of immigrant Arab women toward breast cancer and breast awareness (Figure 13).

Figure 13: Diagram Illustrating the 4 Main Themes
Each theme is depicted with all details below. Italicised fonts represent the sub-themes that arose. Immigrant Arab women quotations are also used to substantiate the recognized themes.

2.10.3 Theme One: Poor / Lack of Knowledge

This theme focused on the breast cancer and breast awareness knowledge of immigrant Arab women including the challenges faced. Poor/ Lack of breast cancer information is defined as poor/lack of knowledge and the ability to understand or recognize breast cancer risk factors including signs and symptoms.

Sub-theme: ‘Poor/lack of breast cancer knowledge’

Since the causes of breast cancer are unknown, many risk factors have been identified by researchers which raise the probability of having breast cancer. The risk of breast cancer is strongly related to the genetic factors and family history amongst others which include: hormone replacement therapy (HRT) for menopausal symptoms, obesity and overweight due to a fatty diet, excessive drinking of alcohol and tobacco smoking, exposure to large amounts of radiation at a young age, never having children or having a first child after age 35, younger age at first period (before age 12) and older age at menopause (age 55 or older) (Cancer research UK, 2014).

In general, the second generation immigrant Arab women participants were more knowledgeable about breast cancer risk factors. Family history, inheritable factors, drinking alcohol, obesity, and eating fatty diet were an invariable feature of the three second generation immigrant Arab women stories.
"The important risk factors are a family history as this disease is heredity. Drinking alcohol, eating fatty diet and been overweight help to have this disease" [No.1, 2nd.G. age range 20-29]

Not only did Arabic immigrant women from either generation have no knowledge of age being a major player as a breast cancer risk, they were also unaware of most of the other major risk factors, such as; prior diagnosis of breast cancer, former benign lumps in the breasts, breast density, obesity, exposure to radiation and hormone replacement therapy.

According to Cancer Research UK (2014), most likely sign/change I due to breast cancer noticed by nearly almost of women is that of:

- Lump or region of hardened tissue inside their breast.
- Alteration in either the size or form of one or both breasts
- Discharge from the nipples (which may contain blood),
- Lump or swelling in either of the armpits,
- Dimpleing on the skin of the breasts,
- Rash on or around the nipple,
- Change in the visual aspect of the nipple, such as becoming recessed into the breast,
- Pain in either breasts or armpits that is unrelated to menstruation (Cancer Research UK, 2012).

First generation immigrant Arab women were asked about their understanding of ‘breast cancer’ including indications and symptoms, causes and risk factors. The majority were ignorant of the subject of breast cancer. They stated poor knowledge of breast cancer as a serious disease, its symptoms and risk factors.

Four out of seven first generation women interviewed admitted they; “never knew anything about breast cancer before.” “Never knew any information” and “Didn’t
know what breast cancer is” Absence of knowledge of breast cancer may have added to the lack of personal experience of cancer in general. Furthermore, this dearth of real awareness and of knowledge of the facts about breast cancer was the result of social taboos and stigma associated with it. Therefore, it was not openly talked about and consequently some women had very little awareness of its existence.

For those women who did express knowledge of symptoms, three of the first generation immigrant Arab women thought that a major physical sign was that of pain, usually accompanied by fever and redness of the breast. The following three quotes demonstrate the poor of knowledge about breast cancer symptoms.

“what I know, breast cancer started with severe pain, redness of breast and high fever which is no any type of pain killer help it, no treatment—I am not sure for how long it will take----” [No. 7, 1st.G. age range 40-49]

The majority of first generation women were unaware that a lump could be something serious and potentially related to breast cancer. They also did not know about the full range of breast cancer symptoms, such as dryness or retraction of the nipple and dimpling of the breast skin.

The second generation immigrant Arab women appeared to have better knowledge about the signs and symptoms than the first generation as revealed in the following quotes:

“Feel of lump or redness in the breast area is the main sign and symptoms.” [No.1, 2nd.G. age range 20-29]

“…changes in breast size and nipple discharge is the signs of that disease” [No.2, 2nd.G. age range 20-29]

Arab immigrant women’s limited knowledge about breast cancer seems to misdirect them into a misconception of being somehow immune to cancer. Most
of the women lacked any notion of being in any kind of danger of breast cancer and were convinced that, as long as they maintained a generally good state of healthy and did not have any cancer history in the family they had scant cause for concern and would be protected and resistant to it.

A worrying feature was that the first generation Arab immigrant women were the least knowledgeable about cancer. This reflects perhaps their perceived sense of lack of susceptibility, since they considered cancer to be a disease of which starts with pain and fever; falsely believing that symptoms like pain (accompanied with fever) to be the main signs of the breast cancer. Hence, awareness of signs and symptoms of breast cancer was overall quite deficient. The above quotes reveal the poor of knowledge concerning symptoms of breast cancer which may result in early detection of breast cancer including postponement of consultation at GP practice for further investigations.

*Sub-theme: Breast Cancer main causation (Alienation)*

A feeling of alienation can arise when the social and cultural features of someone are different from the rest of their social environment. Both first and second generation immigrant Arab women talked about their belief that that the main cause for breast cancer among immigrant Arab women was that of ‘stress and feeling unsettled due to alienation’. They strongly believed undergoing the process of immigration, the stress involved with respect of shifts in modes of living conditions, discrimination and the feeling of being unsettled laid them open to more serious danger of contracting cancer, including breast cancer. They shared how they felt to be under enormous pressure. They worried about the future of their children, adaptation difficulties, financial worries (including helping family back home), difficulties in linguistic communications, discrimination and other
problematic states of affairs all making their effects felt. Many Arab immigrant women as they shared their concerns seemed extremely exhausted. Below are quotes from both second and first generation sharing the misconception that alienation causes cancer.

“Our life is full of alienation and stress because we have different life style and the discrimination that we use to faced it every day, all these factors came us a result from alienation, which is the main causes for this disease, I am sure” [No. 3, 1st. G. age range 30-39]

“In our country we never heard about breast cancer, I heard this word here in England from my friend. I think the difficulties of alienation and the big pressure which we have to adaptation are the main cause of this disease” [No. 10, 1st.G. age range 50-59].

Similarly, all the second generation of immigrant Arab women demonstrated the same unique belief of the first generation Immigrant Arab women regarding the main cause of breast cancer, (alienation and stress), as they reported:

“We use to affect by our family unsettled and stressful situation, the feel of alienation is painful, so even we are not born in our original country but still we get to feel of alienation which I think is the first reason for breast cancer and any disease among Arab women.” [No. 5, 2nd.G. age range 30-39]

“I think the migration in term of alienation is the basic cause for breast cancer, most of Arab families have anxiety of unsettled life which is result from language and financial difficulties. Stress as well ---ohhhh yes all of these aspects is behind this disease.” [No.2, 2nd.G. age range 20-29]

Losing one's traditional culture may be the origin of both sorrow and depression, (Eisenbruch, 1999; Eisenbruch, 1991). Leaving one's country of birth can result
in losing all that is familiar with, such as; language, attitudes, values, societal structures and support organisations. Mourning this loss may be seen as an instinctive response to and a commonplace effect of migration. Furthermore, the stresses experienced after migration to the new country include 'culture shock' and 'clash', both of which can create feelings of cultural confusion, estrangement and isolation resulting in a state of depression (Bhugra, 2004).

Sub-theme: ‘Poor/lack of breast awareness knowledge’

Breast awareness is about knowing how the breasts normally look and feel, being on the alert to any abnormal alterations and seeking advice from a doctor. The charity Breast Cancer Care have issued guidance in the form of five easy steps. The five simple steps are (Breast cancer care. 2012):

(1) Be fully aware of the normal state of ones' breasts,
(2) Be aware of how to notice and find changes;
(3) Visually inspect, physically examine
(4) Report any changes to your GP immediately.
(5) Additionally, if you are over the age of 50, go to breast screening on a regular basis

The immigrant Arab women from both first and second generation appeared to have poor or no knowledge and understanding of breast awareness and being uncertain of how to perform a routine self-examination. This had a close connection to the statements of the women being ignorant of the typical warning signs and symptom. Five first generation immigrant Arab women reported that they visually inspect and feel their breasts in case of pain or developing a fever in the breast feeding period. However, in relation to the steps recommended
above, they were ignorant of what to look for. Below are example of the first generation immigrant Arab woman quotes:

“Breast health!! [Surprised] do breasts have their own health? [Laughing] No idea about it but I know that we should keep our breast clean especially during the period of breast feeding and avoid sleeping on the stomach in order to avoid pressure on the breast when is filled of milk, this is the time when I look to my breast [silence] I never knew about breast awareness”. [No. 6, 1st.G. age range 30-39]

“Why I need to look for my breast [feeling discomfort]. I use to look for my breast when I was young and when I was breastfed my children. I use to do it in case of having pain in my breast” [No. 8, 1st.G. age range 50-59].

Here it’s clear that first generation Immigrant Arab women, widely displayed an uneasiness and ignorance of facts regarding the subject of breast health awareness. Moreover, on being asked about the significance of breast awareness to them, most of the immigrant Arab women responded with silence or an awkward laughter. with many of the others, ‘breast awareness’ was circumscribed by them, in simple terms, as the watching for any pain, or to see if something is wrong during the period of breastfeeding. Generally, Arab women generally concurred that they did nothing on a regular basis to look after their breasts. Of the three second generation women, only one reported that she was not sure about how to examine her breasts:

“I am not certain for the way of breast exam, I use to do it but not always, my friend in the University told me about it theoretically, not as practical” [No.2, 2nd.G. age range 20-29]

All the immigrant Arab women indicated they didn’t know and or aware of clinical examination performed by health personnel, and they had little knowledge about the process of breast cancer screening (mammography). According to three of
the women from the first generation, mammography screening was a "chest x-ray" that is performed in case of a chest infection; while for two other women from the second generation, the meaning of a mammography was likened to that of a brain scan.

“I am quite sure the mammography is a test which is similar to brain scan or brain x-ray, my aunt had it two years ago, they told her that she had brain tumour” [No. 7, 1st.G. age range 40-49]

“Mammography, I am not sure about it, but I think it is something around brain or nerves, everyone needs to do it when they get old I think after 40’s” [No. 4, 1st.G. age Group 30-39]

Evidence from other cultures suggest that a conviction that it is quite possible to protect themselves from the risk of cervical cancer by habitual douching, healthy diets, strong religious beliefs and a generally positive attitude (Lee, Fogg & Sadler, 2006). It has also been discovered that other Asian-American women believe that deterring oneself from any thoughts about cancer and disciplining themselves into a positive frame of mind can serve them in a protective way (Ashing-Giwa et al., 2004, 2003; Bottorff et al., 1998). A lack of awareness of breast cancer or confusion about it among Korean-American women lead to a deficiency in use of screening services (Yu, Hong & Seetoo, 2003; Lee, Fogg & Sadler, 2006; Yu, Hong, & Seetoo, 2003). For instance, the reason most often cited for Korean-American women not undertaking breast cancer screening is the notion that they are in a low-risk category for breast cancer (Juon, Choi & Kim, 2000). Deficiency in knowledge about the cause of risk, the importance of early detection and the early diagnosis of breast cancer, is likely to prevent these Arab immigrant women from being adequately breast aware. What is worse, many
Arabic women were convinced that there is no real need for breast screening in the absence of any real concrete signs or symptoms. Being somewhat dispossessed of even the basic facts and comprehension about the usual appearance of breasts and of all the risk factors involved, women are ignorant of the fact that they must consult a doctor, when, to the best of their knowledge, they would seem to be in perfectly sound health. What is more, a lot of immigrant Arab women depend on their GP to explain the critical necessity of being breast aware, when they don't sense there is really anything the matter.

**2.10.4 Theme Two: Socio-Cultural Beliefs & Attitudes**

This theme emphasises the social and cultural beliefs systems of Arab immigrant women. The socio-cultural theme alludes to the mixture or communication of social and cultural issues in terms of the immigrant Arab women beliefs and attitudes. California Endowment (2003) reported that culture is a coordinated mix of individual execution that may contain all or some of dialect, feelings, activities, beliefs and attitudes of any racial, ethnic, social, or religious groups.

What is clear from this explanation is that culture can affect an individual's social behaviors with persons from the same or other cultures in a substantial way. All societies and their cultures have varying indigenous beliefs concerning human maladies and their cures. People from many other foreign ethnic groups, in addition to British Arab, confront the health care system with their traditional and endemic beliefs and associated practices and this frequently challenges professional health care workers to 'close the gap' with these cultural dissimilarities.

This theme highlights how the socio-cultural beliefs and attitudes of immigrant Arab women may stand as a barrier between breast cancer and breast
awareness. The Socio-cultural barriers of immigrant Arab women were firmly embedded in their beliefs and attitudes, which they obtained, in most cases, from their country of origin and, of utmost relevance, their experience of being alienated as a foreign immigrant which fueled the growth of social and cultural confinements over communicating information about breast cancer, engagement with breast awareness behaviors as with the health care services.

The sub-themes within this theme include: (1) Taboo and fear surrounding breast cancer “Bell of Death”, (2) Health is not a priority for Arab women, (3) embarrassment and modesty, (4), Decision-maker and gender inequality emerged as socio-cultural beliefs and attitudes which are important determinants in health care behaviour, and it’s possible to be considered as powerful barriers to the understanding of breast cancer, and in understanding barriers to early detection among immigrant Arab women.

Sub-theme: ‘Taboo and fear surrounding the breast cancer “Bell of Death”

Despite persistent awareness campaigns taking place throughout the Arab world, there still exists a culture of taboo and fear surrounding breast cancer. However, vast numbers of women continue to live in fear of admission of their illness and do not seek help until the later stages of the disease, when it has become fatal (Sarhan, 2011). Princess Ghida Talal of Jordan, an advocate of breast cancer awareness in the Arab World, explained that women are failing to open up about their disease for fear of being ostracized by their society and even sometimes their own families. They decide instead to avoid or delay diagnosis or treatment with the inevitably tragic consequences for the woman and her entire family (Sarhan, 2011).
In this study, the topic of cancer appeared to be a taboo subject, where the stigma of even saying the word “cancer” gave rise to thoughts and fears that vocalizing the words would give rise to a higher chance of getting it. All first generation and one of the three second immigrant Arab women communicated widely-believed facts that being diagnosed with cancer is alike too being given the death sentence. The superstition that talking about it would enhance its malevolent power. Women tried to express their feeling of cancer as a taboo or fear of death expressed in their own words as the “bell of death”. Below, are two quotes selected from first generation Arab women to illustrate this widespread belief:

“..As general most Arab communities don’t like to talk about this subject or that someone has got cancer. They just see it as a taboo. In fact, most of them do not even mention the word cancer in brackets mean (death), be aware of breast cancer means be aware of death”. [No. 4, 1st.G. age Group 30-39]

“I think it’s a sound of death, it’s like an earthquake because there’s no treatment, and other women (no.7, [No. 7, 1st.G. age range 40-49], she was frightened when she start to say: “I am like a shocked person when I just hear this word. It’s terrible; it’s like the end of life and death. It is terrible when I talk about it, I start shivering believe me?’ [... Pause…] I don’t want to think about this horrible topic. Remembrance of Allah protects us always”. [No. 6, 1st.G. age range 30-39]

Here, women discussed how, culturally, the disease is regarded as a death sentence. One women from the second generation was of a like-minded persuasion to the first generation women depicting the illness as a death ‘alarm’ and voicing its undesirability as a subject to talk about.

“That disease is a bell of death and if we got it, we should start to calculate the remaining days of our lives” [No. 3, 1st. G. age range 30-39]
“In my opinion, this disease is like a voice of near and certain death—[short silence] that’s why I always avoid talking about it” [No. 10, 1st.G. age range 50-59].

During the interviews, the first words most of women repeated were “Isim Allah, Isim Alla Al Rahman” which can be taken to mean ‘Blessings in the name of God’. Two of first generation immigrant Arab women from the age group 50-59, who had already received an invitation to breast cancer screening, had decided not to attend, as they explained to me; the mention of breast cancer filled them with fear of death, sadness and an omen of bad luck:

“Isim Allah, Isim Allah—Al Rahman”. You know, for Arabic women cancer is a “death sentence and disaster” we avoid to hear anything related to cancer and that which prevents us from going for breast examination or screening”. [No. 8, 1st.G. age range 50-59].

Five out of seven of the first generation women were apprehensive about the outcome, which induced them to say (Arabic proverbs) “the door that the wind comes from, close it and rest yourself” which the women explained that for them it can be interpreted as “This means that sometimes, rather than taking a problem, you should just shut off the source of the noise and relax.” two quotes selected below illustrate these beliefs as:

“We used to say the door that brings in wind, shut it down and rest, so to stay away from discovering that we have cancer is better and no worries about death” [No. 8, 1st.G. age range 50-59].

“ I always have fear of death by cancer and that’s why I don’t want put this subject in my mind as Arabic proverb say (If you talk of the devil, he'll appear) so if we keep talking about cancer we will have it” [No. 4, 1st.G. age Group 30-39]
In contrast, all of the second generation were more aware about breast cancer as a disease and they had different views than the first generation women towards the fear surrounding the breast cancer, as all three second generation women said:

“It is so sad that many women continue to bury their heads in the sand when it comes to this disease, I mean breast cancer, mainly due to the difficult cultural and social pressures they face, we need to get off of it” [No.1, 2nd.G. age range 20-29]

Not all immigrant Arab women wanted to talk openly about breast cancer and some women prefer to keep the diagnosis hidden, or restricted to immediate family members. There were some reasons for this, to avoid any negative responses from the community in the form gossip and back-biting. For example, the limited understanding of breast cancer and lack of confidentiality within the women’s community, left some feeling that some community members would gossip and make insensitive comments. Therefore, to avoid these negative remarks, some women chose to keep knowledge of the disease hidden.

The Arab immigrant women highlighted several factors that would fuel gossip and back-biting within their community and stop them from making any serious medical examination, such as breast screening, as a method of breast cancer preventive measures. The immigrant Arab women considered that the reason they feared gossip and back-biting was because they lived in one community, close to each other, actively seeking the support of an Arab community when first immigrating into this country etc. The quotes shown below explain that most Arabs live in one community and are socialised in their own groups; therefore they were known within this community. Several women highlighted the
closeness of the Arab community. Below are one of similar six quotes from first generation women selected because this illustrate this concept as follows:

“as immigrants, when we came to this country, we search for the area where most Arabs live, or the home office usually places us in those communities as it’s aware where most Arabs live, for example in Southampton most Arabs live in -------- and it’s a tight knit community where everyone knows each other.” [No. 6, 1st.G. age range 30-39]

It is clear that the reason for not openly talking about cancer included not wanting the news to spread in the community and be idly gossiped about, which would, they felt, result in community members judging them and making negative remarks. Due to this reason, discretion and privacy was difficult to achieve, and so, for these women likely to deter them from going to a breast screening appointment, as this may fuel gossip. The differences between mammography as a diagnostic tool rather than treatment for breast cancer results were not understood among these first generation Arab immigrant women. Because of the lack of understanding of the differences, this they felt would become a subject of gossip in the immigrant Arab community in England. They would be scared to attend breast screening. Below are one of similar two quotes.

“I don’t feel like I can go to a breast screening because if I go everyone in the community will know, and people will start thinking that I have breast cancer and they will start talking about me behind my back. So I don’t want to trouble myself”. [No. 4, 1st.G. age Group 30-39]

The fear of being labeled in the Arab community, it appears, might result in could have negative effect on the person’s reputation. The concept of “I don’t want to trouble myself” as highlighted in the above first quote suggests the belief that if they do have the disease; if they don’t trouble themselves and leave it be it will
eventually go away quietly. However if they bother with it and seek outside help, they believe the disease won’t go away.

A majority of first generation Arab women in this study pointed out difficulties to attend the breast screening because of the negative remarks of gossips, which makes them awkward to discuss such issues with others. Below are six of seven of the quotes selected:

On other hand, one of three women from the second generation, also suggested that gossiping and back-biting was a fear she had surrounding the breast cancer and its awareness.

“In Arab culture we avoid the backbiting and gossip, but still exist, especially in immigrant communities because they are small and the backbiting spread quickly, imagine if they talk about this disease that befalls you, it will make people turn away from you, like me as second generation also we are trying to be a way from this situation because people in our community wouldn’t stop this habit in each single occasion” [No.2, 2nd.G. age range 20-29]

Additional issues discussed under the taboos and fears sub-theme included the view of breast cancer as a denial, which is linked to perceptions of stigma if diagnosed with breast cancer. Five of the seven first generation immigrant Arab women highlighted that illnesses, such as breast cancer, are often hidden because it can damage the family’s honor and reputation, especially if there are daughters involved since it is thought that this can hinder future marriage proposals. Two out of seven similar quotes of the first generation women are shown below illustrating these views:

“Most of Arab family and me is one of them deny the existence of this disease because, it’s brings a stigma for the whole family, I am sure it’s affect the marriage of our children in the future and we will lose the chance of getting married the other girls in the family, that’s why we denial it”. [No. 4, 1st.G. age Group 30-39]
“If cancer was known by one person from outside of family members it will be a curse and stigma surrounds the family------ the people will not & never forget it to the generation to come. Ohhhhhhh-----therefore the denial and maintain the confidentiality of this disease within the family would be the best for our daughters” [No. 8, 1st.G. age range 50-59].

Furthermore, two highly educated women from the first generation and three women from the second generation all had different opinions in terms of the stigma and the denial that surrounds any cancer related disease. Nevertheless, these women all voiced the need for an Arab female figure to educate the Arab community about cancer-related issues concerning cultural attitudes of denial and stigma which they had all encountered. These women believed that denial and stigma associated with breast cancer was both “unhealthy and backwards”, and cancer awareness would be a step forward to overcoming fears and stigma.

“Most of Arab women who have breast cancer, they keep themselves silent and isolated, hardly talking out openly. Commonly have found that talking about breast cancer, give them stigma. They worry about frightening other women and spread the bad luck, but the thing that they don’t know breast cancer affects their family and community, [long silence]by your help they are going to raise their voice and challenge the stigma which stuck wrongly with cancer in our society” [No. 6, 1st.G. age range 30-39]

“Personally, I am not with denying the disease and fear of stigma which is surrounds breast cancer, it’s true that you can be lonely and you feel like you’re the only one going through it but we need to be free from this beliefs and unhealthy attitudes [ short silence] we need to talk about this disease to be aware of it at an early stage” [No.1, 2nd.G. age range 20-29]

As many of the interviews progressed, some immigrant Arab women became more open as time went on and less emphasis was placed on the denial and stigma attached to breast cancer. However, these women were aware that breast
cancer remains a closed topic not very openly talked about in their communities and, for others, continue to hide their illness. For them they felt that the Arab society needs to liberate itself from the misconceptions, denial, and stigma surrounding breast cancer.

*Sub-theme: ‘Health isn’t our priority (The Arab women’s role within the family)’*

The women’s role in the Arab community was another type of barrier identified by most of the Arab immigrant women in this study. The conception of being sick and unattractive in case of a diagnosis of breast cancer, would prevent her from fulfilling both her matrimonial and maternal roles. As a result, she might lose her position in the family and she would fear that her husband might abandon her. Ultimately, this type of barrier prevent women from going to regular check-ups and breast screening. Five of the first generation Arab women compared their fears of breast cancer diagnosis to the consternation of forfeiting their significance as matriarch within the familial unit.

“I think if a woman has breast cancer, she is not able to take her role as a mother and she is going to be like [a dry tree] or useless, sure you understand me, I feeling well while my husband and children feeling well”. [No. 3, 1st. G. age range 30-39]

“If the women affected by this disease she will be not important in the family and society, she will missed her role as a mother which is so painful”. [No. 4, 1st.G. age Group 30-39]

One second generation woman felt that Arab women are always in fear and worried about other aspects of their life, except their health, which they tended to ignore. Immigrant Arab women in particular; she felt, were often preoccupied with problems occurring in their home country, with no time to consider their own their health.
“There is no space in our mind to think about our health, as immigrants women, we have a lot of problem to think about it rather than health, think about our family here, family in our original country, our situation as immigrant, think about our children and their future in this country as a foreigners—ect”. [No.1, 2 nd.G. age range 20-29]

Two of the women from both the first and second generation pointed out that polygamy is a patriarchal tradition which affects a woman's decision to disassociate from awareness of breast cancer or breast examination. No.5 second generation, age group (30-39) explained:

“--- the first thing the man will say when he know that you got breast cancer: ' that I need to marry another women' because you know that the polygamy is allowed in our religion [smile] so it's easy for him to get married again”. [No. 5, 2nd.G. age range 30-39]

One second generation, educated women said that she would prefer to have mental problem instead of breast cancer:

“For me it is better to have mental illness than breast cancer, at least with mentally problem I am not going to feel that I am abandoned and my husband get another wife, I will be unconscious of this hurt feeling” [No.1, 2nd.G. age range 20-29]

Sub-theme: ‘Embarrassment and modesty’

Cultural specific experiences regarding embarrassment and modesty were also mentioned. This was talked about by both generations of Arab immigrant women. Interestingly; Arab women were particularly uncomfortable being treated by male health professionals. This was something that they had to get used to (as even though they requested them, there were not always female health professionals available), but they found it very embarrassing and shameful exposing themselves to male health care professionals. These women were also aware that unwillingness to be examined by male health care professionals was a commonly held belief within their culture; which often resulted in women avoiding
examinations and sometimes even treatment. Additional cultural taboos were discussed within the immigrant Arab women who contributed to the reasons why cancer was not so openly talked about. Here, women talked how, culturally, it was not acceptable to talk about an intimate body part; such as the breasts (especially in front of a male). They shared that Arab women have been brought up not to reveal their body to anyone, except their husband. This was an embarrassment factor for most of the immigrant Arab women being seen by male health care professionals in the case of physical examination or breast screening would not be acceptable.

The majority of Arab immigrant women talked about the importance of a female doctor or health provider, especially with breast health issues. They asserted that the women had an overwhelming preference, if not exclusive demand, for female doctors to diagnose and treat health issues. They stressed that if summoned for breast screening, they would stubbornly decline to go to the appointment if the health provider was a man because of their sensation of acute embarrassment, fundamentally based on the conventional constituents of Arabic social customs and beliefs. Below are two of seven similar quotes selected from the first generation of Arab immigrant women: as five women asserted:

"The embarrassment and modesty issues often concern Arab women for breast screening and other women health issues if the physician is a male. We cannot expose our bodies it would be too embarrassing in the sense we are taking away our modesty ". [No. 4, 1st.G. age Group 30-39]

Male doctor is one of barrier against us to visit the health clinic, Modesty and embarrassment is one of characteristic of our society and we can’t overcome them, we grew up with it” [No. 3, 1st. G. age range 30-39]
In spite of ample assortment in the extent of social separation between the sexes among the Arab countries, in general communications between male/female in Muslim countries is restricted to the family unit and is outwardly defined by Islamic law. Male and female segregation is widely practiced in public situations, including between adolescents and adult hospital wards and is accordant with Islamic culture. In Arabic culture, overall, it is thought unsuitable for non-family members of the opposite sex to engage in conversation, or any other kind of social interactions. Generally speaking, it is obligatory that same-sex providers be available, where ever possible and medical examinations in the presence of others persons (for instance, opposite sex medical interns or assistants) need to be avoided. In traditional Arabic social culture, these time-honored customs are lifted only for critically vital emergencies. Six of the first generation Arab women proclaimed that, two quotes selected below:

“In Arab country we strictly follow our cultural laws by using separated departments in all health services for example hospital, health centers, pharmacies and everything, so there is no way to get mixed with male health providers” [No. 7, 1st.G. age range 40-49]

“If I asked to go for breast screening the most thing make me worry about it is the gender of health provider, I can’t be with a male because of feel uncomfortable and we are not allowed to be with male according to our culture” [No. 6, 1st.G. age range 30-39]

These thoughts were not confined to the first generation Arab immigrant women. Two out of three of the second generation Arab immigrant women confirmed the words of the first generation women that they too felt modesty and shame would prevent them being attended to by a male doctor or health care professionals for such women’s intimate issues. No1 and 2 age range (20-29) comments illustrate the same views, one quotes selected below:

“for young women is more difficulties to seen by a male doctor than the old women maybe, I never seen by a male doctor, it’s so embarrassing going for breast issues [laughing],
unless I am on flu and there is no female doctor, in this case he is not going to exam any part of my body I have to protect my modesty and don't want to embarrass myself.” [No.1, 2nd.G. age range 20-29]

However participant No.5, view differed. She was the only one out of three of the second generation women age range (30-39), whose views did not comply with the rest of the second generation Arab immigrant women. She stated that it was not culturally important whether the doctor was male or female. She expressed this approach as:

“It is not a taboo to be examined by a male doctor in serious cases; both male and female doctor became a doctor with the Hippocratic Oath. They do not look at us with indecent. Therefore it doesn’t matter for me whether my doctor is male or female, the world has changed and developed and we are staying in the same place”. [No. 5, 2nd.G. age range 30-39]

Sub-theme: ‘Decision-maker and Gender inequality’

One of the barriers for Arab immigrant women taking part in breast cancer screening programs was underlined as social factors. During the interviews, the majority of Arab women from both first and second generation noted that they would need to inform their husbands before they visited a doctor, and moreover they were not allowed by their husbands to have their breasts examined without their expressed permission. The women reported that it was, for the, the normal procedure for women to be obligated to request permission from their spouse, father or brother prior to leaving the house at any time and that this request must always be accompanied with an explanation. Many felt that having to ask permission to attend breast cancer screening would be a highly uncomfortable task and the source of considerable consternation to many families. Below are
two quotes selected from both first generation and the second generation women illustrating similar views:

“Something else prevents Arab women from going to breast screening, every woman knows who is the decision-maker in this matter----- of course is not me and you. The man is the decision maker in our society and we cannot overcome his decision even in the simplest things” [No. 6, 1st.G. age range 30-39]

“In Arab community is certain that the family is governed by reference to the tribal system. ----- The family remain important institution in this community to make a decision for even minor issues and generally the most of Arab families are patrilineal”. [No.2, 2nd.G. age range 20-29]

2.10.5 Main Theme Three: Religious Beliefs and Attitudes

This main theme highlights religious beliefs and attitudes held by the immigrant Arab women which influenced their views towards breast cancer and breast awareness. The theme of Religious Beliefs and attitudes may have an important position in Arab women’s understanding of general illnesses and their treatment. Different people have a different outlook on sickness and demise as a part of the natural course of life, or have the conviction that sickness is the result of natural origins, poor or inadequate diet, and exposure to inclement or harmful weather conditions, God’s punitive measures for religiously offensive actions or for having little or no faith in God. Certain women might defer finding medical assistance while preferring a number of alternative options, for instance; attempts to treat themselves and allowing their God to heal them, help from folk-healers/witch doctors, advice of lay persons, home-made curatives and prayer as treatment for their sicknesses (Bonder, Martin & Miracle, 2001).
Sub-theme: ‘Cancer is God’s punishment and will’

From a religious perspective, these Arab women believed that any cancer was predetermined by forces beyond one’s control, such as their God. It was not in the Arab women’s nature to blame God, but they held a fatalistic view and believed that it was something that was meant to happen. Holding such a belief helped would help them accept a diagnosis of breast cancer.

Thus, if a sin is committed or an act that is considered to be sinful, the Muslim believer might ask of themselves “Is that because God be satisfied or dissatisfied with my performance?” if the person has sin and continues to sin, he lives in fear and horror of the punishment of God. However, in the case the sinner has taken the initiative to repentance, then their God would support the sinner if the intention was freely given with good will rather than continuing to sin. Living within this sense of guilt, most Arab Muslims people are apt to understand any bad luck that happens as being part of God’s punishment for the sin they have performed (Hammad, Kysia, Rabah, Hassoun & Connelly, 1999).

The majority of first generation Arab women reported that the benefits and the retributions given out by God are not restricted to the life after death, but rather may strike in the present, earthly life, such as cancer. Furthermore, the Arab women in this study feel such an all-encompassing dependency on their religion that it tends to pervade into every aspect of their life and actions. Two out of two quotes selected from first generation immigrant Arab women as follows:

“Cancer is created by Allah and he will cure it if the women is believing in God and she is real Muslim— that's why we ask God and 'Insha'a Allah ('if God wills it') keep this black disease away from us'” [No. 4, 1st.G. age Group 30-39]
“always we need to behave good and in right way, we need to be away from anything sin, otherwise we will be find yourself having this disease as a reminder from God Almighty for what have we done from the mistakes and you must be punished” [No. 7, 1st.G. age range 40-49]

Whilst some immigrant Arab woman’s opinion tends to assert God’s intent as the instigator of all diseases, fate and earthly occurrences. Instead of saying this disease is curable, the immigrant Arab women would almost invariably add God-willing. Two out of seven similar quotes selected from first generation immigrant Arab women.

“I am not going to stand against God’s will, I need to accept whatever disease God gave me” [No. 4, 1st.G. age Group 30-39]

“We can’t oppose the will of God Almighty whatever it was, he is the one who gives life and he is the one who causes death” [No. 7, 1st.G. age range 40-49]

On the other hand, all three second generation educated women thought that disease was not God’s punishment. They confirmed that this was a misunderstanding of their religion, as they asserted:

“I am a faithful Muslim women and I believe in every word in Quran, Allah didn’t say that he is going to punished us by diseases, it’s a misunderstanding and a personal concept” [No. 5, 2nd.G. age range 30-39]

“In Islam God has a hundred names and one of his name is merciful, healer and heather so tell me how he is punished us” [No.1, 2nd.G. age range 20-29]

Sub Theme: ‘A false sense of security’
Some of the women suggested that breast feeding prevents serious disease. This belief is thought to originate from the Holy Quran because breast feeding in Islam has a strong religious connotation. Suckling babies for a full two years, nature permitting, is the advice imparted to all women by The Holy Qur'an itself
The Hadith (a book containing collections of Islamic traditions) mentions that the mother who breast feeds for the recommended time will receive the prize of a good deed for each pearl of mother's milk with which she nourishes her new offspring. Many Arab women believed that women who breastfeed for more than two years will not develop serious diseases later in life. These beliefs are based upon the Qur'an, the holy book that guides all practicing Muslim believers. However, the Qur'an does not specifically state that a woman who breastfeeds for more than two years won’t get any diseases. This belief is paraphrased and wrongly translated from the Qur'an to give a false sense of security to Muslim women. Due to this, Arab women believe the longer the mother breastfeeds the more she is protected against diseases. Instead the Qur'an actually states this: {Mothers may breastfeed their children two complete years for whoever wishes to complete the nursing [period].} [Quran 2:233]. From this Qur'an extract, you can clearly see there is no mention of immunity from diseases. Six of the immigrant Arab women from the first generation held a false sense of security, which protected and reassured them that they were safe from a diagnosis of breast cancer: Below are two quotes selected:

“Breast feeding protects women from any disease in the future, this what I am sure about it, it’s mentioned in Quran that the women must feed her baby for completely two years and does not have the words in the holy Quran without benefit, we will be safe from serious disease” [No. 4, 1st.G. age Group 30-39]

“I breastfed my all children for completely two years, so I don’t need to be worry, my mum told me that my immunity system will be strong enough against serious diseases. I am enough healthy now and I will be in the future as well” [No. 6, 1st.G. age range 30-39]

Interestingly three of second generation immigrant Arab women held similar views regarding protectiveness of breast feeding; they expressed thoughts that
breast feeding a child for two years would protect them and their child from serious illnesses for a short period, as well as strengthening the mother and child’s immunity. Unlike the first generation Arab women, who believe that these benefits would last for life, second generation women believed that these benefits would only last until the breast feeding period was over. They also confirmed that all Arab women need to be more aware about their breast health. In addition, they established a link evidencing the reduction of breast cancer risk when breastfeeding for the recommended time, information they had obtained from the TV and internet, which they considered a reliable source. Below are one quote selected.

“Majority of Arab women thoughts that they are away from diseases at all, it might be the breast feeding protect the baby and the mother for a short period against disease but not for all her life. I heard on TV that that the breast feeding could be beneficial by decreasing possibility of breast cancer and breast disease, but sill the women should be aware of it”

[No.2, 2nd.G. age range 20-29]

In 2007, the World Cancer Research Fund published a report which claimed that breast feeding can in fact 'protect' a woman's body against breast cancer and that this is achieved primarily through the activity of suckling affecting the levels of estrogens in the body (World Cancer Research Fund, 2007). They therefore assert their claim, that breast feeding should be viewed as one of the principle preventatives of breast cancer and even cancer in general. The report advises the continuation of breast feeding beyond six months, with balanced feeding adhering to UN Global Strategy on Infant and Young Child Feeding. Importantly, it records that policies and actions intended to prevent cancer should be executed for the entire duration of a person's life span from birth. Proof of diminishing the danger becomes dependent on more factors the longer
the duration of the breast feeding. However, research implies that it is necessary for a woman to breast feed for a substantial period of time for the activity to make any real odds.

Determinations from two substantial cohort research projects made no claims to any general link between breast feeding and the incidence of breast cancer (Kvale & Heuch, 1988). All the same, it contradicts other research findings, that suggest breast feeding diminishes the danger of breast cancer in women under 40 years old and could possibly provide a degree of protection for older women too (Tryggvadóttir, Tulinius, Eyfjord & Sigurvinsson, 2002). Moreover, in 2014 Lee et al. proclaimed the occurrence of breast cancer to be linked with 'nulliparity' and the individual's history of breast feeding. Although there is some evidence of truth in the protective nature of breast feeding but it does not avoid vigilance by breast awareness and early detection and that women who feel that they are protected from life might avoid such practices believing they are safe and immune from any likelihood of developing breast cancer

‘Treatment of cancer by engagement in religious activities’

The majority of immigrant Arab women from the first generation professed to having religious convictions of some sort or another and talked about the significant part this had played in assisting them in their comprehension of any kind of sickness and moreover how to deal and cope with it. Some women turned to religious activities in the form of praying and reading the holy Qur'an. Engaging in such religious activities helped the Arab women connect with their inner self, control their emotions and avoid negative feelings of depression and distress. They felt that, if they were diagnosed with cancer, their faith and prayers would
help them cope. The majority of the women set a great deal a store in their religion and the way in which it would carry them through any future cancer ordeal. All Arab women have a strong belief in God and are religious, whether being diagnosed or not. Therefore, praying to Allah (God) and attending the mosque is already a big part of their lives. However, if being diagnosed with cancer or any serious disease, the women’s faith in Allah would increase and they would turn to more religious activities. For example, they would pray more, visit holy sites, read the holy Qur'an, and listen to recitations of the Qur'an.

For the women in this study, first generation women shared views on how their religion would help them cope with illness and a future diagnosis of cancer: Below are two quotes selected.

“---As Muslim Arab women, we use to practice our religious activity to protect our self from having any disease especially in case of this disease because only God can cure it after he is the one created to assess us how faith we are, we despair the mercy of God” [No. 3, 1st. G. age range 30-39]

“The believer is afflicted with the calamities, so we need to stay with our religious rules and keep praying with pure heart, by this way we cured the cancer with power of God almighty. When stressed or feeling low I pray to god and read the Quran, imagine if I had the disease I would be praying all the time” [No. 10, 1st.G. age range 50-59].

While all second generation immigrant Arab women supported the first generation about the engagement of religious activity in terms of coping with a diagnosis and treatment of breast cancer, on the other hand they confirmed that early detection prior to treatment was more important. They expressed a desire to know how to and be aware of breast cancer preventive measures which they did not currently
know how to practice. Below are one out of three quotes selected from second
generation immigrant Arab women.

“I believe that religious practice is the main protective way against any kind of disease as
Prophet Muhammad say “Pray to Allah and be confident of a response.” But why we don’t
get extra help to look after our self as Prophet Muhammad say “prevention is better than
cure”, so if breast awareness or breast screening is a protective measure, I think it’s ok to
do it” [No.1, 2nd.G. age range 20-29]

Therefore, although the Muslim faith and practice was shown to be important to
both generations of Immigrant Arab women, for the first generation there was a
sense that this could replace breast awareness practice whilst for the second
generation faith was only part of the protective mechanisms and knowing how to
be breast aware was a major preventive action. However, strict adherence to
religious convictions over contemporary, professional health care could explain
to a large extent why immigrant Arab women defer medical consultation until the
cancer has reached a critically progressed state.

2.10.6 Theme Four: Health Care Service Barriers

This theme outlines how the issues of the barriers of the health care service were
embedded in the immigrant Arab women’s' stories.

Sub-theme: ‘Lack of custom and cultural competence’

Throughout the interviews, one of the barriers for the first and second generation
immigrant Arab women which was preventing them from participating in the
screening programs was underlined as 'lack of customs & cultural competence'
by health providers. Some women felt that the health care professionals in their area were not always supportive or attentive to their needs. They felt that there was lack of awareness of their customs and cultural competence. In addition, the women felt that information regarding breast cancer awareness was not clearly explained. Some also felt that nurses were mechanical in the way they treated them and lacked empathy and cultural sensitivity. They felt that there was still a need to take different approaches to bridge the communication barriers and by doing so it would allow them to understand the racial, ethnic, cultural and linguistic differences. The women noted that if this was done they would be felt that more cultural awareness would encourage attendance at breast cancer screenings.

Furthermore, the immigrant Arab women from both the first and second generation reported that they had never met any health care provider, who shared their background; so they found it hard to voice their views and concerns.

In addition, an emerging pattern among first generation immigrant Arab women was a feeling of alienation through perceived lack of consideration by health providers towards their ethnicity. The women expressed that health providers prioritised other minorities, such as Indian and African.

Below are two out of seven quotes selected from first generation immigrant Arab women and one quotes selected from second generation women:

“The majority of health care professionals are still do not have enough knowledge to Arab cultural sensitivity, so they cannot approach them with the treatment they deserve; they don’t have any idea about our culture. I feel that we are foreigners even we are a British nationality but we are not like the Indian or African minority. The health care providers are more familiar with them because they know their culture but she start thinking when I told her from where I am originally, they don’t have idea about Arab countries. If this barrier is gone I would attend an examination” [No. 3, 1st. G. age range 30-39]
“I hope they will know about our culture custom and competence we always feel uncomfortable when we visit the health provider because they thought that we are Asian, the health authority should trained them abut about our culture” [No. 9, 1st.G. age range 50-59].

“Understanding women’s culture will help the health provider to identify usual barriers to effective health care delivery and outcomes that are due to cultural orientation, all the health care provider should have a guide for our culture which need to include all details about our life, religion, beliefs and attitudes, the health authority should provide this guide to all staff to represent Arab people with their culture”. [No.1, 2nd.G. age range 20-29]

Sub-theme: ‘Feelings of being targets of racism and discrimination’:

The indirect barrier of racial discrimination within the health care system does not normally manifest itself so openly. Discrimination is defined as the unfair or detrimental treatment of varying categories of human beings, most often founded on their different ethnic origins, their age or their sex. The definition of racism is closely linked to discrimination, however, it is prejudice directed at a certain individual or social group due to their race or beliefs. Less obvious or under-hand discrimination happens when equal health care services are not provided for all, but when, for reasons of race, culture, religion and language etc., it is in some way rendered impossible for members of one or more minority groups to both use and gain from the service equally in relation to other persons (Henley & Schott, 1999).

A document written by the United Kingdom Central Council (UKCC), 1992, p.3) said e that nurses are strongly obliged to: "Recognise and respect the individuality and self-respect of each patient and client, and react to their requirements of care,
irrespective of their ethnic origin, religious beliefs, personal aspects, and the nature of the health problem or any other factor”.

Cultural ignorance, therefore, can be a significant barrier in the pathway of positive and fruitful interaction with ethnic minority enclaves within health care environments (Latif, 2010). The lack of Arab community identification as a unique group means that they are under-represented in both civic life and in positions of authority in the private sector and proportionate with current numbers in the UK (Aljalili, 2004).

There were two issues that the Immigrant Arab women felt had contributed to their feelings as targets of racism and discrimination within the health services, the first issue was the feeling of being neglected as a minority group. The majority of first and second generation immigrant Arab women asserted that they shared feelings of racism and discrimination being directed at them due to the exclusion of Arab population from official statistics in Britain, which means that the major prospect of health planning and development issues did not include this group’s needs.

Furthermore, one Arab woman, who was herself a doctor felt that despite as an increasing amount of research has been carried out looking at the health needs of different ethnic groups, for example; black minority, south Asian, African Caribbean, Indian and others within the community there was little research to benefit the Arab ethnic group, to identify their specific health needs and cultural issues within the immigrant Arab community. She felt that their health needs were unrepresented in health services. Below are two out of seven quotes selected reflecting first generation immigrant Arab women’s views on this issue:

“I am a doctor and I am quiet surprise, I wonder why we are neglected, I use to read up to date health researches and search through internet, nothing about Arab community health
problem in Britain, most of the research about other minority group like south Asian, African and other, so how the health services could know about our health problem and what type of health education that we need. We are not clearly covered in the census either, we don't have a separate box for our ethnicity and the same in the ethnicity form that we need to fill in when we go to the hospital or surgery” [No. 3, 1st. G. age range 30-39]

“I been here more than ten years now and still I feel that the Arab community is neglected, unknown and we couldn't find our self in one of ethnicity question or boxes when we went to the hospital, most of us ticked under white ethnicity according to our color and the others ticked under other, this is a simple evidence that we are neglected” [No. 4, 1st.G. age Group 30-39]

Others from the second generation shared:

“It’s a really shame when you feel that you are neglected in the country that you hold their nationality or citizen, we need to feel that we are a part of this country by engaged us in their health planning, we need to feel that we are separate ethnic group not mixed with other ethnicity, in this case we are going to be free from feeling of racism or discrimination” [No. 5, 2nd.G. age range 30-39]

“I am a University student and really we are neglected from the health authority, as I don’t feel like they direct their messages towards us in comparison to other ethnic cultures” [No.1, 2nd.G. age range 20-29]

Islam phobia was the second issue that had made the Arab women felt they were targets of racism and discrimination within the health services. Islam phobia was perceived as a new form of racism which caused fear and anxiety among these immigrant Arab women, interfered with their ability to socialize, work, or go about everyday life. Arab immigrant women in this study said that they had felt uneasy since 9/11.
Islamic phobia made them pre-judge the welcome they received from health care professionals and anticipate that it would not be as welcoming of that received by other ethnic groups. Three immigrant Arab women from the second generation confirmed that (one quote selected)

"Assalaam Alikaam" (peace be with you), with this phrase we use to start our conversations with others, but unfortunately the western people as general and in England as well they have Islam phobia and according to this they treat us badly, for this fear and anxiety haunts us when we talk to health staff”. [No.1, 2nd.G. age range 20-29]

Four out of seven first generation immigrant Arab women explained that the anxiety about and fearfulness was due to the fact that the discrimination was often insidious and hard to qualify, such as staff responding to women’s questions or requests in an intolerant and improper manner. Furthermore, a certain percentage of women were afraid of experiencing more outward varieties of Islam phobia, for example; medical workers devising biased, stereotyping and racism-infected remarks.

Below are two quotes selected:

“Fear and anxiety, these two words always with us in our daily life, we are afraid of reaction of people in the market and in the event of the sickness from the health professional staff, we can feel their reaction by how they treating us, looking at us—we try to communicate with them but we fear to receive Islam phobic response from them” [No. 7, 1st.G. age range 40-49]

“Most of health professional--- not all, don’t like Muslims women and treat them according to what happened in 11th of September, they have Islam phobia, some time they said a racist comment and they thought that we are not understand them” [No. 4, 1st.G. age Group 30-39]
Sub-theme: ‘Unfamiliarity with existing services’

Unfamiliarity with the health care system was felt to be another barrier for these immigrant Arab women regarding breast cancer screening. All first and second generation immigrant Arab women did not consider that they had adequate knowledge and were conversance with the health care services; they had no knowledge of mammography as a screening tool for breast cancer. It appears that, unfamiliarity with the system provides challenges for these women. It is very likely that they would find difficulty accessing non-emergency services, such as undergoing a Pap smear or mammogram, unless they have some symptoms or familiarity with the health care system and clear knowledge of the benefits of prevention.

Two of the first generation immigrant Arab women, despite one being a nurse and the other a physician in their own country were unfamiliar with some aspects of the British health care system. They were unaware that breast clinical examination could be carried out in the GP surgery. One of them had assumed that she would need to go to a gynecologist to get a cervical smear and had planned to ask for a referral from a walk-in-clinic. Both of them were unaware of breast cancer screening. Below are their statements:

“I wish that I could have a family doctor and not every time seen by different doctor, ---no idea where we can have the breast exam and breast screening, no anyone told me about it “[No. 3, 1st. G. age range 30-39]

“I am a doctor in my own country---but I don’t have any idea about the availability of breast screening, no one inform me about such services which we don’t have it in my country”
[No. 7, 1st.G. age range 40-49]
Similarly, despite being educated to degree level, another second generation women did not know the routine preventative use of breast screening in England offered to all women; she didn’t have clear knowledge of the diagnostic use of routine breast screening. Thus, inadequate understanding of the British health care system and how it functions, along with ignorance of the services available to them within it creates a barrier of attendance in breast cancer screening for a portion of Arab women in the study.

“No idea about the availability of preventive measure in England, is it available to everyone? Is it free? Where about to do the breast screening and what is mean?” [No.1, 2nd.G. age range 20-29]

It appears that the first generation immigrant Arab women would go to the breast screening if their doctor explained and recommended it. Below are two out of five quotes selected from the first generation and one statement selected from the second generation?

“No any idea about health services related to breast health, all I know the surgery which is some time be useless, no one told me about any other places to go than the surgery” and regarding the mammography, she added:” I never heard this word (mammography),I never practice this procedure, I know that there is an x-ray for the chest but for the breast [laughing] this is something strange and uncommon” [No. 6, 1st.G. age range 30-39]

“We don’t know from where we can get all these information about breast health awareness & how the health care system is work, ohhh---yes we want to know where and how can practice the breast screening and which type of health services available for us, as immigrant and which is not for us” [No. 10, 1st.G. age range 50-59].
“We never been advised by the nurse or doctor about breast awareness, no one teach as, where we need to go? Is there any special clinic rather than surgery, if I get recommendation from my doctor, I will do it” [No. 5, 2nd.G. age range 30-39]

The responses of Immigrant Arab women indicates a possible interest and willing to participate in more preventive measures if they were more knowledgeable of what was available to them and if they had fast and effortless access to these services.

Sub-them: ‘Language as a source of communication barrier’

Language barrier can influence knowledge gained, and access to health care services for immigrant Arab women when English is not the main language spoken at home.

A patient gains access to the health care system, acquires knowledge about it and decides what to do about their health primarily by means of their language It is additionally the way in which the health care provider gains insight into the patient’s personal ideas about health and illness, hence generating opportunity to approach and harmonies contrasting belief systems (Woloshin, Schwartz, Katz & Welch, 1997). Fundamentally, successful interaction via verbal communication is the basis of effective health care. The hindrance of linguistic differences between patients and health care providers can determine the outcome of the occurrence and eventual outcome of disease and not to mention the access to the service to begin with.

In this research it has been found that insufficient ability in speaking English was a basic obstacle for immigrant Arab women and seemed to prevent them in making pivotal relations within their own social enclaves. Even very ordinary
routine activities such as catching a bus or shopping in a supermarket can be a major ordeal for them. One of the first generation immigrant Arab women talked about how she found herself incapable of making the most simple of requests to the bus driver at a local stop and was quite upset by the time she had finished relating her story.

“I was so upset, I cried, not for the direction of the bus or for the ticket money, but because I was unable to express myself and what I need to ask about in English.” [No. 4, 1st.G. age Group 30-39]

First generation Arab women shared many tales illustrating the problems they have experienced in England as a result of their difficulties with the English language. One in particular described being the victim of a road accident and how she had been unable to provide the necessary information to the police officers about what had taken place. Another women took her daughter to the A & E (Accident and Emergency) department of the hospital when her daughter had passed out at home and told of how her daughter returned home without receiving any treatment or medication owing to her mother’s extreme difficulty in communicating effectively with the health workers there about her daughter's condition. Arab Immigrant women talked about confronting communication obstacles in every social situation; at the market, at the general practitioner, at school, and when lost in a place and seeking directions.

All the Interviews with the first generation Arab women the majority admitted that there often did not have sufficient understanding about the information their health providers tried to impart to them and that they invariably left the clinic lacking a clear understanding about their condition or the treatment prescribed. Verbal communication difficulties frequently accompany cultural disparities, creating further problems and confusion regarding breast awareness information.
Lack of, or limited English proficiency caused some women to avoid seeking services until problems became serious. Below are three out of seven quotes illustrating these difficulties shared:

“The language always stopped me to ask and search for health awareness information, this is not only my problem—all my friends get the same problem and when we discussed this issue and at the end we say “leave it to God” [short silence]. I never clearly understand everything what the doctor is telling me only some words. [Laughing]”. [No. 4, 1st.G. age Group 30-39]

“Our English is not the main language spoken at home. We struggle with our limited English proficiency, our language is just good to buy or sale something not communicate with health issues” [No. 3, 1st. G. age range 30-39]

“Some time when I talked to the doctor about general health issue, I feel that the doctor can’t understand me ….oh, yes I can see it in his facial expression, some time I act that I understand what they talking about so I don’t get embarrassing” [No. 7, 1st.G. age range 40-49]

These comments illustrate distinctly how the lack of language proficiency is the principle difficulty for Arab women to accessing health care services. In the situation of a women being unable to speak much English she will feel belittled and uncomfortable in her attempts to interact with English-speaking health workers. To the health care worker they might behave as though they understand what is being said, but in truth, they do not. This can of course be extremely dangerous because misinterpretation has proved to cause delays in correct prognosis and to strengthen the odds of the patient being unable to act on doctor's instructions until too late (Woloshin, Schwartz, Katz & Welch, 1997). Many persons for whom English is their second language have very substantial
difficulties in accessing information about public services and consequently many immigrants and asylum seekers remain ignorant of their eligibility to public health care services and/or how to find and acquire them (Taket, 2009).

On other hand, whilst in this study language barrier was a problem for the first generation immigrant Arab women, thee was not such a difficulty for the second generation immigrant Arab women who did not have any difficulties with the English language as they had both been born, grew up and studied here in England. As three of the second generation women stated:

“I born and grew up and went to schools here in Britain and I am in the university now. Language is not worrying me at all” [No.1, 2nd.G. age range 20-29]

“No problem with language, I am speaking fluently, the problem is with my parents they are really facing language difficulties” [No.2, 2nd.G. age range 20-29]

“My English is good because I born here, but some tie the medical terminology which I can’t understand it very clearly” [No. 5, 2nd.G. age range 30-39]

Language was not then worrying for all of second generation Arab immigrant women but the views of two second generation women disagreed about the preferred language of the doctor; one whose first language was English or one whose first language was Arabic. In certain circumstances they felt that a doctor from another community was preferential owing to issues of confidence in being able to discuss sensitive subjects, as they told me:

“Most of Arab women that I know and me would like to visit female English physician not Arabic origin. The Arabic society is small and neighboring where everyone knows one another. For me language is not a barrier but I don’t want Arabic native doctor, I am not trust her, she is from my community, she is going to tell the others about my issues and
talking to her for such private health concern is difficult, it’s happened with me once and I learned a lesson”. [No.2, 2nd.G. age range 20-29]

“I wish that I could have English female GP, I will not feel embarrassed and I can talk to her about sensitive subject. Moreover, I may need to tell her some private information and the Arabic physician I could meet her in any Arabic event or gathering but the English doctor I will never meet her again and she will never know my friends, family and husband. [Pause] I am scared that the Arabic doctor would talk about my condition with others even by accident”. [No. 5, 2nd.G. age range 30-39]

Arab immigrant women whose English-speaking level was slow experienced difficulties in every area of the health care process, from the time they make their first appointment, through diagnosis, treatment to being discharged. These difficulties affected the standard of care they received and for some prevented them seeking help in the first place until their condition has become critical.

Sub-theme: ‘Unavailability of Arabic breast cancer and breast awareness information’

Not knowing about breast cancer information was expressed unanimously among Arab women. The women particularly relied on health care professionals to provide them with information about breast cancer and breast awareness. The women who participated in this research had problems accessing information, they highlighted the need for health care professionals to provide sufficient informational support that was culturally appropriate (e.g. in mother-tongue language). All first and second generation said that they had not seeing any available breast awareness information written in Arabic but were e keen for this information to be made available. They did not know where to get such
information and had not seen any (in Arabic) at their doctors surgery or when visiting the hospital for other reasons. Below are two quotes selected from seven of the first generation Immigrant Arab women:

“The Arabic breast health information is not available, I never seen it in the surgery or hospital, I never read about this issue, there is a lot of information in the surgery and I use to go over them while I am waiting for the doctor appointment—-but nothing for breast health, all I had seen about heart disease, diabetic, old people issues, flu vaccine. I hope to see this information in our language available to us” [No. 10, 1st.G. age range 50-59].

“I would like to get the right information about breast cancer awareness and breast awareness which is designed according to our ethnicity and culture, but unfortunately is not available for us, you can go with me now to the general hospital or surgery and you will see by yourself” [No. 6, 1st.G. age range 30-39]

The three second generation, immigrant Arab women shared the same view as the first generation that they had not seen any such information in Arabic. The cultural and language consideration of appropriately written information, available in Arabic, was a priority for both generations, one out of three statements selected:

“I never saw Arabic leaflets talking about what you asking for. If the information is going to be available in the future for us by Arabic language, it should be culturally appropriate to our ethnicity and in this case the information will be useful and understandable. Even though in good at English I still prefer Arabic so I can share it with my mum” [No. 5, 2nd.G. age range 30-39]

Despite the NHS and Breast charities providing such information, none of the immigrant Arab women had seen it. To summarise the above quotes, both
generations expressed the need for leaflets or information to be readily available in their language at a proximity close to them, such as their surgery or hospital. They also said that they would like to be personally offered such leaflets when they attended doctor’s appointments for other reasons.

Sub-Theme: ‘Lack of privacy and availability of female physician’

Maintaining people’s privacy is fundamental to maintaining dignity, and this is particularly important within the public health care system. Here the term privacy conveys the ability to be on one’s own in a real physical sense, to have no physical interference from another, no danger, threat or unsolicited physical contact (Department of Health (DoH), 2006). It may also mean not being seen or listened to by anyone outside of the person you are communicating with, in certain situations (DoH, 2006).

A strong regard and respect for one’s privacy was key to them. According to the immigrant Arab women in this research, the feelings of awkwardness and embarrassment that were induced through having their breasts screened and examined by, for example, a male doctor was really a paramount concern to them. None of the first or second generation women interviewed had ever been to a breast screening clinic before, except for one, who recalled getting the invitation, but declined to attend, owing to information she had received from a friend about the hospital gowns not being in line with conventional Islamic rules concerning modesty in women’s clothing. Tales of generally negative experiences from family and friends was a commonplace factor in the discouragement of Arab women in seeking professional medical attention for breast cancer, or the possibility of it. Anxiety over the remiss of respect for women’s privacy is therefore one of the
foremost obstacles in the provision of culturally-suitable breast awareness for immigrant Arab women. Below are three quotes, selected from the first generation of Immigrant Arab women statements:

“If I decide to do the breast screening I want to have privacy. I’m not sure that I will be given the privacy, with someone like a male can open the door or the curtains in any minute. I wear hijab as well, so they should consider that” [No. 3, 1st. G. age range 30-39]

“No men should be permitted in the woman’s breast screening room without permission. The most important aspect for us is respecting our privacy with in such sensitive issues.” [No. 4, 1st.G. age Group 30-39]

“Most of health professionals don’t have any understanding of what does mean by privacy of Arab women and some of them if they have some knowledge they does not apply. We need to be sure that no male can enter the breast screening room by anyway, we need to change our clothes and put gown on the same room of breast screening. The gown should design to maintain our privacy and dignity during breast screening.” [No. 7, 1st.G. age range 40-49]

All of the second generation immigrant Arab women agreed with those of the first generation regarding the need for privacy where breast screening is provided. They also contended that there was a necessity for health workers to be properly trained in dealing with cultural disparities between differing ethnic groups and had formed the opinion that a policy for ensuring privacy could increase immigrant women’s usage of a vital public service to which they are entitled. The women reported that to guarantee maximum privacy they would like would be a separate room with the changing room close to the actual room in which the screening would be carried out. One out of three quotes are below:

“Arab culture places a high value on women privacy and any medical examinations should be done in the presence of a same sex health provider. I feel that the health staff had slight
From the statements above the immigrant Arab women from both generations seem to have fears or concerns that their privacy might be disrupted. They need reassurance that privacy would be maintained at screening. The policy of breast screening allows for this, but clearly the women were unaware that this is standard. It appears that many of the research participants concerns were frequently rooted in an understanding of current practice. They were particularly concerned about physical exposure during clinical examination should be minimized and performed as necessary. Owing to the strict traditional rules governing the appearance of Muslim women in public, the uncovering of the body in a medical examination would need to be kept to a very minimum for the necessary functions alone. In Arab society, the Muslim women are obligated to wear modest clothing. In public, many women wear baggy, non-revealing clothing (called Hijab in the Arabic language) with covered hair, arms, and legs. When outside of the home, most of Muslim women wear baggy clothing which conceal any contours of the body (called Hijab in the Arabic language) and NHS nurses have a responsibility to observe and honour the Hijab throughout the procedure of the examination, particularly, if the immigrant Arab women have requested it. A further preferential practice would be too notify all outside of the room by the use of a door sign telling them to knock first and also wait a few moments for the patient to make themselves decent prior to coming in. All these considerations need to be reassured in the breast cancer screening information, another big obstacle reported by the immigrant Arab women in this study is the problem with the availability of women health care professionals in the case of
clinical breast examination if there was doubt of breast lump. One of the research results indicate that a very large percentage of women, completely irrespective of their nationality or religion, have an overwhelming preference to be examined by a doctor of the same sex (Wright, 1989).

Female doctor’s play an essential part in strengthening women's awareness of how crucial is the factor of an early discovery of breast cancer (Alkhasawneh, 2007). This matter is held to be of the utmost importance because women, being extremely unhappy discussing their body and sexual matters with male doctors, would often decline to arrange breast screening altogether (Rajaram & Rashidi, 1998, 1999; Matin & LeBaron, 2004).

However, all immigrant Arab women from first and second generation were especially eager to be have their breast examinations performed by female medical professionals, as well as conducting discussions about women’s’ health matters with greater sensitiveness, understanding and respect. Locating a woman doctor in a hospital or clinic they felt was y not so easy for them; three of first generation Arab immigrant women confirmed that and one quote selected:

“We would like to be seen by female doctor and discuss some sensitive issue with respect. They should consider our culture sensitivity.” [No. 8, 1st.G. age range 50-59].

Three of the Second generation immigrant Arab women agreed with first generation women. One quote selected:

“Some time if you find a female doctor that mean you are lucky, but you can guaranteed to find her next time” [No.1, 2nd.G. age range 20-29]

From these quotes, it is evident that professional gender is of great importance to Immigrant Arab women. It appears that if a female doctor is unavailable in the
practice, these women shared that they might delay their appointment or, for some, they would not seek medical support. Four of the first generation immigrant Arab women tended towards self-diagnosis of their symptoms because of the lack of a female doctor. Since many of the women considered that the women’s breast is an intimate part of the female body under no circumstances could they consider being examined by a male health professionals? Therefore, they tended to ignore appointments with a doctor, if the doctor is male. Three quotes selected:

“I don’t know why there are no enough female doctors for this sensitive issue, I am looking for a female doctor for my daughter, she suffered from eczema over her breast nipple, it is itchy and have discharge some time, but I couldn’t get any female doctor, and she is still have the same complain” [No. 3, 1st. G. age range 30-39]

“few months ago I got red rash over my right breast, many time I contact the surgery to get an appointment with a female doctor but I couldn’t find any, I show my breast to my sister and she told me is look like allergy from certain food, I stopped eating egg, but still some time the redness appear----I can’t let the male doctor see me, impossible” [No. 6, 1st.G. age range 30-39]

“Most of the doctors are male, I don’t know why? I stopped to take an appointment from surgery, always when I go back home for a holiday I went there to a female doctor and no any barriers are going to face me, but the problem always I been late for diagnosis, next month I am going to do an operation in my home land (hysterectomy), I been late for the treatment” [No. 8, 1st.G. age range 50-59].

Sub-theme: ‘Referral system is too complicated’

All immigrant Arab women from the first and second generations confirmed that inadequate referrals and recommendations from the medical staff was one of the
main barriers against breast cancer awareness. It’s clear that they were confused about the referral system which they described as a “complicated system”. Furthermore, the referral system for other medical treatment making them wait a long time until their situation is worse. They also confirmed that clinics did not know how long it would take for a patient to obtain an appointment with a specialist. Below is two out of seven statements selected:

“The referral system is too complicated and we feel confused about it, I keep ask the GP to refered me to a specialist doctor and they keep delaying and gives arguments, I couldn’t understand why” [No. 3, 1st. G. age range 30-39]

“If you get referred by doctor to the general hospital for any medical condition, it’s better to forget it, after you need to be on waiting list for months, later on they are going to tell you that you are too late and your problem getting worse, I have this experience with my hernia”. [No. 4, 1st.G. age Group 30-39]

2.11 Discussion

2.11.1 Introduction

The findings from the phase one of this qualitative study provide a comprehensive and insightful understanding of the knowledge, beliefs and attitudes of immigrant Arab women to breast cancer and breast awareness. All the immigrant Arab women who took part in this study were grateful to have been given the opportunity to share their knowledge and attitudes and often challenging experiences, as expressed by [No. 5, 2nd.G. age range 30-39]: “I would like to thank you for giving me the opportunity to chat about this situation, in such a relaxed environment, also for encouraging me to increase breast cancer
awareness and focusing on the hidden problems that Arab women go through every day”. All the more particularly, this qualitative study captured:

- A detailed understanding of immigrant Arab women’s breast cancer and breast awareness knowledge, beliefs and attitudes
- How breast cancer attitudes, behaviours and beliefs may affect breast awareness practices.

The immigrant Arab women’s knowledge, beliefs, attitudes, experiences and ways in which they managed them were embedded across the study, and many findings emerged as a result. The themes were often re-framed to capture the essence of the immigrant Arab women’s knowledge, beliefs and attitudes on breast cancer and breast awareness practice. These include knowledge of breast cancer and practices of breast awareness, socio-cultural influences (beliefs and attitudes towards breast cancer), religious beliefs and attitudes, and health care service barriers which may affect their awareness towards breast cancer. For this reason, the findings of the study will be discussed collectively. Figure 14 provides a precise of the theme of the research and their sub-themes. The main themes are discussed individually with their sub themes. The findings raise significant implications for the research and practice. These issues will be argued in the final chapter of this thesis.
2.11.2 Lack/Poor of Knowledge

Knowledge about breast cancer is critical for all women, including immigrant women. A lack of knowledge about causes and treatment for breast cancer and breast cancer awareness, which is a prime element in early referral for treatment. Previously, the scope of immigrant Arab women's lack of knowledge and its consequences has not been extensively documented.

The women from both generations in this study had either poor or no knowledge about breast cancer. Previous research carried in the UK have suggested that Arab and Asian women are in many respects similar to socially-disadvantaged, white British women in that they also have a generally low degree of knowledge
about breast cancer and ideas about their own susceptibility to it (Scanlon, 2004). Furthermore, Knowledge and lack of understanding concerning the breast and cervical cancer or the significance of breast cancer awareness is common in published literatures for speakers of Arabic as a first language in Canada, Australia and Jordan (Matuk, 1996; Lesjak, Ward & Rissel, 1997; Maaita & Barkat, 2002).

In this study, first generation immigrant Arab women demonstrated poor or complete lack of accurate knowledge concerning signs and symptoms. False beliefs, like pain being a predominant sign of breast cancer, were common. This Similar findings have been found in other studies (Rashidi & Rajaram, 2000) that shows that some kind of discomfort, health problem or pain at the time of already advanced cancer (whatever type) is what finally brings many immigrant women to see a health care provider. This finding also correlates with the literature (White, 1997), suggesting that Muslim Asian women are prone to unawareness of breast cancer as a serious disease and, therefore, default on mammography screening (Banning, Hassan, Faisal & Hafeez, 2010).

None of the immigrant Arab women from the first generation were aware of the cause and main risk factors such as age, family history etc. In contrast, the second generation, immigrant Arab women were better informed and identified family history as an important risk factor for breast cancer.

Many women from both generations shared the same view concerning the main cause of breast cancer being that of 'alienation' Unsettled life pattern, stress, discrimination, plus financial problems made some, but not all feel alienated. Some considered that alienation was a main, hidden reason behind cancer for immigrants. Alienation may be a substantial intercessor with immigrants between
cultural assimilation and physical health and a gauge of their adjustment (Miller et al., 2006). Such views may lead immigrant Arab women’s views to misunderstandings about risk factors, causes and treatment outcomes for breast cancer. It is also likely to deter Arab women from being breast aware, or attending routine breast cancer screening.

Congruent with the results of a number of studies, this study found that all immigrant Arab women from first and the second generation had a poor knowledge and understanding of breast awareness in term of breast examination and breast screening’ such that it is likely to deter Arab women from being breast aware or attending routine breast cancer screening (Scanlon, 2004).

One of the reasons for this lack of knowledge and understanding can be attributed to their socio-cultural, religious beliefs as well as feeling that current health care services do not meet these needs, (as seen in figure 15 below). These feelings can result in poor or complete lack of knowledge, as well as such issues being covered up and not openly talked about (Bailey, Erwin & Belin, 2000; Scanlon & Wood, 2005). Another explanation can be due to the limit or non-availability of informational and educational material on breast health awareness and breast cancer in one’s mother-tongue language (Watts, et al., 2004). The poor knowledge and understanding of breast cancer awareness is reported in this research through first generation women who did not realize a lump in the breast area to be potentially one of the serious breast cancer signs. Whilst this shows their lack of awareness of breast cancer and symptoms, an alternative explanation could be that in the first instance their symptoms were not taken seriously, as they may have attributed it to other factors, such as muscle strain, and therefore waited before acting in the hope that the symptom would resolve.
itself (Bottorff et al., 2007). The immigrant Arab women did not encounter any breast cancer prevention in their country of origin. Consequently, there appears to be a tremendous need to increase breast cancer awareness among this population for both generations, along with early risk assessment, such as regular breast awareness practice and an annual clinical breast examination.

Figure 15: How the Breast Cancer and Breast Awareness Knowledge is Influenced by the other Themes as Seen in the Findings.

In conclusion, I have constructed a diagram highlighting the interplay between the themes and breast cancer and breast awareness knowledge. Above in figure 15 it shows how the socio-cultural, religious and health care services' beliefs, attitudes and practice may affect the level of knowledge toward breast cancer and
breast awareness. These beliefs and attitudes may become barriers against their knowledge.

2.11.3 Socio-Cultural Beliefs and Attitudes

The study has shown how culture plays an influential role in shaping Arab women’s beliefs and attitudes toward breast cancer and breast awareness. Additional to this, cultural beliefs and attitudes among the immigrant Arab women and within their communities were also embedded in their behaviours. These issues were centred on cultural fear and taboos regarding a diagnosis of breast cancer, embarrassment and modesty, health is not their priority as well as male dominant decision-making and gender inequality. These cultural beliefs, attitudes and explanations have been consistently reported in other cultural studies (Remennick, 2006; Berner et al., 2002; Rajaram & Rashidi, 1998, 1999; Matin & LeBaron, 2004). And not just confined to cultural influences present in Arab women communities, but exist in other ethnic groups too, such as East Asian (e.g. Korean) and Middle Eastern Asian (e.g. Israeli) cultures (Ashing-Giwa et al., 2004; Baron-Epel et al., 2004; Im, Park, Lee & Yun, 2004; Harandy et al., 2009; Taleghani, Yekta & Nasrabadi, 2006). These beliefs are particularly fixed in uneducated, first generation immigrants (Gurm et al., 2008) who, despite living in the UK for most of their lives, continue to maintain their strong cultural beliefs and practices from their country of origin (Meneses & Yarbro, 2007).

Within the Arab society, breast cancer as an illness is feared and is almost always associated with negative connotations such as killer and death, especially if the illness is not well understood (Azaiza & Cohen, 2006). Breast cancer is a disease much socially maligned and stigmatised in the Arab community and also present among the immigrant Arab women in this study.
Denial and stigma were a serious problem for most of them and they felt that, it might keep them from getting early diagnosis and being breast aware in the future. In spite of the tenets of the Islamic religion ruling that those inflicted with such diseases should be cared for and treated kindly, the social mores of Arabs move towards stigma and social ostracism when confronted with cancer (Hammad, et al., 1999). The same finding was noted with other ethnic groups, such as South Asian women, in whom were discovered firm convictions concerning cancer being a terrible, agonising and fatal illness (Choudhry, Srivastava & Fitch, 1998; Johnson, et al., 1999). Moreover, Bottorff, et al. (2001) noticed that these convictions put women off engaging in cancer screening thereby rendering them insusceptible to believing heath care staff about their advice regarding early cancer detection and subsequent effective treatment.

This study findings suggest that there is another factor influencing immigrant Arab women being breast aware. This factor might be the fear of gossip and backbiting. Congruent with the results of another study in Israel, this study found that the visit of Arab women a breast screening to a medical centre is sufficient to ignite gossip in their community, which is a major worry for them in conjunction with the breast screening process (Baron-Epel, Granot, Badarna & Avrami, 2004). Both generations of immigrant Arab women believed that they might be subjected to negative comments from community members, who might insinuate that they must have done something bad to deserve the cancer. This is another way that cancer is stigmatised in Arab cultures, resulting in women covering up their illness. In a tight knit community, the immigrant Arab women might consider this was a situation in which they could not avoid people who might gossip and make
negative and insensitive comments; therefore they would feel it necessary to keep their cancer private; a strategy found to be common in other BME and breast cancer studies (Gurm et al., 2008; Henderson, Gore, Davis, & Condon, 2003). Embarrassment and modesty were another socio-cultural barriers which exist in immigrant Arab women in this study. It is, highly valued in this culture and women are the central object in this. The same barriers are were faced by South Asian communities to maintain the family’s honour and reputation (Banning et al., 2009; Botorff et al., 1998). Therefore, it is not considered appropriate to openly talk about an illness, which can compromise the family’s status and honour and bring shame upon them. It is also not considered appropriate for women to talk about or show private body parts to others, especially males (Bottorff et al., 1998; Howard, Bottorff, Balneaves & Grewal, 2007). This particular research work has revealed how strongly modesty is highly valued in immigrant Arab communities and because women are culturally conditioned to refrain from any conversation about the private physical areas and sex-related subjects, this would discourage them from breast screening. This research outcome is further supported by other studies in USA among Immigrant Muslim women and Asian women, which investigates attitudes towards breast and servical cancer i.e. (Rajaram & Rashidi, 1998, 1999; Matin & LeBaron, 2004). However, it must be realised that the Arab community is not the sole owner of this cultural phenomenon. Other ethnic groups in the world, such as Korean Asian women, also practice similar ethics towards verbal discourse about their breasts and towards revealing them for screening purposes (Ashing, Padilla, Tejero, & Kagawa-Singer, 2003; Baron-Epel, Granot, Badarna, & Avrami, 2004; Bottorff et al., 1998). By the same token, the historical
Korean taboos around exposing the breasts may deter the Korean American women from coming forward to seek breast screening services (Im, 2000).

In this current research, felt that their physical well-being was not a priority because it was not pivotal to their traditional role in the Arab community. The first generation immigrant Arab women considered that they are, first and foremost and above all else, obliged to wed a man, bear his children and take the role of looking after the family. Others have reported similar findings that for many Arab women the most suitable place in most communities is in the home, concealed from society and where she can be under the close, watchful eye of her husband and the back and call of her children (Taraki, 1995).

Immigrant Arab women underlined that their place in the community relies hugely on their roles of home maker and their significance in society was derived from their competence and effectiveness as a provider to her family. These cultural beliefs, values and explanations have been consistently reported in a study conducted by (Baron-Epel, Granot, Badarna & Avrami 2004) to find the perception of breast cancer among Arab Israeli Women. The essential theme that acknowledges as a barrier toward breast cancer awareness was the role of the Arab woman in her society which is constructed through marriage, bear children and evidence of familial commitment.

The findings of the current study suggest a pressing need to develop culturally effective education programs to target an urgent necessity for creating culturally efficient education curriculum aimed at immigrant Arab women to increase their breast cancer screening awareness, with the goal of increased breast cancer
screening behaviours. In order to address cultural barriers, health care workers could try to include men in breast cancer screening efforts.

Decision-making and gender inequality was another barrier faced by some of immigrant Arab women in this study. Previous research tells us that the ethnical and cultural ethos of Arabic people invests only men with the position of 'master' of the household; wielding full control and authority over all who belong to it. Sometimes, therefore, women’s rights and freedoms are severely curtailed, extending as far as even being unable to either make or act on any personal decisions concerning her sexual health. In this study, some of the women shared a deep apprehension and reluctance to leave the home, being obliged to request permission from their husband or some other male family member to do so, fearing the repercussions of explaining the reason for this.

Arab families are usually governed by a male member who is considered as the decision maker. If a family member is diagnosed with cancer, the decision to take treatment is usually made by the head male member as the major decision maker. Arab women continue to face discrimination and inequality everywhere. This finding was emphasized in the 2005 Arab Human Development Report (AHDR) which determined inequality between the sexes as among the biggest barriers to humanistic progression in the Arab world. Furthermore, women who are victims of personal crises are confronted with a two-fold dilemma of being in addition a victim of social disempowerment along with a prohibition in personal decision making. Similarly, another research carried out by ((Hammad, et al., 1999; Howard, et al., 2007) revealed that the social power and influence of men occupies the sphere outside the home, whereas that of women rests exclusively
in the home, and more senior male, the family patriarchs are asked to make decisions concerning the health of any individual member of the family. This traditional hierarchy within the family and its practices greatly exacerbates informed consent and privacy matters.

2.11.4 Religious Beliefs and Attitudes:

The majority of first generation immigrant Arab women held the belief that cancer was predetermined by external forces such as God or chance (fatalistic attitude). High levels of external locus of control are prevalent in Arab culture (Al-Issa, 1995 & Chaleby, 1987). It has been suggested that fatalism is often associated with passive behaviours due to the belief that action will not influence the outcome (Sheppard, Adams, Lamdan & Taylor, 2010). This type of coping can have a negative effect on women’s breast awareness experience, especially if an attitude is based on the underpinnings of fatalism which is called in Arabic language “Al Qada’a wa AlQader” and the cancer is seen as a form of punishment measure taken by God (Gurm et al., 2008). The belief that breast cancer is a form of punishment for wrong doing is common in ethnic minority cultures (Ashing-Giwa et al., 2004; Balneaves et al., 2007; Moore, 2001).

Many Arab women in this study also believed that only God has control over disease, they considered cancer as a test for their sins. This attitude towards cancer is rife throughout the countries and cultures of the Middle and Near East, and has been observed in a research undertaken by Arevin, Noureddine, & Kabakin, (2007) among Lebanese /American women towards cervical cancer screening.

First generation, immigrant Arab women in this study were prone to the conviction that God is the sole giver of all things and this is the root of their beliefs so that
being breast awareness is, therefore, not necessary. Their belief in God appears
to be bound up with their belief in destiny, given that some women interpreted
destiny as God’s will. It is also not surprising that external beliefs are prominent
in Arabic minority women, given the importance placed on religion. This can also
be actively managed in the form of prayers or meditation (from a spiritual
perspective) in order to seek comfort and control in any case of disease (Gurm
et al., 2008).

These types of beliefs, attitudes and behaviours of religious determination are not
exclusive to the Arab world and may also be found in many other ethnic groups,
such as black women. One of the previous research shows how African American
women have historically practiced prayer and pietism both to help them cope with
and to assist treatment of physical illness. Even though the beliefs of these
women vary from those of other religions, these beliefs and their religious
institutions occupy many roles and are the source of both spiritual and mental
support to them (Abrums, 2000). Another study shows that religious beliefs
discouraged old Latinas women in USA from having breast cancer screening
(Borrayo, Buki & Feigal, 2005).

In addition, the present study findings are consistent with findings of a research
conducted by Lee, Tripp-Reimer, Miller, Sadler & Lee (2007) among Korean
American women. The study found that a strong faith in God and in God’s actions
help them in a positive way by relieving their stress, which, in turn, improves their
physical health and perhaps lowers cancer risk. The same findings identified

It has been reported by leaders of Asian American communities that Asians tend
to believe that having cancer is within God’s control and Gods will (Ashing-Giwa
et al., 2004, 2003). It has also been shown that Palestinian, Indian and Jordanian women hold similar beliefs of God’s control over cancer, causing many to devalue the necessity of breast cancer awareness (Baron-Epel et al., 2004; Petro-Nustas, 2001).

The way in which immigrant Arab women’s’ beliefs, attitudes and behaviours support is sought through religion and spirituality can be divided into intrapersonal and interpersonal resources (Fischer, Ai, Aydin, Frey & Haslam, 2010). Intrapersonal coping strategies emphasise individualism, such as seeking strength and support within a divine being, whilst the interpersonal aspect places emphasis on external resources, such as support from church-based community members or pastors (Krause, Ellison, Shaw, Marcum & Boardman, 2001).

Women in the present studies engaged in both inter- and intrapersonal coping strategies. This was evident in their discussions of having faith in their God to get them through any illness; engaging in religious activities such as praying and reading the Holy Qur’an to feel closer to God, and attending places of worship, such as the mosque and receiving support from the mosque members.

Although some of the second generation women revealed barriers of culture and communication, religious barriers to breast awareness was not an issue. All immigrant Arab women stated that as Muslims, they practice two years of breastfeeding, as dictated by the Qur’an. In Islam, Breastfeeding babies is rooted in the religion and the Qur’an advises mothers to feed their progeny, where possible, for a period of no less than two years (Shaikh & Ahmed, 2006).

Research participants from both generations of immigrant Arab women were fully conversant in the benefits to a mother’s health from breast feeding her children,
the most often referenced being the belief that it created a more effective physical immunity to diseases, illness and especially to breast diseases.

The principle tenets of Islam and how they dictate proper conduct have a profound control over Arab immigrant women. However, the women’s understanding of these tenets was confused by cultural ideas and activities. Whilst second generation women knew breast feeding was protective they realised it did not make them totally immune from breast cancer. In this study, the type of generation played a key role in shaping immigrant Arab women’s attitudes and behaviours towards breast cancer and breast cancer awareness, knowledge, attitudes and beliefs. Second generation immigrant Arab women who were born and raised in UK seemed to be adapted to their host culture and showed that they were keen to search for breast cancer awareness behaviours, while first generation immigrant Arab women, who immigrated to the UK and had varied lengths of residency here, felt strongly about holding onto the religious attitudes and beliefs from their native Arab country, surrounding breast cancer risk and the need for breast awareness.

2.11.5 Health Care Services Barriers

The research findings have shown that the health care system in itself presents a number of challenges for immigrant Arab women to obtain any health care services. These include the lack of cultural competence, feelings of being targets of racism and discrimination, unfamiliarity with existing services, language as a source of communication barrier, and specifically relevant to breast cancer awareness, the unavailability of breast cancer information in Arabic. They also perceived that any breast screening provision would lack privacy and that a female physician would not be available. They also considered the referral
system was too complicated to comprehend fully. Despite breast screening in the UK is available, free of charge, to all women in the age group of 47 to 73 years on a three-yearly schedule, generally the immigrant Arab women were unaware of these services. Such preventive services such as clinical breast examination and breast screening may not be commonly available in many of Arab countries, though this can vary.

Sensitivity and professional competence in dealing with persons of foreign cultures involves a group of appropriate attitudes, policies and actions which amalgamate to form a system among professionals which achieves successful work in multi-cultural situations. By the word 'culture', we generally refer to things such as; incorporated human behavioural practices which encompass language, ideas, communications, activities, customs, beliefs, values and institutions of racial, ethnic, religious and social groups. By the word 'competence', the researcher generally refer to things such as the ability to perform effectively either alone or as part of an institution in the context of dealing appropriately with differing cultural beliefs, behaviours and the requirements of particular consumers and their communities (Cross, Benjamin & Isaacs, 1989). The present qualitative study has shown how custom and culture competence plays an influential role in closing the inequalities gap in health care for immigrant Arab women from both generations. It’s the way in which immigrant Arab women and health care professionals may unite and improve their communication about their anxieties over health matters, free from the interference or hindrance of cultural disparities. This matter has been an on-going and ever-present feature in all the literature. The importance of cultural competence is in its function of reducing inequalities in the service of the health care system and increases culture-sensitive detection
of diseases. In summary, those health care services which respect and respond positively and effectively to the beliefs and practices around health care, as well as the cultural and linguistic requirements, of diverse patients, may contribute to more successful results in the health of all patients.

The immigrant Arab women in this study stated that they felt that all health professionals should be culturally aware and competent so that it would encourage them to be more breast aware and open for discussion. Consistent with the literature a number of investigations have revealed how relationships with culturally-aware medical care providers have substantial positive consequences in increasing the actuation of intentions to participate in cancer screening (Burnett, Steakley & Tefft, 1995). Interestingly, this matter is apparent in another study by Coughlin, Uhler, Richards & Wilson (2003) in which the researchers suggest that Hispanic women are more liable to submit themselves to cancer screening if they have health care workers who are conversant with their customs and are competent regarding their culture. Similarly Giammona (2002) reported that the providers of health care in California/USA is un aware of the cultural custom and identify the cultural beliefs and attitudes that could encourage the ethnic population to attend the breast cancer screening and could go some way to explaining why some women have a rather poor or even total lack of breast cancer to breast health awareness including limited h inadequate or culturally unsuitable information (Watts, et al., 2004).

Nurturing better understanding and sensitivity regarding ethnic groups, in addition to culturally competent health workers to support them is crucially important. To substantially influence of health care workers on breast cancer awareness practices, it is necessary for health services to uphold a high degree of cultural
knowledge for the purpose of successfully boosting outreach and service delivery for immigrant Arab women.

While prejudice includes ideas, attitudes, insensitivity and ignorance rather than concrete actions or obvious disaffirmation of opportunity, discrimination can be defined as making inequality in medical practice with patients or favouritism on the basis of a particular category of human and paying no heed to individual characteristics approaching the patient with certain preconceived ideas about them and denying them equal opportunity (Ammer, 1997). Although, witnessing the nature of these kinds of attitudes and behaviours can be very difficult to substantiate, its effects are very tangible. On the other hand, Experience of discrimination and systemic racism causes stress, impacts a person’s health and access to the health care system. This study has showed that both generations of immigrant Arab women had experienced discrimination which they felt was related to Islamic phobia. Some considered that they had not received the same welcome from professional health care people as the majority of other ethnic minorities. The current study's results has links with numerous other studies undertaken in other countries, in which it was revealed that the discrimination they felt was significantly more than the rest of the people in that country (Gee GC, Spencer MS, Chen J, Takeuchi D. 2007; Montgomery & Foldspang, 2007; Harris, Miller & Davis, 2003; Sharareh, Carina & Sarah, 2007). Nurturing sensitivity and empathy towards issues of ethnic minorities, in addition to providing a culturally competent workforce is essential to overcome feelings of prejudice and discriminatory behaviours.

One of the ways that feelings of discrimination could be overcome is feeling that consulting health care professionals are from within the same culture.
2.11.6 Unfamiliar with Existing Services

Research has shown that breast cancer and breast health awareness is a relatively new phenomenon to immigrant Arab women, which may also contribute to their lack of services knowledge and familiarity with the concept of breast health services. An additional antecedent believed to impact immigrant Arab attitudes toward the seeking of formal health care services involves individuals’ erroneous perceptions concerning the awareness of breast cancer and official breast cancer health awareness services, along with a lack of familiarity with professional providers. Immigrant Arab women’s reluctance to seek out breast health care services has also been linked to their lack of familiarity with the official health care system. The outcome of the study revealed a consistent link with that of help-seeking theories and health behaviour models (Wills & DePaul, 1991). According to previous models developed, each individual must have knowledge about existing health services in order to seek appropriate services. In their study in Canada Vissandjee, Thurston, Apale and Nahar (2007) point out that remaining uninformed of existing services and adapting to novel health care practices, represent significant challenges for many immigrants in accessing health care in Canada.

In this study, many of the immigrant Arab women believe that the recommendations made by physicians and health care providers are the most effective ways to promote the familiarity with breast cancer awareness, but that the lack of communication is particularly detrimental to increased breast cancer awareness practices among immigrant Arab women. The findings of this current study is consistent with Shirazi, Champeau & Talebi (2006) study among immigrant Iranian women in California. Immigrant women who had been resident
in the USA for more than a decade and who carried a history of breast abnormality were more apt to have never had a breast cancer examination owing to their lack of familiarity with the US health care service. Likewise, women living in the US for a decade or more were prone to have had a mammogram purely on their doctor's advice.

Doctors’ recommendations play an important role for immigrant Arab women to go for breast cancer screening and making them familiar with health care services. All the women in the present study spoke much about their GP’s not informing them about such breast health services (for example breast cancer screening) and its importance. Immigrant Arab women had never had health professional recommendations or explanation about available breast health services. This is not an uncommon barrier to screening. The literature reports this as the main reason as to women do not consider screening (Matuk 1996; Rawl, Champion, Menon & Foster, 2000; Quan et al., 2006). Specifically George (2000), in his systematic reviews on barriers to breast cancer screening, pointed out that in 8 out of 13 studies, lack of physicians’ recommendation as a major barrier for not having screening. This is consistent with others (Azaiza & Cohen, 2006; Shirazi et al., 2006; Soskolne, Marie & Manor, 2006; Johnson et al., 1999; Bryant, Browne, Barton & Zumbo, 2002) who discovered that the most decisive factor concerning screening was becoming aware of the service and its availability via a recommendation from health care professionals.

It is interesting that most immigrant Arab women in this study indicated that they would consider regularly practice breast health awareness if they were advised to and familiar with the service by their physicians. This is consistent with previous research by Schueler, Chu & Smith-Bindman (2008), which suggests that
patients are highly influenced to participate in cancer awareness examinations through the recommendations of their health providers.

Bottorff, Balneaves, Sent, Grewal & Browne, (2001) found that south Asian women in Canada had not received a physician’s recommendation for cancer screening on any occasion. In this study a lack of knowledge or literacy did not hinder some elderly, south Asian women’s use of these tests because their physicians took the lead on this. Some elderly women without literacy, as well as new immigrants, did not use any of these tests, mainly because their doctors did not guide them as to these services.

The outcome of from current study interviews suggests that those who took part may have been far more willing to get involved in preventative practices had if they been more fully aware and familiar with the services which they were eligible to use. It is likely that the dearth of adequate and relevant informational assistance is among one of the influential factors.

In this research study, language as a source of communication barrier played a role in shaping the women’s experiences. Mostly, it contributes to the women’s ignorance of breast cancer and breast awareness owing to insufficient confidence in their ability to speak English to seek consultation for other medical conditions obtain information. This is, therefore, likely to result in the women being unable to gain full information and advice from health care professionals; despite being satisfied by the care they received by them.

Language is a big concern for most of the first generation of immigrant Arab women. The inability of immigrant Arab women to communicate in English often hinders their access to health care and in particular preventive health care. This study has shown that language barrier has a substantial connection with the
knowledge about breast cancer and breast health awareness in first generation Arab women. As English was not their main language it proven difficult in terms of health services as they found it difficult to understand medical terminology or comprehend what the health professional were saying. This situation may deter women from opening up about their personal, private health matters (Meadows, Thurston & Melton, 2001).

Likewise, other studies have found similar language barriers, (Meadows, Thurston & Melton, 2001) (2001) discovered that the language competencies of south Asian immigrant women in Canada assisted in defining the nature of their interaction with the health care service. Within immigrant communities, lack of proficiency in English represents a massive bulkhead to preventative medical services because individuals may be incapable of manoeuvring themselves through health care situations (Woloshin, Schwartz, Katz & Welch, 1997 & (Fiscella, Franks, Doescher & Saver, 2002). In other minorities facing the same language barrier issues, there has been a study in USA reporting lower figures for mammography among Spanish-speaking Hispanic people by comparison with those having some proficiency in the English language and access to health care was far worse for Spanish-speaking than for English-speaking patients (Fiscella, et al., 2002). Preventative measures can be missed through poor communication between the patient and health professional as a result of linguistic incompatibility or being under the misbelief that it is of no great importance.

Studies that show the factors which determine the English speaking ability have generally focused on the main ethnic groups in the UK, but according to the 2001 census, less is known about the Arab community. There is good evidence for the
three main ethnic communities in the UK (Indian, Pakistani, and Bangladeshi) regarding their capability to speak English. Information on the matter attests to English-speaking ability being less among women than men and additionally that, among people for whom English is a second language, the ability to develop and consolidate their English language skills decreases with age (Szczepura, 2005). This study’s findings have shown that the second generation of immigrant Arab women had little or no difficulty at all with the English language. Born in the UK and educated here, they were proficient in English. However, despite all these western influences, they would prefer a Non-Arab physician due to trust issues and the sensitivity of the subject. A non-Arab physician would lessen the risk of the Arab community finding out. This finding is linked with earlier Canadian research undertaken in the Arabic-speaking community in Halifax, Nova Scotia, where the interviewees there, in some instances, also preferred a non-Arabic-speaking doctor due to the issues of trust and confidentiality (Amin, 2008).

2.11.7 Unavailable of Arabic Information

The majority of the first and second generation of immigrant Arab women experienced particular barriers to breast health care services. Unavailable information in Arabic on breast-cancer-screening and breast awareness information may serve as an obstacle to accessing breast awareness services. Hence, the provision of Arab immigrant women with breast cancer awareness information and support is a crucial part of a good preventative health care service.

One of the key aims of the NHS Cancer Information Strategy is to provide “accurate, comprehensive and comprehensible” health information on cancer, ensuring that it is accessible to all those who need it (NHS Executive, 2000).
A particular challenge has been overcoming barriers, such as language difficulties, which prevent women from attending the screening program” (The NHS Information Strategy Team, 2000). So, in order to guarantee comprehension of the benefits and restrictions of breast cancer screening to women and to guarantee informed consent for ethnic minorities, the NHS has invested in the development of interpreting services and in ensuring the availability of translated health material (The NHS Information Strategy Team, 2000). The Cancer Screening Program specifically produces a number of leaflets, booklets and posters that are disseminated through the 95 Breast Screening Units in the UK and these are also downloadable from the NHSBSP web page. Key leaflets are translated into several languages, including the Arabic language (NHS Breast Screening Program, 2010).

It has been revealed through this research, that such information pamphlets in Arabic on breast screening services and breast awareness practice are not visible or readily available, in any public medical centres, including GP surgeries and hospitals. However, there is a correlation between the outcome of this research and Breast Cancer Care's own research in 2005 among black and minority ethnic (BAME) women. The results indicated that nearly double the number of BME women among the general population perceived a deficiency in their knowledge of breast cancer, which may be traced to uncertain and poor accessing the information or because breast awareness campaigns aren't reaching out equally to all women.
The results of this study intimate that the provision of breast cancer information and the availability of it to Arab immigrant women is seriously challenging and some ten years on, the availability of printed information written in their native language not forthcoming. One method of tackling some of the problems would be by providing portable information which may be kept and looked at again and again in the more comfortable environment of the home.

2.11.8 Perceived Lack of Privacy and Availability of Female Physician

A respect for personal privacy is paramount in giving effective health care to Arabic immigrant women. Both generations reported that they feared a lack of privacy where breast screening is provided as is the main issue that worried them. Additionally, they argued that health care providers ought to be instructed in dealing with cultural diversity and consideration and should be given to such privacy strategy being pivotal in increasing the utilisation of health care services, such as breast screening.

Ensuring privacy is of fundamental importance to the further enhancement of screening programs (PATH, 2003). The lack of privacy in the health facilities that provide screening seems to be one of the most important barriers in the health care service, as perceived by the immigrant Arab women. However, the awareness towards breast cancer among immigrant Arab women seems to be connected to complaints of embarrassment caused by the lack of privacy afforded to the patient during both the physical breast examination and the screening, and perhaps intensified by experiencing a need for greater privacy in the surgery and breast cancer screening clinic visits. Immigrant Arab women feel that health professionals need to consider the privacy issue at hand by having more female
health professionals available especially in the event of handling breast health care, also the hospital gowns and female changing room’s needs to be in accordance with the conditions of Arab Muslim modesty. Such as long dresses with long sleeves and changing rooms should be close by to the breast screening room. This is an indication of the importance of privacy in health services for immigrant Arab women when dealing with breast screening. The individual's rights to confidentiality and privacy are highly valued, widely endorsed, but routinely violated. The conclusions of the research shows similarities to previous research, a descriptive, cross-sectional study, which was carried out among Egyptian women to determine obstacles towards breast cancer screening in their country. The lack of privacy in the screening place was the most frequently identified potential health care service barrier (71.4%) (Mamdouh et al., 2014). In addition, many studies on empowering factors for attending breast cancer screening have repeatedly shown that women reported, when attending any preventive treatment, the health care system is lax in protecting their privacy (Ahmed, Fort, Elzey & Bailey, 2004, 2005; Ahmed, Fort, Micah & Belay, 2001). The same-sex doctor is a further factor in public medical services that influences many facets of the public health care. The gender of the health care professional is one factor that has been investigated in numerous researches, particularly with regards to patient satisfaction with the service (Sandhu, Adams, Singleton, Clark-Carter & Kidd, 2009; Hall & Roter, 2002; Roter & Hall, 2004; Gross et al., 2008). In this study, all immigrant Arab women from first and second generation particularly refused to be seen by a male physician for breast examinations, breast screening and discussions about female health issues, even if spoken with respect and sensitivity. Finding a female doctor in the surgery or in the hospital
had, in the past, proved quite difficult for them; immigrant Arab women tend to ignore doctor appointments because of the lack of female doctors. They feared that if they discovered a symptom they would struggle to see a female doctor. Delay in seeking diagnosis could be related to fear of not having access to a female health professional. This is concurrent with another study which reported that the importance of health care physician’s gender to Somali culture. Their findings with Somali women resident in the USA revealed that the women's decision to seek out professional help for health concerns and problems was largely dependent on whether any same-sex medical consultant happened to be available at the time. This was found to be the case, especially where a physical inspection was required or the consultation involved any disclosure and discussion about sensitive, private and personal matters. It was concluded that it was the norm to elect to miss an appointment over the necessity of attending one that entailed interfacing with an opposite sex doctor (Carroll et al., 2007).

In Arabic culture, the role of women health care professionals is very specific. The existence and availability of women doctors is far more attractive and acceptable to Arab women. To be able to place one’s trust in a doctor is of the utmost importance as recent studies discovered that patient trust in the doctor had a strong link with patient adherence, contentment and an improved condition of health. (Kenny et al., 2010; Houle, Harwood, Watkins & Baum, 2007; Al-Faris, Al-Hamdan & Babelli, 1994). Immigrant Arab Muslim women in this study were reserved when it came to discussing their health matters with male doctors and particularly when the matter has a sexual connection or connotation. Some said that for them, in Islamic law expounds that women should only be 'unveiled' in
the presence of other women and some close male family members and only if it is unavoidable. The findings of the present study also correlate with the cross-sectional study that was conducted among Egyptian women to determine the barrier toward breast cancer screening in Egypt. Mamdouh et al (2014) discovered that the principle reason behind women refraining from attending breast screening was the inability to be examined by a female doctor or nurse (42.9%).

2.11.9 Referral System is Too Complicated

The referral system acted as a barrier for most of the immigrant Arab women because, in their country of origin, they could go directly to a specialist without a referral. The findings from the present study and current literature show a similar concern. The system for referring patients to a specialist consultant from a GP may be an obstacle because some women are uncomfortable with monitoring procedures that hinder them from getting satisfactory health care. The study findings are consistent with Panos & Panos (2000), they reported that, most of the immigrant women are normally able to go straight to a specialist in their country of origin. This system allows them to circumvent the referrals system. Understanding that the treatment they received from that provided by health care providers in their native countries can have an extensive influence on attitudes and approach to the health care services in the UK (Anderson, et al., 2003).

Immigrant Arab women in this study had lack of understanding, they anticipated that their health care professionals would recommend a clinical breast exam and breast cancer screening without being notified by a referral process. Immigrant Arab women felt that they had experienced longer waiting times for a consultation
with a specialist, but were unsure why this was. In all probability the obstacles have more connection to the usage of health services rather than to the approach to it (Smith, Chaturvedi, Harding, Nazroo & Williams, 2000). The explanations for referrals are often unclear to the immigrant Arab women, which can produce worry and lead to non-attendance. The health care system itself is often found to be a barrier by many studies, due to long service wait times as a result of referral system (Holt, Clark, Kreuter & Rubio, 2003; Peek & Han, 2004; Rauscher, Hawley, Earp, 2005; Tinley et al., 2004; Young & Severson, 2005).

2.12 Limitations of the Study (Phase One)

I acknowledge specific limitations and challenges of my work which might be addressed in future research with similar topics. The biggest challenge I faced was the recruitment of immigrant Arab women. Direct recruitment was less effective than snowball sampling through word and mouth. As a hidden population, they were harder to reach than I had anticipated. Secondly, the sensitivity of the issue of breast cancer and breast awareness behaviour proved difficult for Arab women to volunteer to be interviewed. However I believe that I managed to recruit sufficient women to explore in depth the issues raised and appeared to reach data saturation. As I am from the same culture as the women interviewed, speaking the same language, I believe those that took part, and recommended me to others, did so because they felt I was trustworthy and this encouraged them to be more open with me.

Some limitations could influence the results of this study. Obtaining information from a small, purposeful sample of immigrant Arab women may not have been
representative of all Arab women of Islamic beliefs who reside in the UK, or other women without Islamic beliefs and different ethnic backgrounds. Although the small sample was quite diverse in terms of the participant’s age, educational and English language skills and their length of residency in the UK, women from first generation were over-represented in the sample compared to the second generation.

There is presently very limited information regarding screening practices and the breast cancer incidence in Arab women in England, and few national surveys that specify rates of screening among this population. In this study, as in others, results could have been influenced by a social attractiveness response, if those taking part answered questions in a way they felt was preferential. However, a key observation from the present study participants was noted.

I was not able to involve the participants in the analysis of the data, or to invite any feedback from the participants other than that of offering the initial verbatim transcription to comment upon. This was, mainly due to my own time constraints, and partially due to lack of time and interest on part of the participants. None of the previous research in the area of immigrant Arab women’s breast cancer awareness has used a participatory or collaborative research method; therefore there is a particular need for such research. While I was solely in charge of the whole research from designing to analysing and writing the report under supervision, future work could collaborate with research participants or other stake holders, such as health care providers including physicians, nurses and community health workers.

The immigrant Arab population in England is very densely populated by Arab women, a close-knit culture, practicing a similar lifestyle based on the Muslim
faith and Islamic guidelines. With a population of approximately 240,000 Arabs in the UK and 110,000 in London (national statistics, 2011), and the high risk for breast cancer that these women face, even a small sample study, such as this, points to the importance of breast cancer screening as a preventive public health objective.

In the next chapter, I sought to address some of the limitations of this study by:

- Compare and contrast the findings from the one to one interviews with that of a more diverse population through recruitment in two other cities, a further city in the South of England and that of the Capital, London and include a larger number of second generation.

- Compare and contrast the findings from the qualitative data here and that of a validated set of questions (Breast Cancer Awareness Measure, B-CAM) designed to reliably assess awareness of breast cancer and to help for measuring the levels of breast cancer awareness to see which, if any produced similar or different findings. One of the criticism of this part one of the study could be that of social attractiveness and answer in a way that pleased me, as the interviewer.

- Compare and contrast the breast cancer awareness knowledge between first and second generation by using B-Cam questioner.

- Explore in more detail information needs, and the usefulness of current educational material (NHS and one well known breast cancer charity) relevant to Arab immigrant women in England.
Chapter Three
Phase Two

Knowledge of breast cancer awareness and the usefulness of breast awareness educational material (NHS and Breast Cancer Care Charities produced leaflets) – Mixed Methods Approach
3.1 Introduction

For the purpose of constructing the context for this phase, it is necessary to mention in some detail the methods employed to carry out the second phase, sampling issues, and the issues of insider-outsider roles. This chapter is divided into 3 parts. The first part focuses on the decision to use qualitative methods as the main approach for this phase. In addition, I used the validated questionnaire namely the Breast Cancer Awareness Measure (or B-CAM version 3) to fully describe the prior knowledge and attitude to breast cancer awareness for further groups of immigrant Arab women across two further cities, one in the South of England and London to address the limitations of phase1.

The second part of this chapter focuses on sampling as another important methodological aspect which needs particular attention. It highlights issues regarding hard to reach populations, outlines successful strategies to aid recruitment, B-Cam process, focus group design and data analysis. Finally, I present the findings and discussion (part 3).

Phase two aimed to explore further, in detail, the current knowledge of breast awareness with two further groups of immigrant Arab women and to inform practice and gaps in knowledge regarding breast cancer and breast awareness educational materials. This time qualitative data were collected using focus group discussions. to provide a breadth of experience, attitudes and beliefs in a way in which would not be feasible using other methods, such as one-to-one interviewing used in the first phase of the study (Morgan, 1997). A focus group is a meticulously planned discourse configured to explore themes that are not well-known such as specifically held attitude and beliefs on the value or traditional practices preferred by an ethnic group (Krueger & Casey, 2000). Whilst such
attitudes and beliefs may be in part be unconnected to a group or its context, they are more prone to emerge through some kind of social meeting and the interfacing that is part of a focus group. Focus groups differ from one-to-one interviews, whose goal is to ascertain the attitudes, convictions and sentiments of the individual, in the respect that the focus group seeks to reveal a spectrum of opinion and emotions within a social setting. The focus group allows the investigator to acquire a considerable quantity of data in a relatively brief time. Where the focus group is especially helpful is in situations where there is an imbalance of power between those taking part and the decision-makers and/or professional, or where they feature the common culture and language of a certain group and that is of interest, or where there is a desire to investigate the extent of agreement among the group members on a particular subject (Morgan, 1993). In addition, knowledge and attitude to breast cancer awareness was collected using a validated questionnaire, B-Cam version 3. It provides a validated set of questions on Breast cancer awareness which can be used regionally and nationally to monitor or track how breast cancer awareness changes over time as well as compare the findings from this study with those of other populations in the UK.

3.2. Part One: Research Approach

This section will discuss the rationale for using both quantitative and qualitative data collection methods, describe the study population, data collection and data analysis.
Phase two aimed to further explore in detail the current knowledge of breast awareness with a group of immigrant Arab women and to inform practice and gaps in knowledge regarding breast cancer and breast awareness educational materials by:

- Assessing the knowledge of the immigrant Arab women's' awareness of breast cancer warning signs and symptoms, risk factors and perceived barriers to seeking medical help by using a quantitative tool, namely the Breast Cancer Awareness Measure (or B-CAM version 3) which comprise a validated set of questions designed to reliably assess and measure levels of breast cancer awareness. This information was collected to provide an opportunity to compare the BCAM findings of the current study population with British white women assessed using the BCAM measure and described in the literature. It was also hypothesised that there would be a measurable differences between responses from 1st generation compared to that of 2nd generation Arab women as measured by this questionnaire.

- Explore the usefulness of current educational material (NHS and Breast Cancer Care Charities produced leaflets) relevant to Arab immigrant women in England through qualitative focus group discussions.

- Explore the factors that motivate Arab immigrant women to be more breast cancer aware through qualitative focus group discussions.
3.3 Data Collection Process ‘Quantitative Design (B-CAM)’

The Breast Cancer Awareness Measure (B-CAM) established by Cancer Research UK, University College London, Kings College London and Oxford University in 2010 (Linsell et al., 2010). It consist of questions about knowledge of symptoms, knowledge of risk factors, age-related risk, and the NHS Breast Screening Programme, confidence to notice a breast change, anticipated delay in presentation and frequency of breast checking. It also measures barriers to seeking medical help with symptoms that might be serious. It has shown moderate to good test re-test scores, is sensitive to change with construct validity (Linsell et al., 2010). The Breast Cancer Awareness Measure (B-CAM) is a unique self-completion questionnaires universally accepted as a valid and robust measure of breast cancer awareness. It is suitable for use in surveys of breast cancer awareness within the general population since the readability of the B-CAM is high with over 90% of women finding it acceptable (Linsell et al., 2010).

Advantages of using the B-CAM are numerous. It not only provides a validated set of questions on breast cancer awareness, it allows comparison between different groups of populations, can be used regionally and nationally and used to monitor or track awareness changes over time or evaluate the impact of awareness-raising interventions.

Following an intervention to publicly elevate breast cancer awareness, the B-CAM tool was used to differentiate levels of breast cancer awareness. It found higher levels of cognisance and figures rose with a more intensive intervention, which indicates an adequate sensitivity towards change. The Breast-CAM was particular successful in differentiating between those women who were
recognised as having a greater extent of breast cancer awareness (for example, senior cancer doctors) and those of a corresponding degree of education without cancer awareness knowledge (for example non-medical academics) (Linsell et al, 2010).

For the above reasons, I chose to use the B-CAM tool to assess immigrant Arab women’s awareness of the breast cancer warning signs, and identify barriers that might inhibit seeking medical help to compare findings from this first and second generation immigrant Arab population with other populations according to previous literature findings.

I hypothesised that there could be a measurable differences between responses from first and second generation of immigrant Arab women. I anticipated that the older first generation were most likely to be more breast cancer unaware, incorporate cultural beliefs and attitudes that cancer equals death and keep such matters hidden. Conversely, the younger generation I thought might be more open to talk about their illness and encourage the older generation to be more open (Deepak, 2004).

The research questions were:

1. Are there any differences in the levels of knowledge and understanding about breast awareness and breast cancer among immigrant Arab women and the general population in the UK?

2. Does the knowledge among first and second generation Arab women differ within this study such that, second generation are more informed than first generation?

The B-CAM V2 consist of six domains and it has been translated and utilized successfully within an Arab culture. It has been used to collect data from two
hundred Saudi females, aged twenty and older living in Jeddah, to assess their knowledge of breast cancer warning signs, risk factors and screening programs (Radi, 2013) see chapter one, (Table 2). However the BCAM V2 has been updated to BCAM V3 by adding another domain to assess the knowledge about breast cancer risk factors. Whilst this version, to the best of my knowledge, has not been translated in to Arabic, forward and back-translations of the original questionnaire (seventh domain) in to Arabic and English were carried out to ensure lexical equivalence, preserving the original construction and ensuring the linguistic validity of the questionnaire. However, to the best of my knowledge, this is the first time that is been used among Arab immigrant women in England. The rationale for using BCAM V3 was that it is an updated version, with additional information collected and provides contemporary measurements. It was validated with the support of Breast Cancer Care and Breakthrough Breast Cancer (Linsell et al. 2010) and it has been used in in the general population in other studies (Burgess et al 2009; Linsell et al. 2009; Forbes, Atkins and Ramirez 2010). In addition all current BCAM survey data has archived with the UK Data Archive for ease of reference to researchers in the future and it could, therefore, be used for comparison with future work.

3.3.1 Content of B-CAM

The B-CAM may be delivered by interview or self-completion questionnaire and is made up of seven domains, as shown in table 7 below (see appendix 2.1) for a copy of the full B-CAM questionnaire.
Table 7: Breast Cancer Awareness Measure (BCAM) Seven Domains

<table>
<thead>
<tr>
<th>Domains</th>
<th>Breast Cancer Awareness Measures[B-CAM] Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Knowledge of the symptoms</td>
</tr>
<tr>
<td>2</td>
<td>Confidence, Skills and Behaviour in relation to Breast Cancer</td>
</tr>
<tr>
<td>3</td>
<td>Anticipated Delay In Contacting The Doctor</td>
</tr>
<tr>
<td>4</td>
<td>Barriers to Seeking Medical Help</td>
</tr>
<tr>
<td>5</td>
<td>Knowledge of Age-Related and Life Time Risk</td>
</tr>
<tr>
<td>6</td>
<td>Knowledge of Breast Screening</td>
</tr>
<tr>
<td>7</td>
<td>Knowledge of Risk factor</td>
</tr>
</tbody>
</table>

3.4 Part 2: Sampling

Exemplary extracts of qualitative research are not intended to be statistically representative of the entire research sample. Nevertheless, the concept of the sampling approach for a qualitative study is as essential as that for quantitative research and it is an important methodological aspect which needs particular attention. In this study the main consideration is that of the sensitive nature of the topic within the sensitive environment of the study. A convenience sample, comprising women who had agreed to participate in the focus group discussions, were asked to complete the BCAM V3. These women were recruited using a variety of methods to be discussed in a separate section (see section 3.5.2).

3.4.1 Accessing Immigrant Arab Women

Having something in common with, or being in some way akin to the group under research, will not necessarily ensure access. However, for some investigators possessing common features with the group has been shown to be an effectual
implement for the study procedure (Keval, 2009). At the point when investigating themes concerning race and ethnicity, coordinating both researcher and participants by ethnicity and social attributes, for example, imparted language, convictions, information or religion has been seen as being great (Sin, 2007). The prevalent belief is that insider status affords easier and faster access to possible participants owing to the concept of similitude between researcher and interviewee. The significance of this lies in the time involved in gaining the interviewees confidence and building a workable rapport with them; the time being less lengthy because those taking part are rather more susceptible to opening up to the researcher through a sense that the researcher is more prone to empathise and understand them than outsiders, permitting access and producing more in-depth data (Bhopal, 2001; Breen, 2007; Dwyer & Buckle, 2009; Mercer, 2007; Temple & Edwards, 2002).

Others have challenged this perception that insider status ensures access to the study participants (Bhopal, 1995; Wray & Bartholomew 2010). This is because the research group may have grave misgivings over the manner in which they are depicted in the study. Prospective interviewees might in addition refuse an interview conducted by an insider due to being afraid of and criticised by them may be reluctant to publicly chat about their understanding (Shah, 2004). Likewise, in spite of having in common such things as ethnicity, being an outsider to their particular community can result in the researcher being approached with doubt and understood as a danger (Bhopal, 1995).

At first I thought my imparted ethnicity (Arab background) would permit immediate access to the Arab affiliations, mosques and clubs in the local community. While I believe that my imparted ethnicity empowered me to enrol a significant number
of the Arab women through numerous Arab group affiliations, this was not always the situation. One woman declined to join in. At the point when I inquired as to whether she would be eager to impart her experience, she shared her uneasiness in talking about this subject. It is possible that she would not want to discuss her convictions and attitudes with anybody, or maybe all the more particularly myself, as we were from the same society and she may have had concerns around namelessness, privacy and how she may be portrayed in subsequent reports.

Taking from this perspective it may be struggled that some interviewees might be at greater ease speaking with an outsider on the grounds that there is less probability of being judged (Tinker & Armstrong, 2008). Consequently, imparted ethnicity may not as important as previously considered. However, irrespective of being an insider and/or an outsider, it is imperative for investigators to gain the confidence of and form relationship with the research participants to gain access and obtain more in-depth data (Cohen et al., 2001).

3.4.2 Shared Knowledge

One benefit of being an insider is that it involves a greater knowledge and deeper comprehension of the research group’s culture (Jaspal, 2011; Le Gallais, 2003). It can also make it easier to establish a rapport and communicate in a less unnaturally manner when the interviewer is well acquainted with their study group’s language and cultural expressions (Bonner & Tolhurst, 2002).

Before I began this study, my familiarity with my own particular society was somewhat fundamental or constrained. It was only following this this exploration that I began to develop a deeper interest and understanding regarding
discussions about the general beliefs and attitudes held and the explanations for these beliefs and attitudes. I gained further awareness of Arab civilisation, and the different facets of the women’s health issues involvements (i.e. socio-cultural barriers around breast cancer, linguistic barriers), I began to ask questions as I tried to understood and began to notice similar social convictions and behaviour in further situations (In the beginning, I think that my basic understanding and knowledge sometimes positioned myself as an outsider. However, reflecting on this, I came to conclude that the limited insider information grows as the study progresses, as detail is added and prepares you to be an insider to some deeper level. Wray & Bartholomew (2010) agreed that this idea supports the contention that insider-outsider parts are better placed on a continuum and that parts change and grow all through the study process

Prior cultural information allowed me to ask suitable and applicable queries. Also, shared language operated to my advantage when interviewing the Arab women, as in many examples the immigrant Arab women would often return to their Arabic language once sharing in depth, aspects of their knowledge, beliefs and attitudes. Commonly, it is not always necessary for the researchers to be insiders or to have experience of the subject under study for them to be admitted to the study participants. If the group are keen to share their stories, then they will talk (Breen, 2007). Though, it is likewise significant that the investigator has the know-how to induce the trust of and build a rapport with those taking part to create an atmosphere that is of cordial and relaxed to provide an opportunity for participants to “open up” about their personal experiences without difficulty (Keval, 2009).

It has additionally been discussed that too much awareness and having former learning about the study participant’s social beliefs and attitudes can place the
researcher at danger of obscuring objectivity (Hewitt-Taylor, 2002). However, sometimes sharing this knowledge can be seen as benefit, both to the investigator and the interviewees expose themselves and not assume certain information. Participants may not discuss issues because they are under the presumption that the researcher might know this information. In a comparable way, the investigator may utilise their insider information, assuming they already know the answers and neglect to provide additional probes and inquiries as they may feel the reactions are too obvious (Dwyer & Buckle, 2009; Tinker & Armstrong 2008; Young, 2004), while the outsider researcher can admit to not knowing, inquire with curiosity to learn more and fewer inhibitions. Moreover, an interviewee may feel empowered by an outsider’s lack of knowledge about their culture because they would feel themselves to be in control “in an upper hand position” as the experts and hence give contextual, detailed information, raising the depth of data collected (Tinker & Armstrong, 2008).

3.4.3 Role of Gender

In addition to my ethnicity, I feel that as a female sharing the same gender was important in this research. Gender may be of greater influence in the process of a research about an ethnic group because certain ethnic cultures have a drastically different stance on the interactivity between the sexes and especially between men and women who are married (Thyer, 2001). A strict segregation of the sexes is observed, even at such familial occasions as weddings and religious worship venues; men and women are kept apart in separate rooms (Egharevba, 2001). Arab society places incredible accentuation on shyness in regards to the sensitive subjects linked with private body parts that are not at any time discussed publicly.
As a female, I believe my gender yielded increased access to this research population of all Arab women and that, it is possible, a male researcher would not have gained either access or willingness to share, if he had led the group discussion.

3.4.4 Participant’s Biographical Data

A total of thirty four immigrant Arab women took part in two focus group interviews (sixteen women in Portsmouth) and (eighteen women in the London group). Each participant's biographical information was documented from a specifically designed questionnaire. Details included: age, ethnic origin, main language spoken at home, marital status, highest qualification obtained, number of years living in UK, employment status and whether the women were first or second generation living in the UK (Table 8).
Table 8: Biographical Characteristics of the Participants

<table>
<thead>
<tr>
<th>Biographic</th>
<th>Number of Women (Portsmouth) N=16</th>
<th>Number of Women (London) N=18</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>7</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>30-39</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>40-49</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>50-59</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>60-70</td>
<td>1</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Ethnic Origin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arab/Iraq</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Arab/Algeria</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Arab/Jordan</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Arab/Saudi Arabia</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Arab/Syria</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Main Language</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Arabic</td>
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<td>16</td>
<td>27</td>
</tr>
<tr>
<td>English</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>French</td>
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<td>0</td>
<td>2</td>
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<tr>
<td>Marital Status</td>
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<tr>
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<tr>
<td>Married</td>
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<td>Highest Qualification Obtained</td>
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<tr>
<td>Degree</td>
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<td>5</td>
<td>12</td>
</tr>
<tr>
<td>Still studying</td>
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<td>2</td>
<td>4</td>
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<tr>
<td>Below degree</td>
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<tr>
<td>A level</td>
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<tr>
<td>Illiterate</td>
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<td>3</td>
<td>5</td>
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<tr>
<td>Number of years living in the UK</td>
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<td></td>
</tr>
<tr>
<td>1 to 3</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>4 to 6</td>
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<td>4</td>
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<td>7 to 9</td>
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<td>7</td>
<td>8</td>
</tr>
<tr>
<td>10 years and over</td>
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<td>13</td>
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<tr>
<td>Employed full- time</td>
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<td>0</td>
<td>1</td>
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<tr>
<td>Employed part-time</td>
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<td>4</td>
<td>11</td>
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<tr>
<td>Unemployed</td>
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<td>12</td>
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</tr>
<tr>
<td>Still studying</td>
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<td>2</td>
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</tr>
<tr>
<td>First</td>
<td>7</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Second</td>
<td>9</td>
<td>12</td>
<td>21</td>
</tr>
</tbody>
</table>

From Table 8 it is evident that the immigrant Arab women represented quite a heterogeneous group with regards to age range. The majority of immigrant Arab women, in both groups, had an average age of 46.5 years and represented youngest to eldest (range 20 – 70) age groups. Across the two focus groups, the
34 immigrant Arab women represented 5 different Arab countries: Iraq, Algeria, Jordan, Saudi Arabia and Syria. The main language spoken at home was that of Arabic, although this varied between the two focus groups with slightly more in the London group “speaking Arabic at home” (16/18) than the Portsmouth group (11/16). The majority of women attending, across both focus groups, were married although two participants (Portsmouth focus group) and four (London focus group) were widowed. A total of eight of the women were single (5 Portsmouth focus group) and 3 in the (London focus group).

The women from the Portsmouth focus group were more educated than those of the London focus group (7 of the Portsmouth women vs. 5 of the London women had a university degree) and (2 of the Portsmouth women vs. 8 of the London women were below degree level). Among the others, 5 in total, from both focus groups, were illiterate (not able to read and write in either Arabic or English). The years of residency in England among both focus groups ranged from 2-14 years, 13 were first generation born outside of the UK (7 women (Portsmouth focus group) and 6 women (London focus group), but the biggest group was that of second generation women; 21 were second generation (Portsmouth=9 women, London=12 women). However, despite being born in the UK they had left for periods of time joining parents working in other countries.

3.4.5 B-CAM Questionnaire administration

In Portsmouth and London, the Breast Cancer Awareness Module (B-CAM) version 3 (Cancer Research United Kingdom, King’s College London and University College London, 2010) was completed prior to the focus group discussion taking place. Immediately before starting the focus group, I checked each participant understood about the requirement to fill in the B-CAM questions
to ensure that they were clear on what taking part involved. I informed the participants that they could take part in the focus group without the BCAM questionnaire if they wished, however all the participants completed the BCAM questionnaire. For those participants who were illiterate, I offered to read out the questionnaire in Arabic in a quiet, private area. The BCAM self-completion questionnaire has been previously validated to be read out as well as self-completion (Linsell et al, 2010).

Prior to filling out the questionnaire, instructions was given that the participant should try to answer all the questions and to answer the questions posed as honestly as possible. The questionnaire took approximately 30 minutes to complete; during this time, no specific questions from the questionnaire could be answered by the researcher. The participants were given the choice to fill out the B-CAM surveys in English or Arabic. In Portsmouth, seven out of the sixteen women chose the Arabic language questionnaire, whilst in London ten out of the eighteen chose the Arabic language version. In Portsmouth my supervisor and I were present to assist and make sure everything was understood. The same process was applied in London, however instead of my supervisor, my colleague and PhD researcher (S.A) was present. After all the B-Cam measures were completed, I checked everybody was ready to proceed. I commenced with the focus group discussions by once again explaining the objectives of the discussion in more detail.

3.5 Focus Group Design

Similar to the first study in phase 1, phase 2 used a qualitative design for the purpose of acquiring a deeper understanding in which immigrant Arab women
were asked to explore the usefulness of current educational material (NHS and Breast Cancer Care Charities produced leaflets) relevant to them as well as explore the factors that might motivate them to be breast cancer aware. However, instead of semi-structured interviews, utilised in phase one, focus groups were used. The reason that focus groups were used was that they are “a form of group interview that capitalises on communication between research participants in order to generate data” (Kitzinger, 1995, p. 299). Focus group discussion was employed to find viewpoints, practises, and beliefs relating to a particular subject, in a joint environment that is reciprocally supportive (Morgan, 1997; Krueger & Casey, 2000). Though, face-to-face interviews are more suitable for discovering individual and personal subjects, currently this method is more widely acknowledged to facilitate rather than prevent revelation of private subjects (Culley, Hudson & Rapport, 2007).

Farquhar (1999) stated that, the researcher needs to be mindful that not everybody will be willing to reveal private thoughts or behaviour in a gathering setting. In any case, focus group method were utilized for this study, as this strategy for information gathering was to animate arguing among participants who offer comparative encounters and serve as skilful witnesses (Krueger, 1988). This system for information gathering has been especially effective when exploring ethnic groups, as they are more prone to take part in settings where there is potential to meet different individuals who offer comparable encounters of an individual kind (Ruff, Alexander & McKie, 2005; Wilmoth & Sanders, 2001).

Culley et al (2007) have also suggested that being in a discussion setting can possibly diminish tensions for members that individual interviews can possibly create. Moreover, a discussion gathering can improve the probability of coming
to information immersion because of the quantity of members taking part in the meeting (Ruff, Alexander & McKie, 2005). Considering this, utilizing a focus group technique was considered to be suitable for this phase. Moreover, all findings from this phase can be compared and contrasted with those obtained through individual interview in phase one of the study. Utilization different methods to collect data, (such as individual interviews and focus group discussion) can create the triangulation of the whole findings (Campbell & Fiske, 1959). The triangulation of the findings, within the same paradigm, qualitative research, can be useful for the particular purpose I wanted to look at, that of similarity and differences in knowledge, views and attitudes to breast cancer self-awareness behaviour.

The two focus groups were designed using information that emerged from the research questions. This enabled the research to explore and attempt to explain the themes that caused most areas of concern. Holloway and Wheeler (2002, p.110) state that “in focus group discussion participants with common characteristics or experience are sought for the purpose of eliciting ideas, thoughts and perceptions about specific topics or certain linked to an area of interest”. The topics provided were broad with prompts given to immigrant Arab women used to expand points made, rather than steer them to preconceived selections.

I was the facilitator for both of the focus group discussions. My first academic supervisor was responsible for taking notes for the Portsmouth’s focus group discussion and operating the digital audio recorder. However, a colleague was asked to take the same responsibility for the London focus group discussion as my academic supervisor was unable to attend. As a facilitator, I often expressed
ideas and words in a particular way. The ways in which these ideas were expressed included probing for details, moving things on at the point where the discussion was wandering or summing up the discussion to recap.

At times, I gently challenged participants not in a confrontational way, but instead to extract differences between individuals and to “squeeze out” a spectrum or breadth of experiences on the subject being explored. The focus groups discussion allowed for in-depth coverage of Arab immigrant women’s experiences and thoughts expressed in their own words, giving them the opportunity to raise issues that may not have been previously considered and add to the richness of data.

I kept an open mind and developed skills for eliciting information which could assist the focus group process. I underwent a number of training workshop sessions from the Graduate School development programme at the University of Portsmouth; this included sessions on how to investigate each question thoroughly, how to put the question to interviewees in a different manner without altering the meaning. In addition, I also read literature on conducting focus groups, for example “Focus Groups” By Krueger & Casey (2000) was particularly useful; aiding me in obtaining the necessary skills and confidence required for conducting the focus group discussion. The atmosphere was in no way menacing; all immigrant Arab women were mutually introduced and were positioned in a circle to aid communication and to guarantee ease in disclosure of personal information and overall productiveness. Prior to starting the focus group, I provided some guidance for conduct within the focus group.

- Switch off all mobile phones during the focus groups
- Try to speak one at a time
- Respect each other’s views
- The Arab women were also requested to leave what was said within the room and that conversations remained confidential and not shared with others outside of the group.

All of the women agreed to abide by the guidance which was deemed necessary for the smooth running of the focus group discussion.

I tried to put the immigrant Arab women at ease and introduced myself and the purpose of the focus group, including the range of topics to be discussed. Research questions were asked inductively, continuing from general to particular, by utilizing a specific focus group interview guidance which prepared earlier.

### 3.5.1 Practice Focus Group Discussion

Holloway and Wheeler (2002) claim that pilot studies are not normally utilised in qualitative studies, however inexperienced researchers might carry out a practice focus group interviews as a preliminary exercise to be accustomed with the sort of information collection. I led a pre-focus group exercise to provide me with insight into the procedure of leading a focus group discussion. A preparatory practice session provides an opportunity to identify that faults can be recognised and remedied at little cost.

I carried out the practice focus group discussion with a group of four immigrant Arab women from Southampton who, although they met the selection criteria, were friends of mine. I used the interview schedule intended for the main focus group discussion and the women completed the B-CAM questionnaires. This was carried out at a quiet room in the University of Southampton/Student union. The small practice focus group discussion was recorded to guarantee the proper
application of the digital audio recording device and to hear the interviewee's responses interjected by my questions. Throughout this practice focus group, I tried hard to look for signs of awkward/uncomfortable body language and non-audible replies in addition to the particular manner of my questioning and responses received. Conducting this practice focus group interview lifted my degree of confidence. I actually developed my own personal way and techniques for interviewing groups of people. Furthermore, it guaranteed that I fully understood both the collection process and preliminary analysis of qualitative information. Practicing leading this focus group discussion gave me the opportunity to:

- Probe relevant participants’ responses by using expressions like “Could you elaborate more on that point?” while keeping firm eye contact to encourage the participant to feel free to continue speaking. I then summarized the concluding findings of a theme in order to acknowledge their contribution and sometimes this encouraged further talk (Holloway & Wheeler 2002).

- I tried to conduct the group discussion with an impartial mind and a degree of sensitivity. Possessing an open mind meant I needed to embrace other people’s, views and suggestion which may differ from my own beliefs. Being open to differing views of the participants didn’t mean believing or accepting, but listening, observing and trying to comprehend every situation I came across. Sensitivity requires listening skills while being empathetic with the participant. This created a trust between me and the participant, allowing them to become increasingly comfortable with sharing
their views. Throughout I tried to put aside any preconceived notions and to be sure to be reflexive and intuitive pursuing topics raised with a sense of curiosity and interest.

- The focus group heavily relied on group discussion and, consequently, I found that the facilitation of the discussion was critical. The main limitations regarding the discussion setup were the distraction from the main focus of the discussion, as participants would occasionally disagree and form irrelevant dialogue. After the focus group I discussed with the participants what the experience had felt like. Some participants were also difficult to encourage to participate and found the focus group environment alienating at first to contribute to. Additionally at times, felt a certain pressure to agree with the dominant view.

- I was able to ensure that the digital device used for recording the discussion captured all those taking part. The restrictions that were realised with the sound recording of the focus group discussion included the failure to check the functioning of the recorder prior to the discussion. At an early point in the discussion, I found that the recorder was not recording due to battery power depletion; therefore I had to replace batteries and restart the discussion, which proved to be slightly inconvenient for the participants. In addition, outspoken individuals would often dominate the discussion and talk over others, therefore making the others less audible in the playback of the recording.
Transcribing and initial analyses of this data, provided an opportunity to develop some of these skills. The transcription took much longer than I had anticipated.

One of the precautions taken was to ensure that each participant had the opportunity to voice their opinion/answer, therefore, prior to the start of the discussion, I encouraged all participants to answer, as each of their opinions were highly valued in the focus group discussion. In addition, I also requested no interruptions to be made while another participant was speaking, as each would have their turn. To aid in identifying the participants during the recording, each individual was given an assigned number to identify themselves with, prior to giving an answer; this made it much simpler to analyses the discussion and to differentiate the voices of each participant.

I was reminded to adapt the focus group discussion style to ensure the language used was a mix of English and Arabic, for easier comprehension; the Arabic language was used where there were difficulties in comprehension.

The administration of the B-CAM questionnaire also made me realise the importance of translating the (B-CAM) and focus group discussion questionnaire in to Arabic language, to make it easier for participants understand. I adapted the focus group discussion guide to include alternative wording that appeared more suitable for the different topic areas. An example of what words would cause difficulty to the participants were medical terminologies concerning warning signs and symptoms of
breast cancer. These words were difficult for some of the practice focus group participants to interpret correctly, as they were unfamiliar terms and difficult to provide an accurate translation. For example the literal translation for the English word “mammogram” to a corresponding Arabic word was inaccurate. The literal translation being breast cancer examination’, Another example is the literal translation for lump, which in Arabic would be misinterpreted and have no relation to breast cancer, therefore I used the translated term for ‘tumour’.

3.5.2 Sampling and Recruitment Procedure

Snowball sampling and chain referral sampling were the foremost recruitment approaches. Attempts were made to include two focus groups, one in Portsmouth and the other in London, to increase the numbers taking part with more diverse demographic characteristics. It was hoped that recruiting from these two cities with large Arab communities would help offer and develop a deeper understanding of the intersections of age, educational status, and number of years living in England for this BME population.

Similar inclusion and exclusion criteria used in Phase One were also agreed for Phase Two. These criteria were a) the women participants had to be of Arab origin and born outside of the England (known as first generation) and Arab women born in England (known as second generation), b) the women selected had to be between age range 18 to 70 years; the cut off age was selected at 70 years, because after the age of 70 it is requested screening appointments and not routine appointments asking a woman to attend a screening for breast cancer c) It was also considered important that no one taking part had any personal
experience of breast cancer, for the reason that these people would exude an entirely different experience which would not attest to that of other members of the focus group. Also, it was considered that the topic area would be much too sensitive a subject of discussion to share experience of living with a diagnosis of cancer with those who have not.

In order to include diverse immigrant Arab women, advertisement messages, invitation letters, information sheets and consent forms were translated into Arabic language. A number of Arab community organizations in Portsmouth and London serving immigrant Arab women were initially contacted, asking for help in connecting with their members. Table 9 provides a list of these Arab community associations centres that I contacted.

**Table 9: List of Arab Communities Contacted in Portsmouth and London**

<table>
<thead>
<tr>
<th>Portsmouth</th>
<th>London</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community of Al-Islam</td>
<td>Egyptian Community Association</td>
</tr>
<tr>
<td>Portsmouth central Mosque</td>
<td>Arab Network in Britain</td>
</tr>
<tr>
<td>Arab community association</td>
<td>British Arabs Resource Centre</td>
</tr>
<tr>
<td>Al Mahdi Centre</td>
<td>Arab society of London</td>
</tr>
</tbody>
</table>

From all the Arab societies that I contacted listed above, only the Arab community centre in Portsmouth and the Arab society of London responded to my initial email contact and offered assistance. These Arab community associations were asked to publicise the call for interested immigrant Arab women to engage in the research by both written and verbal message throughout their memberships.

They were then sent details of the study and sent the information in both languages (English and Arabic) to display on bulletin boards in common spaces in their community centres (Appendix 2.2). Some of the contacts also suggested
publishing it on their Face Book page and in the community newspaper. The community associations’ leaders helped with recruitment by communication with their members to see if they would be interested in taking part. Announcements about the research were also made at their meetings. Fliers were also disseminated at more occasional activities, anywhere there was a chance to meet possible members who would be keen to promote recruitment of the research. Furthermore, advertisements were posted in public places such as Arab grocery stores and mosques, especially to reach women who did not use any of the above services. The advertisement asked interested Arab women to contact the researcher via phone or email were also requested to forward details of all interested women (who gave permission to release their contact details), after receiving information about the study from the Arab communities’ association. I received contact details and made contact with each individual in order to answer any questions and, if they were happy to take part, confirm their interest in the focus group study.

In total, eight women from Portsmouth and ten women from London were contacted via Arab communities’ association service staff. Only one woman from London responded to the advertisement message posted in a mosque. For the rest, nearly half of the total women were recruited through snowballing method (eight women from Portsmouth and seven women from London).

In total, sixteen women from Portsmouth and eighteen women from London signed the consent form, confirming their volunteer participation in the focus groups discussions for the present study. Two focus research groups took place over a period of seven months. The first focus group was conducted in
Portsmouth on the 5th July 2011 and the second focus group was in London on the 23rd February 2012.

3.5.3 Process of Focus Group Data Collection

The Arab communities’ association distributed an information pack which included an invitation letter, information sheet and a consent form, (appendix 2.3). Each potential participant received comprehensive information documents and consent forms for permission relating to taking part in the focus group discussion. This information was sent out to all the participants at least one week before the scheduled date and time. In the consent form, all the participants in the study were given the choice to decline participation, the chance to pose their own individual questions during the focus group and the right to withdraw if and whenever they so wished and without consequence.

All those involved were assured of the quantitative information being statistically analysed anonymously. It was recommended that they did not include their names on the question forms so as to attain maximum anonymity. The completed form, together with the audio recording and transcription were processed by and everything was kept under lock and key in a safe office. At the end of the study, the results were shown as group data.

The qualitative information was analysed without reference to personal names or other means of personal identification

Having read the written information, discussed any queries, each woman signed the written information sheet if they agreed to take part. There were a couple of women who had no formal schooling and could barely sign their names in Arabic. Under such circumstances, written information, whether Arabic, or English could
not be fully comprehended. Instead, I also read out the information in Arabic. I also read out the consent form to one women and a fellow participant to the other. A singular version of the permission form was returned to the participant for keeping and the other copy kept in a locked drawer at my home.

Before starting the focus groups I made sure the participants understood and signed the consent form before proceeding. However, in the London focus group occasion, I was surprised to see an Arab lady attending with one of the participant, who introduced herself as a friend and a neighbour of one of participant. I had not been informed about her neighbour, even when I confirmed the appointment with the original participant via phone, I also found the Arab woman to be quite doubtful about me and my purpose. She was concerned that I might work for the government and would report any discussions to the government a concern. I noticed with a couple of other Arab women lacking formal literacy. Although the main participant explained the purpose of the focus group discussion in Arabic and I also tried to reassure, I still noticed her discomfort or lack of confidence and reassured her that she had no obligation to participate. She took the information sheet and consent form to her husband, who was present outside the focus group location and she came back quite satisfied, as her husband approved it. The main participant, younger, educated and fluent in English, signed the form on her behalf (the Arab woman did not know how to sign her name) and insisted that everything was all right and I should proceed with the meeting.

Both focus groups were again reminded about the reason of the research and were asked to contribute, where they could to all the issues raised. The confidentiality of the data and their personal details were also emphasised. Basch
(1987) suggests, where possible, focus group discussions should take place in a comfortable and an informal atmosphere. To make the process more informal and provide a relaxed environment that would empower an open discussion, the Arab women were seated in a circle and refreshments were given. Before starting the focus groups discussion, I welcomed and thanked the participants for attending. I introduced myself and my academic supervisor, who attended the Portsmouth focus group, and I also introduced my colleague helping me at the London focus group discussion. I pointed out the objectives of the focus group, highlighting there were no right or wrong answers but that it was hoped that hearing their views might increase knowledge and understanding about their experiences as part of an Arab community in England. I explained the process of this focus group and how it would be conducted.

The focus group discussion questions were displayed on a Power Point in both Arabic and English for more clarity and elaborated explanations to make it easier for the participants to concentrate on the discussion issues and overcome any communication barriers, such as misunderstanding, language and a reminder of the topic areas to encourage their participation (Appendix 2.4). After one hour of discussion we took a break. During the break, the women each shared a dish they had brought for the group. This is an Arab custom when attending an event or any social situation when there is an expectation to bring a dish of some kind of food to share. This gave a pleasant and fun atmosphere, as everyone enjoyed each other’s food and got to know one another. After the break, we resumed the discussion. During the second half of the focus group discussion, I gave out both the Breast Cancer Awareness Brochure and the NHS breast cancer awareness leaflet. Participants reviewed both leaflets. These two leaflets were selected
because they are currently used to increase awareness and knowledge of breast cancer and breast screening programs (Appendix 2.5). Finally, I asked if anyone had any further questions or wished to voice any further points and this signalled the end of the session. Recordings had been made of the conversations with both of the groups and were of approximately 80 and 110 minutes in length (an average of 95 minutes). All those involved in the two sessions were dutifully thanked for their time and contribution and received a £10 Boots gift card as a token of appreciation from the researcher for so generously sharing their experiences. All participants were asked if they wanted to see a copy of the focus group discussion; eight participants from the Portsmouth focus group and ten women from the London focus group were keen to receive the study findings. The members of the Arab community association requested a formal presentation of the research report upon completion. These actions terminated the proceedings in a highly positive air. All the immigrant Arab women had the choice to have their travel expenditures repaid.

3.5.4 Topic Guide
The discussion within the focus group was nurtured through practice interviews, based around the research questions posted. The focus group discussion covered the following three main topic areas:

1. Topic one focused on knowledge of breast cancer awareness and motivating elements. The aim was to investigate the factors which encourage the immigrant Arab women to be breast cancer aware.
2. Topic two focused on reviewing the contents of leaflets and educational materials (NHS and Breast Cancer Care charity). It was hoped to explore the accessibility and understanding of current breast cancer awareness educational materials.

3. Topic three focused on the media and whether written brochures and educational materials are the best way to disseminate information. It was hoped to explore ways of improving future educational materials and methods of dissemination.

Prior to introducing the three main topic areas, an ice-breaker/introduction exercise took place, which comprised the participants getting to know each other, and comparing each other’s dishes brought to the focus group discussion. I moved from a series of broad questions to more specific ones, based around these three main topic areas.

3.5.5 Venue

The circumstances of the research procedure is highly important in qualitative study. Holloway and Wheeler (2002) proclaim that context is defined as "surroundings and conditions" in which the research takes place, but additionally can refer to the culture of those involved and last, but by no means least; the venue.

The venue of both focus group discussions was taken into consideration, since if setting chosen does not allow the participants to feel at ease, this may impact upon their emotions which and, in turn, influences how they respond during the discussion. The location, therefore, needed to be one where participants felt comfortable and secure, as well as being conveniently located. Inconvenient
locations can possibly discourage participants affecting their keenness to take part in the research.

The first focus group interview took place in the Boardroom at the University of Portsmouth, School of Health Science and Social Work. The second focus group interview took place in the assembly room of the Arab community association in London, both locations provided relaxed venues, quiet with sufficient chairs and what transpired, was a rather informal and comfortable setting for both focus group discussions.

The focus group discussions were conducted in both languages; Arabic and English, as preferred by the women. As I am fluent in Arabic, I was able to conduct the discussions in Arabic (where preferred). This allowed me to engage more directly with participants, creating a more trusting environment. This also aided in the comfort level of the women and eased the flow of discussion. Notes were taken during the discussions by the first academic supervisor for Portsmouth focus group and by my colleague.

Finally, I gave some guidance to all participants at the close of each focus group session on how to obtain further information and support regarding breast cancer awareness.

3.5.6 Ethical Consideration

Consent was sought from the ethical committee of the School of Health Science and Social Work at the University of Portsmouth (UoP) in 2011. However before receiving conclusive approval, I had to clarify the proposed recruitment procedure by adding a paragraph to the participant information sheet informing participants that they would be required to complete a biographical questionnaire and the B-CAM questionnaire. I was also required to add an additional statement and tick
box stating the participant agreed to give permission for their anonymous quotes to be used in future publications. I addressed all of these points. The final approval letter via email was acquired for the research from the UoP ethical committee on 9th of June 2011 (Appendix 3.3).

3.5.7 Written Information and Informed Consent

Firstly, I made sure that all participants in both focus groups had received written information and understood the purpose and consequence of taking part.

The written information contained full details of the rational for the research project. It was explained that the women’s participation in the study was voluntary and without giving any reason, they could withdraw at any time. The information sheet also outlined the anticipated time required at the focus group discussion (estimated to be between 1-2 hours). It was also explained that the focus group would be audio-taped using a digital recorder and that I would be transcribing all audio-recorded interviews and then analysing the data, removing all names from subsequent publications.

The written information also informed the immigrant Arab women that they would be asked to complete the biographical questionnaire before taking part in the focus group discussion. It was explained that this information would be collated and used to describe characteristics of those who had agreed to take part, but that all data would be made anonymous, with all names removed. In addition, they were asked to complete the questionnaire produced by Cancer Research UK, namely the Breast Cancer Awareness Measurement questionnaire (or B-CAM for short), to measure their knowledge and practice of breast cancer awareness and identify any obstacles that prevented them from seeking medical assistance.
3.5.8 Anonymity and Confidentiality

To ensure confidentiality and protection of identity, the names of all women who took part were omitted and, in the transcription, each group (Portsmouth and London) were referred to using the following pattern: region (L*London, P*Portsmouth; method. I also added the method of data collection (FG*focus group); and the participant’s age in years. In the focus groups, participants took a number from (1 and over) for themselves. The purpose of the numbering system was for the purpose of transcription so that I knew who was speaking. Participants were asked to read out their number at the beginning of the discussion and when speaking about their favourite food (Portsmouth I believe) so that when I transcribed, I would recognise the voice that matched the participant’s number. Sixteen women (Portsmouth focus group) and eighteen women (London focus group) self-picked their numbers and had some fun over this process.

Furthermore, all possible identifying information was removed from the written reports. Descriptive and demographic data such as age, educational status and number of years living in the UK were only included in reports when they were deemed relevant and important to the presentation of the data and not directly attributed to the qualitative data quotes. However, where necessary in some of the information, anonymity was used to contextualize certain findings. Special care was given to leave out those kinds of details, such as street names or workplace that might cause a particular woman to be identified within a small community where people tend to know each other well.

All conversation was audio-taped with participant’s permission. All transcriptions and tapes entered into the computer and stored on flash disks were kept securely
in a locked place. I was the only one with immediate access to this information, it was stored in my personal computer, which was password protected and restricted to my use only.

3.6 Reflections on Phase Two

In qualitative research, the participants and the investigator alike have an effect on the attainment of the data collection and its analysis, so they must not be disconnected in any way from the practical aspect of the research. According to Parahoo (1997, p. 292), “reflexivity is a continues process whereby researchers reflect on their preconceived values and those of the participants, such as reflecting on how data collected will be influenced by how the participants perceive the researcher”. Holloway and Wheeler (2002) elaborated that the investigator is obliged to reflect on their personal activities, emotions and disagreements during the study. In order to give credibility to the study, I embraced a self-critical position towards my interview style, the analysis of the data, including tentative coding, relationships and suppositions.

It is often quite difficult to take into perspective ones preconceived notions and their effects and this renders reflexivity somewhat difficult to execute. The information is validated by the researcher returning to the interviewees in person and confirming whether their interpretation was in fact accurate. This process of validation gives the opportunity to clarify the data for the investigators to discern and acknowledge their own personal biases (Parhoo, 1997). The three reasons for reflexivity are:

- Assisting the investigator in self-monitoring to discover whether anything is going awry and rectify it.
- Assisting with data analysis and navigating the sheer volume of data.
- Self-injunction and demonstrating how others may find credibility in the investigator's rendition.

Throughout this research, I wrote down any feelings, preconceptions, conflicts and assumptions that I had about the study. This enabled self-monitoring to prevent bias and increase objectivity.

My part as a researcher from the insider/outsider perspective requires acknowledgment in the reflection process. These have been explained in detail in part 2: sampling, respectively.

3.7 Process of Audio Recording

3.7.1 Note Taking During the Interview

An essential part of the research procedure is note taking, in spite of having, to some extent, a disruptive effect on the interviewee (Holloway & Wheeler, 2002). So, in order to control this, I alerted the women that my colleague would be making hand written notes on paper through the course of the focus group discussion and that it would be done in a way that would attempt to minimise distraction for them. A person who is not facilitating the actual discussion can make notes far more easily about those behaviours of the participants other than the verbal kind, as well as the reactions and remarks of the researcher (Holloway & Wheeler 2002). At Portsmouth, my first academic supervisor took notes for the Portsmouth focus group and the notes were in English, while in London one of my colleagues; another PhD researcher, who was not a participant, took over this responsibility, but the comments were written in Arabic, which is the Arab women's native language. Then, I interpreted and transcribed the Arabic notes into English.
3.7.2 Audio Recording and Transcription of Data

With the permission of the participants, I audio-recorded the two focus groups discussion for data collection. A 'Philips' Digital phone recorder - model PDR3 was used to record the focus group discussions verbatim. The digital recorder was the same one that I used in phase one of the study. Again, this tape-recording aimed to counter criticism of qualitative research, as ‘prone to systematic bias’ (May, 1991). Following my practice focus group, I ensured that the following took place to facilitate the success of the focus group discussion:

- The central positioning (in the middle of the table) of both recording devices to ensure maximum reception and volume for all voices.
- A plaque reading “do not disturb” sign was affixed to the door to deter any interruptions from outside.
- The digital voice recorder, laptop computer and over-head projector were tested in advance of the focus groups discussion to be certain that it was in functioning properly. New batteries were inserted in the recording device and tested for any possible interruption of the power supply.

Both focus groups data were interpreted verbatim by me in to English language by process called forward interpretation. This process involves the use of two interpreters, who translate the qualitative research data, such as field notes or interview transcripts from the source language (non-English) into the target language (English) and another bilingual researcher according to Dunckley, et al. (2003), who is also involved in the translation process will back-translate the documents from the target language to their source language, and finally both
versions will be compared to check accuracy and equivalence. Any differences that have occurred during the process are then discussed between the two bilingual researchers (McDermott & Palchanes, 1994). However, Dunckley, et al. (2003) reported that this technique is an accurate method for checking the accuracy of the translation and it is considered to be the best method for cross cultural research (Jones, Lee, Phillips, Zhang, & Jaceldo, 2001).

In current research, I chose to interpret the data myself in order to be totally immersed within the data (Dearnley, 2005), also the focus group data were checked for accuracy and validity by an additional researcher (SA) who is from an Arab origin and has a fluent understanding of the Arabic and English language. Any comments in Arabic language was translated and transcribed in English. Finally, both versions have been compared and there were no major or minor alterations that has been found. This process provided confidence that the translated English transcripts accurately captured the true meaning of the participants’ experiences. In addition, this process was especially important as meanings can be lost in translation when transcribing verbatim, particularly when some words do not exist in Arabic language or are difficult to translate (e.g. when cultural dialects are used) (Wallin & Ahlstrom, 2006).

I took steps to ensure that names were removed and that confidentiality was maintained throughout by adopting a number coding system on all the audio recording files and, verbatim transcriptions which were securely stored, password protected, on my home computer only. Additionally, hard copies of the transcriptions were stored in a locked cabinet at my home. Electronic copies were saved in a personal computer protected with a password only accessible by me.
3.8 Data Analysis

3.8.1 Quantitative Data (B-Cam)

The survey data were analysed using the Microsoft Excel software 2013 and Statistical Package for the Social Sciences (SPSS, Version 21), I entered the data into the Excel spreadsheet manually and then transferred it to the SPSS software. This Excel software was chosen as it allowed me to organize, format, filter and then display in a visual presentation. Based on the spreadsheet it was easy to manipulate, process, and view the data.

Categorical data are reported as numbers (n) and percentages (%). Chi-square/Fisher exact test was used for statistical analysis to explore any association between the generation (first or second generation) of the study participant and answering correctly the B-CAM questions. Statistical significance was considered at 5% level, where a p-value of <0.05 is considered to be statistically significant.

I constructed variable labels following the B-CAM instructions for coding and data entry. For example for Domain One “Knowledge of breast cancer symptoms”, I created variables labelled from symptom 01 to symptom 11. I recorded each symptom named by the participants using the coding frame below.
After coding and entering the symptoms named and listed according to the BCAM code list, I coded for any symptoms not on the list. To do this coding I put the next blank variable (after symp01 to symp11) as 12. No participants reported any additional symptoms. Furthermore, if the response to this question was ‘Don’t know’, or the participant did not answer, I coded for example symptom 01 -99 (Don’t know) or -98 (missing data) as appropriate, and then moved on to the next question (See the appendix 2.1 A, for data entry and coding). I also considered the variable, type of generation in the analysis by giving a different code to each generation and as a whole sample (1st generation 01, 2nd generation 02 and the whole sample 03). I double entered the data from the B-CAM questionnaire on to the spread sheet prior to analysis to check the accuracy of the data. Fortunately, no question was left blank.

The assembled data, is clearly presented with illustrative relevant tables and figures. The study objective, here was to assess the knowledge of these symptoms.
immigrant Arab women’s awareness of breast cancer warning signs and symptoms, risk factors and perceived barriers to seeking medical help.

The majority of BCAM questionnaires were closed questions comprising 7 domains. The first question is an open question aiming to find out how many early warning signs of breast cancer the woman can think of without specific prompting. However, the open question allowed the participants to add in their own responses in their own words. Following this, there is a series of closed questions about the early warning signs of breast cancer as shown in Table 10.

**Table 10: Type of questions in Breast Cancer Awareness Measure (BCAM)**

<table>
<thead>
<tr>
<th>Domains</th>
<th>Knowledge of breast cancer symptom</th>
<th>1 open and 1 closed question about warning signs of breast cancer</th>
<th>Knowledge of age-related and life time risk</th>
<th>Set of closed questions about breast screening</th>
<th>Risk factors</th>
<th>Set of closed questions about what might increase the chance of getting breast cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain 1</td>
<td>Confidence, skills and behaviour</td>
<td>3 closed questions about findings changes in breasts</td>
<td>2 closed questions about who will most likely get breast cancer and how many women will develop breast cancer in their lifetime</td>
<td>1 closed question about what might stop the women from going to doctor</td>
<td>1 closed question about seeking help</td>
<td>1 closed question about what might increase the chance of getting breast cancer</td>
</tr>
<tr>
<td>Domain 2</td>
<td>Anticipated delay in contacting the doctor</td>
<td>1 closed question about seeking help</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domain 3</td>
<td>Barriers to seeking medical help</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domain 5</td>
<td>Knowledge of breast screening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The B-CAM is a self-completion questionnaire but the researcher may deliver additional clarification for only domain one (open questions) as seen below:
Due to a number of women being illiterate in both of the focus groups, I read out five copies of the B-CAM questionnaire (Arabic version) in a private room. When I had completed reading to them I asked for verbal clarification to confirm information had been understood.

During closed questions, I did provide prompt questions. When the participants asked for an explanation, I read out the relevant ‘Explanation’ if necessary, standard explanation provided under some of the questions. Only few women asked for a relevant explanation, which I read out to them.

3.9 Results of -BCAM Questionnaire

3.9.1 Domain 1: Knowledge of Breast Cancer Symptoms

Comprised one open question and a sequence of closed questions about the initial warning signs of breast cancer.

Open Question

In spite of using prompt questions and giving sufficient more time to the participants across the two focus groups to consider their answers, the e open
question section was limited to a poor response as only half (8 out of 16 participants of Portsmouth focus group) and just under a quarter of the London focus group participants (5 out of 18 participants) completed this open response question. The majority of the participants either reported that they didn’t know or left the question unanswered. Among the 13 (38%) women who answered the open question across both focus groups, only 6 women correctly identified two of the signs and symptoms of warning signs of breast cancer. Despite correctly identifying two warning signs, these women also provided some inaccurate signs and symptoms.

Of the six who responded, they reported, correctly two breast cancer warning signs, namely that of swelling of the breast is one of the breast cancer warning signs (46%), as well as breast rash (38.5%) However, as well as correctly identifying breast cancer warning signs, all thirteen (38%) women also suggested that high fever, chest pain and loss of appetite were breast cancer warning signs which, according to current guidance, are not seen as relevant warning signs of breast cancer. (Table 11).

Table 11: Percentage of Participants Having Correct and Incorrect Knowledge of Breast Cancer Warning Signs N=13 out of 34

<table>
<thead>
<tr>
<th>Warning Signs</th>
<th>Frequency</th>
<th>%</th>
<th>Warning Signs</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swelling of the breast</td>
<td>6</td>
<td>46</td>
<td>High fever</td>
<td>13</td>
<td>38</td>
</tr>
<tr>
<td>Breast rash</td>
<td>5</td>
<td>38.5</td>
<td>Chest pain</td>
<td>13</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Loss of appetite</td>
<td>13</td>
<td>38</td>
</tr>
</tbody>
</table>
Close Questions

It is a series of closed questions about the early warning signs of breast cancer. The researcher may provide further clarification or explanation for three of the questions as shown below, if the woman says she could not understand what the researcher mean by the question.

- Do you think a change in the position of your nipple could be a sign of breast cancer? [Explanation]: such as pointing up or down or in different direction to normal
- Do you think pulling in of your nipple could be a sign of breast cancer? [Explanation]: where the nipple no longer points outwards but into the breast
- Do you think pain in one of your breasts or armpit could be a sign of breast cancer?
- Do you think puckering or dimpling of your breast skin could be a sign of breast cancer? [Explanation]: like a dent or orange peel appearance
- Do you think discharge or bleeding from your nipple could be a sign of breast cancer?
- Do you think a lump or thickening in your breast could be a sign of breast cancer?
- Do you think a nipple rash could be a sign of breast cancer?
- Do you think redness of your breast skin could be a sign of breast cancer?
- Do you think a lump or thickening under your armpit could be a sign of breast cancer?
- Do you think changes in the size of your breast or nipple could be signs of breast cancer?
- Do you think changes in the shape of your breast or nipple could be signs of breast cancer?

The correct answers are that all can be signs of breast cancer
The possible answers to the closed questions in this section were: “yes”, “no”, or “don’t know”. All participants in both groups answered this close questions. 

Table 12 shows the response rate of six Immigrant Arab Women’s correctly identified breast cancer warning signs.

**Table 12: Responses Rate of Six Correctly Identified Warning Signs out of the List of 11 among Immigrant Arab Women N=34**

<table>
<thead>
<tr>
<th>Breast cancer warning signs (6 warning signs correctly identified out of the list of 11)</th>
<th>Frequency</th>
<th>Response rate %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain in one of the breasts/armpit</td>
<td>33</td>
<td>97%</td>
</tr>
<tr>
<td>Redness of breast skin</td>
<td>21</td>
<td>62%</td>
</tr>
<tr>
<td>Modification that occur in the shape of breast or nipple</td>
<td>16</td>
<td>47%</td>
</tr>
<tr>
<td>Nipple rash</td>
<td>14</td>
<td>41%</td>
</tr>
<tr>
<td>Discharge or bleeding from breast nipple</td>
<td>14</td>
<td>41%</td>
</tr>
<tr>
<td>Lump or thickening in the breast</td>
<td>12</td>
<td>35%</td>
</tr>
</tbody>
</table>

There are 11 potential warning signs listed for the above closed question responses, but the women correctly identified only six of them. The most frequently recognised correct symptom was pain in one of the breast/armpit (97%). Following by other correct symptoms identified by 62% of immigrant Arab women who recognised that the redness of breast skin is a potential warning sign for breast cancer. In addition, 47% of women responded correctly selecting that modification in the shape of the breast or nipple was a breast cancer warning sign. Nipple rash and discharge or bleeding from the breast nipple were also correctly identified by 41% of women and lump or thickening in the breast by 35%. Whilst correctly identifying the above warning signs there were a number of other five warning signs such as change in the position of breast nipple, pulling in the
nipple, puckering or dimpling of breast skin, lump or thickening under the armpit and change in the size of breast or nipple which were not correctly identified by any of the women.

Figure 16 below shows the frequencies and percentages of immigrant Arab women in both first and second generation (13 and 21) having correct knowledge of five or more non-lump associated symptoms. Results showed that Immigrant Arab women belonging to the second generation were more likely to recognise the five or more non-lump symptoms in comparison to women belonging in the first generation (57% Second Generation versus 23% First Generation).

![Figure 16: Frequencies and Percentages of Immigrant Arab Women Recognising Five or more Non-Lump Symptoms by Type of Generation (First and Second Generation)](image)

3.9.2 Domain 2: Confidence, Skill and Behaviour in Relation to Detecting a Breast Change

Question 1: Frequency of Breast Checking

An additional close question was asked about frequency of breast checking behaviour by asking:
How often do you check your breasts?

(Rarely or never), (At least once every 6 months), (At least once a month), (At least once a week)

The correct Answer: “At least once a month”

(Breast awareness is about women knowing how their breasts look and feel normally so that they feel confident about noticing any changes that might be unusual for them)

Figure 17 below shows the percentages of first and second generation immigrant Arab women who answered the question regarding the frequency of breast checking. The correct answer would be checking their breasts at least once a month for the total sample and by type of generation. Just six women (18% of all first and second generation women) claimed to examine their breasts a minimum of once per month. However, the results show that 15% of the immigrant Arab women from the first generation were less likely to examine their breasts at least once a month compared to 19% of the second generation. These results propose that the Arab women are unaware of the breast awareness messages.

Figure 17: Frequencies and Percentages of Immigrant Arab Women Checking their Breast at Least Once a Month
Question 2: Confidence to notice a change in breasts:

This question asked was:

*Are you confident you would notice a change in your breasts?*

The women selected one of four options:

(Not at all confident), (Slightly confident), (Fairly confident), (Very confident).

Figure 18 shows the percentages of immigrant Arab women confident to detect a change in their breasts.

![Figure 18](image)

Figure 18: Comparison of first and second generation of immigrant Arab women responses for the categories related to their confident to notice a change in their breasts.

No participants reported being fairly or very confident in noticing any change in their breast, with 32% were slightly confident, but the majority 68% of immigrant Arab women were not at all confident in noticing a change in their breasts. There were some differences between the generations; 31% of first generation women are ‘slightly confident’ compared to 33% of second generation women and 69% of first generation and 67% of second generation women ‘not at all confident’.
3.9.3 Domain 3: Anticipated Delay in Seeking Help:

The aim of this question posed was to assess to what extent women thought they might defer seeking medicinal help in the wake of finding a breast change. The question asked to the immigrant Arab women was:

If you found a change in your breasts, how soon would you contact your doctor?

1-3 days, 4-6 days, 1 week, 2 weeks, 1 month, 6 weeks, 3 months, 6 months, 12 months and never

“Correct Answer” The women should contact their doctor’s surgery within a few days of discovering a breast change.

Figure 19 below shows the percentages answering this question by 1st and 2nd generation.

Figure 19: The Percentages of Answering Correctly Anticipated Delay in Seeking Help.

Second generation women were more likely than first generation women to correctly identify the answer (57% selected 1-3 days and 43% 4-6 days versus
8% & 31%). However 62% of first generation immigrant Arab women reported that they would never contact their doctor if they discovered a breast change.

3.9.4 Domain 4: Barriers to seeking medical help

The aim of the closed questions here was to assess the barriers faced by women when seeking medical attention with various breast cancer symptoms. The range of answers they were required to give included “yes often”, and “yes sometimes” or “no” to each statement.

The range of answers were about what may prevent the participant from going to the doctor. The question and potential responses are set out below:

```
“Could you say if any of these might put you off going to the doctor?

- Service barriers
  - Worried about wasting the doctor’s time
  - I find the doctor difficult to talk to
  - Difficult to make an appointment with the doctor

- Practical barriers
  - Too busy to make time to go to the doctor
  - Too many other things to worry about
  - Difficult to arrange transport to the doctor’s surgery

- Emotional barriers
  - Too embarrassed to go and see the doctor
  - Too scared to go and see the doctor
  - Not feeling confident talking about my symptom with the doctor
  - Worrying about what the doctor might find may stop me from going to the doctor
```

Figure 20 below shows the percentages of women responding “yes often” or “yes sometime” to each possible reason for putting off going to the doctor by generation.
The most frequently identified barriers (faced by first and second generation women when seeking breast cancer medical care) appears to be focusing on emotional and practical barriers rather than services barriers. Nonetheless, there were some differences between first and second generation in reporting these barriers. The first generation women stated they were ‘too scared to go and see the doctor” more often than second generation (92% versus 80%), and also were more likely to “‘worry about what the doctor might find’ (92% versus 76%) than the second generation women. The biggest concern for second generation women, was that of “embarrassment to go and see the doctor”.

Figure 20: Proportions of Immigrant Arab Women from Both Focus Groups Reporting Reasons for Putting off Going to the Doctor by Type of Generation
Similar responses were around the practical barriers with some differences between first and second generation. Both considered themselves too busy to make time to go to the doctor (90% versus 86%) and having too many other things to worry about (85% versus 82%). However, women from first generation were more likely to report difficulties arranging transport than second generation (70% versus 50%). The first generation also considered communication with their doctor particularly difficult reporting ‘I find my doctor difficult to talk to’ almost four times more frequently than the second generation (70% versus 18%).

3.9.5 Domain 5: Knowledge of age related and lifetime risk

**Question 1: Age related risk:** Immigrant Arab women were asked:

In the next year, who is most likely to get breast cancer?
A 30 year old woman/A 50 year old woman/A 70 year old woman/A woman of any age

The correct answer to this question is “a 70 year old woman”

Figure 21 below shows the frequencies and percentages giving the correct answer (70 year old woman) by generation (first and second) and the total sample.
Figure 21: Percentages of First and Second Generations of Immigrant Arab Women Correctly Identifying a 70 Year Old Woman as at Greatest Risk for Breast Cancer

Overall, 53% of immigrant Arab women appropriately identified a 70 year old woman as at higher risk of breast cancer. Second generation women were more likely than first generation women to correctly identify a 70 year old woman as at most risk, 38% of all (n=13) first generation women and 62% of all (n=21) second generation women (62% versus 38%). It was apparent that women belonging to the second generation were more aware of increasing age as high risk of breast cancer than the first generation.

Question 2: Lifetime risk

Immigrant Arab women from both generation were asked?

How many women will develop breast cancer in their lifetime?

1 in 3 women/1 in 9 women/1 in 100 women/1 in 1000 women

The correct answer is that about 1 in 9 women will develop breast cancer during their lifetime.
Figure 22 below, shows the percentages answering this question correctly (1 in 9) for the total sample (N=34) by type of generation.

![Graph showing percentages of Immigrant Arab Women Correctly answering “1 in 9” for how many women develop breast cancer in their lifetime by Type of Generation.]

Overall, 47% of respondents from both first and second generation correctly answered 1 in 9 women will develop cancer in their lifetime. First generation women were less likely than second generation women to answer 1 in 9 correctly (38% versus 52%).

3.9.6 Domain 6: Knowledge about NHS breast cancer screening program

In this domain, there were three types of questions to measure the immigrant Arab women’s information of the NHS Programme about breast screening and whether they have had attended breast screening as part of the NHS Breast Screening System.

**Question 1: Knowledge of NHS Breast Screening Programme**
Up to 2010, in the UK women are asked to attend for breast cancer screening after the age of 50 years and up to 70 years at every three years. The government is planning to extend the age range for routine breast screening to include women from age 47 to 73. This has started in some areas and the plan is for full nationwide rollout by 2016 (Breast cancer care, 2012). Figure 23 below shows the knowledge of immigrant Arab women toward NHS Breast Cancer Screening Programme.

Figure 23: The Knowledge of Immigrant Arab Women toward NHS Breast Cancer Screening Programme
In total (56%) of immigrant Arab women from both generations knew about the NHS Breast Screening Programme. Immigrant Arab women from the second generation were more likely to know of the existence of the NHS Breast Screening Programme than the first generation women (71% versus 31%). Of the total participants 19 (56%) women who knew about the NHS Breast Screening Programme, only 3 (9%) women had attended NHS breast cancer screening.

**Question 2: Knowledge of the Ages at Which Women are First and Last Invited for Screening on the NHS Breast Screening Programme:**

Figure 24 below shows the percentages of immigrant Arab women who gave the correct responses to enquiries regarding the ages, at which women are called for NHS Breast Screening both as a total sample (N=34) and by type of generation.

![Figure 24: The Correct Response to Enquiry Regarding the Ages, at Which Women Are Called for NHS Breast Screening (47-73).](image_url)
In total, only 32% of women from both generations provided a correct response (47-73 years old) to the inquiry "At what age are women first and last invited to the NHS Breast Screening Program?"

The first generation immigrant Arab women were less likely than second generation women to give the right responses with 23% of first generation women versus 38% second generation women giving the correct answer regarding ages for the first and last routine appointment to attend NHS breast screening service.

3.9.7 Domain 7: knowledge of risk factors

These questions in this domain aimed to assess women’s knowledge of breast cancer risk factors. These questions asked “Do you agree that each of these risk factors can increase the chance of getting breast cancer? Table 13 shows the percentage of immigrant Arab women having correct knowledge about risk factors of breast cancer (N=34).

Table 13: Percentage of Immigrant Arab Women Having Correct Knowledge about Risk Factors of Breast Cancer (N=13 1st Generation and 21 2nd generation, Total=34)

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>1st Generation</th>
<th>2nd Generation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Having a close relative with breast cancer</td>
<td>8 61%</td>
<td>13 62%</td>
<td>21 62%</td>
</tr>
<tr>
<td>Alcohol drink</td>
<td>7 53%</td>
<td>13 62%</td>
<td>20 59%</td>
</tr>
<tr>
<td>Family history of breast cancer</td>
<td>6 46%</td>
<td>12 57%</td>
<td>18 53%</td>
</tr>
<tr>
<td>Lack of physical exercise</td>
<td>5 38%</td>
<td>10 48%</td>
<td>15 44%</td>
</tr>
<tr>
<td>Hormone replacement therapy</td>
<td>1 8%</td>
<td>3 14%</td>
<td>4 12%</td>
</tr>
<tr>
<td>Having children later on in life or not at  all</td>
<td>1 8%</td>
<td>2 10%</td>
<td>3 9%</td>
</tr>
<tr>
<td>Late menopause</td>
<td>0 0</td>
<td>3 14%</td>
<td>3 9%</td>
</tr>
<tr>
<td>Early menarche</td>
<td>0 0</td>
<td>2 10%</td>
<td>2 6%</td>
</tr>
<tr>
<td>Obesity</td>
<td>0 0</td>
<td>2 10%</td>
<td>2 6%</td>
</tr>
</tbody>
</table>
Altogether, 61% and 62% of immigrant Arab women from first and second generations responded correctly that having a nearby relative with breast disease as a possible risk factor for breast cancer with 46% (1\textsuperscript{st}) and 57% (2\textsuperscript{nd}) identified that family history is a main risk factor for breast cancer. Likewise 53% and 62% were mindful of alcohol drink as a risk factor. In addition, 38% (1\textsuperscript{st} generation) and 48% of 2\textsuperscript{nd} generation women were aware that absence of physical exercise is another risk factor for the breast cancer. Additionally 8% (1\textsuperscript{st}) and 14% (2\textsuperscript{nd}) generation women were aware of hormone substitution treatment as other danger elements of breast cancer.

Even less well known, across all generations was the potential risk factors of having children later on in life, or not at all, late or early menarche and obesity with less than 10% being aware of these risk factors. All of those who did respond were second generation. No first generation women were aware of these particular risk factors.

**Chi-squared Test Results (p-value):**

Categorical data are reported as numbers (n) and percentages (%). Chi-square/Fisher exact test was used for statistical analysis to see if there was any association between the generation of the study participant and answering correctly the B-CAM questionnaires. Statistical significance was considered at 5% level, where a p-value of <0.05 is considered to be statistically significant.

More than half of second generation Arab women (57%) recognised five or more none lump breast cancer symptoms and they answered correctly anticipated delay in seeking help. Similarly, 62% correctly identified that a 70 years old woman was at greatest risk for breast cancer and answering 1 in 9 to the question...
about breast cancer lifetime risk (52%). The second generation were more knowledgeable regarding the existence of the NHS breast cancer screening programme (71%). The same with other questions regarding the age at which women are called for NHS breast screening, confidence to note a change in their breasts and checking their breast at least once a month.

The results, however suggest that there was statistically significant association between the generation of the study participant and the question about anticipating delay in seeking help (p-value < 0.05). But there were no statistically significant associations between the generation and the other questions (p-value>0.05) as depicted below in Table 14.

Table 14: Chi-squared results: Number and Proportion of 1st and 2nd generation Immigrant Arab Women correctly answering BCAM questions

<table>
<thead>
<tr>
<th>B-CAM Questionnaire</th>
<th>1st Generation</th>
<th>2nd Generation</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognising five or more non-lump breast cancer symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (23%)</td>
<td>12 (57%)</td>
<td>0.079</td>
</tr>
<tr>
<td>Checking their breast at least once a month</td>
<td>2 (15%)</td>
<td>4 (19%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Slightly confident to notice a change in their breasts</td>
<td>4 (31%)</td>
<td>7 (33%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Answering correctly anticipated delay in seeking help (1-3 days)</td>
<td>1 (8%)</td>
<td>12 (57%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Correctly identifying a 70 years old women at greatest risk for breast cancer</td>
<td>5 (38%)</td>
<td>13 (62%)</td>
<td>0.291</td>
</tr>
<tr>
<td>Correctly answering “1 in 9” for how many women develop breast cancer in their life time</td>
<td>5 (38%)</td>
<td>11 (52%)</td>
<td>0.497</td>
</tr>
<tr>
<td>Knowledge of the existence of the NHS breast screening programme</td>
<td>4(31%)</td>
<td>15 (71%)</td>
<td>0.34</td>
</tr>
<tr>
<td>The correct response to enquiry regarding the ages, at which women are called for NHS breast screening (47-73)</td>
<td>3(23%)</td>
<td>8(38%)</td>
<td>0.465</td>
</tr>
</tbody>
</table>
3.9.8: Discussion of BCAM Findings

The aim of the BCAM survey was to investigate the level of breast cancer awareness knowledge among immigrant Arab women in England. As regards to awareness of breast cancer warning signs, pain in one of the breast/armpit was the most frequently identified symptoms of breast cancer by participants 97%, also they were aware of other breast cancer warning signs such as redness of breast skin 62%, modification in the shape of the breast or nipple 47% and nipple rash and discharge or bleeding from the breast nipple 41%. Knowledge of other warning signs of breast cancer was not recognised by all participants such as a painless breast lump, lump under the armpit, and dimpling of the breast skin, nipple retraction, change in the position of breast nipple and change in the size of breast.

In contrast to previous research conducted by Grunfeld, Ramirez, Hunter & Richards, (2002) among 996 of general female population in UK, the researchers found that a painless breast lump, lump under the armpit, and dimpling of the breast skin, nipple retraction or nipple eczema as symptoms of breast cancer. The results of current study are important, as it might be an evidence to suggest that one of the major determinants of delay behaviour among Arab women is the discovery of redness of breast skin and modification of breast or nipple rather than discover of a painless breast lump. In line with previous work (Facione and Dodd, 1995) our results demonstrate that although some of breast cancer symptoms is equated with a potential cancer, other potentially serious symptoms may be misinterpreted.
Regarding awareness of five or more non-lump symptoms of breast cancer risk factors, the women belonging to the second generation were more likely to recognise the five or more non-lump symptoms in comparison to first generation (57% versus 23%). This finding is consistent with a randomised controlled trial of an intervention to promote early presentation including 867 women recruited from seven breast screening units in London and Surrey. The women aged 67-70 years and attending for their final routine appointment on the UK NHS Breast Screening Programme to receive: a scripted 10-min interaction with a radiographer plus a booklet, a booklet alone or usual care. The objective of the randomised controlled trial was whether or not a woman was breast cancer aware based on knowledge of breast cancer symptoms and age-related risk, and reported breast checking. The baseline of breast cancer awareness was 4% (Linsell et al., 2009).

Furthermore, North East London Cancer Network carried out a survey of breast cancer awareness among 1,515 women aged 30 and over in the City of London and the London Boroughs of Hackney, Tower Hamlets, and Newham, using the Breast Module of the Cancer Research UK Cancer Awareness Measure. The women from different ethnic groups (White, Asian, and Black) were invited to complete the Breast Cancer Awareness Measure using a face-to-face, computer-assisted interview. The survey found that the women belonging to Asian ethnic groups were very much less likely to recognise five or more non-lump symptoms than white women (11% versus 22%) and women belonging to black ethnic groups were also less likely to recognise five or more non-lump symptoms than white women (11% versus 22%) (Forbes, et al., 2010).
An alternate survey was intended to explore the knowledge of 1402 women in Iran, Tehran regarding breast cancer and self-reported practice of breast self-examination. Data were collected via a structured questionnaire containing 15 questions on demographic status, history of personal and family breast problems, subjective knowledge about breast cancer covering its symptoms, the screening methods and practice of breast self-examination (BSE). The survey found that 64% of the women were familiar with breast cancer and 61% believed that 'the disease is relatively common among women in Iran'. Most women (44%) perceived (a painless mass, retraction of nipple, and bloody discharge) as a breast cancer symptom (Montazeri et al., 2008).

On other hand, the findings of current study is in contrast with what was reported by Habib, Salman, Safwat & Shalaby (2010) in their study of awareness and knowledge of breast cancer among 247 university students in Al Medina Al Munawara region in Saudi Arabia, which revealed that students were aware of painless lump in the breast, bloody or any discharge from the nipple and changes in the skin of the breast as the most common warning signs of breast cancer.

The findings showed an inadequate awareness about breast cancer symptoms among Immigrant Arab women in England. This finding is congruent with a previous survey conducted in 2005 which looked at the levels of breast awareness from a population of women from black and minority ethnic groups (Indian, Pakistani, Bangladeshi, Black African, Black Caribbean, Chinese and Irish), older age groups and people from socially disadvantaged backgrounds contrasted with the Britain’s general population. Approximately 33% of the BME women who partook in the review said they didn't feel they had adequate knowledge about breast cancer, equating to over twofold the rate of ladies from
the overall public (15%) (Scanlon & Wood, 2005). Additionally the investigation found that 38% of BME respondents accepted that the only symptom of breast cancer is a lump, in contrasted with 22% in the general population. Other populations that were more inclined to hold this perspective included 31% of women of aged 65 and over and 30% of women from socially disadvantaged backgrounds. The best informed women were those of the general population aged between 50-64 years, a population most likely to receive information about signs and manifestations when called for regular breast screening (Scanlon & Wood, 2005).

Regarding awareness of breast checking, only 18% of all women (N=34) claimed to examine their breasts a minimum of once per month. First generation were less likely to examine their breasts at least once a month compared to the second generation (15% versus 19%). The results from the BCAM questionnaire again reflect similar findings to a study carried out in 2005 which examined levels of breast awareness among women from black minority ethnic groups in Britain; results indicated a large portion of (43%) of BME women claimed a lack of practice in breast awareness by examining their breasts, compared to a much smaller percentage (11%) of the general population. In this study not knowing what to look for was the primary reason given by 56% of BME women; different reasons included neglecting to check, fear, being unaware that they ought to and not trusting it was vital at their age (Scanlon & Wood, 2005). One of the major promoters in breast cancer examination and delivering the message of the necessity for regular examination has been that provided by health care providers. Prior studies report that breast awareness practice suggested by a physician was the single strongest indicator of breast cancer screening breast
awareness behaviour (Dundar, Ozmen & Ozturk, 2006; Friedman, Moore, Webb & Puryear, 1999). Numerous studies conducted in different regions in Saudi Arabia investigated female knowledge and attitudes towards breast cancer; discoveries uncovered include absence of comprehension of the significance of breast self-examination and under-used mammography screening (Abdel Hadi, 2000; Alam, 2006; Dandash and Al-Mohameed, 2007).

In the present study, more than half of Arab women (68%) were not at all confident in noticing a change in their breasts with 32% of all women slightly confident. Similar levels of confidence were found across the generations. Although a small group, representative of Arab women none were found to be very confident. Levels of confidence differ somewhat to those found in a previous BCAM survey conducted by Forbes, Atkins & Ramirez (2010) who found that overall, about half of the 1,390 general UK native population who answered the question “Are you confident would notice a change in your breasts?” reported that they were fairly or very confident that they would notice a change. While Asian and black women were more improbable than white women to be confident to notice any breast changes (45% versus 48% versus 58%), but this was only statistically significant for Asian women. Furthermore, the proportions in each Asian and black ethnic subgroup who reported that they were confident to notice a breast change were specifically Indian (53%), Pakistani (54%), Bangladeshi (42%), other Asian (50%), black Caribbean (54%) and black African (49%).

Second generation women in this current study were more likely than first generation women to answer correctly, anticipated delay in seeking help (1-3 days) (57% versus 8% ). The result was statistically significant association between the first and second generations (p-value < 0.05). But there were no
statistically significant associations between the generations and the other questions (p-value>0.05). However, it should be noted that the sample size was small. The findings of the current study contrast with those of a previous cancer (CAM) survey by Waller, et al (2009), that found that African group showed poorest recognition of symptoms, but were nevertheless most likely to anticipate seeking help quickly across cancer symptoms. Furthermore, in BCAM survey conducted previously, Forbes, et al. (2010) also found that of the 1,467 women living in inner North East London who answered the question about how soon they would contact their doctor if they found a change in their breast, 73% responded that they would contact their doctor a week or sooner, 25% between one and six weeks and 1% after more than six weeks. Delays in seeking medical advice and diagnosis are a major concern. The most frequently reported barriers to going to the doctor with a symptom that might be serious was emotional and practical barriers. The first generation women were more likely to report these barriers than second generation women. The most commonly emotional barriers reported were ‘too scared to go and see the doctor’ and ‘worry about what the doctor might find’. While the practical barriers were ‘difficulties arranging transport’, ‘too busy to make time to go to the doctor’ and having too many other things to worry about. The only services barrier reported by first generation women was ‘I find my doctor difficult to talk to’, this barrier could be related to the ability to speak English language.

Current barriers for Arab women to accessing breast cancer care and going to the doctor appears to be around emotional and practical barriers rather than services barriers. The qualitative study raised important contextual issues around services barriers such as lack of appropriate gowns and perceived lack of cultural
competence of healthcare professionals, feelings of being targets of racism and discrimination, unfamiliar with existing services, inaccessible language as a source of communication barriers, unavailability of Arabic breast cancer information, perceived lack of privacy and availability of female physician and a referral system seen as too complex. Consistent with these findings, a study with a similar design conducted by (Forbes, et al., 2010) found that there were significant differences between ethnic groups in the proportions who reported some barriers. Asian women were much more likely than white women to report that worry about what the doctor might find, embarrassment and, in particular, not feeling confident talking about their symptom might put them off going to the doctor. Embarrassment was reported by 59% of Indian women, 46% of Pakistani and 66% of Bangladeshi women. Worry about what the doctor might find was reported by 46% of Indian women, 63% of Pakistani and 69% of Bangladeshi women. Not feeling confident talking about their symptom was reported by 53% of Indian women, 49% of Pakistani and 59% of Bangladeshi women. It was also observed that all non-white women were less likely than white women to report that they would be worried about wasting the doctor’s time. Over 50% of white women reported that worry about wasting the doctor’s time might put them off going to the doctor for a symptom that might be serious (Forbes, et al., 2010).

In the current study, more than half of Arab women from both generations knew that a 70 year old women was at greater risk of breast cancer than a younger woman. According to the type of generation, the second generation women were more likely to know the correct answer than the first generation women (62% vs 38%). This finding is in an agreement with what was found in the national survey in 2000, when 30% of women recognised older age as a risk factor for breast
cancer (Grunfeld, Ramirez, Hunter, Richards 2002). This finding is also consistent with what was reported by Forbes, et al. (2010) in their study, which revealed that Asian women were more likely than white women to accurately recognise a 70 year old woman as at greatest risk (23% versus 11%). Furthermore, Scanlon and Wood, (2005) conducted a study to investigate breast awareness, breast cancer knowledge and understanding, and breast awareness behaviours among women from different black and minority ethnic groups in Britain. Face-to-face interviews were conducted with 816 BME women, and telephone interviews were conducted with 552 women from the general population. Scanlon and Wood (2005) likewise found that nearly around half of the BME women (53%) did not realize that the danger of breast cancer increases with women when they getting older, contrasted to (21 %) of them from common populace. Besides, (24 %) which is consider as higher quantities of socially disadvantage women were un aware that the danger of breast cancer increase with age, contrasted with (19 %) of general population women.

Less than half of the immigrant Arab women across both generations correctly identified the lifetime risk of breast cancer as 1 in 9. The reason for this may be due to the Arab women correctly analysing their own risk to be lower; since studies have shown that Arab women living in their own country are less inclined to developing breast cancer (Amin, 1990).

This finding is consistent with what was reported by Grunfeld, Ramirez, Hunter & Richards, (2002), the researchers assessed knowledge and beliefs of breast cancer and examine age and socio-economic variations in responses among 996 women in UK. The participants were too optimistic regarding a woman's risk of developing breast cancer, 31% reporting that a woman had a 1 in 1000 chance
of developing breast cancer, 35% reporting a one in 100 risk and 23% correctly indicating a 1 in 10 risk.

First generation women were much less likely to have a good knowledge of the NHS Breast Screening Programme than the second generation (31% versus 71%). In previous research conducted by Forbes, et al. (2010), using the BCAM version 3 questionnaire they found that overall, 52% of the 1,390 general UK based population know of the existence of the NHS Breast Screening Programme. Asian women, in particular, were much less likely than white women to know of the Programme. However, about the same proportion of Pakistani women know of the existence of the NHS Breast Screening Programme as white women, but only 46% of Indian and 29% of Bangladeshi women answered “yes” to the existence of the NHS Breast Screening Programme.

In another study conducted by (Radi, 2013) among 200 Saudi females aged 20 and older living in Jeddah/Saudi Arabia the researchers set out to measure the knowledge of breast cancer warning signs, risk factors, screening programs and breast self-examination (BSE) using the Arabic version of the Breast Cancer Awareness Measure (Breast CAM V.2). The study found that Saudi females had inadequate knowledge about breast cancer screening program and BSE. The majority 71.5% were aware of the availability of breast screening program, while only 27.0% were invited for breast screening program and 20.5% had undergone breast screening on breast screening program.

In the current study, regarding the right responses to the correct age that the women are initially invited to attend breast screening, all Arab women responded incorrectly to less than half of the correct answers (47-73 years old), this was lower in the older first, generation women compared to the younger second
This finding is consistent with that reported by Forbes, et al. (2010) in their BCAM survey of awareness of breast cancer among women living in inner North East London. The study revealed that Asian women were significantly less prone to give the right responses to the inquiries concerning the ages at which women are first and last welcomed to the NHS Breast Screening System than white women. Likewise, they found that black women were less inclined to give the right reply about the last welcome to screening than white women. Furthermore, (Vahabi, 2010) in her a cross-sectional exploratory study assessed breast health knowledge and practices among Iranian immigrant women residing in Toronto. The study among 50 adult women with no history of breast cancer found that about 50% of the study participants did not know the recommended time interval for screening mammography.

Regarding awareness of breast cancer risk factors, in current study, more than half of first and second generation knew about having a close relative with breast cancer as established risk factor for the breast cancer (61% & 62%). While the second generation were more aware about family history as a risk factor than the first generation (57% vs 46). Also the same thing were with risk factors of alcohol drink (62.0% vs 53%) and absence of physical exercise (48% vs 38%). However, knowledge of other risk factors of breast cancer (late menopause, early menarche and obesity) were not recognised by first generation women. This finding is in concurrence with what was accounted for by Alam (2006) in her investigation of information of breast cancer and its risk factor and preventive variables among 864 ladies in Riyadh; she reported heredity and hormone substitution treatment as common breast cancer danger components as responded by women in
Riyadh. Furthermore, this finding is in agreement with what was reported by Grunfeld, Ramirez, Hunter & Richards, (2002) among 996 women in UK, the researchers found that women had limited knowledge of their relative risk of developing breast cancer, a family history of breast cancer and a personal history of breast cancer were the most frequently cited risk factors, whereas less than one third recognised the role of advancing age.

The findings in this study provide evidence of the specific lacks in breast cancer awareness and obstacles to early presentation that can be used to design interventions to promote breast cancer awareness and early presentation among immigrant Arab women.

3.10 Part 3: Qualitative Data Analysis

Once the two focus groups were completed, both focus group discussions audio tape recordings were transcribed verbatim. I carefully listened to each of the original audio-taped focus group discussions and compared the recording with the relevant transcript to check for accuracy. Field notes which I had written it in the Arab women’s mother language (Arabic) were translated by me, into English and then transcribed.

Auditing transcripts recognises that qualitative data analysis starts immediately after focus groups discussion have taken place and continues with accurate listening, reading, and initial themes were recognised from the transcribed data (Miles & Huberman, 1994). This checking was greatly important to be familiar and more close to the research data (Boyatzis 1998). On the other hand, it was a long procedure, though I believed that it was vital to guarantee the precision of
transcription. In addition, as I went through listening to the recordings I made margin remarks directly on the transcript to begin writing of ideas that emerged. The initial plan was to analyse the qualitative data by using the qualitative computer software programme, N-Vivo 9. Although training and practicing was completed in using the N-Vivo software, the software required a 10GB hard drive which was not available at the time. Due to this setback, a separate method for qualitative analysis was adopted; the transcripts were analysed manually using the thematic analysis (Braun & Clarke, 2006). Whilst it can be argued that qualitative computer software, such as NVivo, can be time proficient in term of coding and writing coding reports, I felt "closer to the research data" utilizing the thematic analysis approach. Others have proposed comparable usefulness to manual coding (Dean and Sharp, 2006).

Inductive thematic analysis by Braun & Clarke (2006) was utilised for the analysis of the two focus group datasets. Thematic analysis is a strategy for distinguishing, analysing and reporting themes within research data (Braun & Clarke 2006). This method was utilized on the grounds that it permitted me to complete a comprehensive analysis and recognise related and appropriate themes that can catch the participant’s thoughts of the usefulness of current educational material (NHS and Breast Cancer Care Charity produced leaflets) and capture the factors that motivate them to be aware of breast cancer.

The process of thematic analysis is not connected to one specific hypothetical outline, thus supporting its usage in this qualitative research. Backwards to literature review chapter, the breast cancer studies among ethnic minority groups showed that women’s social and cultural beliefs and attitude is influential in the way that breast cancer and its awareness information is experienced. In view of
this, the strategy of thematic analysis focused on a contextualise epistemology; at time that I was wanted to comprehend the Arab women’s thoughts of the usefulness of breast cancer awareness leaflets through individual and greater social and cultural condition.

The semantic level was adopted to conduct the thematic analysis. Through which I extracted clear and understandable meanings represented in the research data. This required the information to be defined, outlined. After that, clarifying the data linking it to more extensive implications and suggestions; and expressed its connection to earlier relevant studies (Patton, 2002). Thematic analysis has been condemned as being excessively ambiguous in its technique (Holloway & Todres, 2003).

On the other hand, Attride-Stirling (2001) contends that the research data ought to be defined in an orderly way to increase expressive and valuable findings. To overwhelmed criticisms inside thematic analysis, I followed the six reasonable and point-by-point key stages of Braun and Clarke's (2006). The deliberate organized methodology was followed as well in phase 1 of the present study.

Braun and Clarke (2006) recommend to use an inductive method in the process of analysis because it's firmly connected to the data itself from the transcriptions step. Therefore, I employed to analyse the transcript data of two focus groups.

Firstly, in phase with familiarising with data, each transcript was read thoroughly, several times, whilst making notes where appropriate. However, in phase 2, generating initial codes, in this phase, interesting extract parts were distinguished concerning any outstanding opinions or developing points through reading and re-reading the transcript data very carefully. Through reading the data
transcription, I was eager to recognise the more logical and explicit extract instead of a latent level (Braun & Clarke, 2006). While in phase 3 of thematic data analysis, searching for themes was carried out to produce a list of codes, an additional critical look at these codes was conducted in order to gather them into potential themes. This was done by creating a map of the codes and themes. At that point, in phase 4 within reviewing themes, all the themes were revised in excessive detail and additional refined to ensure that the codes were considerable to each theme. However, checking for additional coding was carried to assure if there are any codes have been missed in past stages. While in phase 5, defining and naming themes, it was achieved through re-read the transcripts data again. Both transcripts was re-read to at long last, the theme and sub-theme were checked to make sure they told a clear statement and captured the depth and breadth of the data. They were then given a concise name and defined to capture each theme. See Appendix 2.6 for a worked example of the thematic analysis process, Appendix 2.7 for Table of themes and subthemes with an example of supporting data.

In order to achieve trustworthiness, an independent researcher opened coded to make tentative main themes then we met to discuss the similarities and differences and seek clarity and agreement by discussion and consensus. See Table 15 (appendix 2.6) for steps taken to achieve trustworthiness.

3.11 Qualitative Findings

The two focus groups data were interpreted through thematic analysis which revealed highlighted four main themes with either one or two sub-themes within each main theme. The four main themes with sub-themes were:
Main Theme One: Making sense of breast cancer awareness

Sub-themes: (1) Knew nothing about it (2) What, why and how?

Main Theme Two: Leaflets format and layout

Sub-theme: (1) Positive and negative notes

Main Theme Three: Leaflets content

Sub-themes: (1) Preferred language, (2) Cultural sensitivity information

Main Theme Four: Empowerment as motivational factors

Sub-themes (1) Preferred source of information, (2) Accessibility (Availability and Displayed)

Figure 25, appendix 2.7 is a final thematic map of the defined themes, which will now be explored in more detail. For the reasons of simple understanding, I feel that it would be best to demonstrate each of the main theme with the subthemes within these.

Every theme is portrayed in detail below. Italicised fonts textual styles signify the sub-themes within each main theme. Quotes are used that best illustrate the themes. All names have been removed and replaced with numbers.

The source of the quote is referenced either to the Portsmouth Focus Group (labelled PFG) or the London Focus Group (labelled LFG). Additional analytical considerations and significance of the findings with connection to existing literature, will be investigated in the discussion section.

3.11.1 Theme one: Making sense of breast cancer awareness

This theme highlights how immigrant Arab women’s breast cancer awareness was an unfamiliar issue for them. Many Arab women had never even heard the phrase “breast cancer awareness.” While others had heard about the phrase breast cancer awareness, but were unsure what was meant by this term, how
they could practice breast awareness and from where they could get the correct
information to guide them in this practice. Discussion of this issue made most
Arab women puzzled and confused about the breast cancer awareness
information. They emphasised that it is important for them to understand all the
facts related to breast cancer and breast awareness, making sense of the
information that allows the women to practice the breast awareness measures
which in turns helps them to detect breast cancer earlier.

Sub-Theme One: ‘Knew nothing about it’

Most of the first generation immigrant Arab women had extremely restricted
information about breast cancer in terms risk factor, signs and symptoms and the
measures for early detection. Generally, they were not aware that a breast mass
or lump can be one the main signs of breast cancer disease. Likewise they had
little comprehension that practising breast cancer awareness measures and
undergoing breast cancer screening could detect breast cancer in the early
stages.

“as mention before we don’t have clear idea about what is mean by breast cancer
awareness, or the factor that helped to get this disease, no idea about even what is the
sign and symptom associated (seven women nod and say they never knew about what is
mean by breast cancer awareness and the disease itself)” PFG.11

“I never knew that we need to be aware about our breasts and if we need to be aware about
something serious related to breast cancer, we should know what the causes behind and
the main signs or risk factor for it” (six women nod and say that they agree with her) LFG.2
In contrast, the majority of second generation immigrant Arab women had more knowledge regarding the meaning of breast cancer awareness practice. In discussing breast awareness, most of the second generation women equated breast self-examination with breast awareness, they were aware that self-breast examination was one approach to breast awareness. Several second generation women declared it was of particular importance for women who had a relevant family history of cancer to conduct breast self-examination regularly:

“Breast awareness mean breast self-examination for any abnormality, such as redness and enlargement, no have much information about breast cancer, I mean the risk factor or the sign that we need to look for?” PFG 12

“Breast awareness mean to me-- breast self-examination after each menstrual period especially when you have family history of breast cancer---it’s important to be aware for these type of people, But I need to know more information about the cancer itself” (seven women nod and say that they agree with her) LFG 4

Second generation women in the focus groups had generally limited experience knowledge of the significance of physical changes that can present in the breasts and its connection to breast cancer. It could be argued that this lack of knowledge regarding symptom recognition is influenced, in part, by the lack of knowledge of the first generation; in the previous findings from Phase 1, many first generation consider breasts an embarrassing and private topic, so they tend to avoid such discussions. Not being discussed, or practiced within the first generation women could influence that of the second generation in their own r own attitude to breast awareness practice.
In addition five out of nine (Portsmouth focus group) and eight out of twelve (London focus group) second generation women made suggestions regarding the information outlined in the NHS breast screening leaflet claiming they should contain the number of various cancer affecting women (such as uterine and colon cancer) and the risk factors in association with breast cancer.

Participants stated they believed an additional risk factors not mentioned in the BCAM questionnaire was that for Arab minority women one risk factor was that of alienation, related emotions of unsettlement and difficulties of adaptation in their new environment as immigrants. Although to date, there is no proven link to suggest this as a possible cause and therefore, it cannot be put on an NHS leaflet, it does show that this is a belief held by many immigrant Arab women in this research study. Whilst acknowledging that this may not be accurate, some of the women thought that there should be some form of awareness of these beliefs within the NHS.

“I think the breast cancer NHS leaflet missed some information related to the risk factor which is specific to our situation as immigrant here, the alienation and what it caused such as stressful life and anxiety related to the difficulties of adaptation in the new country, if the women knows these factor in the leaflets, she will calm down and she will try to feel happy here” PFG 12 (four women had agree and had the same statement).

“I hope that we can see information about uterine and colon cancer as well. Some missing information I think missed out from the information which we believe it’s important as risk factor or cause of cancer….the alienation and stressful life as cause of it, adaptation and its difficulties. I’ve seen it every day around me, in my Mum eyes and all first generation parents….they should know this feeling affect their health negatively and it could be the cause behind the cancer.” LFG 16 (Seven women had agree and they had the same statement)
Sub-theme Two: ‘What, why and how?’

Due to the limited knowledge of breast cancer and its awareness, the first generation women were curious and wanting to gain some perspective and understanding regarding the definition of breast cancer awareness, the reason for the importance of breast cancer awareness and how to do it.

“we I need to know more and more about what you call it ‘Breast Awareness’ what it does mean and is every women need to know about it and how to do it, it’s really interested---we are in need for such information” (all women node and agreed with her) PFG10

“I am a member of Arab community association here for long time and I asked you in front of all women to provide us with all information that you know about breast awareness what, why and how to do it. Give as a lecture in the community” (all women node and agreed with her) LFG 13

There is a general assumption that knowledge comes from experience and that, if women had experienced breast awareness, they would have full knowledge about it. This may not be so with second generation immigrant Arab women. From the discussions within both focus groups, although women had heard about breast awareness, they did not necessarily understand the purpose of it or how to practice breast awareness. They expressed that first generation women would feel safer and encouraged to practice breast health examinations and attend breast screening if they acquired the relevant knowledge and skills.

“I use to do exam my breast while I am taking shower, but I do not know what to look for and what is the mechanism of the breast test….some time I wonder why I am doing it, to look for what …. I am not sure---if the first generation had enough knowledge you will see them practicing breast examination and they will learn us how to do it ” (her friend agreed with her) LFG 11
“It’s very helpful if we can know what is the rationale behind breast cancer awareness and also we need to know how to do it, ----yes I use to do the breast exam by myself often but not as monthly routine because I do not have enough information about it, my mum doesn’t know anything--- if she had knowledge she will be aware about breast screening and she will seek for it” (few women node and agreed with her) PFG 13

3.11.2 Theme Two: Leaflets format and layout

At the start of the focus group discussion, the breast cancer awareness and breast screening (NHS and breast cancer care charity) leaflets were distributed to all the immigrant Arab women as well as displayed on the large presentation screen. The purpose of showing the two most influential leaflets currently used to provide breast cancer awareness was to provide feedback on the format and layout of the information and the use of photographs. The format and layout of the information in the leaflets is crucial to the way in which people access the key messages. Feedback within this theme was variable. It highlights the positive and negative notes of immigrant Arab women regarding the format and layout of the breast cancer awareness leaflets (NHS and Breast Cancer Care Charity). The first and second generation immigrant Arab women favoured the Breast Cancer Care charity leaflets rather than the NHS version. They commented that the format and layout of breast cancer care leaflets was much more readable and acceptable to them in both versions Arabic and English.

Sub-theme One: ‘Positive and negative notes’
The first and second generation immigrant Arab women were positive about the Breast Cancer Care Charity information leaflets with regard to the layout and the way the tailored report was arranged in sections, and emphasized the importance of presentation and the use of colour to catch the attention. They felt that the English and Arabic version leaflets were acceptable and used effective images, as well as large font, spacing of text and bold headings used throughout the leaflets which made them easy and acceptable to use.

In contrast, most of the women felt the NHS leaflets had many negative notes regarding the layout, presentation of the information that did not use effective images, restricted to black and white colour, without bold headings, large font and adequate spacing of text. Examples of first and second generation women from both focus groups quotes are below, with the negative comments of the NHS leaflets highlighted in red:

“I like the breast cancer care leaflets rather than the NHS one; it’s colourful and bright and catches your attention but compared to the NHS leaflets which lacks for anything that draws my attention” (six women put their hand up and say we also) PFG 2

“From the first look to the both leaflets automatically you would choose the breast cancer care leaflets, looking at the NHS leaflets you can see there aren’t many images, colours and doesn’t have an attractive design, its plain when compared to other leaflets” (few women node and agreed with her) PFG 6

“I love it, I mean the breast cancer care charity leaflets, look wow to me, I like the images on it, the large font, spacing of the text, I like the colour pink with light purple (the women love this colour) but the design on the NHS leaflets don’t make me want to read more, I
could fall asleep whilst reading it” (Six women laughing and put their hand up and say we also) LFG 2

There were suggestions from both generations of immigrant Arab women for the addition of humour (e.g. caricature jokes) and an attractive visual presentation (for example: colours, pictures, and diagrams) to enrich the appeal of breast cancer awareness messages. They suggested putting up a picture of Muslim women wearing a hijab as representative on the cover of the Arabic version leaflet. In addition adding some diagrams with statistical information regarding the incidence of breast cancer among Arab population in Britain. This they felt would encourage others to be more aware about breast cancer.

“…..it would be fun if the leaflets contained some jokes like caricature type to make the subject softer and it will be some balance with the word cancer. If the leaflets include picture of you or an Arab health professional talking by her word about the subject, most or all women will pick up these leaflets (most of women nodes and agree with her)” LFG, 3, 1st G.

“In both leaflets I can’t see any statistical information as diagram, figure, writing with in the paragraphs, I need to know the breast cancer cases in our population [Arab] is it high/ do we need to worry and take an action? I think every women sitting here needs to know” (most of women from both generation nodes and say they are agree with her) PFG, 5, 1st G.

“if the leaflets had jokes, believe me every women would read it, in addition put on the Arabic version picture of Arab women wearing the Hijab on the cover of the leaflets and inside it, we trust you…put your picture with your words under it (most of women suggest to put my picture)” PFG 5, 1st G.

All of the second generation immigrant Arab women (15 out of 21) from both focus groups encouraged the addition of vital information in highlighted text boxes with
varying colours in order to prevent overlooking such information. Utilising bullet points in order to shortening information was also amongst the suggestions made in order to simplify the search for any specific information.

“Both versions of the leaflets, need to highlight the important information within the text box to prevent overseeing. In addition, using bullet points to make the information simple and easy to understand it. This is going to be useful for the women who do not have the patience to read the entire leaflet”. (First generation women agreed with her) LFG 16

“I think it’s going to be more effective if the important information were presented as bullet points and put them in the shading colour box. By this way no need to search for important information, it’s going to be clear and easy to catch it”. (Second generation agreed with her. (Most of 1st generation women agreed) PFG 3

3.11.3. Theme Three: Leaflets Content

This theme describes the language preferred for breast awareness information leaflets in order to provide culturally sensitive information, which previously, the women thought had not been used in these leaflets. They suggested that the leaflets should word the information carefully and make sure that the message can be understood. The women gave suggestions on how this can be achieved which I have illustrated in the sub-themes below.

Sub-theme One: ‘Preferred language’

The immigrant Arab women from both generations showed enthusiasm to read the content of the circulated breast cancer and breast awareness information leaflets that I provided (NHS and Breast Cancer Care). However, the first generation women felt that they would have to read the English and Arabic version several times in order to fully comprehend the sentences. The language
was thought to be too difficult with an abundance of technical terms difficult for some of the first generation Arab women to understand quickly with English being their second language. All first generation Arab women, with little exclusion, felt that the quality of translation needed to be improved. Some thought the wording too technical, and some of the words were too complex to understand; for example anatomical scientific words were used such as the collar bone in Arabic, when translated in Arabic this word is hard to know unless you have familiarity with scientific terminology in Arabic, which the participants did not possess. Eight out of thirteen of the first generation Arab women preferred the Arabic version leaflets, but still they did not agree with the translation of some words; for example the word mammogram, does not translate literally because in the Arabic language there is no word for mammogram, instead it's written the same way it's pronounced in English using Arabic letters, this proved to be confusing as the participants didn’t know the definition of the word. Using simple plain language was suggested. They felt that there was a need to incorporate simple explanations of ‘mammogram’ and the scientific terms like ‘collar bone’ in to Arabic language. They felt that this could be achieved by having a picture pointing to the collarbone.

“I read it twice but it’s still difficult for me to read the English version, to be honest I am not going to understand anything. While the Arabic version is good but there are some difficult words which I don’t know the meaning to, such as “mammogram” and “collarbone” (two women put their hand up and said that they agree with her)” PFG 8

“I need to read it many times to understand it; it’s difficult for me especially it’s containing medical terminology which I never knew about before such as mammogram, we don’t have this name in Arabic” (one women had the same statement) PFG 1
“This is the second time I've read the leaflets in both versions, I find it difficult for me to understand the English version. The Arabic version is not bad but it includes some medical words which I couldn’t understand such as mammogram”, they use the same English pronunciation in Arabic as well and the bone which I don’t know where it is “collarbone”. (Two women had the same statement) LFG 3

Although most of the women in the focus groups could read either in English, Arabic or both, five women (from the first generation of immigrant Arab women) from both groups were illiterate unable to read or write in either language. For these, they felt that images on the information leaflets might support understanding. They were predominantly in support of materials consisting of audio and video, as they preferred a lively, and possibly interactive (discussion/chat-show) format. All the second generation women, from both focus groups were educated to a level where English was not a problem or a barrier and could comprehend the leaflets as they had a better understanding of medical technical terms. Interestingly, eight out of thirteen first generation women with good levels of reading and writing, from both focus groups, also expressed a preference of listening through audio and video materials rather than current or illustrated information sheets.

“I can’t read these leaflets; the only thing that I can understand is the pictures. CD audio and video in the Arabic language is better because it helps us women to fully understand the subject, and after listening and watching the video we can have a rich discussion and raise any questions. Why not---you can do it for us in the community centre” PFG 15 (one illiterate woman lifted her hand up and had the same opinion with the rest of the first generation women)

“Is there any audio and video materials in Arabic language for illiterate people, which I am one of them LFG 7----another two women added LFG 8 & 12 “We are just about to say that,
“it’s going to be fabulous especially if you are the one responsible for it in our community centre and we will discuss the video at the end of the session”

Sub-theme Two: ‘Cultural sensitivity information’

Comments were made regarding the level of appropriateness of information provided in the leaflets. All first generation women, from both focus group, felt that the leaflets should address the issue of embarrassment which they felt is associated with breast screening. They said that many Arab women would be embarrassed having to undress to the waist during breast cancer screening and there should be measures to overcome this feeling. The participants were all of practicing Muslim faith; they explained that in their faith they cannot wear the same medical gowns offered to other patients when examined. The attire they preferred to wear was that of a long gown (ankle length), with long sleeves and a high neck, also known as an “Abaya” in Arabic terminology. The suggestion could be written in the Arabic version of the breast cancer awareness leaflets and re-stated in the invitation letter to breast cancer screening attendance. If possible, the written information could reassure the Arab women that the breast screening examination will be carried out by female health professions and the examination room used for breast screening mammogram would be strictly attended by female health professional only.

“The one who wrote the leaflets information should know that the embarrassment is one of the main cultural barriers against the breast cancer awareness measurement such as breast screening. I am sure that if provide us the privacy of the room from any of the male staff attending and find the way to undress us until waist. If this happens we will be sure to attend the breast cancer screening. The best clothes to wear for the breast screening is
the Abaya which is long dress with long sleeves and we can open it from front to expose
the breast through screening” (six women node their head in agreement) PFG 6

“The first thing that will stop me from going to breast cancer screening is the
embarrassment, I couldn’t find anything written for us in these leaflets about this issue, I
hope they can confirmed in the leaflets and invitation letter that we can dress our clothes
like Abaya or long dress with long sleeve .... If it’s written: screening will be done by
female health professionals, confirmed of the privacy of the place by no one is going to
attend rather than the female examiner, sorted out the undressed issue which is worrying
me, in this case I will attend” (Eight women lift their hands in agreement) LFG 2

While the entire second generation of women suggested they wanted to be given
a gown which resembles an “Abaya” as previously explained, which they felt
would I encourage them to proceed with the examination with confidence and no
embarrassment. They did not think it needed to be discussed in the content of
the leaflets, rather than it needs to be confirmed in the invitation letter. They
agreed about wearing Abaya and that the breast screening invitation needs to
stress that it will be conducted by female health professionals with reassurance
of the privacy of the screening room. Here is a response from a second
generation women that did not think embarrassment should be included in the
leaflets:

“For first generation such as our Mums, they need to understand there is no more
embarrassment, we need to stay healthy, it’s better to be safe than feeling of
embarrassment. I agree with others to wear Abaya and the screening should done by
female, all of these actions for more privacy. It’s important to make sure that there is
nothing like a lump because the longer you leave it the worse it is for anyone
surely” PFG14. The rest of the second generation agreed with her.
“I think to be sure that we are well and free from breast cancer, the first generation should attend the breast screening — doesn’t matter to wear long dress, it’s acceptable culturally, we need to put their embarrassment away, … sure I am with them for the female gender of the health professional and I think all the second generation here agree with me” LFG11
(the rest of the second generation lift their hands and say that they are agree with her)

Another cultural barrier which needs to consider in the information of the leaflet was “the decision maker”. Twelve out of thirteen first generation immigrant Arab felt they lacked the freedom to reach decisions concerning their breast health without the approval of a male. The women conversed about the structure and family relationships regarding decisions made to participate in breast cancer screening’ the discussion showed evidence of patriarchal family structures. For them, their culture deemed it necessary for male family approval, usually that of the father, husband or son; it was mainly their decision if the woman was to partake in any breast cancer awareness services. It was claimed that many husbands would restrict their wives in consulting a physician for any issues regarding breast health; this is mainly because it is not permitted for women to uncover their bodies for a physician examination. The first generation women were worried about their husband’s approval to attend the screening examination and felt that this should mentioned on the information leaflets to talk to the male about the importance of the examination.

“The information of the leaflets should share and talk to the male gender. I mean the man of the family—they need to include him in the Arabic leaflets which is design to us because according to our culture the male in the family is important and has higher value, he is the one responsible for any simple decision” 6 PFG (Four first generation women agreed with her)

Another woman added:
“The man is the dominant in the Arab culture, they need to know how to approach him and let him be a part of decision making regarding breast cancer screening and by this way you can guarantee his cooperation to let his wife or sister to go to breast screening” PFG 10

“I have experience with my husband, he didn’t let me go to the breast cancer screening when I had received the letter two years ago, he said ‘it’s not important and I never heard about it before’ so first and foremost it’s his decision” LFG 2

3.11.4 Theme Four: Empowerment as Motivation Factors

Having breast cancer awareness information and dissemination was felt to be empowering for the immigrant Arab women in this study. Others have also suggested that the empowerment and encouragement of women to seek knowledge regarding breast cancer would greatly assist their perception and behaviour regarding breast cancer and encourage them to seek early screening and medical assistance (McCready et al, 2005). A woman receiving consultation about breast cancer awareness and breast self-examination by health care providers demonstrates greater knowledge, confidence and was more likely to practice it routinely ((Abu Salem & Abdulla Hassan, 2007; Hacihasanog & Gozum, 2008). Thus, the concept of empowerment in terms of the reliable source of information and their accessibility could motivate immigrant Arab women regarding breast cancer awareness.

Sub-theme One: ‘Preferred source of information’

The immigrant Arab women were asked to identify where they thought women would currently obtain information regarding breast cancer and breast cancer
awareness. Nine out of thirteen of first generation women said that they were unaware of any reliable health information source telling them about breast cancer and breast awareness. None of the women had had previously seen the circulated leaflets. The resources that they currently used for health related information was through interpersonal support, mainly coming from friends, family and relatives.

“I use to get the information from my close friends who they are here now in the focus group, I am not sure if we have the right information, we don’t have the reliable information about breast cancer and how it is important, otherwise you will find us with good knowledge about this subject” PFG15 (Her four friends said she is telling the truth)

“My family, friends and relatives my source of health information, I use to ask one of them if I am not sure about any health issue” 3 LFG (three first generation women said that they are the same)

While seven out of twenty one of the second generation women mentioned that they got health information from English language printed materials such as local newspapers, magazines, leaflets and books.

“I use to read the newspaper while I am in the bus going to my college, some time I find some information brought my attention so I read it, I like to read any printed material such as magazine and books” PFG16 (another five second generation had the same statement)

“My source of information is the printed material ---any type of leaflets, booklet- and magazine--I love to read the information so I can concentrate on it, it’s give me the time to think about it” PFG 8 (her friend said she is also the same)

Four second generation women acquired health and medical information from Arabic educational materials displayed in hospitals or clinics such as posters;
they find it an easier way to read through while they waited for their appointment in the surgery or hospital.

“I prefer the information that is included in the posters because it is easier to understand and it saves me more time because while I am waiting for my doctor’s appointment I can go through the posters.” PFG14 (another woman nodded in agreement to the topic)

“The posters are more attractive to me and are easier to go through it really catches your attention, when you are waiting for your appointment in the hospital or the surgery I prefer posters more than leaflets.” LFG5 (another woman also put her hand up and agreed to the same thing)

An additional ten of the second generation women mentioned the internet, short announcements from television channels shared on Facebook as additional sources of health information.

“search through internet I use to do for any information that I need to know ….I use to watch a lot of channels on TV and some time there is a short announcement talking about important health issue which represent important information----the information shared on Facebook” PFG 3 (four second generation women said the same thing)

“The internet and Facebook which I depend on, it’s my source to look for any information related to health issue….. The TV announcement and the posters in health clinic which I find it more reliable and easy way to get the information” LFG 13 (four second generation women said the same thing)

When asked, about improvements in access to relevant health information to help raise breast cancer awareness in the Arab female community, eight out of thirteen first generation woman in both focus groups emphasized that specific
education classes, bilingual leaflets and posters would empower their community to fight breast cancer awareness ignorance.

“I think the best source of information to our community is the Arabic version of leaflets, posters and the most important is to arrange the educational classes with all the community association in Arabic language so we can have discussion and ask questions about the subject... something live discussion or videos. The NHS should develop a bilingual leaflets which can be distributed by health professionals when we visiting them”

PFG 11 (Four second generation women said the same thing, but the most important in the information is how to overcome the social and cultural barriers and to ensure us that the cancer is a treatable disease)

“NHS Bilingual brochure which I agree with to deal with all barriers that we have with some information about the treatment in case if we have it...health professionals to distribute these tools, watching videos. If you want to help our community the first thing you need to think about it is educational lectures in the mosque or community centres in Arabic language (like this live focus group). After the lectures the other source could be posters and leaflets” LFG 7(Four second generation women agreed with the same statement)

Five first generation immigrant Arab women, across both groups, recognised that health care providers play an essential part in propelling women to undergo a Pap test for cervical tumour. They also considered that similar the education provided by health care providers on the examination and its purpose for breast awareness, alongside being called for regular screening, could also be used to motivate them and others, to make appointments for breast screening. However, one suggestion put forward, and supported by others, was that of combining breast cancer awareness and screening information at the same time women attended for cervical screening. They asserted:
“If the health care provider had spoken to us and given us information regarding breast cancer and breast awareness and screening test at the same time when we attend the Pap test it’s going to be great, we will be aware what is mean and what is the purpose behind, I think in this case many women will be attend the screening, she can offers group of women for watching videos as well”. LFG 2, 10,3,7,8 and 12

Similar thoughts were voiced by the second generation women; they claimed that the best source of information that can be used to inform the Arab women on breast examination, its purpose and recommendation of screening is by health care providers. They thought this source of information would increase the knowledge of immigrant Arab women and they would then be aware about both breast cancer and the need to attend breast cancer screening appointments when called.

Seven out of twenty one second generation women stated:

“The health care provider such as the nurse is the best source of information. Her information it’s going to be up to date and better than leaflets or posters for first generation because the other source may be get neglect and not read….they can arrange with groups of women to watch videos explaining the breast awareness in details…her recommendation would learn the women toward breast cancer awareness”PFG14 (Three second generation women said the same thing)

Sub-Theme Two: ‘Accessibility’

The first generation women raised the issue of accessibility of the information materials related to breast cancer awareness. However, ten out of thirteen women said that they had never seen such breast cancer awareness information leaflets and/or posters on public display in places, such as their local surgery, hospital and Arab community centres. They did say, they frequently found other
different information leaflets related to other health issues such as asthma, eczema, smoking, pregnancy, immunization, but all of this information was written in English.

“I used to look for any new leaflets in the surgery but every time I looked, I found the same leaflets that have nothing to do with breast cancer or breast cancer awareness. All leaflets talk about pregnancy diets, eczema and immunization. I never see anything related to breast cancer awareness or breast cancer” PFG 5 (Four of the first generation women agreed with her)

“I always searched for any new leaflets in the surgery or hospital, but there is nothing about breast awareness or breast cancer, all I see is about smoking, immunization and other subjects, I have copies of them in my home if you want to see them, I am sure these leaflets are not available” LFG 10 (four women nodded their head and said the same thing)

However one woman from the Portsmouth focus group said “that one day I asked the nurse about breast cancer leaflets in Arabic version and she told me you need to call and order one and they will send it by post because is not available in surgeries and hospitals”. PFG 11 and the other two women said “it happens with me when I asked the nurse about Pap test information in Arabic, she told me information leaflets with other languages are not available with me and you need to order it, she was not sure if there is an Arabic version. But we did not do it, it is too much and a complex process” PFG 4 and 6

It seems that breast cancer and breast cancer awareness leaflets (Arabic version) are not readily available in the hospital and to receive these Arabic version leaflets required firstly, knowledge that they are available and then pre-booking to obtain.

From the above quote it seems that two women tried to obtain the Arabic version leaflet and were advised by the nurse on how to do so through pre-booking,
however the women did not go through with it as they considered it to be too much of a hassle.

Nine out of thirteen first generation women suggested that it would be useful to display a range of Arabic information materials such as posters and leaflets in the patient waiting areas and consultation rooms. While others suggested that this type of information needs to be made more widely available, outside of healthcare settings through less traditional, non-health channels such as supermarkets, mosques and Arab community associations. They thought it would be much quicker to disseminate through these other sources than it would be to pick it up from a hospital or surgery because these are the places they went to on a more regular basis.

“I think if there were more leaflets in different places, rather than health care centres, because we only go to health care centres if we have got a condition or a problem…. In my opinion I think that it would be quicker that people go pick up leaflets in supermarkets or at mosques because they are the places they are going to go on a regular basis.” PFG 11 (Four women agreed with the statement and had the same suggestion)

“the best way to display the information about breast cancer to Arab population is by making the Arabic leaflets available in our local supermarkets, local mosques and Arab clubs and associations” LFG 3( Three women agree with her statement)

According to the second generation women, several women mentioned that in the month of October there were aware that there are diverse and innovative awareness campaigns on breast cancer. As an Arab community, they felt that similar educational campaigns in universities and schools could be started. They felt that this might encourage daughters to talk to their mothers about the breast cancer information such as symptoms and the importance of early diagnoses. All twenty-one second generation women suggested that the campaigns should
include workshops, lectures, and walks and suggested a “pink hijab day” to create more awareness among both men and women about breast cancer. It was felt that the Arab association should be encouraged to cooperate with breast cancer campaigns in England to distribute breast cancer awareness information in the form of attractive leaflets that could fit in wallets or handbags, so they could be easily accessed for later reading rather than being binned straight away when given out.

“The best way to display the breast cancer information is to have breast cancer awareness campaigns in October as well; we can show the leaflets (Arabic version), having lectures, workshops, arrange activities and we can call it pink hijab after the most of Arab women wearing scarf….it’s going to be amazing event to raise the level of breast cancer awareness within our community” PFG 1(eleven women loved the idea and they agreed with her statement”

“I wonder why we don’t have special October event, we can cooperate with other campaigns and arrange one for Arab population, what do you think we need to call it?” few women replay and said “we can call it pinks scarf or pink hijab, it’s going to be successful and we are sure the awareness is going be better year after year among Arab women” LFG 15

The women were generally extremely quick to build upon their own and others ideas, including their own attention to breast cancer and strengthened the need to expand breast awareness to the more extensive Arab groups. They suggested that this can be achieved through the usage of breast awareness campaigns to access Arab gatherings which were difficult to reach, for example uneducated women (illiterate), including their families about the requirement for breast cancer awareness and early identification
3.12 Discussion

It is commonly noted that knowledge and understanding contributes to women’s support in breast cancer awareness (Amin, Mulhim & Meqihwi, 2009; Taha et al., 2010). Despite the second-generation immigrant Arab women’s limited knowledge about cancer awareness and practice they were keen to acquire further knowledge as they felt it would make them feel more secure to discuss further with health care providers about practice and frequency of breast examinations. Secginli & Nahcivan (2006) in their research studied the variables related to the breast cancer screening behaviours of 656 Turkish women, they found that the major predictor of regular breast cancer screening was the knowledge of screening guidelines. Similar findings were found by Juon et al (2004). The strongest element of routine breast screening according to Juon et al (2004) was found to be the knowledge in screening guidelines. Secginli & Nahcivan (2006) also found that a chief indicator of regular screening among Turkish women was knowledge of breast cancer screening guidelines.

3.12.1 Health related information:

Health related information is a noteworthy component of the delivery of health care (Adebajo, 2004). This information can be given through a number of different ways such as written health information brochure, audio-visual demonstrations. The NHS has published a “Patient Information Toolkit” to help in developing local protocols for producing public or patient health related information (NHS, 2003). As the UK has progressively turned into a multi-cultural society, the educational materials that are presently accessible are least likely to be utilised by the
numerous minority ethnic individuals, whom are underprivileged either educationally or financially (Adebajo, 2004). Whilst there has been a focus, to date, in the planning of healthcare information for minority communities; much of this information has a focus on sexual health, alcohol, heart disease and diabetes. This claim is supported by reviews of research applicable to the UK (Johnson, et al., 1999; Bhatt & Dickinson, 1992). The general conclusions have been that customary procedures and dependence on printed materials or information provided in the English language are insufficient and ineffectual (Bhalla, 1990; Murphy et al., 1994).

Limited exploration on the accessibility and availability of suitable health related information has let to this phase 2 of the research study which set out to explore the usefulness of two currently available educational material namely, (NHS and Breast Cancer Care Charity produced health related information leaflets on breast awareness). Doak, Doak & Root (1996) recommend that noteworthy criteria for evaluating health information leaflets include readability, quantity and organisation of the content, style of writing, graphs, composition, evidence of motivation for learning and cultural suitability. This research has highlighted several important aspects with regard to the provision of breast cancer awareness leaflets. The findings highlight how the first generation of immigrant Arab women (from both focus group discussions) were unfamiliar to the concept of breast cancer awareness and had little breast cancer awareness knowledge. A few previous studies have studied Arab women in developed countries such as USA and Canada to provide insight about breast cancer and breast awareness. The lack of literature in this field of study particularly in the UK suggest that this
exploration is the first UK study to exclusively investigate experiences of immigrant Arab women across the generations.

Previous studies have revealed insight into the absence of knowledge and awareness related to cancer for immigrant Arabs living in America particularly that of attending cancer screenings as one of the breast awareness measures (Odeh Yosef, 2008; Shah, Ayash, Pharaon & Gany, 2007; Mellon, Gauthier, Cichon, Hammad & Simon, 2012) Such lack of breast cancer awareness knowledge, has not always been acknowledged by health care professionals (Odeh Yosef, 2008). Yet, not knowing about breast cancer risk and breast awareness symptoms can negatively affect subsequent breast cancer screening behaviours (Al-Omran, 2005).

Moreover, it was found by Schwartz, Fakhouri, Bartoces, Monsur & Younis, 2008 (2008) that in comparison to the general female population in Michigan, Arab women from Metropolitan Detroit had a decreased likelihood of ever undergoing a mammogram. In addition when Arab women were contrasted to other ethnic populations in the USA, they had less knowledge regarding mammography and breast awareness.

Sadler et al., (2001) and (Ahmad, Gupta, Rawlins & Stewart, 2002) argued that they have reliably observed the South Asian immigrant women attitudes towards breast cancer; they concluded that those who had poor English literacy, lack of education and less acculturated to the western methods of living were more likely to internalise myths and have incorrect perceptions about cancer. Furthermore, Rankin (2001); Darr, Astin & Atkin, (2008) and Kandula et al (2010) studied the educational health information related to other health condition, for example
cardiovascular disease and diabetes, it has also been found that there is absence in the availability of this type of materials among South Asian ethnic group. The second generation immigrant Arab women, regardless of their knowledge of breast cancer awareness, had constrained experiences of what this involved, including its significance and the accompanying physical changed that they should be aware of breast cancer. The immigrant Arab women from both generations were keen to acquire further knowledge about breast cancer awareness because they felt it would make them feel safer and encourage them to attend regular breast screening opportunities when invited to attend.

3.12.2 Breast Cancer Awareness written Information key findings:

It is broadly perceived that patients frequently overlook things that are advised to them amid their health consultation (Kenny, 1998). Moreover, the restricted time accessible for a general practitioner (GP) limits the degree to which the nurses can straightforwardly provide counsel and vital information regarding aspects of care.

Written communication is perceived to be a valuable adjunct to verbal communication. In order to create consumer health information, which is efficient and effective, the following standards below have been suggested by Coulter and Ellins (2006):
3.12.3 Format and Layout:

The immigrant Arab women in this study highlighted some positive and negative notes regarding the format and layout of the breast cancer and breast cancer screening leaflets (NHS and Breast Cancer Care Charity). Both generations
preferred the format and layout of the Breast Cancer Care charity leaflets rather than the NHS leaflets version of Arabic and English.

The Breast Cancer Care leaflet presented the information clearly and in short blocks of text with sub-headings and bullet points which were helpful in dividing long sections of informative text. The leaflet contained colourful illustrative figures and other appropriate visual aids such as images. In contrast, the women felt the NHS leaflets produced in black and white with no colour were not so appealing. Also without any figures, diagrams and images, it failed to catch their attention or draw in the reader.

All women, from both generations, suggested some ideas to improve the format and layout of breast cancer awareness information leaflets. They suggested to put an image of Muslim women wearing the hijab as a representative for breast cancer awareness on the cover of the Arabic version of the leaflet. Additionally, suggestions were made implementing a diagram with statistical information highlighting the prevalence of breast cancer amongst the Arab population in the UK. It was also encouraged to emphasise on vital information in text boxes by highlighting them in varying colours in order to avoid overlooking. This could form of encouragement for them to take a breast cancer awareness information leaflet as the way it will be presented will catch their eye and speak out to them as it will feel familiar.

3.12.4 Content of Current Breast Awareness Information Leaflets:

The findings of the study reveals some difficulties in reading the English version where it included medical or technical terms, particularly for first generation women where English was a second language, which some may not speak at all. However some of them did not agree with the quality of translation of the Arabic
Language, they preferred to read simple plain language. This highlights the necessity of testing the readability of all breast cancer information material before it is presented to the Arab women community. Jackson and Peters (2003) have observed in their study that people who came to Britain from different countries may utilise terminology, which is different than the words chosen by those selected by interpreters. Which made it a challenging for them to find whether a word was incorrect or whether it was due to individual preference or educational level.

The availability of health information in other languages was very limited in the past (NICE, 2004). However, progress has been made in this area whereby NHS and breast cancer information leaflets are now available in Arabic languages (Breast Cancer Care 2012). On the other hand, it may be insufficient to translate the health messages in a simpler information. Translated information needs to consider cultural sensitivity among ethnic groups (NICE, 2009). Therefore it is important to take in to consideration the cultural sensitivity messages that reflect religious and socio-cultural beliefs and attitudes. Whereas, many breast cancer charities such as Macmillan have been working on producing good quality, culturally sensitive information (Trevatt & Kelly, 2006), this needs to be addressed at a policy level, to ensure that appropriate services and information are being developed to reflect a multi-ethnic society and appropriately disseminated. It is also necessary for healthcare professionals to be aware and provide such relevant information. Breast cancer awareness information available in the Arabic language should be made accessible in the ethnic local communities, hospitals and GP practices, not limited to access via the internet or order.
Cultural sensitivity appropriateness of breast cancer awareness information is essential. All first and second generation women suggested that the information in the leaflet should reassure them that it is permitted for them to wear a long dress with long sleeves when attending the breast screening. The reason being that it would encourage them to attend screening while not compromising their cultural and religious practices. The differences in languages, national cultures and faith systems are crucial components in the lifestyles of ethnic minorities; therefore culturally sensitive and appropriate education tools for the variations within those communities are also vital (Anderson et al, 2003).

In order to overcome the language barriers among women of various ethnicities, the UK based Breast Cancer Care Charity since established a national interpreting telephone helpline services available for ethnic minority groups within working hours. However, Watts, et al., (2004) found that translated written information materials from different languages, still contain some medical words that simply do not exist for some ethnic vocabulary particularly for people who are illiterate or with a low level education level. In another study, more than half of the Punjabi male participants and 10% of women who were living in England at that time, were able to read and write in Punjabi language (Ghosh, 1998). For this reason, to overcome the issue of literacy, it could be more and useful to produce health educational materials using different techniques and mediums, such as CD’s and DVD’s. Others have confirmed the usefulness of these different mediums for health information dissemination Watts, et al. (2004) and Husson, Mols & van de Poll-Franse (2010).
3.12.5 Other Media

Some illiterate women from the first generation were in favour of audio and video educational materials. Others have found that this material is particularly useful for those with low levels of literacy. The finding is steady with Jackson and Peters (2003), who provided a computer based health promotion audio-resource in Asian dialects, which was field-tested in three cities in England (Nottingham, Sheffield and Leicester). The researchers found that participants liked both ways to access information, through reading and listening. The immigrant Arab women in this study had quite high expectations of the type of audio and video materials that should be included, preferably in an interactive format.

Most of the immigrant Arab women from first and second generation expressed concern over the lack of media resources about breast cancer awareness for the immigrant Arab women-British community. The women suggested multiple methods for educating the Arab community, including focus group discussion, videos, bilingual educational materials, and television advertisements. These findings highlight a need for increasing targeted cancer education amongst the Arab community in Britain in order to spread an awareness of available breast cancer awareness services. Family members, neighbours and friends have been reported to be the most used source of information regarding breast cancer for the first generation Immigrant Arab women, whilst the knowledge gained amongst second generation Arab women has been provided through newspapers, radio, internet and magazines. Prior research conducted among Jordanian women in Jordan, has implied that generating breast cancer awareness through various media sources and culturally appropriate educational interventions could expand
knowledge regarding breast cancer and early detection inspections in women (Petro-Nustas, 2001; Taha et al., 2010; Petro-Nustus & Mikhail, 2002).

A study conducted in 2005 by Gerber and associates assessed patients with low health literacy levels using a media based educational intervention about diabetes. The 244 participants were selected from five facilities across Chicago; through the process of randomisation, they were either selected to receive the intervention or standard care (control). The intervention group comprised a kiosk containing a portable computer with a touch screen placed in clinical waiting areas. The interactive PC included sound/feature to include requests to impart information, provide psychological support and promote self-management skills for diabetes. A significant increase was found in the intervention group, in particular for the participants with low health literacy, there was a greater understanding of their perceived susceptibility to diabetes complications. On the other hand, no significant differences were noted in both groups regarding clinical outcomes, self-efficacy, knowledge or medical care. The results concluded both groups had low health literacy with 55% of the standard care group and 56% of the intervention group.

In 2006, Johnson et al conducted a study to evaluate the quality of patient information materials about Osteomalacia in South Asian languages in UK, the research aimed to explore the best practice on producing written and audio health materials in minority ethnic languages. Based on current UK patient information guidelines and the policy of Health Department in Australia (2001), Johnson et al (2006) developed specific model to help in producing printed and audio public/patient education materials in ethnic minority languages. The researchers recommended that the educational materials should be ‘road-tested’ with ‘local
or native’ possible users, the model consist five steps as shown in Figure 26 below.

![Figure 26: A Model for Producing Culturally Competent Written and Audio Health Information in Community Ethnic minority Languages from Johnson et al (2006, p. 14)](image)

ARC The five step process includes assessing content and format, validating, translation, dissemination and evaluation. The principal step suggest was that of assessing, and including materials from both nations home of immigrants and their nation of origin, and updating it to agree to current best information, which can then be evaluated by health experts. Hence, this approach once incorporates considers issues around the evidence base of health information is relevant to the target population and confirms that whatever is to be distributed is consistent with best current medicinal supposition.
The second step is validating, which means presenting these materials to individuals from the pertinent ethnic group, and utilizing their opinion to consider how the material can be further advanced. This can most effortlessly be accomplished through focus groups such as the one conducted in this study to investigate the issues that need to be fused. Ideally, those included should have some knowledge and understanding of the breast cancer awareness topic (maybe as carers, or professional community members) to guarantee a fit with models of disease. It is vital to have materials surveyed by individuals whose educational level and attention to health awareness frameworks and science are like those possibly at risk. This point has likewise been made by Bhopal and associates in Edinburgh in connection to the interpretation and utilization of wellbeing personal satisfaction and behavioural surveys (Hunt & Bhopal, 2003).

Furthermore, the above steps should conclude with step three “translation”, which means having materials evaluated and interpreted by native dialect speakers who are conversant in English utilizing basic dialect. It might be required, as Hunt & Bhopal (2003) proposes, to finally test the last translated forms on monolingual speakers of the native language.

Once those educational material drafts have been arranged and checked, and if needed reviewed by the clinical group, they are prepared for presentation and dissemination.

Prior validation stage may also provide an opportunity to understand preferred method for getting the message across to the target population highlight any matters, for example, proficiency, favoured media, and awareness of broad media channels, for example, 'Arabic dialect' radio and TV.
Consideration might also be applied to the patient care pathways, to distinguish the most suitable focuses within the health care services framework at ‘which’ and by ‘whom’ materials can be brought to the consideration of potential clients. Finally, evaluation and intermittent re-evaluation ought to be carried out to enhance ongoing quality, and potentially review of inside written text. This will reflect both clinical advances and perhaps at the same time changing social and language deliberation, and the need to create new forms in dialects of individuals not earlier signified.

3.12.6 Education of Others:

Women in this study were primarily focused on educating and communicating with their husbands about breast cancer and its awareness. Previous research on Arab women with breast cancer have found that support from the husband is particularly valued (Azaiza & Cohen, 2006), a finding also supported in this study where husbands were identified as a main source of support and were involved in various aspects of medical decision making, including breast cancer screening. Health care professionals may need to utilize the husband as a resource in family communication, especially for reaching out to at-risk women. It’s important to share the breast information leaflets with males of the family, so their level of breast cancer awareness and breast screening test is increased, thus their acknowledgement of its importance. The knowledge and attitudes of males regarding breast cancer towards their wives’ breast cancer screening is an area, which is delicate and generally unexplored in literature. A qualitative study by Flores & Mata (1995) discovered that Latino males needed particular knowledge about their partner’s breast and cervical cancer screening measures, or suggested recurrence of such examinations. An improved understanding of the
husband’s knowledge suggests an improvement in preventative measures. On the other hand, a postal survey taken place in Geneva by Chamot & Perneger (2002) concluded that the male population were found equally as knowledgeable about breast cancer and mammography as women, they additionally had an increased positive attitude towards breast cancer screening in contrast to women.

3.12.7 The role of the Health Care Professional:

Health care professionals can and should be instrumental in providing breast cancer and breast cancer awareness educational tools. Leslie et al. (2003) confirmed that the health care professionals were an effective tool in providing women with health education, increasing their knowledge regarding breast cancer and the benefits of breast screening.

Approaching the first generation immigrant Arab women is an important task which should be recognised by Health care professionals to assess their health informational needs, particularly breast cancer awareness information. Additionally, it is significant that they receive breast cancer awareness information in their mother language, this way it provides them with an opportunity to understand the information deeply and provide an opportunity to ask questions. Information written by the women’s own languages might also be useful for second generation women. Such information should therefore be offered to all immigrant Arab women from both generations in England. NICE (2009) recommend that all ethnic minority women should be offered complete, flawless and unbiased information regarding breast cancer awareness. These information must be culturally appropriate custom-made according to the women’s needs.
There are specific implications this study has on healthcare providers; it is vital to note that immigrant Arab women have diverse levels of information, beliefs and attitudes toward breast cancer, regardless of their education level and setting. Enhancing breast cancer awareness towards immigrant Arab women is made possible with GP’s and nurses by encouraging screening while recognising culturally specific beliefs and practices, whilst attempting to abstain from stereotyping. The health care system and this group of women can be brought together by social workers and community associations to increase the awareness about breast cancer in such hidden community.

3.12.8 Dissemination

The immigrant Arab women pointed out, in both focus group discussion, that the NHS should develop a tailored bilingual brochure; as well as posters displayed in hospitals and clinics, which incorporates the social and cultural barriers that immigrant Arab women face when discussing cancer. The educational tools need to address the secrecy, fears and misconceptions of breast cancer, the brochure should emphasize that cancer can be a treatable disease when detected early. Similar visual aids and learning tools tailored to the patient’s culture have been successfully implemented with African-American women (Baty, Kinney & Ellis, 2003; Charles, Kessler, Stopfer, Domchek & Halbert, 2006), and such methods may help improve immigrant Arab women’s understanding as well. Similar approaches have been used for other health related topics in leaflets for asthmatics or for cessation of smoking information.

Finally, the focus group discussions revealed suggestions for different routes to facilitate the dissemination of relevant and culturally sensitive information. The second Arab generation women suggested an educational breast cancer
awareness campaign; setting an event called “National Pink Hijab Day”. Where women could wear pink hijabs (head scarf) similar to the pink ribbon currently used by breast cancer charities as part of a mass media campaign. This would make the information easily accessible as Arab women could access the leaflets in both languages through the campaign. This experience is similar to experiences that began in 2004 in a small school in Columbia, Missouri called “Global Pink Hijab Day”. The event commenced when a group of women decided to wear pink hijabs on one day in order to encourage people of the public to question them about their hijabs and Islam. As the number of participants rose, the “Susan Komen” Foundation became involved and the “Global Pink Hijab Day” was established. This is worn yearly for Breast Cancer awareness.

The campaign is a major influential source of breast cancer awareness information; broadly utilised for the distribution of health information to both patients and the general public. The strength of breast cancer campaigns is its potential to reach large sections of the population. The finding is consistent with research conducted by Marcus & Crane (1998). The process of the research included reviewing published evidence for cervical cancer screening interventions; they later identified 200 studies which were categorised in interventions designed to increase the number or proportion of women screened for cervical cancer, and interventions designed to reduce loss to follow up among women with abnormal Pap smear. The studies involved mass media campaigns, community outreach strategies, patient letters and opportunistic screening. It was concluded that the most effective method of raising awareness was through mass media campaigns, this also aided in producing a positive background context in which other interventions can be successfully organised.
Moreover, a systematic review of literature by Black, Yamada & Mann (2002) examined the viability of community-based procedures to expand the support and participation of women in cervical cancer screening. A total of nineteen studies were incorporated in the review; findings suggested mass media campaigns to be most commonly evaluated, either independently or in arrangement with different interventions. Of the 19 studies, seventeen measured outcomes in terms of Pap smear test, in addition, twelve of these stated statistically significant improvements when contrasted with controls. The most effective studies of mass media campaigns targeted a definite sub-population with tailored material. Every one of the five studies that combined mass media campaigns with other interventions were viable at expanding Pap smear rates or early cancer detection. Similar campaigns could be useful to replicate for breast cancer awareness for the immigrant Arab population living in the UK.
Chapter Four

Discussion of the Overall Research, Implications and Conclusions
4.1 Introduction

This research adds a number of significant contributions derived from a mixed methods approach to bring new knowledge from the findings, context of the research and the methods used. A discussion of the findings with a focus on practical and research implications will follow.

The aim of this research was to explore the knowledge, beliefs and attitudes of breast cancer and breast cancer awareness among immigrant Arab women living in England; there is currently a dearth of evidence exploring this area. The reason for undertaking the present series of research phases therefore, was to reveal new insights into the knowledge, beliefs, attitudes and practice of immigrant Arab women concerning breast cancer and cancer awareness. The present research programme has a number of features that distinguish it from a previous study conducted in the UK which used a qualitative approach to study a mixed group of South Asian, black, Arab and indigenous white British socially disadvantaged women in Sheffield and London. In a previous study, Scanlon, 2004, postulates that language and cultural difficulties limited the findings; including the Interpreter involved had not been briefed fully beforehand and had no health background. It was, therefore, important to study Arab immigrant women only in order to gain a better understanding of their unique and common experiences within a contemporary context likely to be influenced by one’s ethnic and cultural background.

With little previous research conducted in this area, the qualitative paradigm was adopted to explore in-depth the knowledge, beliefs and attitudes (Creswell, 2007) of immigrant Arab women toward breast cancer and its awareness promotion. Qualitative research ‘is a form of social enquiry that focuses on the way people
interpret and make sense of their experiences and the world in which they live’ (Atkinson, 2001, p7). It is an appropriate approach to answer the psycho-social questions posed for this research study.

I took the role of the interviewer being fluent in Arabic and English, as well as being part of the same culture. The current study also considered the type of generations, whether the women were first generation or second generation, to explore perceived differences in levels of knowledge, and breast awareness practice which had not been included in previous UK studies. In addition, there were no previous studies conducted looking at assessing the usefulness of current educational material (NHS and charity produced leaflets) relevant to this population.

4.2 Summary of the Research Phases

Two phases were carried out, two qualitative studies were sequentially carried out on different immigrant Arab women populations that represented three cities, within the South of England. An exploratory sequential design was employed, whereby the research dominance was given to the qualitative paradigm. In the second phase, qualitative data collection and analysis was combined with the administration of a validated quantitative a validated survey tool, namely the Breast Cancer Awareness Measure (or B-CAM Version 3). A mixed methods approach was adopted in Phase Two to gain a detailed description of the population together with an opportunity to compare and contrast findings across first and second generation immigrant Arab women as well as compare findings with those of the general population as documented in current literature. The mixed method enabled me to explore the research aim by utilising numerous
sources of data and a variety of research methods which encourages the validation of data through triangulation (Denscombe, 2008). In this way, any results or conclusions are liable to be additionally convincing and accurate (Yin, 2003). The two phases are highlighted below:

Phase 1:

The first phase used a qualitative approach, semi-structured interviews with 10 immigrant Arab women from south of England; to explore the knowledge, attitudes and beliefs related to breast cancer and breast awareness practices. Thematic analyses of this study revealed four key themes (1) Poor/lack of knowledge, (2) socio-cultural barriers, (3) religious beliefs and attitudes (4) health services barriers. It is evident from phase one findings that cultural and religious beliefs and attitudes are highly influential in shaping immigrant Arab women’s knowledge and experiences of breast cancer and breast awareness.

First generation women’s socio-cultural and religious beliefs and attitudes have a significant effect upon their knowledge of breast cancer and breast awareness. However it plays an influential role in shaping their beliefs and attitudes toward breast cancer and breast awareness. On the other hand the second generation women appeared less influenced by beliefs and attitudes inherited from the Arab culture and religious practices. However, the majority of both generations, revealed lack of or limited confidence and skills to practice breast cancer awareness behaviour.

Furthermore, the study has shown that health care system in itself presents a number of challenges for immigrant Arab women to obtain any health care services. These include the lack of cultural competence, feelings of being targets of racism and discrimination, unfamiliarity with existing services, language as a
source of communication barrier, and unavailability of breast cancer information in Arabic. However, the language barrier played a role in shaping the first generation women’s experiences, it contributes to the women’s ignorance of breast awareness owing to insufficient confidence in their ability to speak English and to seek for breast cancer awareness information. Based on that breast cancer and breast health awareness is a relatively new phenomenon to immigrant Arab women, which may also contribute to their lack of services knowledge and familiarity with the concept of breast health services.

Phase Two:
The second phase consisted of quantitative data collected through a self-completion validated questionnaire of the Breast Cancer Awareness Measure (BCAM) as well as two qualitative focus groups. Two focus groups were conducted for immigrant Arab women in England, one in Portsmouth and the other was in London to explore knowledge of breast cancer awareness and to inform practice and gaps in knowledge regarding the usefulness of current educational material (NHS and Breast Cancer Care Charities produced leaflets) relevant to them. To date, there have been no previous studies looking specifically at this immigrant population living in England. Phase two addressed a number of issues that had not been the subject of any previous research. Although data collection were predominantly qualitative, quantitative data were also obtained to fully describe the population, and to compare and contrast two methods of data collection to provide breadth and depth of understanding (Johnson, Onwuegbuzie & Turner, 2007).
With reference to the literature, other quantitative study results showed that all Arab women had lower levels of knowledge of breast cancer and cancer awareness information (symptoms, risk factors and warning signs) than those of women from the general population (Forbes, et al., 2010). However, despite the lack of information among the second generation of Arab women, they were more knowledgeable than first generation who persistently reflected poorer knowledge regarding the risk factors, warning signs of breast cancer, breast cancer screening and knowledge of age related breast cancer and life time risk. In addition the BCAM survey showed that both generation had little or no confidence and skills to feel self-assured to check their breast and they were more likely to report that emotional and practical barriers prevented those seeking medical help and accessing breast health services. Differences in breast cancer knowledge and experiences varied between the first and second generation. Although not statistically significant the trend was that second generation were more knowledgeable of breast cancer risks. A larger sample may reveal differences that are statistically significant. In addition, the qualitative studies provided contextual data to explore further reasons behind each perceived barrier. Although the findings are from a small sample it still suggests that younger women are becoming part of western society with better English language skills and access to relevant information. In contrast, older women with poorer language skills, education, and embedding into society, are more likely to be breast cancer unaware or taking up screening opportunities; the very generation at risk (due to increased age and post-menopausal) who would benefit most from education and attending breast screening services.
Regarding the qualitative methodology adopted, thematic analyses provided a pragmatic approach which revealed important keys themes with context specific descriptors and interpretations which were not revealed in the quantitative measure (B-CAM). This was the strength of the qualitative approach as it revealed influences, background and circumstances for the experiences, barriers and practices revealed.

Both generations preferred the format and layout of the Breast Cancer Care charity leaflets rather than the NHS leaflets version of Arabic and English in term of content, format and layout. Both generation agreed that the current NHS breast awareness leaflet did not provide sufficient accessible information on breast cancer awareness. They claimed that breast cancer awareness translated information needs to consider cultural sensitivity that reflect religious and socio-cultural beliefs and attitudes of Arab women.

However, the immigrant Arab women revealed that with low levels of literacy and written English, other sources of information such as audio-visual educational materials should be considered. They suggested multiple methods for educating the Arab community, including focus group discussion, videos, bilingual educational materials, and television advertisements.

Women in this study were focused on educating and communicating with their husbands about the importance of breast cancer awareness, the immigrant Arab women revealed that the male in the family is the main source of support and are involved in various aspects of medical decision making such as breast cancer screening. Furthermore, the immigrant Arab women from both generations were keen to acquire further knowledge about breast cancer awareness because they felt it would make them feel safer and encourage them to attend regular breast
screening opportunities when invited to attend. The participants were more likely to report that they preferred the leaflets to be written in Arabic language, however they have not found this to be widely available.

4.3 Overall Interpretation of Research Findings

The qualitative study’s findings delivered a thorough and perceptive interpretation of the knowledge, beliefs and attitudes toward breast cancer and breast cancer awareness. All the Immigrant Arab women that participated in this research were thankful to be provided with the opportunity to share their knowledge, beliefs and attitudes for breast cancer which may affect breast awareness practices among them. This additionally permitted me to scope different attitudes and concerns. In particular, the two qualitative studies captured a detailed understanding of immigrant Arab women breast cancer and breast awareness knowledge.

- A thorough comprehension, of immigrant Arab women’s breast cancer and breast awareness attitudes and beliefs which may affect breast awareness practices.
- Motivating factor that make the immigrant Arab women more aware of breast cancer
- Socio-cultural, religious and health service barriers were richly described.

While with quantitative survey (B-Cam) I was able to assess:

- Levels of knowledge related to warning signs, symptoms, risk factors and NHS Breast Screening Programme awareness.
- Levels of confidence to perform breast awareness practice.
- Barriers to seeking medical help
While the qualitative and quantitative findings captured similar aspects of the immigrant Arab women’s lack/poor knowledge toward breast cancer and awareness and barriers, the qualitative findings provided contextual details and provide a more thorough comprehension, of the influences affecting breast cancer awareness attitudes, beliefs and knowledge likely to influence breast awareness practices.

The themes illustrated with verbatim quotes provided contextual information, thoughts behind decisions regarding beliefs and attitudes embedded within socio-cultural, religious beliefs and their relationship and hindrance in accessing health services (e.g. health services that lacked ‘cultural competence’, ‘cultural sensitivity information’, ‘embarrassment & modesty’ and ‘empowerment as motivational factors’ toward breast cancer awareness), Table 16 below provides a summary of themes and sub themes across the qualitative studies.

The immigrant Arab women’s knowledge and understandings of breast cancer awareness were embedded across the two qualitative studies, and many similar findings emerged as a result. The findings were often reframed to capture the essence of the women’s experiences in a given study. These include their knowledge, beliefs and attitudes towards breast cancer (especially in relation to cultural influences, religion and health services). The findings are colour coded to show the similarities across the studies. The red colour represents issues around knowledge toward breast cancer and cancer awareness. The blue colour represents beliefs and attitudes as a barriers to seek for medical help and the brown represents the viewpoint of the women toward the usefulness of (NHS and Breast Cancer Care charity) breast cancer awareness leaflets.
Table 16: Illustration the Summary of Qualitative Studies Themes and Sub Themes

<table>
<thead>
<tr>
<th>Immigrant Arab Women: Knowledge, Beliefs and Attitudes towards Breast Cancer and Cancer Awareness Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative Study (Semi-Structured Interview)</td>
</tr>
<tr>
<td>Poor/lack of knowledge</td>
</tr>
<tr>
<td>• Poor/lack of breast cancer information</td>
</tr>
<tr>
<td>• Poor/lack of breast awareness information</td>
</tr>
<tr>
<td>• Breast cancer main causation (Alienation)</td>
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<tr>
<td>Socio-cultural beliefs &amp; attitudes</td>
</tr>
<tr>
<td>• Taboo and fear surrounding breast cancer</td>
</tr>
<tr>
<td>• Health isn’t their priority</td>
</tr>
<tr>
<td>• Embarrassment &amp; modesty</td>
</tr>
<tr>
<td>• Decision maker and gender inequality</td>
</tr>
<tr>
<td>Religious beliefs &amp; attitudes</td>
</tr>
<tr>
<td>• Cancer is God’s punishment and will</td>
</tr>
<tr>
<td>• A false sense of security</td>
</tr>
<tr>
<td>• Religious attitudes for treatment of cancer</td>
</tr>
<tr>
<td>Health services barriers</td>
</tr>
<tr>
<td>• Lack of custom and cultural competence</td>
</tr>
<tr>
<td>• Language as a source of communication barrier</td>
</tr>
<tr>
<td>• Unavailability of Arabic breast cancer information</td>
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<tr>
<td>• Lack of privacy &amp; availability of female physician</td>
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<tr>
<td>• Referral system is too complicated</td>
</tr>
<tr>
<td>• Feeling of being targets of racism and discrimination</td>
</tr>
<tr>
<td>• Unfamiliarity with existing services</td>
</tr>
</tbody>
</table>
4.4 Practical Implications

The current research findings call attention to various socio-cultural and religious implications that may require further exploration and need to be addressed at a policy, practice and research level. Despite living in a high income society with existing public health and evidence based guidelines/information available to all women, immigrant Arab women in this study had incomplete breast awareness. The findings from this study suggest developing user-focused educational resources could provide more appropriate culturally sensitive breast cancer awareness knowledge and encourage early referral and access to additional support and services, where appropriate.

The core duty of the NHS and the National Cancer Equality Initiative (NCEI) primary responsibility is to promote equality breast cancer services as a part of the whole health services in Britain (NCEI, 2010). Taking this into account, Reform Strategy, 2007 and NICE, 2002; 2004; 2009 are good examples of numerous strategies to raise awareness of risk factors of breast cancer. For example, NICE, in 2004, provided guidance to improve breast cancer awareness based on a) health education and prevention b) access to screening c) access to healthcare training for cultural competency. Although guidelines plan have been recognised, the establishment and quality of health care offered to breast cancer is varied (NICE, 2004).

The needs of Arab women might not always be achieved, due to their poor awareness of the services regarding breast cancer including what support is available or may be because of lack of cultural competence within available services. Cultural competence is an essential element in the quality of healthcare
provided for ethnic health groups; this is a subject which needs to be acknowledged and recognised by cancer services. More recent guidance has been published for this reason which will make certain that future NICE guidance outlines aspects of utmost significance which will be aimed to concentrate on areas of breast cancer awareness (NICE, 2009).

The following sections make suggestions based on the findings, on how immigrant Arab women needs could be addressed in the future.

**4.4.1 Socio-Cultural and Religious Barriers**

The findings of qualitative studies showed that the socio-cultural, religious beliefs and attitudes have a significant effect in breast cancer awareness knowledge and experiences among immigrant women.

Improving the quality of information to address religious and cultural relevance and provide accessible and applicable advice and support, will encourage ethnic groups such as Arab women to be breast aware since, without, they are least likely to access it themselves. Thus, there is a necessity to understand the deep concept of religious beliefs and attitudes among Arab women hindering breast cancer awareness and seeking breast cancer screening/treatment.

Furthermore, the NICE (2004) guidelines confirmed that health care professionals need to provide appropriate health care and advice within a religious background. It is therefore recommended that healthcare professionals are provided with adequate training that enhances their understanding as to the significance of relevant information and advice to ensure immigrant Arab women become more breast cancer awareness.

A recent study outside the UK, has shown that American immigrant Arab women would like healthcare professionals (such as physicians, nurses, consultants) to
address their religious needs when they provide them with health care (Dubaybo, Hammad & Darwish-Yassine, 2013). The findings from this study suggest similar needs. Religious background are often unrecognised by healthcare professionals (NICE, 2004), If healthcare professionals do not have sufficient background knowledge regarding religious practices and do not know how to approach such topics or do not feel confident in doing so (Kai et al., 2007; Kristeller, Zumbrun & Schilling, 1999) reaching out to immigrant Arab women will not be easily achieved. It is, therefore, recommended that healthcare professionals should be provided with adequate training that enhances their understanding of the significance of this type of approach to support immigrant Arab women be more aware about breast cancer awareness. Additionally, dissemination of relevant information through breast awareness educational resources to the Arab local community network, could be an important and useful source to immigrant Arab women. This could include Arab community associations and places of worship (mosques) and local community languages school (i.e. Arabic language schools)

4.4.2 Providing of Culturally Sensitive Health Care

One of the primary objective of the Department of Health is to decrease inequalities within cancer services (DoH, 2007) in order to decrease the inequalities in the provision of health services (NCEI, 2010). For this reason, there has been increased activity to overcome any gap. The National Cancer Action Team (NCAT) reported in their annual report that they have been co-operating with cancer charities in order to establish the BME National Cancer Patient Advisory Panel (NCPAP) for ethnic minority group. The main objective of the (NCPAP) is to provide them with the chance to share their cancer experiences
which will be utilised to advance cancer services that satisfy their needs (Allberry, 2008).

The report of the National Cancer Action Team (NCAT) have also listed many measures to improve the cancer health services among BME group. Linking with different charities related to cancer has been identified as an essential collaborative alliance. This will provide both BME patients and care providers with the opportunity to discuss their experiences, such information gathering could be usefully engaged in improvement and tailoring specific services to meet all requirement for BME patients living with cancer disease (Allberry, 2008). Although this is an enhancement of cancer services, there remains variation in access to appropriate care and support for BME groups; The Department of Health (2007) suggests that there is still a lot to be done to ensure that the NHS is able to meet the cancer needs of BME patients at both a community and citizen level.

According to a recent study in the UK by Kai et al (2007) which found health care providers do not generally feel great comfortable when they are in contact with some minority group, such as BME, because of their deficiency of realisation and comprehension of their cultural beliefs. Kai et al (2007) stated that the healthcare professionals were aware of cultural ignorance and realised they did not take into account the cultural backgrounds. Similar findings were highlighted in this current research study that immigrant Arab women also felt ignored and misunderstood by health care professionals.

Specific cultural needs for Muslim Arab women may differ from that of other ethnic minority women’s health needs. Understanding what these might be, and their influence on subsequent decision making should enable the health professionals to accommodate specific religious and cultural requirements. Some of these
requirements were related to their culture and faith, for example Immigrant Arab women cannot wear the same medical gowns as other patients when examined. All of them preferred to wear a long gown (ankle length), with long sleeves and a high neck, also known as an “Abaya” in Arabic terminology; the belief is that this will encourage them to proceed with the examination with confidence, no embarrassment and modesty. Furthermore, the difficulties in reading the English and Arabic version information leaflets where it includes medical and technical terms. Consequently, the breast cancer early detection measures (i.e. clinical breast cancer examination and breast screening) provided to immigrant Arab women should consider these cultural influences and ensure services can meet specific needs. As recommended in the NICE (2004) guidelines, in order for all staff to receive education and cultural awareness training, local commissioners and cancer networks are advised to work closely with local delegate and cancer networks. In the NCEI (2010) report, specific recommendations for how this issue can be accomplished have been suggested. For example, adequate training for the healthcare professionals about cultural competence needs to be produced, which needs to go ahead with diversity training presently provided by the NHS.

Moreover, this can be achieved by organizing a particular training and learning programme that contains awareness of cultural competence abilities and diversity importance to challenge inequalities, especially in densely populated Arab populated zones.

Kai (2005) expressed that the programme of PROCEED (Professionals Responding to Cancer in Ethnic Diversity) is one of the good examples for such a training programme, which aims to improve healthcare professionals’ abilities in reaching health needs of minority ethnics groups. This training programme is
supported by Cancer Research UK. Another example that provides beneficial training is the “Train The Trainer programmes” (TTT), which aims to teach and provide healthcare professionals with sufficient skills and knowledge about different health related experiences through a tested learning and development programme Karayurt, Gursoy, Tasci & Gundogdu (2010) and Meneses & Yarbro (2007). The aim of the programmes such as TTT is to help establish, good knowledge and learning by intellectual and practical building techniques. Previously, TTT programmes successfully organized an effective different training among 32 nurses from 20 countries for breast cancer cultural competent attention in USA. All nurses who participated in this training programmes of ‘cultural variety’ expressed that their alertness, and confidence increased and helped them to provide health care to address diversity for ethnic minority groups (Meneses & Yarbro 2007).

One of the greatest challenges for understanding relationships between people from minority ethnic groups and the NHS is the absence or incompleteness of data. Understanding the ethnic origin of a population can improve healthcare delivery so that, as appropriate, resources can be planned and tailored to support accordingly whether this involves breast cancer awareness programmes, health education needs with appropriate resource allocation. Therefore the NHS services should adopt the Office for National Statistics (ONS 2011) guidance to collect data by including a separate “Arab” ethnic group in all future NHS ethnicity recording forms. This would enable planned future health requirements and inform development issues related to the Arab ethnic immigrants resident in the UK.

4.4.3 Breast Cancer Knowledge and Awareness
Increasing breast cancer awareness knowledge within the Arab communities in England is vital to dispel cultural taboos and fear of breast cancer. In turn, it helps to encourage openness, to talk about breast cancer within the community. Johnson et al. (1999) expressed that this is particularly important amongst women from first generation minority ethnic groups as they may not be as educated or fully adapted to the western culture, thus their poor awareness knowledge towards breast cancer awareness may influence attendance at breast screening or seeking diagnosis. This can be attained through healthcare professionals, who can address any knowledge gaps and provide Arab women with accurate and culturally sensitive information. Furthermore, through community development and outreach programmes to educate and raise awareness within the wider Arab community, by targeting local community groups (e.g. community centres or places of worship (mosques)) which are accessed by Arab women on a regular basis in different area populated by Arab ethnicity in England.

There is also an opportunity to consider training members of the Arab community on breast cancer awareness and accessibility to breast cancer awareness by providing enough financing assets (NICE, 2004) from local cancer networks. This could provide an opportunity for breast cancer to be talked over publicly and in a positive way. NCEI (2010) acknowledged that community improvement projects are known to be particularly significant and appealing to minority ethnic groups. This could be extremely effective if health care professionals (i.e. nurses and the community health visitors) worked in association with members of local Arab communities to help improve the community member towards lack of knowledge regarding health issues.
Efforts aimed at removing barriers to breast health promotion and early detection must be combined with investment in public health infrastructure and service delivery at the provider and facility level to improve prompt access to effective breast cancer diagnostic and treatment services. The role of public health is important with health visitors extremely well placed to identify these ethnic group women’s specific needs which are likely to include cultural and social norms. Much of the current health visitor’s work continues to be working with mothers as a priority (Bowen, Duffy, Ryan, Hart, & Jones, 2008). Therefore, providing specific training for health visitors, particularly those working in areas with high numbers of Arab populations to be culturally aware, to deliver relevant and appropriate health messages in collaboration with community leaders is essential to ensure breast cancer awareness information is reaching, and being understood by these Arab ethnic minority groups.

The knowledge and understanding of Arab women can be positively impacted by precise and diverse sources of information regarding breast cancer and its awareness using a variety of social media and networks (Al-Qattan & Saleh, 2008). Social media and networks have been used successfully with Arab American women where levels of secrecy about cancer have also been reported (Mellon, et al., 2012). For those Arab women who do not know anyone with cancer, and therefore cannot gather information from their relative or friends (Haji-Mahmoodi et al., 2002; Shirazi et al., 2006; Dandash and Al-Mohameed, 2007) social media and networks can be particularly useful. For that reason, it is suggested that the men and women from immigrant Arab communities work together to promote breast cancer awareness campaign media, that should be
raised through channels which are considerably approached by immigrant Arab community. For instance, cultural radio for example, Sout al khaleej, (an Arab community station) and television channels, such as the BBC Arabic television channel.

4.4.4 Information needs

Over ten years ago, the availability and accessibility of educational information materials in various languages was previously highlighted as being highly limited. NICE (2004) reported that the accessibility and availability of the educational information materials in various languages were inadequate. Whilst, an improvement in this area has since been made whereby breast cancer awareness leaflets have been made available in the Arabic language; despite this improvement the availability of this information is limited to PDF versions available through the internet, or instead, rather than readily available within healthcare services, need to be ordered in. This reduces the convenience of having them available locally (i.e. in surgeries or local hospitals) (Macmillan Cancer Support, 2011).

One suggestion has been that for first generation immigrant Arab women, with limited English proficiency, that they should be offered breast cancer information in their own language, by a health care professional when visiting a health care centre (surgery or local hospital) to maximise a better understanding regarding breast cancer awareness. This may also provide the Arab woman with an opportunity to ask questions about any worrying features; in addition, English-speaking women from both generations of immigrant Arab women may also find this useful.
Watts, et al. (2004) argues that even though current educational information materials have been translated into various languages is helpful, it may be ineffective, especially for the people who cannot read and write in their mother languages. Therefore, information through other methods such as auditory and visual learning tools for example, CD and DVD, might be advantageous in overwhelming the obstacles of limited reading ability among immigrant Arab women. Educational tools such as these have previously been invaluable (Husson et al., 2010) and proven its effectiveness in delivering information to people with limited reading and writing skills (Trevatt & Kelly 2006). NICE (2009) reported that, it is insufficient to use translated health educational material in a simple format unless they are also culturally appropriate to diversity groups. Consequently, it is vital to contain information that consider the sensitivity of the culture, acknowledging the socio-cultural and religion influences that the immigrant Arab women may adhere to. Although NHS and charities such as Macmillan have been focusing on producing good quality, culturally sensitive information (Trevatt & Kelly, 2006), it is imperative for the NHS services to address these issues in their policies as well. Breast cancer and breast cancer awareness Information in Arabic dialect should also be made available in the Arab association’s centres, worship places, surgeries and general hospitals, not simply through internet and mail order.

4.4.5 Implications of the Research

Future studies could develop the work from this research study to extend exploration to immigrant Arab women from a wider geographical spread across the UK to further investigate predictors of barriers toward breast screening. Specific consideration ought to be given to ensure the inclusion of women with
restricted English capability and illiterate group in further studies. Additionally, research should not be limited to breast cancer awareness among women, but aim to explore the knowledge, beliefs and attitudes of men toward breast cancer and other type of cancer.

To date, NCEI (2010) confirmed that presently, there is no conclusive evidence about efficient action that identifies the necessities of minority ethnic women. In this study, most of the immigrant Arab women, across both generations, wanted further educational support to increase their knowledge about breast cancer and its awareness. Upcoming studies could assess the effectiveness and viability of, for example, specific educational programme interventions tailored to the needs of immigrant Arab women groups. In order for the current research to be progressed further forward, it is vital to ensure the availability of adequate funding resources for the researcher (Molassiotis & Jacobs, 2012). Numerous recommendations were suggested by the National Cancer Research Institute (NCRI) strategic planning group, to develop the environment of research (NICE 2004). The suggestions included increasing funding to post-doctoral researcher, and directing funding in areas of breast cancer awareness among minority ethnic women.

4.5 Reflections on Research Methodology

This part will demonstrate my experience in completing this research, including researching hidden population and the qualitative and quantitative studies. Next, my involvement as insider and/or outsider researcher will be acknowledged.
Finally, there will be an explanation and reflection on using the mixed method in the current research and study strengths and limitations.

4.5.1 Researching Hidden Populations

Within the context of health, it appears that minority ethnic groups are overwhelmingly seen as ‘slipping through the net’ (Doherty, Stott & Kinder, 2004). The immigrant Arab community are often under-represented in health research, mainly in the UK and USA and particularly when researching sensitive topics such as cancer (Laird, Amer, Barnett & Barnes, 2007; AlGallaf, 2014). This may be because they are seen as ‘hard to reach’, or referred to as the ‘hidden population’, because they are not easily reachable, reluctant to participate and often do not wish to be found (Laird, et al., 2007).

The reasons behind the lack of understanding of the concept of research participation can be due to the type of subject itself, especially if it is related to socio-cultural taboos and stigma (i.e. breast cancer is psychologically connected with fear of death as a bad sense), the topic sensitivity, issues of belief (i.e. fear of misunderstanding), private circumstances (i.e. work obligation, the demands of childcare, research venue), or basically because they want to keep their own concerns private (Knobf, 2011; Michalec, Willigen, Wilson, Schreier & Williams 2004; Marpsat & Razafindratsima, 2010; Rooney et al., 2011; Underwood & Alexander, 2000). Potential obstacles to participation in research among other ethnic minorities, have been investigated in one study by Rooney et al (2011) who found that there were several barriers behind lack of participation in research. These included, if participants had little knowledge about the research, ignorance of the research process fear of stigma associated with a particular disease,
linguistic barriers (i.e. lack of translated material to aid understanding), fear of being misunderstood and time and venue of the research (because of personal situation, such as family, work and/or education).

Others have suggested that lack of participation may be due to linguistic barriers but also that researchers do not approach potential participants because they believe that some ethnicity group will not want to contribute (Wendler et al, 2006). On the other hand, the author found slight alteration in the readiness of African-American and Hispanics ethnic groups to partake in health researches which bear the theme of cancer and HIV, summarising that field researchers in health should give a choice to the minority ethnic groups to encourage their participation in health researches.

It is essential to note that readiness to take part may vary in the US contrasted with the UK, particularly as there is more better accentuation on health insurance in the US and along these lines interest in exploration, for example, clinical trials, can be an open door for contributors to get to free medical care access (Wendler et al., 2006).

Conducting research with hidden groups can be both very interesting and challenging at the same time. Nevertheless, it is important to include such groups in order to overcome the inequalities gap within the health context. To increase the contribution of hard-to-reach or hidden population within health research, a diversity of sampling approaches needs to be considered. Snowball sampling and community networking are considered to be the best and effective sampling approaches in gaining access to hard to reach populations (Black, Frisina, Hack & Carpio, 2006; Knobf et al., 2007).
The latest research exploring recruitment strategies among BME communities has proven that using different approaches to recruitment can increase research participation (Vickers, Craig & Atkin, 2012; Stirland et al., 2011). In their study, Stirland et al., (2011) questioned UK and US investigators to discover different enrolment approaches used when studying BME population. The researchers explored five effective recruitment approaches, set out in Table 17 below.

Table 17: Five Effective Recruitment Approaches to Increase Research Participants (Stirland et al., 2011)

<table>
<thead>
<tr>
<th>Recruitment approaches</th>
<th>How criteria can be met</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establishing trust and relationship with</td>
<td>• Effective communication (clearly explaining the research to participants can diminish any trust issues or suspicion that participants may have.</td>
</tr>
<tr>
<td>gatekeepers/community leaders</td>
<td>• Providing translated materials to enhance understanding of the research aims and objectives</td>
</tr>
<tr>
<td>Personal touch</td>
<td>• Face to face contact</td>
</tr>
<tr>
<td></td>
<td>• Offering incentives and reimbursements as a way of showing participants that their time is valued and they are in no way out of pocket for participating in terms of travel costs</td>
</tr>
<tr>
<td></td>
<td>• Providing refreshments</td>
</tr>
<tr>
<td>Cultural sensitivity and understanding</td>
<td>• Based around gender (e.g. ensuring a female is present with a male researcher when researching female participants.</td>
</tr>
<tr>
<td></td>
<td>• Understanding cultural beliefs and influences such as religion.</td>
</tr>
<tr>
<td>Targeting areas</td>
<td>• Choosing area have a high minority ethnic population that need to be study</td>
</tr>
<tr>
<td></td>
<td>• choosing a venue that is convenient for them</td>
</tr>
<tr>
<td>Persistence</td>
<td>• Follow up phone calls to participants and gatekeepers regarding the study</td>
</tr>
<tr>
<td></td>
<td>• Reminder emails to participants and gatekeepers regarding the study</td>
</tr>
</tbody>
</table>
In addition, the use of interpreters found it useful to overcome language barriers and found that providing an audio version of information sheet can also increase the rate of participation in health studies. (Rooney et al., 2011 & Lloyd et al., 2008). Furthermore the audio information sheet is particularly useful for the participants who are illiterate in their native language.

Atkinson & Flint (2001) define snowball sampling as a type of non-probability sampling system. Snowball and chain referral sampling have been discovered to be exceptionally positive techniques in the recruitment of hidden or hard to reach people, under the supposition that peoples who are outstanding or significant to the group are better placed to recruit hidden people than an outsider (or the investigator) (Aitken, 2005; Benoit, 2005). This kind of sampling method seeks one member refers potential members, who can then refer other conceivable members with a comparable attribute of interest, and so on (Vogt, 2005). Leeway of this system is that it can be a snappy process as trust among people fitting in with the same group may develop and be recognised.

Disadvantages of this approach is that the membership of the sample may not be illustrative a since it is conceivable that just the individuals who are comparable or impart the same informal communities are in contact (Penrod, Preston, Cain & Starks, 2003). Joining sampling strategies, for instance with chain referral method, may can lessen this bias.

Chain referral sampling is another term used for a type of snowball sampling. It is similar in that chain referral sampling selects members through member referrals, but, in contrast, tries to do this by means of numerous informal communities and thus is not bound to only one interpersonal organization (Penrod et al., 2003). However, the author reported that the weakness of chain
referral sampling is that regardless it has the capability of bias sampling, particularly if the members are enrolled through comparable informal communities, for example, group clubs. Thereby, the individuals who don't go to such clubs are still unseen and unrepresented and possibly the ones whose voice needs to be heard (Penrod et al., 2003).

Lastly, by combining different approaches to provide a multiple recruitment method it may increase participation (Knobf, 2011). These can incorporate all the systems specified above and moreover conveying customized letters to potential members and media presentations such as Arab community radio, pamphlets and magazines, particularly mediums that are associated with or used by the immigrant Arab population. However, achievement rates of these methodologies can differ with particular ethnic minority populaces and can be reliant on careful planning and access (Yancey, Ortega & Kumanyika, 2006).

Another potential influence on accessing potential participants from such communities is that of the insider-outcast position of the researcher. This is of specific importance relevance to the present study and is talked about in depth in the following part.

4.5.2 Insider/Outsider Perspective

Numerous qualitative studies have recorded observations on the way that the research’s beliefs and knowledge may have the effect of placing them as either insiders or outsiders that can influence the gathering of data as well as information aggregation (Bonner & Tolhurst, 2002; Dwyer & Buckle, 2009; Etherington, 2005; Gunaratnam, 2003). Researchers who take the part of insider
can be represented as individuals who are acquainted through the people whom they are investigating and with whom they have characteristics in common, for instance; age, sex, sexual orientation, ethnicity, linguistic, faith and an empirical stage (Asselin, 2003). While the outsider is a person who does not belong to the category of the individual under research, also who is unacquainted with the research field they are planning to investigate (Louis & Bartunek, 1992).

The mechanics of insider-outsider stances are not straight-forward and to avoid ambiguity as either/or, they should be positioned on a continuum, rendering a possibility for researchers to be simultaneously an insider and an outsider, or with the roles switching during the research procedure (Ritchie, Zwi, Blignault, Bunde-Birouste & Silove, 2009).

Embracing both an insider and outsider role has been termed 'part dualism' (Hurworth & Argirides, 2005). "This can be an important device when "connecting steadily with sources and at different times venturing back to decipher the information all the more comprehensively" (Ritchie et al, 2009 p109). As an Arab woman, but a female researcher who has basic or limited knowledge about Arab culture, I feel I was both an insider and an outsider and this status changed at varying stages of the research. Born in an Arabic community but having departed from it while still a tender age, results in the tendency for me to be perceived by both outsiders and insiders as an 'insider'. I stand on the edge of the Arab community, especially in the more traditional aspects of their culture, but have the same position in relation to the Western world. As an Arabic speaker, I can be on the inside, but by the same token, I am an individual who does not currently live within the Arab society. I exist on the periphery of both worlds and their respective cultures, but neither member nor stranger. Cultural knowledge does not have an
unceasing development; new cultural characteristics emerge as old ones fall by the wayside, having become defunct. Hence, the frequent replenishment of cultural idiosyncrasies creates a cultural evolution, culture is nowhere stationary. Nonetheless, the pace of change and the facets of Arab culture that shift render my knowledge limited about current knowledge, beliefs and attitude. It was likewise important to consider the degree to which one can be an insider and/or an outsider, and the effect this can have on the study process. Singh-Raud (1999) believes that “one can always be regarded as an outsider, unless one is researching oneself… only a certain degree of ‘insiderness’ can be claimed”.

4.5.3 Qualitative Studies

The qualitative design studies provided me with the chance to explore thoroughly the knowledge, beliefs and attitudes of breast cancer and breast cancer awareness among immigrant Arab women. Similar findings were revealed across a number of settings, comprising different immigrant Arab women populations offering confirmation of findings. Both of the qualitative studies demonstrate mutual findings to provide contextual understanding, which in turn increases the findings validity. The semi-structured face-to-face in-depth interviews provided an opportunity for immigrant Arab women to tell their stories. Furthermore, it permitted me to obtain a more profound understanding of the beliefs and attitudes which were characterised by Arab women. In the focus groups, Arab women also had an opportunity to share their knowledge, attitudes and beliefs about breast cancer awareness and the usefulness of educational information leaflets, these opinions were collected from Arab women from various locations within England. The communication between the participants was one of the specific points of interest in the utilization of focus group discussion, whereby they could react to
others’ encounters which is not possible within an individual interview (Kitzinger, 1994). At the same time, and on the basis of previous findings from the one to one interviews (Phase One) sharing concerns about social stigma and fears of gossiping and breeches of confidentiality, participants from both focus groups were asked to respect confidentiality and not to discuss what other women had shared outside of the discussion group. This was particularly important because some of the women knew each other from belonging to the same Arab Association Centre as well as part of a wider Arab network. The confidentiality of the data and their personal details were also emphasised.

The focus group data collection method turned out to be especially helpful for the research participants who took the opportunity to voice concerns and put forward issues to the rest of the discussion group. While the weakness of this method is that a few participants may not feel able to share their perspectives in the event that it digresses from other people’s perspectives (Kitzinger, 1994). This did not appear to be the circumstance since the Arab women in both focus groups appeared to connect and/or separate their insight and considerations from other focus group participants, which empowered additional discussion particularly around the deliberation of the NHS and Breast Cancer Charity brochures. Focus group discussion, therefore, provided a particularly helpful method to empower diverse views.

I found that conducting the focus groups was a more difficult procedure in contrast to that of the semi structured individual interview. Many points needed to be considered while running a focus group discussion, whilst I needed to be aware of the group discussion in terms of everybody having a reasonable chance to add to the discussion, I also needed to listen to the dialogue and follow the schedule
of the discussion. There were some incidents that occurred with some of the participants during the discussion, where they were overly engaged to speak and sometimes inhibited other women from participating in the discussion. It was also occasionally challenging to return the focus of the participants to the central discussion point when they went off the subject, particularly if it was linked to an additional private event.

Arab women felt that discussing their understanding of breast cancer awareness, beliefs and attitude, had helped and enhanced their awareness of breast cancer. I was additionally inspired that the participants felt speaking to me, being shown leaflets that they had not seen before, had helped them, which confirmed the significance of conducting this research for me personally.

Most of the immigrant Arab women were recruited through a privately funded Arabic School in the south of England and Arab community associations in London and Portsmouth. It is, therefore, possible that there may be a difference between the immigrant Arab women interviewed in these locations and those in the Arab community as a whole as not all Arab women want to attend or able to attend due to factors such work and life constraints. Consequently, these women’s encounters may be distinctive from those of other Arab women who are not members of these centres and thus findings cannot be applied to. This highlights the struggle in accessing this hidden (hard to reach) population.

4.5.4 The B-CAM Survey (Quantitative design)

The validated questionnaire ‘Breast Cancer Awareness Measure’ (B-CAM 3) in Phase Two provided the opportunity to assess the knowledge of immigrant Arab women’s awareness of breast cancer warning signs and symptoms, risk factors
and perceived barriers to seeking medical help. The survey was completed prior to the focus group discussion-taking place. This provided an opportunity to directly compare the findings within this same population (N=34).

Since the study was not based on a population-based sample and the sample small, the findings may be hard to generalise to all immigrant Arab women in England. There may have been a selection bias due to the inability to select random participants from the Arab community; additionally, women attending the community centres may vary from those in the Arab community. Nevertheless, because the participant characteristics are fully described to include educational level, marital and employment status, first or second generation, the findings are “transferable” and the reader can relate the findings to other similar populations.

4.5.5 Use of Mixed Method

The adoption of mixed method and the integration of qualitative and quantitative research methods was considered to be highly appropriate for the applied nature of this research. The exploratory studies allowed me to delve into the topic from a broad perspective. As a consequence, I was able to explore the knowledge and understand range of beliefs and attitudes that played a significant role in shaping the Arab women’s breast cancer awareness experiences. Data collection variation leads to better validity. Moreover, the corroboration of qualitative and quantitative data allowed the research objectives to be further examined through specific validated measure (B-CAM), so, generalisation can be complemented by evidence from the literature.

Prior to conducting this research, I had no experience of conducting qualitative research, although I had an understanding of the theoretical underpinnings of
qualitative research. Consequently, I was more confident in conducting, collecting and analysing quantitative data. Adopting a mixed methods approach has been an important learning process as my skills have developed in conducting and analysing data qualitatively. Using both methods has enabled me to gain a deeper understanding of both types of research and the value and appreciation of integrating qualitative and quantitative approaches in health research.

4.5.6 Data Analysis

Dwyer & Buckle (2009) contended that the insider researcher could display the opinion and comprehension of the research participants due to extreme closeness to the research data; this can block the capability to persevere un-biasness in the process of data analysis. At the same time, it is possible to display the information in a truthful manner because of his knowledge of research data and the participants are well understood. However, the explanation above can be right, especially when there is a personal relationship between the researcher and the participants or any personal experience, preventing their capability to stay unbiased. On the other hand, Tinker & Armstrong (2008) and Young (2004) affirmed that the outsider researcher is able to provide a pivotal data analysis due to his ability to maintain a distance and being uninformed about the participant’s reality. All over, Pike (2003) confirmed that any position the researcher adopt is not a significant issue because the researcher within qualitative studies gives the opportunity of being subjective in their own right, regardless any position they conduct. To certify that the participant’s data are interpreted correctly, the researcher can enhance credibility of the findings by checking the research codes
and themes, and validate the research findings by other independent researchers (Tinker & Armstrong, 2008).

Ritchie et al (2009) indicated that to promote a good standard research with credible information, it is ideal to have a research group originated of insiders and outsiders. A good example of this was my supervisors; the first supervisor has considerable ability in qualitative research design and had previously worked at Breast Cancer Care Charity on secondment to Breast Cancer Care (Head of Research and Evaluation in 2010) but had little knowledge of ethnic population. My other supervisor represented the same ethnic origin; my first and second supervisors also had countless knowledge in guiding the research in this diverse approach. Consequently, I have had the opportunity to seek the advice from both of my supervisor as appropriate.

It is not simple to have an insider-out sider position. At the beginning I felt that my position by way of an insider was from the Arab viewpoint and later an outsider from the point of view of cancer. By continuously looking into this issue, I observed that it was more muddled, than previously considered and eventually I was taking both insider and outsider position. Another time I was feeling that I was more an insider than an outsider researcher. However, my position was enormously reliant upon the circumstance; being in a position where I was an insider and outsider on a continuum allowed me to admire the complexities, and use both the advantages and disadvantages of being in both settings (Mercer, 2007). From this, we can deduce that the researcher needs to accept any position that he would take, acknowledge all the advantages and disadvantages, value the difficulties, and account the pros and cons of taking both positions into different circumstances (Mercer, 2007). Etherington (2005), indicated that despite
whichever stance, it is vital to be reflexive from start to finish through the study stages keeping in mind the end goal (Ritchie et al. 2009) to ensure that the study is directed in a correct manner (Bartholomew, 2010). Additionally, Dwyer and Buckle (2009) indicated that it is not the main consideration as to whether the researcher is an insider or outsider, but it is more important that they are able to be truthful, original, open and pointedly attentive to data analysis and, within the research process, they are obliged to carefully and sufficiently represent their involvement in the research. It is for this reason that not accepting one position over the other contributes to the quality of the researcher, and contributes the quality of the researcher. (Dwyer & Buckle, 2009).

Figure 28 below shows some of the challenges faced by me in conducting the whole research in terms of being an inside/outside researcher. The figure conveys that there are multiple dimensions to the insider/outsider dichotomy; researchers are continually moving between these dimensions which are subordinate upon period, area, contributors and subject. I responded to this issue by reflection and critique of all encountered problem areas throughout and in particular, at each stage of my study.

However, since I perceived my role was that of an outsider research during the first study and insider in the second one, my perceptions on the method of research deliver a prospect for discussion of an under-researched methodological issue which has been proven critical to the rising number of health science researchers that work with ethnic minority groups such as Arab women. Unchanging and distinctive features of the researcher includes identity, such as gender, ethnicity and sexual orientation, on the other hand additional features,
such as age, place to live and stay are constantly changing. Each feature provides one dimension to the insider/outsider continuum (Knotter, 2011).

Figure 27: Continuum of Culture Awareness Development through Different Phases of Research Study
Figure (27) conveys my position as an insider-outsider as a continuum within the research process. In current research, at the beginning before I commenced phase one (first qualitative study), I participated in particularly “less intimate” outsider researcher. Although I shared the same gender, ethnicity and language as the participants, my sensation as an outsider came from the basic knowledge
I possessed since my migration to western society, thus adapting to the western culture from a young age. In addition due to political difficulties, visitation to the Middle East was extremely limited which meant I was less informed of the culture and its developments. The action taken to overcome this issue was to increase my reading of pertinent literature with regard to Arab culture and insider/outsider researcher; awareness was therefore increased after phase one. By contrast, at the second phase and through the data collection, I felt that my involvement was mostly that of “familiar” insider researcher. This sense was based on the feeling that I was now better informed about the Arab culture. The continuous change in emotions, regarding my position as an insider-outsider, lead to the appreciation of both the pros and cons in both positions.

4.6 Study Strengths and Limitations

The presented study provides novel data in an attempt to exclusively understand the knowledge, attitudes and beliefs of immigrant Arab women toward breast cancer and breast cancer awareness. Its primary quality originates from the utilisation of an extensive variety of techniques to address the aim of the study, and its originality. Unlike an earlier study conducting in the UK (Scanlon, 2004), which included an Arab minority group from then UK embedded in discussions representing other minority groups (19 Arab women out of 88 from different ethnic backgrounds). Scanlon (2004), postulates that in her research, language may be a barrier in a mixed ethnic group for Arab women to take part in the focus group discussions and suggested one to one interviews to overcome language difficulties in order to explore more cultural issues in detail. This study conducted one-to-one qualitative interviews in Phase One to overcome language difficulties
and, in Phase Two, provided an immigrant Arab women only group discussion to provide a safe and inclusive environment to share experiences. The methodical evidence in the current study offers systematic evidence which may provide guidance for practice and future research. It is however important to note that caution and consideration must be given to the study design and methodology used.

Benton (2000) reported that the qualitative study has already been condemned on the reason of omission issues of reliability and validity, and being narrative. The use of a triangulation technique was used to strengthen the reliability of this study. I acknowledge some of the limitations and challenges of current study which might be addressed in future research on similar topics. Although the small sample was quite diverse in terms of the participants’ age, educational and length of residency in Britain and included sampling from two cities in the South West of England as well as the capital city, London, all the immigrant Arab women were Muslims. They, therefore, may not have been representative of all Arab women from non-Muslim backgrounds. Therefore further research in the future need to be carried out to represent Arab women from different religious backgrounds.

Most of the immigrant Arab women were recruited through a privately funded Arabic School in the south of England and Arab community associations in London and Portsmouth. There may be a difference between the immigrant Arab women attending these discussions and those in the wider immigrant Arab community as not all Arab women are able to attend these centres due to work and life constraints or indeed wish to attend. Consequently, these women’s encounters may be distinctive to those of Arab women who are non-members of these centres and thus findings cannot be generalised. Nevertheless, the thick
description of all participant characteristics to include level of education, marital status, employment status and whether first or second generation, provide “transferable findings for readers to relate to other potential similar populations. The limitation of access to this population highlights the struggle in accessing a hidden (hard to reach) population.

We only asked the opinion of immigrant Arab women about breast cancer and breast cancer awareness practice. Yet, the findings suggest that men are often seen as the decision maker in the family. Exploring the views of immigrant Arab men may be important to investigate in further research studies. Neither did this research study include or represent the healthcare providers’ perspectives on this issue. Future research could collaborate with other stakeholders such as healthcare providers including physicians, nurses and community health workers.

4.7 Conclusion

This research has made a useful contribution to an unstudied area which has, to date, received limited attention in England. A significant confirmation has been revealed regarding the necessity to routinely provide socially and ethnically sensitive informational materials to Arab women and to encourage their awareness toward breast cancer. Despite the findings from this research, which adds to the body of e existing literature on Arab minority breast cancer awareness, improvement is required around this zone in order to enhance immigrant Arab women’s perception and awareness of breast cancer; especially those belonging to the first generation with particularly low breast cancer educational needs. This will, in turn, allow existing inequalities to decrease and obtain this critical objective set by the DoH (2007).
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Appendices
1. Phase One Appendices

1.1 Invitation letter, information sheet and consents forms for phase one in both languages (English and Arabic)

Invitation letter
Version 2. Dated 1/5/08 Identification Number:

School of Health Sciences
And Social Work
St George's Building,
141 High Street,
Portsmouth PO1 2HY.
England
Tel: (023) 92845300
Fax: (023) 9284 5200

Dear Women,

RE: Research in Knowledge, attitudes, beliefs and practice of immigrant Arab women toward breast cancer and breast awareness in England

My name is Afrah Redha and I am a PhD researcher from University of Portsmouth. As part of my study, I am carrying out a qualitative study and would like to explore the issues of Immigrant Arab Women who resident in England (like you) and to investigate different cultural understanding and beliefs, level of knowledge and confidence as well as practice that have not been captured but need to be incorporated in this study. There has been little empirical research in this area in UK. It is anticipating that the present study will provide information to identify and describe barrier to early detection of breast cancer for Arab Immigrant Women in England.

I am looking to interview 50 Arab women. Taking part in the study would involve being interviewed by me at a time and place of your convenience. The interview will be audio recorded and will last between 30 minutes to 1 hour, depending on what you would like to share at interview. I have attached a copy of the information sheet, which gives more details on what taking part in the study involves.
I would be grateful if you would indicate on the enclosed form whether you think you may be interested in taking part in the study. It should only take a few minutes to fill in and I have enclosed a stamped addressed envelope for your convenience. In the meantime, if you have any questions on the study that you would like to discuss with me please telephone me on 02380232857 or alternatively email me at afrah.redha@port.ac.uk.

Many thanks for taking the time to read this letter.

Yours sincerely,

Afrah Redha
PhD Researcher
School of Health Sciences and Social Work
University of Portsmouth
PARTICIPANT INFORMATION SHEET

Knowledge, attitudes, beliefs and practice of immigrant Arab women toward breast cancer and breast awareness in England

You are being invited to take part in a research study. Take time to decide whether you would like to take part or not. It is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your colleagues if you wish. Please ask if anything is not clear or you would like more information.

What is the purpose of the study?

The purpose of this study is to explore the knowledge, beliefs, attitudes and practice of Arab women toward breast cancer which may affect the practice of breast cancer awareness. Until now, most research has focused on the knowledge beliefs, and attitudes of South Asian and Black minority ethnic women and there has been very little research among immigrant Arab women in UK. Therefore this study aims to:

• To explore level of knowledge, beliefs and attitudes towards breast cancer and breast cancer awareness practice among immigrant Arab women.

• To explore their breast cancer perception.

• To explore practice of breast cancer awareness among Immigrant Arab women.
• Inform practice and gaps in knowledge regarding educational materials relevant to this population.

**Why have I been chosen?**

As you are one of Arab women resident in England, I would like to explore your attitudes and to investigate different cultural understanding and beliefs, level of knowledge and confidence as well as practice of breast cancer awareness as early detective method for breast cancer. If you agree to take part you will be one of 50 women who have also agreed to be interviewed.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

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

I will make arrangements with you to conduct the interview at a time and place of your convenience. This may be at your home, at your place of work if a suitable quiet and private room is available or at the University of Portsmouth School of Health Sciences and Social Work. If you decide to travel to your place of work outside of your usual working hours or to my office at Portsmouth, reasonable travel costs incurred can be reimbursed.

The interview will be audio taped. Your views are important and should be represented in your own words. It is up to you how long the interview takes. You can ask to stop the tape or discontinue the interview at any time. I estimate that the interviews will take between 30 minutes and 1 hour depending on what you want to tell me.
Will my taking part in this study be keep confidential?

All information collected will be treated confidentially. It will be number coded with your name removed so that you cannot be recognised from it. Any names that you use within the interview will also be removed. You will also not be identified by name in any subsequent report or publication. However, although I will make every attempt to safeguard confidentiality, this cannot be guaranteed.

What will happen after the Interview?

After the interview and the audiotape have been fully transcribed you will be given a copy of it to read to check that the information you have given has been represented correctly. Let me know if you are not happy with anything that has been typed up and it will be removed.

All of the interviews will be analysed to find categories or themes and a report written up. I will randomly select three participants to be shown a summary of the initial analysis of their interview and ask them to check the appropriateness (or otherwise) of the category system. If you are selected, this will involve you in being asked questions such as “Do you think this quotation from your interview fits this category?” Your response will be noted and adjustments made as necessary. Your consent to be randomly selected in this part of the study will be sought before your interview takes place. If you would not like to take part in this stage of analysis it will still be possible for you to take part in an interview.

A letter will be sent to you when the final report has been completed with a brief overview of the findings. If you would like to receive a full copy of the report this will be available to you upon request. All the tapes will be securely stored until destroyed after 1 year.
What are the possible disadvantages of taking part?

It is hoped that taking part in the interview will not prove stressful to you. It is up to you exactly what you share in the interview. However, if you feel upset by what you have shared, the interview can be immediately terminated.

What are the possible benefits of taking part?

It is hoped that the information that we get from this study will provide information to identify and describe barrier to early detection of breast cancer for immigrant Arab women in England.

Who has reviewed this study?

The University of Portsmouth / school of Health Science and Social Work have reviewed this study.

Thank you for taking the time to read this information sheet. If you require any further information or would like to take part in the study, please contact:

Mrs. Afrah Redha
PhD Researcher
School of Health Sciences and Social Work
University of Portsmouth
Tel 02392 84 5246 (work)
02380232857 (home)
Email: phb60112@port.ac.uk
CONSENT FORM

Title of Research:

Knowledge, attitudes, beliefs and practice of immigrant Arab women toward breast cancer and breast awareness in England

Name of Researcher: Afrah Redha (Contact Tel. No: 02380232857)

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I am willing to consent to audio recording of my interview

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

4. I am willing to be randomly selected to be sent a copy of the initial analysis of my interview to comment on the findings. (Delete as appropriate)

5. I agree to take part in the above study.

Please Note: Although we will make every attempt to safeguard confidentiality it will not be possible to guarantee this issue.

Name of Participant __________________________ Date __________________________ Signature ________________

Name of Person taking consent (If different from researcher) __________________________ Date __________________________ Signature ________________

Researcher __________________________ Date __________________________ Signature ________________
رسالة دعوة

عنوان البحث:
دراسة نوعية لاستكشاف المعرفة والموافق والمعتقدات من سرطان الثدي والتوعية حول سرطان الثدي بين النساء العربيات المهاجرات في إنجلترا.

اسمي افراح نعمة محدرضا العبادي وأنا باحثة دكتوراه في جامعة بورتسموث. كجزء من دراستي، أقوم بإجراء دراسة نوعية لوضع مستوى المعرفة الإلزامية والتأملات المتصلة في ممارسات النوعي لسرطان الثدي للنساء العربيات المثلى (مثلك) في مختلف المعتقدات والثوابت الثقافية ومستوى المعرفة والثقة في ممارسة الفحوصات للكشف المبكر عن سرطان الثدي والتحقيق في مختلف المعتقدات والمستوى الثقافي والثقة والثقة من ممارسة الفحوصات للكشف المبكر عن سرطان الثدي للنساء العربيات المثلى (مثلك).

للاستفادة من البحوث التجريبية في هذا المجال في المملكة المتحدة تخصص المرأة العربية. ومن المتوقع أن تكون الدراسة الحالية من شأنها أن توفر معلومات لوصف وتحديد الحاجات من ممارسة الفحوصات الخاصة بالكشف المبكر عن سرطان الثدي عند النساء العربيات المثلى (مثلك).

انا اتطلع لمقابلة خمسون امرأة عربية. ولكي تكوني إحدى المشاركات بالبحث وجزء مهم فيه يجب أن تكون من عشرين سنة فما فوق.

وستكون في الدراسة ستنتم إلى إجراء مقابلة مكثفة وقائية، ومن ثم بحث متقدم وملحوظ من صحيحة المعلومات معاً. تستمر مisposableات ثمانين دقيقة إلى ساعة، وستكون المقابلة ممتعة ومملوءة بالالتزامات، وستكون في الدراسة، الذي يعنى المبدع من التوصيات حول دورك في الدراسة وما توصياته من أهمية.

وساكن ممتنًا لو كنت راغبة أو مهتمة بالمشاركة بالبحث، وإن كان ذلك كما نعمة اذن الرجاء إلى الاستمارة المنطقية.

ولن يستغرق منك ذلك بضع دقائق، ولكنك ستكون مثلك للدراج، حتى نحن الذين لا نستطيع الرجاء نحن، إننا نريد أن نتفاعل مع إجابة قلنا: الرجاء الأتصال دون تردد على الهاتف 02380032857 أو البريد الإلكتروني Afrah.redha@myport.ac.uk.

شكراً جزيلاً لأخذ الوقت الكافي لقراءة هذه الرسالة.

مع شكري وتقديري

افراح نعمة محدرضا العبادي
باحثة دكتوراه
كلية العلوم الطبية
جامعة بورتسموث
دراسة نوعية لاستكشاف المعرفة والمعتقدات والتوجهية حول سرطان الثدي بين النساء العربيات المهاجرات في إنجلترا.

انت مدعو إلى المشاركة في دراسة نوعية بحثية. خذ الوقت الكافي لتقرر ما إذا كنت تريدين المشاركة أو لا. ومن المهم أن نفهم لماذا يتم إجراء البحث ولماذا مشاركتك فيه مهمة. يرجى اتخاذ القرار في البداية لقراءة المعلومات التالية بعناية ومناقشتها مع الأصدقاء والأقارب وزمليتك إذا كنت تريدين. لا تتردد بالسؤال إذا كان أي شيء غير واضح أو كنت تود الحصول على مزيد من المعلومات.

ما هو الغرض من الدراسة؟

غرض هذه الدراسة هو استكشاف المواقف والمعتقدات والسلوكيات عند المراء العربي من سرطان الثدي التي قد يؤثر على الوعي بسرطان الثدي. ونأمل أيضًا باستخدام النتائج التي سيتوصل إليها البحث من المرحلة الأولى على وضع استبان خاص بالمراء العربية المهاجرة في إنجلترا على النحو التالي:

- تقييم خبرتك ومعتقداتك والممارسات للكشف المبكر عن سرطان الثدي ومشاركة الوعي بسرطان الثدي بين النساء في مجتمعنا.

ومن المهم أن نناقش المعلومات وتتابع البحث ممكن الاستفاده منه للبرامج التعليمية والتثقيفية للنساء العربيات الذين يعيشون في إنجلترا للكشف المبكر عن سرطان الثدي.

لماذا تم اختيارك؟

باعتبارك أحدى النساء العربيات وقديم فيه إنجلترا، نود مشاركتك ودعم البحث الجاري الخاص بالمراء العربيه والخاصة بك لدراسة قضايا مختلفة تخص مستوى المعرفة والمعتقدات والثقة بمارسه فحص ال的信任. بالإضافة إلى ذلك، نود أن نكون واحدة من خمسين امرأة سيتم أيضاً الافتكا معهم على إجراء المقابلات.

هل يجب ان تشارك؟

والامير متروك لكي لتقرري ما إذا كنت ستشاركان أم لا. إذا قررت المشاركة سوف يطلب منك الموافقة على
التوقع على استمرار القبول. إذا قررت المشاركة ثم فكرت بالانسحاب بعدها فلك الحريه بالانسحاب في اي وقت.

ويكون اختياري اي سبب.

ماذا سيحدث لي إذا كنت وافقت على المشاركة؟

سادا معكم الترتيبات لإجراء المقابلة في وقت ومكان يكون مناسب لك. وقد يكون هذا في منزلك او مكان عملك اذا كانت هادئة ومناسبة. كذلك الغرفة الخاصة متاحة في مكتبتي وفي مكان عملي في جامعة بورتسموث. إذا قررت الذهاب لإجراء المقابلة في مكان عملك الخاص بك خارج ساعات العمل المعتمدة لمكتبتي في بورتسموث سوف تكون مسؤولين عن تسيير نقلك.

المقابلة ستستغرق بواسطة جهاز تسجيل على اشرطة سمعية. أراكم مهمة وينبغي ان تكون واضحة بكلماتك الخاصة. يمكنك ان تطلب من الشريط لوقف او قطع المقابلة في اي وقت. بتدريبنا ان المقابلات سوف تتخذ وقت مائي النصف ساعه إلى ساعه على الأكثر.

هل معلومات البحث ستحتفظ وتعمل بسرية؟

جميع المعلومات التي يتم جمعها ستتعامل بالسرية التامه وسكون ارقام مشفره بدلا من ذكر اسمك المشاررك وتمتازژة اسم المشاررك كليا. حتي ان كنت تستخدم اسماء وهميه داخل المقابلة ستتم ازالتها ايضا. ولن تكون هناك اي علاقة باسماء المشاركين في أي نتائج البحث او نشر تقرير لاحق يخص موضوع البحث. ولكن ، سنطلب كل محاولة لضمان سرية البحث.

ماذا سيحدث بعد المقابلة؟

بعد المقابلة سوف تحللها للايجاد فئات او مواضيع مشتركة وسأقوم باختيار ثلاثة من المشاركين عشوائيا ليتم عرض موجز من التحليل الأولي للمقابلة وطلب منهم للتحقق من مدى ملاءمة الفئات التي تم تحليلاها. اذا كنت مختارة في هذا الاقتباس من المقابلة الخاصة بك بلان هذه الفئة؟ أريدك سوف ينحظر الاعتبار وعلى اساسها سيتم إدخال التعديلات حسب الضرورة. موافقتك على أن يكون اختياري عشوائيا في هذا الجزء من الدراسة سيطلب منك قبل ان تجري مقابلة. اذا كنت لا تود ان تشارك في هذه المرحلة فلك الحق بذلك مع بقاء امكاننيك للمشاركة لإجراء المقابله.

رسالة سترسل لكم رسالة عندما يتطلب التقرير النهائي مع لمحة موجزة عن النتائج التي توصل إليها البحث. اذا كنت ترغب في الحصول على نسخة كاملة من التقرير ، فان ذلك سيكون متاحا لك عند الطلب. جميع الاشرطة وسيتم تخزينها بشكل على رغبتك حتى سنة واحدة.

ما هي العيوب المحتملة من المشاركة؟
نأمل منك المشاركة في البحث بدون أن تكون قد سبنا أي أزعاج أو وجود جراء المقابلة. والفائدة الممكنة من منحك المعرفة، وعلى كل النساء العربيات المهاجرات في انجلترا. والامر متروك للمشاركه مع ذلك، إذا كنت تشعر بالضيق من أي جانب سيتم إلغاء المقابلة على الفور.

ما هي الفوائد التي يمكن أن تجنيها من المشاركة؟

من المؤلم أن المعلومات التي نحصل عليها من هذه الدراسه من شأنها أن توفر معلومات لتحديد مستوى المعرفة والانجذاب ووصف وتحديد العوائق من ممارسة الإجراءات الخاصة بالكشف المبكر عن سرطان الثدي عند المرأة العربية المهاجرة في انجلترا.

من المسؤول عن هذه الدراسه؟

جامعة بورتسموث.

شكركم على اخذ الوقت الكافي لقراءة هذه المعلومات، اذا كنت بحاجة للاي معلومات اضافية او تودين ان تشارك في هذه الدراسه، يرجى الاتصال ب:

افراح نعمه محمد العبادي
باحثة دكتوراه
كلية العلم الطبي
جامعة بورتسموث
هاتف : 84 524602392 (العمل)
(الموبيل) 07824668617
البريد الالكتروني: Afrah.redha@myport.ac.uk
نموذج الموافقة

عنوان البحث:
دراسة نوعية لاستكشاف المواقف والمعتقدات والمعتقدات من سرطان الثدي والتوعية حول سرطان الثدي بين النساء العربيات المهاجريات في إنجلترا.

اسم الباحث: أفرح نعمة محمد العبادي
للاتصال رقم الهاتف: 02380232857

يرجى تشير المربع

1. أؤكد أنني قد قرأت وفهمت ورقة المعلومات للدراسة المذكورة أعلاه وليفرررة لطرح أي استفسار.

2. أنا على استعداد للمشاركة في الدراسة المذكورة أعلاه.

3. أفهم أن المشاركة طوعية ولدي الحق بالانسحاب في أي وقت دون إبداء أي سبب.

4. أنا مستعد لأكون اختياري عشوائياً على أن ترسل نسخة من التحليل الأولي للدراسة وتحليل المعلومات.

5. أنا أوافق على المشاركة في الدراسة المذكورة أعلاه.

يرجى ملاحظة: سنبذل كل محاولة لضمان سرية المعلومات بالكامل.

______________________ _________________________
اسم المشارك                التاريخ التوقيع

______________________ _________________________
اسم الشخص المسؤول       التاريخ التوقيع

يرجى تشير المربع
Appendix 1.2: Interview schedule

Printed research information given:

Yes [ ]   No [ ]

Consent Form signed:

Yes [ ]   No [ ]

- Test all recording equipment to make sure they work.
- At the beginning of the interview briefly describe the project aims again.

Notes:

The topic areas to be considered will be summarized, which will be presented as open/ended questions for the scheduled interviews.

The prompts parts in bold/italic will be put only if the answer doesn’t cover the expectations by the participants

Firstly I would like to thank you for taking part in my research and for signing the consent form. I would also like to remind you that you do not have to answer any
questions that you do not feel comfortable talking about. You are free to stop the interview at any time or if you feel you need a break, please let me know. With your permission, the interview will be recorded but be assured that what you say will be kept confidential and anonymous and the tape will be destroyed at the end of this research.

I am interested to hear your knowledge, beliefs and attitudes of breast cancer and breast cancer awareness, in particular if your beliefs and attitudes have in any way been affected by your ethnicity. There are no right or wrong answers so please feel free to talk as honestly and openly as possible. If there is anything I have missed out that you feel you would like to talk about, please feel free to bring it up anytime.

**Does that sound okay? Any questions before we start?**

**Question 1**

What is your knowledge about breast cancer?

*(Prompts: How would you describe their understanding/knowledge of breast cancer? What comes to your mind when you think about breast cancer? What is your knowledge of breast cancer symptoms, risk factor, early warning signs and treatment? Or breast cancer as disease what is meaning to you? Or is an itchy, painful lump a sign of breast cancer? How does Arab culture deal with breast cancer?)*

**Question 2**

What is your reaction towards Breast cancer?
Question 3

What are the causes of breast cancer?

(Prompts: Can breast enlargement cause cancer? Or is breast cancer linked to breast feeding, menopause, hormone replacement therapy? Or can injury or stress cause breast cancer?)

Question 4

What do you know about ways to detect breast cancer at an early stage?

(Prompts: "Have you ever examined your breast for early detection of breast cancer? Or is breast cancer awareness considered as a help of prevention and early detection of breast cancer? Or do you believe that breast awareness will help prevent breast cancer? From where did you gain this knowledge? Have you experienced any constrains in practicing breast cancer early detection examinations? Why? What are these constrains? What can make it easier for you to practice breast cancer early detection examinations? In your opinion what could influence your decision to seek breast cancer early detection examinations

Question 5

What are your main sources of information regarding breast cancer screening test? (Prompts: is your doctor or nurse sources of your information? Or as an immigrant are the leaflets of information helpful? Or where can people get more information about Breast cancer awareness?)

Thank you for your time.
Appendix 1.3: List of the final codes for phase one study

Poor of knowledge

Lack of knowledge

Lack of custom and cultural knowledge

Health is not their priority

Embarrassment and modesty

Decision maker

Fear surrounding breast cancer

Cancer is God’s will

Cancer is God’s punishment

Breast feeding as protection against diseases

Religious practices for treatment of breast cancer

Referral system is complicated

Feeling neglected and understood

Lack of privacy

Lack of availability of female physician

Communication barriers

Unfamiliarity with health services
Appendices/Phase 2

Appendix 2.1: Breast Cancer Awareness Measure (B-CAM)

Breast Module of the Cancer Awareness Measure (Breast-CAM)

Toolkit

Version 3
25th August 2010
The Breast-CAM was developed by Cancer Research UK, King’s College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

**DOMAIN 1 KNOWLEDGE OF SYMPTOMS**

First of all, please would you name as many early warning signs of breast cancer as you can think of:

Prompt “anything else” until the woman can think of no more warning signs or symptoms. If a woman says she does not know or cannot think of any signs or symptoms for breast cancer, please prompt with “Are you sure?” and if necessary “Take a minute to think about it”.

Please write down all of the warning signs and symptoms of breast cancer that the woman mentions in the box below.

**Anything else?**
Can you tell me whether you think any of these are warning signs of breast cancer or not?

Do not prompt. If the woman asks for explanation, please read out the relevant ‘Explanation’ where available. Please only read these out if necessary.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think a change in the position of your nipple could be a sign of breast cancer? [Explanation]: such as pointing up or down or in a different direction to normal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think pulling in of your nipple could be a sign of breast cancer? [Explanation]: where the nipple no longer points outwards, but into the breast</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think pain in one of your breasts or armpit could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think puckering or dimpling of your breast skin could be a sign of breast cancer? [Explanation]: like a dent or orange peel appearance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think discharge or bleeding from your nipple could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think a lump or thickening in your breast could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think a nipple rash could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think redness of your breast skin could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think a lump or thickening under your armpit could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think changes in the size of your breast or nipple could be signs of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think changes in the shape of your breast or nipple could be signs of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**DOMAIN 2 CONFIDENCE, SKILLS AND BEHAVIOUR IN RELATION TO BREAST CHANGES**

The next three questions are about finding changes in your breasts.

**How often do you check your breasts?**

**Tick one box only.**

<table>
<thead>
<tr>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely or never</td>
</tr>
<tr>
<td>At least once every 6 months</td>
</tr>
<tr>
<td>At least once a month</td>
</tr>
<tr>
<td>At least once a week</td>
</tr>
<tr>
<td>Don’t know</td>
</tr>
<tr>
<td>Refused</td>
</tr>
</tbody>
</table>

If the respondent gives an answer that falls between two categories, please tick as the most conservative response, in other words, less frequent breast checking.

**Are you confident you would notice a change in your breasts?**

**Tick one box only.**

<table>
<thead>
<tr>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
</tr>
<tr>
<td>Slightly confident</td>
</tr>
<tr>
<td>Fairly confident</td>
</tr>
<tr>
<td>Very confident</td>
</tr>
<tr>
<td>Don’t know</td>
</tr>
<tr>
<td>Refused</td>
</tr>
</tbody>
</table>

**Have you ever been to see a doctor about a change you have noticed in one of your breasts?**

**Tick one box only. Do not prompt.**

<table>
<thead>
<tr>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Never noticed a change in one of my breasts</td>
</tr>
<tr>
<td>Don’t know</td>
</tr>
<tr>
<td>Refused</td>
</tr>
</tbody>
</table>

**DOMAIN 3 ANTICIPATED DELAY IN CONTACTING THE DOCTOR**

The next question is about seeking help

If you found a change in your breasts, how soon would you contact your doctor?

Record the response verbatim

<table>
<thead>
<tr>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know</td>
</tr>
<tr>
<td>Refused</td>
</tr>
</tbody>
</table>
**DOMAIN 4 BARRIERS TO SEEKING MEDICAL HELP**

The next set of questions is about what might stop you from going to the doctor. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor? You may answer 'yes often,' 'yes sometimes' or 'no'.

<table>
<thead>
<tr>
<th>Tick the appropriate boxes</th>
<th>Yes often</th>
<th>Yes sometimes</th>
<th>No</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too embarrassed to go and see the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too scared to go and see the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worried about wasting the doctor’s time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I find my doctor difficult to talk to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult to make an appointment with the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too busy to make time to go to the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too many other things to worry about</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult to arrange transport to the doctor’s surgery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worrying about what the doctor might find may stop me from going to the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not feeling confident talking about my symptom with the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For women completing questionnaire in language other than English</td>
<td>Yes</td>
<td>No</td>
<td>Not applicable</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>My doctor does not understand my language or culture</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Is there anything else that you can think of that might put you off going to the doctor?

**Record verbatim**
**DOMAIN 5 KNOWLEDGE OF AGE-RELATED AND LIFETIME RISK**

The next question is about who you think is most likely to get breast cancer.

**Tick one box only. Do not prompt**

In the next year, who is most likely to get breast cancer?

<table>
<thead>
<tr>
<th>Option</th>
<th>Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>A 30 year old woman</td>
<td>☐</td>
</tr>
<tr>
<td>A 50 year old woman</td>
<td>☐</td>
</tr>
<tr>
<td>A 70 year old woman</td>
<td>☐</td>
</tr>
<tr>
<td>A woman of any age</td>
<td>☐</td>
</tr>
<tr>
<td>Don’t know</td>
<td>☐</td>
</tr>
<tr>
<td>Refused</td>
<td>☐</td>
</tr>
</tbody>
</table>

The next question is about how many women you think will develop breast cancer in their lifetime. Please look at these pictures/imagine groups of 3, 9, 100 and 1000 women.

**Tick one box only. Do not prompt. If it is a face-to-face interview, please show the respondent the prompt card associated with this question (found at the end of this script and response sheet). If the interview is over the telephone, please ask the respondent to imagine a group of 3/9/100/1000 people.**

How many women will develop breast cancer in their lifetime?

<table>
<thead>
<tr>
<th>Option</th>
<th>Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 in 3 women</td>
<td>☐</td>
</tr>
<tr>
<td>1 in 9 women</td>
<td>☐</td>
</tr>
<tr>
<td>1 in 100 women</td>
<td>☐</td>
</tr>
<tr>
<td>1 in 1000 women</td>
<td>☐</td>
</tr>
<tr>
<td>Don’t know</td>
<td>☐</td>
</tr>
<tr>
<td>Refused</td>
<td>☐</td>
</tr>
</tbody>
</table>
## DOMAIN 6 KNOWLEDGE OF BREAST SCREENING

The next set of questions is about breast screening.  

**Tick one box only. Do not prompt.**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there an NHS Breast Screening Programme?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>If NO or DON’T KNOW</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>go to the Domain 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>If YES</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At what age are women <strong>first</strong> invited to the NHS Breast Screening Programme?</td>
<td>Write age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At what age do women receive their <strong>last</strong> invitation to the NHS Breast Screening Programme?</td>
<td>Write age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you ever been invited for breast screening on the NHS Breast Screening Programme?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you ever had breast screening on the NHS Breast Screening Programme?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The next set of questions is about what might increase the chances of getting breast cancer. How much do you agree that each of these can increase the chance of getting breast cancer? You may answer Strongly disagree, Disagree, Not sure, Agree, or Strongly agree.

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a past history of breast cancer</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Using HRT (Hormone Replacement Therapy)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Drinking more than 1 unit of alcohol a day</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Being overweight (BMI over 25)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Having a close relative with breast cancer</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Having children later on in life or not at all</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Starting your periods at an early age</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Having a late menopause</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Doing less than 30 mins of moderate physical activity 5 times a week</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
مركز ابحاث السرطان في بريطانيا والتوعيه ضد سرطان الثدي (BCAM) وحدة قياس الطبعة الثالثة

قد تم تطوير اداة مسح كام لابحاث السرطان بواسطة مركز ابحاث السرطان البريطاني, الجامعة الملكية في لندن وجامعة اكسفورد في سنة 2008

Cancer Awareness Measure toolkit version 2
السؤال الأول: العلامات التحذيرية

هناك العديد من العلامات والأعراض التحذيرية لسرطان الثدي. يرجى كتابة ما تستطيع وتعتقد أنه من علامات واعراض سرطان الثدي؟
هل تعقدين أن الألم باحد الثديين يعتبر علامة لسرطان الثدي؟
هل تعقدين أن وجود تجاعيد أو دنبلة في جلد الثدي علامة لسرطان الثدي؟
هل تعقدين أن خروج الأفرازات أو الدم من الحلمة هي علامة لسرطان الثدي؟
هل تعقدين وجود عقده أو تثخن في الثدي هو علامة لسرطان الثدي؟
هل تعقدين وجود عقدة أو تثخن تحت الأبط هي علامة لسرطان الثدي?
هل تعقدين أن احمرار جلد الثدي هو علامة على سرطان الثدي؟
هل تعقدين أن وجود عقدة أو تثخن تحت الأبط هي علامة لسرطان الثدي؟
هل تعقدين ان أي تغير في حجم الثدي أو الحلمة هي علامة لسرطان الثدي؟
هل تعقدين ان التغير بشكل الصدر أو الحلمة هي علامة لسرطان الثدي؟
الجزء الثاني

الثقة بالنفس، المهارات والسلوكيات ذات العلاقة باكتشاف التغييرات بحالة الثديين (سؤال 3 و4)

السؤال الثالث - 3- تكرار فحص الثدي

كم مره تقومين بفحص ثدييك؟
- قليل و ولا مره
- مره كل ستة اشهر
- مره كل شهر
- مره كل اسبوع

السؤال الرابع - 4- الثقة بالنفس في اكتشاف التغييرات بحالة الثديين

هل انت واثقه بقدرتك على اكتشاف وملاحظة اي تغييرات بحالة الثديين؟
- لست واثقه ابدا
- واثقه قليلا
- واثقه بصورة جيدة
- واثقه بصورة جيد جدا
الجزء الثالث
التوقعات بالتأخير لمراجعة الطبيب (سؤال 5)

الجزء الرابع
الحواجز التي تمنعك دون طلب المساعدة (سؤال 6)

السؤال السادس
الحواجز التي تمنعك دون طلب المساعدة (سؤال 6)

السؤال السادس
الحواجز التي تمنعك دون طلب المساعدة (سؤال 6)

من بعده الأحيان الأشخاص يمتنعون من الذهاب إلى الطبيب حتى في الحالات التي توجب مراجعة الطبيب. هناك عدة أسباب تضع النساء في حالة تأخر عن مراجعة الطبيب فهل من الممكن أن تذكر ما هو مناسب لك من الأسباب المدرجة أدناه؟
لا أعرف
ممكن أن اكون محرجة
ممكن أن اكون خائفًا

لا
ممكن أن اكون محرجة
ممكن أن اكون خائفًا

لا
من الصعب التحدث مع الطبيب
من الصعب تحديد موعد مع الطبيب
مشغولًا و لا أستطيع تحديد موعد مع الطبيب
لدي أشياء أخرى تقلقني
من الصعب ترتيب النقل للذهاب إلى الطبيب
اكون قلقًا حول ما إذا كان الطبيب متواجد
لا أشعر بالثقة باخبار الطبيب حول مأاعليه

عوامل أخرى (ارجعوا تحديدها)
الجزء الخامس
المعرفة بعامل خطر العمر وعلاقته بالأصابه بسرطان الثدي (السؤال 7 و 8)

السؤال السابع: العمر كعامل خطرة لسرطان الثدي

<table>
<thead>
<tr>
<th>السلاسل من العمر</th>
<th>النساء بعمر الثلاثين من العمر</th>
<th>النساء بعمر الاربعين من العمر</th>
<th>النساء بعمر السبعين من العمر</th>
<th>النساء معرضات للأصابه بأي عمر</th>
</tr>
</thead>
<tbody>
<tr>
<td>30</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>اعلاه</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

السؤال الثامن: الخطورة مدى الحياة

كم عدد النساء اللاتي يصبن بسرطان الثدي في فترة حياتهم؟

<table>
<thead>
<tr>
<th></th>
<th>أمراه واحدة ما بين كل ثلاثة نساء</th>
<th>أمراه واحدة ما بين كل تسعة نساء</th>
<th>أمراه واحدة ما بين كل مئة أمراه</th>
<th>أمراه واحدة ما بين كل ألف أمراه</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

الجزء السادس
المعرفة ببرنامج الكشف المبكر لسرطان الثدي (سؤال 9)
السؤال التاسع: برنامج الخدمة الصحية الوطنية للكشف لمبكر عن سرطان الثدي

<table>
<thead>
<tr>
<th>لا</th>
<th>لا</th>
<th>نعم</th>
</tr>
</thead>
</table>

هل يوجد برنامج صحي وطني للكشف المبكر عن سرطان الثدي؟

إذا كان الجواب نعم فبما عمر تتوجه أول دعوة للنساء لأجراء فحص سرطان الثدي.

<table>
<thead>
<tr>
<th>لا يعرف</th>
</tr>
</thead>
</table>

هل سبق لك وان ذهبت لفحص سرطان الثدي بالأشعة؟

الجزء السابع
فمبدأ فإن المجموعة التالية من الأسئلة هو حول ما قد يزيد من فرص الإصابة بسرطان الثدي.

كم كنت توافق على كل من هذه يمكن أن تزيد من فرصة الإصابة بسرطان الثدي؟ قد أجبت بشدة مختلف، لا، توافق، أو توافق بشدة.

<table>
<thead>
<tr>
<th>الوضع</th>
<th>لا توافق بشدة</th>
<th>مختلف في الرأي</th>
<th>غير متكرر</th>
<th>توافق</th>
<th>توافق بشدة</th>
</tr>
</thead>
<tbody>
<tr>
<td>وجود تاريخ سابق من سرطان الثدي</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>استخدام (العلاج بالهرمونات البديلة)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>شرب أكثر من 1 وحدة من الكحول يوميا</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>زيادة الوزن (مؤشر كتلة الجسم أكثر من 25)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>وجود قريب مع سرطان الثدي</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>انجاب الأطفال في وقت لاحق في الحياة أو لا على الإطلاق</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>بدء دورتك الشهرية في سن مبكرة</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>وجود انقطاع الطمث في وقت متأخر</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 دقيقة من النشاط البدني المعتدل 5 مرات في الأسبوع</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2.1A: Data entry and coding

Please name as many warning signs of breast cancer as you can think of. Create 13 variables labelled from symp01 to symp11, plus othsym01 and othsym02. Each symptom named must be recorded using the coding frame below. For example, if the respondent names ‘pain in the breast’ and ‘bleeding from nipple’, code symp01 as 3 in symp02 as 5.

After coding and entering the symptoms named from the list below, code for any symptoms not on the list. To do this, code the next blank variable (symp01 to symp11) as 12. Then type the symptom verbatim into othsym01. You may do this for up to two additional symptoms e.g. if the respondent names three possible symptoms from the list, plus ‘chest pain’ and ‘tiredness’, enter 12 in symp04 and type ‘chest pain’ in othsym01 and ‘tiredness’ in othsym02.

If the response to this question is ‘Don’t know’, or the respondent refuses to answer, code symp01 -99 or -98 as appropriate, and move on to the next question (position).

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nipple position</td>
<td>1</td>
</tr>
<tr>
<td>Pulling in of nipple</td>
<td>2</td>
</tr>
<tr>
<td>Pain breasts/armpit</td>
<td>3</td>
</tr>
<tr>
<td>Puckering/dimpling</td>
<td>4</td>
</tr>
<tr>
<td>Discharge/bleeding nipple</td>
<td>5</td>
</tr>
<tr>
<td>Lump/thickening breast</td>
<td>6</td>
</tr>
<tr>
<td>Nipple rash</td>
<td>7</td>
</tr>
<tr>
<td>Redness breast skin</td>
<td>8</td>
</tr>
<tr>
<td>Lump/thickening armpit</td>
<td>9</td>
</tr>
<tr>
<td>Change size breast/nipple</td>
<td>10</td>
</tr>
<tr>
<td>Change shape breast/nipple</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
</tr>
<tr>
<td>Refused</td>
<td>-98</td>
</tr>
<tr>
<td>Don’t know</td>
<td>-99</td>
</tr>
</tbody>
</table>
Can you tell me whether you think any of these are warning signs of breast cancer or not?

<table>
<thead>
<tr>
<th>Create 11 variables as shown below.</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think a change in the position of your nipple could be a sign of breast cancer? position</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think pulling in of your nipple could be a sign of breast cancer? pullin</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think pain in one of your breasts or armpit could be a sign of breast cancer? pain</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think puckering or dimpling of your breast skin could be a sign of breast cancer? pucker</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think discharge or bleeding from your nipple could be a sign of breast cancer? ditch</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think a lump or thickening in your breast could be a sign of breast cancer? lump</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think a nipple rash could be a sign of breast cancer? rash</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think redness of your breast skin could be a sign of breast cancer? redness</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think a lump or thickening under your armpit could be a sign of breast cancer? armpit</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think changes in the size of your breast or nipple could be sign of breast cancer? size</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
<tr>
<td>Do you think changes in the shape of your breast or nipple could be sign of breast cancer? shape</td>
<td>1</td>
<td>2</td>
<td>.99</td>
<td>.98</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How often do you check your breasts? check</th>
<th>Rarely or never</th>
<th>At least once every 6 months</th>
<th>At least once a month</th>
<th>At least once a week</th>
<th>Don't know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>-99</td>
<td>-99</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Are you confident you would notice a change in your breasts? confid</th>
<th>Not at all confident</th>
<th>Slightly confident</th>
<th>Fairly confident</th>
<th>Very confident</th>
<th>Don't know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>-99</td>
<td>-99</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Have you ever been to see a doctor about a change you have noticed in one of your breasts? doctor</th>
<th>Yes</th>
<th>No</th>
<th>Never noticed a breast change</th>
<th>Don't know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>.99</td>
<td>.98</td>
</tr>
</tbody>
</table>
If you found a change in your breast, how soon would you contact your doctor? **Delay**

<table>
<thead>
<tr>
<th>Question following by variable name</th>
<th>Yes</th>
<th>Yes sometimes</th>
<th>No</th>
<th>Don't know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too embarrassed to go and see the doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Too scared to go and see the doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Worried about wasting the doctor's time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>My doctor is difficult to talk to</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Difficult to make an appointment with the doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Too busy to make time to go to the doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Too many other things to worry about</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Difficult to arrange transport to the doctor's surgery</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Worrying about what the doctor might find may stop me from going to the doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Not feeling confident talking about my symptom with the doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>For woman completing questionnaire in language other than English</td>
<td>Yes</td>
<td>No</td>
<td>Not applicable</td>
<td>Don’t know</td>
<td>Refused</td>
</tr>
<tr>
<td>My doctor does not understand my language or culture</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>-99</td>
<td>-68</td>
</tr>
<tr>
<td>Age of risk</td>
<td>Under 30 year old woman</td>
<td>A 30 year old woman</td>
<td>A 60 year old woman</td>
<td>A 70 year old woman</td>
<td>A woman of any age</td>
</tr>
<tr>
<td>------------</td>
<td>-------------------------</td>
<td>---------------------</td>
<td>---------------------</td>
<td>--------------------</td>
<td>------------------</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>-69</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How many women will develop breast cancer in their lifetime?</th>
<th>1 in 3 women</th>
<th>1 in 9 women</th>
<th>1 in 100 women</th>
<th>1 in 1000 women</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>-69</td>
<td>-69</td>
</tr>
</tbody>
</table>

Create 0 variables as shown below.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Create 0 variables as shown below.</th>
</tr>
</thead>
<tbody>
<tr>
<td>If there is NHS Breast Screening Programme? screening</td>
</tr>
<tr>
<td>At what age are women first invited to the NHS Breast Screening Programme? firstage</td>
</tr>
<tr>
<td>At what age do women receive their last invitation to the NHS Breast Screening Programme? lastage</td>
</tr>
<tr>
<td>Have you ever been invited for breast screening on the NHS Breast Screening Programme? invite</td>
</tr>
<tr>
<td>Have you ever had breast screening on the NHS Breast Screening Programme? attend</td>
</tr>
</tbody>
</table>

How much do you agree that each of these can increase the chance of getting breast cancer?

<table>
<thead>
<tr>
<th>Create 0 variables as shown below.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

| Having a past history of breast cancer patient | 1 | 2 | 3 | 4 | 5 |
| Using HRT (Hormone Replacement Therapy) | 1 | 2 | 3 | 4 | 5 |
| Drinking more than 1 unit of alcohol a day | 1 | 2 | 3 | 4 | 5 |
| Being overweight (BMI over 25) | 1 | 2 | 3 | 4 | 5 |
| Having a close relative with breast cancer familial | 1 | 2 | 3 | 4 | 5 |
| Having children later on in life or not at all | 1 | 2 | 3 | 4 | 5 |
| Starting your periods at an early age | 1 | 2 | 3 | 4 | 5 |
| Having a late menopause | 1 | 2 | 3 | 4 | 5 |
| Doing less than 30 mins of moderate physical activity 5 times a week | 1 | 2 | 3 | 4 | 5 |

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Appendix 2.2 Study Poster

Breast Cancer and Breast cancer awareness knowledge, Beliefs Attitudes and practice

I am interested in hearing about YOUR knowledge, beliefs and attitudes toward breast cancer & the usefulness of awareness information leaflets

Benefits of taking part:
- Your opportunity to share your experience
- £10 boots voucher to thank you for sharing your knowledge

Having breast cancer can be life changing event for women and their families. Until now, most research has focused on the knowledge of white women and different ethnic group with very little research exploring the knowledge, beliefs and attitudes of Arab women.

I am therefore interested in hearing about your knowledge, attitudes and beliefs regarding breast cancer and breast cancer awareness. Women interested in taking part will be interviewed in a group setting by the researcher at a time and place of your convenience. If you would like to be interviewed in your own language, it will be fine. Your responses will be kept strictly private and your name will not be used in the study.

If you would like to share your knowledge or know of someone who may be interested, please contact, Afrah Redha for further information on 02392 524602392 84 or by email at afrah.redha@myport.ac.uk
المعرفة والمعتقدات والاتجاهات لسرطان الثدي وتوعية بسرطان الثدي

أنا مهتم في الاستماع حول معرفتك والمعتقدات والمواقف

فوائد المشاركة
- فرصتك لتبادل المعرفة
- شكرا على تقاسم 10 £
المعرفة الخاصة بك

يمكن وجود سرطان الثدي تكون الحياة المتغيرة الحدث بالنسبة للنساء وأسرهن. حتى الآن، ركزت معظم الأبحاث على معرفة النساء البيض ومجموعة عرقية مختلفة مع القليل جدا من البحوث استكشاف المعرفة والمعتقدات والمواعف من المرأة العربية.

أنا مهتم في ولتسمع عن الخاص بك المعرفات والمواعف والمعتقدات بشأن سرطان الثدي والتوعية حول سرطان الثدي. سيتم مقابلتهم بناء المهتمات بالمشاركة في إعداد مجموعة من الباحثين في وقت ومكان محدد. إذا كنت ترغب في إجراء مقابلات معهم في اللغة الخاصة بك، سوف يكون على ما يرام. سيتم الاحتفاظ ردودكم الخاصة بثقة ولن نستخدم اسمك في الدراسة.

إذا كنت ترغب في تبادل المعرفة الخاصة بك أو تعرف شخص قد تكون مهتمة، يرجى الاتصال أفرام رضا للحصول على مزيد من المعلومات حول 84 524602392 02392 أو عن طريق البريد الإلكتروني في afrah.redha@myport.ac.uk
Appendix 2.3 Invitation letter information sheet and consent form

Dear Women,

Knowledge of breast cancer awareness and the usefulness of breast awareness educational material relevant to Arab immigrant women in England

My name is Afrah Redha and I am a PhD researcher at the University of Portsmouth. As part of my study, I am carrying out a qualitative study and would like to inform practice and gaps in knowledge regarding breast cancer and breast awareness educational materials by:

- Assessing the knowledge and usefulness of current educational material (NHS and Breast Cancer Care Charity produced leaflets) relevant to Arab immigrant women living in England.
- Determine the factors that motivate Arab immigrant women to be breast cancer aware.

There has been little empirical research in this area in UK. It is anticipating that the present study will provide information to identify and describe barrier to early detection of breast cancer for Arab Immigrant Women in

I am looking for 10 to 20 Arab women to take part in two focus group. Taking part in the study would involve being interviewed by me at a time and place of your convenience. The interview will be audio recorded and will last between 30 minutes to 1 hour, depending on what you would like to share at interview. I have attached a copy of the information sheet, which gives more details on what taking part in the study involves.

I would be grateful if you would indicate on the enclosed form whether you think you may be interested in taking part in the study. It should only take a few minutes to fill in and I have enclosed a stamped addressed envelope for your convenience. In the meantime, if you have any questions on the study that you would like to discuss with me please telephone me on 02380232857 or alternatively email me at afrah.redha@port.ac.uk.

Many thanks for taking the time to read this letter.

Yours sincerely,

Afrah Redha
PhD Researcher
School of Health Sciences and Social Work
University of Portsmouth
Information Sheet

Knowledge, attitudes, beliefs and practice of immigrant Arab women toward breast cancer and breast awareness in England

Researcher
This study will be conducted by Afrah Redha a PhD researcher at the School of Health Sciences and Social Work, University of Portsmouth.

Invitation to Participate
You are being invited to take part in a focus group discussion as part of a research study. Take your time to decide whether you would like to take part or not. It is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your colleagues if you wish. Please ask if anything is not clear or you would like more information. Thank you for taking time out of your busy schedule to consider participation.

What is the purpose of the study?
The purpose of this study is to inform practice and gaps in knowledge regarding breast cancer and breast awareness educational materials by:

- Assessing the usefulness of current educational material (NHS and Breast Cancer Care Charities produced leaflets) relevant to Arab immigrant women living in England.
- Determine the factors that motivate Arab immigrant women to be breast cancer aware.

Why have I been chosen?
You have been identified as an Arab women resident in England. I would like to assess the usefulness of current educational material (NHS and Breast Cancer Care Charities produced leaflets) as well as determine the factors that motivate you as immigrant Arab women to be breast cancer aware. If you agree to take part you will be one of 8 -10 women who have been invited to take part in one of two focus groups.
Do I have to take part?

Your participation in this study is completely voluntary and you may withdraw your consent to participate at any time during the process. If you choose to do so, any information derived from your participation will be deleted from the evaluations findings. You will be asked to fill out a brief demographic questionnaire before taking part in the focus group discussion., This may mean that, although you have shown an interest in taking part you may not be asked to attend as we might not select everybody to take part so that we can include a number of different people to represent different experiences, ages, length of time resident in England, different education backgrounds, fluent in English or Arabic speaking only. If you are not selected, we do thank you for your interest in the study.

What will happen to me if I take part?

The methods of data collection for this study will be focus group discussion. A focus group involves inviting and selecting people to come together and share ideas on the chosen topic areas described above. Your views are important and should be represented in your own words. There are no right and wrong answers.

We will also ask you to complete a short written questionnaire on your current knowledge of breast cancer and breast awareness. The sessions will be audio-taped and the audio-tapes transcribed, to ensure accurate reporting of the information that you provide. You can leave the focus group discussion at any time you wish and do not need to give a reason for doing so. We estimate that the focus group meeting will take between 1- 2 hours.

Will my taking part in this study be keep confidential?

If you choose to participate, you will not be asked to use your name within the focus group discussion. If by chance, you or someone you know addresses you by name in the sessions, the transcribers will be instructed to delete all names from the transcription. Transcribers will sign a form stating that they will not discuss any item on the tape with anyone other than the researchers. The audio-tapes will be stored in a locked file before and after being transcribed. Tapes will be destroyed within 2 weeks of completing the transcriptions and the transcriptions will be destroyed 3 years after the completion of this study.
Writing up the findings

All findings used in any written reports or publications which result from this project will be reported in aggregate form with no identifying information. It is, however, useful to use direct quotes to more clearly capture the meanings in reporting the findings from this form of study. You will be asked at the end of the interview or focus group if there is anything you said which you do not want included as a quote, and we will ensure that they are not used.

What will happen after the Interview?

After the focus group interview and the audiotape have been fully transcribed you will be given a copy of it to read and to check that the information you have given has been represented correctly. Let me know if you are not happy with anything that has been typed up and it will be removed.

All of the focus group discussions will be analysed to find categories or themes and a report written up. I will randomly select three participants to be shown a summary of the initial analysis from the focus group discussions and ask them to check the appropriateness (or otherwise) of the category system. If you are selected, this will involve you in being asked questions such as “Do you think this quotation from the focus group discussion fits this category?” Your response will be noted and adjustments made as necessary. Your consent to be randomly selected in this part of the study will be sought before the focus group discussion takes place. If you would not like to take part in this stage of analysis it will still be possible for you to take part in the focus group discussion.

A letter will be sent to you when the final report has been completed with a brief overview of the findings. If you would like to receive a full copy of the report, this will be available to you upon request.

What are the possible disadvantages of taking part?

It is hoped that taking part in the focus group discussion will not prove stressful to you. However, if you feel upset by what you have shared, please come and speak with me afterwards.

What are the possible benefits of taking part?
It is hoped that the identifying and highlighting the usefulness of current educational material (NHS and charities produced leaflets) relevant to this population may help to inform practice and gaps in knowledge regarding educational materials for this population.

What can I do if I have any questions?
If you have any questions about this study at any time, you may contact Dr. Ann Dewey at the University of Portsmouth or you may phone her at 023 92 84426 or e-mail her at Ann.Dewey@port.ac.uk and she will be happy to answer any of your questions.

Who has reviewed this study?
The University of Portsmouth / school of Health Science and Social Work have reviewed this study.

Thank you for taking the time to read this information sheet. If you require any further information or would like to take part in the study, please contact:

Afrah Redha
PhD researcher
School of Health Sciences and Social Work
University of Portsmouth
Tel 02392 84 5246
Email: afrah.redha@port.ac.uk
Consent Form

Research Title:
Knowledge of breast cancer awareness and the usefulness of breast awareness educational material relevant to Arab immigrant women in England

Name of Researcher: Afrah Redha (Contact Tel. No: 02380232857)

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I am willing to consent to audio recording of my interview

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

4. I am willing to be randomly selected to be sent a copy of the initial analysis of my interview to comment on the findings. (Delete as appropriate) YES/NO

5. I agree to take part in the above study.

6. I give permission for my anonymised quotes to be used in publications.

Please Note: Although we will make every attempt to safeguard confidentiality it will not be possible to guarantee this issue.

Name of Participant ___________________________ Date ___________________________ Signature ___________________________

Name of Person taking consent (if different from researcher) ___________________________ Date ___________________________ Signature ___________________________
استمارة المعلومات حول الدراسه النوعي لأساتذتك في
المعرفة والمواقف والمعتقدات وممارسة المرأة العربية المهاجرة نحو سرطان الثدي والتنوعية
حوِّل الكشف المبكر عن سرطان الثدي في إنكلترا

البحث

يمكن إجراء هذه الدراسه من قبل الدكتوره أفراح العبادي الباحثه في جامعة بورتسموث.

دعوة للمشاركة

عزيزي المرأة العربية تدعوك للمشاركة في نقاش ضمن مجموعه من النساء العربيات المهاجرات. خذي وقتك لقراءة معلوماتك في اجراء هذه الدراسه وماهو محتواها.

يرجى منك أيضا أخذ الوقت الكافي لقراءة المعلومات التالية ومشاركتها مع الآخرين. إذا كنت ترغب في الشغل في هذا المشروع، فلديك رداً على ما كنت ترغب في مزيد من المعلومات حول موضوع الدراسه. شكرا لك لأخذك الوقت من جدولك المزدحم في قراءة هذه المعلومات.

ما هو الغرض من الدراسه

الغرض من هذه الدراسه هو توضيح الفجوات المعرفية الاجتماعية والاجتماعي لمرض سرطان الثدي. تواجه المرأة العربية في الكشف المبكر عن مرض سرطان الثدي وعدم ممارسته من خلال:

أول: تقديم مدى الفائدة من المناشط التعليمية والندوات التي تقدم من مؤسسة الصحة الوطنية البريطانية والمراكز الخيرية لرعاية سرطان الثدي في بريطانيا.

ثاني: تحديد العوامل التي تدفع النساء العربيات لزيادة وعيهم واتخاذهم الفعال في الكشف المبكر عن سرطان الثدي.

لماذا تم اختياري انا؟

قد تم التعرف عليك كأمرأه عربيه مقيمة في إنكلترا. وانا اود أن أقدم مدى مدى الفائدة من المناشط التعليمية والندوات التي تقدم من مؤسسة الصحة الوطنية البريطانية والمراكز الخيرية لرعاية سرطان الثدي.

هل لابد لي من المشاركة؟

 участиеك في هذه الدراسه هو طوعي تماما، وذلك في حسب مواقفك على المشاركة في أي وقت خلال عملية الحياة. إذا اخترت القيام بذلك، سيتم حفظ أي معلومات مستقاة منك في نظام لاحقة تتم تقييم نتائج البحث.

سيطلب منك معلومات استمارة بالمعلومات الشخصية ومكانك. وتحدث عن ركعتي اهتمامك بذلك لأن الدراسا سيقوم باختيار مجموعة من المشاركين في البحث. وربما لايمكنني اختيار المشارك في البحث حتى لو أذهنت اهتمامك بذلك لأن الدراسا سيقوم باختيار مجموعة من المشاركين في البحث.

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What a study is if I participate?

Once your application is approved, you will be contacted to participate in the study. The purpose of the research is to improve our understanding of the language of women with breast cancer. The research will involve group discussions, where you will be asked to share your experiences and ideas about the topic.

What happens after the interview?

After the meeting and discussion, all the information recorded on the audio tape will be transcribed as a written text and will be sent to you to read and check if you want. The research team will analyze all the information collected during the discussion and will classify it into categories. The researcher will randomly select three participants to be given the initial report on the analysis of the information for the examination of the system for classification. If you are selected, you will be able to read the classified results of the participants.

What if I don't participate?

We expect that participating in the study and discussion that will be held will not cause you any inconvenience or pressure, and if you feel any pressure or concern about continuing to participate, we encourage you to talk to me without hesitation.
ماهي الفوائد من المشاركة بالبحث؟

الباحثة لديها الأمل على أن تحديد وتسليط الضوء على مدى فائدة المواد التعليمية الحالى (مشرورات) والمنتج من مؤسسة الصحة الوطنية وجمعيات الخيرية التي تعنى بسرطان الثدي والكشف المبكر عنه في بريطانيا والتي تخص فئة النساء العربيات المهاجرات في إنكلترا قد تساعده على نشر التغذية ومعرفة المعلومات التي تواجهه المرأة العربية في إنكلترا والتي تمنعها على أن تكون على دراية ومعرفة عن مرض سرطان الثدي وطرق الكشف المبكر عنه.

ماذا يمكنني أن أفعل إذا كان لدي أسئلة؟

إذا كان لديك أي سؤال حول هذه الدراسة العلمية يمكنك الاتصال بجامعة بورتسموث بالدكتور آن دوي أو الدكتور أفراح العبادي على رقم تلفون 0239284442 أو المراسلة عن طريق البريد الإلكتروني ann.dewey@port.ac.uk afrah.redha@myport.ac.uk

وسنكون سعداء بالرد على جميع أسئلتك.

من الذي سيقوم بتقييم هذه الدراسة؟

جامعة بورتسموث كلية العلوم الطبية والأجتماعية ستقوم بمراجعة هذه الدراسة. شكراً لأخذكم الوقت الكافي لقراءة هذه المعلومات وإذا كنت بحاجة إلى المزيد من المعلومات أو الأسئلة يرجى الاتصال ب-----

Afrah Redha
PhD researcher
School of Health Sciences and Social Work
University of Portsmouth
Tel 02392 84 5246
Email: afrah.redha@port.ac.uk
Appendix 2.4: Power Point Display Presentation Shows Focus Group Discussion Questions in both English and Arabic languages

The term breast cancer and it’s awareness – what do you think of it; what do you think it involves?

مصطلح سرطان الثدي والوعي بحالة الثديين ماذا يعني لك وما هو مضمونه؟

How do you find out about how to be breast aware?

كيف يمكنك ان تكون لديك المعرفة الكافية حول كيف ان تكوني واعية لصحة ثدييك؟
Which type of information leaflets have you seen?

Was the information useful and easy to understand, if so how useful was it?
If it was not useful, why was it not useful?

أي نوع من المعلومات عن طريق المنشورات الصحيحة رأيت وهل كانت المعلومات مفيدة وسهلة الفهم وكيف كانت مفيدة؟
وأذا كانت المعلومات غير مفيدة، لماذا لم تكن مفيدة؟

If an organization were putting together educational materials (brochures, posters, etc) for a public awareness campaign to encourage women to talk with their doctor about breast cancer screening exams, what type of information should be included in the materials?

أذا كانت هناك منظمة لجمع المواد التعليمية (الكتب أو الملصقات) تقوم بعمل حملة نوعية عامه لتشجيع النساء على التحدث مع أطباءهن حول طرق الكشف المبكر عن سرطان الثدي، فما هي نوع المعلومات التي ينبغي إدراجها في هذه الملصقات؟
What type of message do you think will encourage women (you) to talk to their health care professional about mammograms?

MANOUG ALARSAH ATE TANNEDEEN BANNA SASSHEEJ NSASHEEJ
Lاجرإي محادثات معي الرعاية الصحيه المهنيه
 حول تصوير الثدي بالأشعة السينيه؟

What type of message do you think will encourage women (you) to talk to their health care professional about breast cancer?

MANOUG ALARSAH ATE TANNEDEEN BANNA SASSHEEJ NSASHEEJ
Lاجرإي محادثات معي الرعاية الصحيه المهنيه
 حول سرطان الثدي؟
What type of photo or graphic would you like to see with your message to motivate women to get mammogram and breast exam?

أي نوع من الصور أو الرسومات تحبين أن تشاهديها مع الملصقات لتحفيز النساء للذهاب إلى تصوير الثدي؟

Who do you have the most trust and confidence in to deliver a message about the importance of getting a mammogram? And, information about breast awareness or breast cancer?

من هو الذي تثقين به في إيصال المعلومات حول أهمية عمل اشعة الصدر (الماموكرام) والمعلومات الخاصة بزيادة الوعي بسرطان الثدي؟
Motivational factors for women

What would motivate women to talk to their doctor or physician about getting a mammogram or breast exam?

ماذا يحفز المرأة بأن تتحدث مع طبيبها للحصول على فحص سرطان الثدي؟

What are the barriers that stop you talking to healthcare professionals?

ما هي العوائق أو العوائق التي تمنعك من التحدث إلى الطبيب أو ذوي الأختصاص الطبي؟
How can a program encourage women to get a mammogram or breast exam?

كيف من الممكن أن يتم عمل برنامج لتشجيع النساء إلى عمل فحص اشعة سرطان الثدي أو الفحص الطبي؟

Who (organizations or individuals) needs to be involved in encouraging and motivating women to get a mammogram or breast exam?

من الممكن أن يكون ممثلي منظمات أو أشخاص في برنامج تشجيع وزيادة الوعي لدى النساء بخصوص عملية فحص الثدي بالأشعة السينية أو الفحص الطبي؟
• How can these motivational factors overcome the challenges or barriers we discussed previously?

كيف يمكن لهذه العوامل المحفزه ان تتغلب على التحديات والعوائق التي ناقشناها سابقا؟

• Which message do you think might increase awareness about the breast cancer?

أي مسح بأعقادك ممكن ان تزيد الوعي عند المرأه حول مرض سرطان الثدي؟
Appendix 2.5: Breast Cancer Awareness Leaflets (NHS & Breast Cancer Charity).

NHS Breast Cancer Awareness leaflet (English Version)
Breast Cancer Charity leaflet about Breast Cancer Awareness (English Arabic Version)
Your breasts, your health: a quick guide

**Introduction**

Whatever your age, breast shape or size, it's important to take care of your breasts. Breast cancer is the most common cancer in the UK, so it's important to look after your breasts by being breast aware.

Being breast aware is part of caring for your body. It means getting to know how your breasts look and feel so you know what is normal for you. You also feel more confident about noticing any unusual changes.

Most breast lumps won't turn out to be breast cancer, but if it is, breast cancer is the second most common cancer in women so it's important to check its development.

If you have any doubt, it's better to check and get it checked.

**How do I check my breasts?**

There is no right or wrong way to check your breasts. Try to get used to looking at and feeling your breasts regularly.

You can do this in the bath or shower, when you are lying down, or when you get dressed.

You decide what is comfortable and best for you.

Remember to check all parts of your breast, your arms and up to your shoulders.

**How to check**

- Look in the mirror and check for any obvious changes.
- Feel your breasts while lying down and standing.
- Check for lumps or changes in size, shape, or sensation.

**Call our helpline on 0800 800 8000**

Visit [www.breastcancermatters.org.uk](http://www.breastcancermatters.org.uk)
What changes should I look and feel for?

Everyone's breasts look and feel different.

For many women it's normal to have lumpy breasts and/or tenderness or pain around their periods. It's also common to have one breast larger than the other, or breasts that are different shapes.

When examining your breasts, try to be aware of any changes that are different for you. The real players show what these could be.

- A change in size or shape
- A lump in breast or underarm
- A discoloration of breast skin
- A change in nipple position or a nipple that's not pointing up
- If you notice any of these changes, you should see a doctor or nurse.

Call our helpline on 0800 800 6000
Visit www.breastcaremore.org.uk

When should I see the doctor?

You know better than anyone how your breasts look and feel normally, so if you notice a change, do go and see your GP (Your doctor) or see a nurse.

Most breast changes are normal, and not a sign of breast cancer. But you do need to find out what is causing the changes. If you feel you can't see a female doctor, or ask for a female nurse to see you, you can ask for another doctor with you.

Call our helpline on 0800 800 6000
Visit www.breastcaremore.org.uk
When will I get invited for breast screening?

Women are invited for a mammogram (breast X-ray) every three years from the age of 50 to 70 (60 in Northern Ireland) as most breast cancers occur after the age of 50.

This age range is to be extended to all females in the future. You may be asked to book a breast test at your next appointment.

Women under 50 are not invited for routine screening. Any mammogram was arranged would be dependent on your age, clinic or the presence of symptoms.

If you are over 70, you can ask to be screened every three years as you can still be at risk.

Breast cancer can develop between screening mammograms so it's important to continue to be breast aware and report any changes to your GP even if you've had a mammogram recently.

Does breast cancer run in families?

Breast cancer is a common disease, with 1 in 8 women in the UK developing it during their lifetime.

So it is not unusual to have one or two people in an extended family who have had breast cancer.

Breast cancer can run in the family and may be caused by a faulty gene.

If this is your case, talk to us at your Breast Cancer Care charity leaflet about Breast Cancer Awareness

Arabic Version

Breast Cancer Care Charity leaflet about Breast Cancer Awareness

Arabic Version
هل يمكنني تقليل خطر إصاعتي بسرطان الذي؟
لا يعرف على وجه اللحم ما الذي يؤثر في الحالة، في هذا السياق، يظهر أن بعض الطرق مثل تمارين اللياقة البدنية والغذاء الصحي يمكن أن يقلل من خطر الإصابة بالسرطان.

ملاحظات:
- الإجهاض غير طبيعي: يشير إلى أن الإجهاض غير طبيعي يمكن أن يكون خطراً على الصحة.
- الحفاظ على صحة جيدة: يمكن أن يقلل من خطر الإصابة بالسرطان.
- تجنب المخاطر: يمكن أن يقلل من خطر الإصابة بالسرطان.

لا يوجد نص يمكن قراءته بشكل طبيعي.
Appendix 2.6: Example Showing Thematic Analysis Process (Braun & Clarke, 2006) with One of Focus group Selected Transcript.

The familiarisation process begins with the transcription of the data from the audio recordings to a word document. I generated codes when transcribing pauses and punctuation as I felt it important that the data represented the participant’s accounts as accurately as possible for both the meaning and content, for example, a pause of two seconds was transcribed as “...”.

Following this, a hard copy of the transcript was read through several times, with extracts of interest highlighted and initial thoughts written and revisited (see Figure 1) below.
Here is NHS leaflet about breast cancer and its awareness which is in English and Arabic translated, how does this compare to the charity leaflet for breast cancer care?

- “...as mentioned before we don’t have a clear idea about what is mean by breast cancer awareness.”
- “...seven women nod and say they never knew about what is mean by breast cancer awareness.”
- “...it’s important we should see these leaflets before. I need to know why and how to do it.”
- “...I never done this before. (Few women nod and say we agree with her)”
- “...I don’t have experience.”

- “The same me, it kept making me think about cancer, more and more about cancer and that reminded me of my friend.”
- “...I don’t want a leaflet reminding me about it. But this one breast cancer care...”
- “...leaflets, it’s nice and enough to look at the photos and illustrations and you can understand everything.”
- “...Are the most women doing it... I don’t think we should see it practically.”
- “...I can’t do it either, let me see the leaflets and learn.”

- “...read both leaflets and I want to hear your opinion about both of them.”
- “...There’s some information in this leaflet (breast cancer care) that I really hadn’t realised its really good and acceptable. The NHS one is not acceptable, there are no photos and not colourful, they should use a large enough font/Headings should stand out from the main text and be consistent.”
- “...Use colour, I mean not many colours and ensure good contrast is maintained between front and background make the leaflets attractive.”
- “...I think the charity one is much better (all women agree) because more detail in it than the NHS one.”
- “...Women nod and say yes we never seen it before.”
- “...I like to read short paragraphs or bullet points to identify key messages, easy and quick to read. The NHS leaflet is not readable at all.”
- “...white space even all in one paragraph.”
- “...They should put sufficient white space between paragraphs or bullet points.”
- “...identify key messages, images and photo. I think highlighting the key points is useful.”
- “...”...All this information about breast cancer and breast awareness which we are never realised before, that’s useful. I liked the breast cancer care leaflets, it’s encouraged you to read it and easy to understand it by looking at images. I never seen these leaflets before anywhere.”
- “...a good source of reference. All this information is interesting and useful if it’s available in Arabic language which takes in to account the Arab culture.

- “...sensitivity. The whole idea of these leaflets is nice. This leaflet will help breast cancer care. Overall I thought it is very good but where we can find them.”
- “...I think the idea of the breast cancer care leaflet is good and I think the structure.”
- “...tackling you through the information is good. It’s helpful and easy. Why the NHS leaflet not like that.”
Stage 2: Generating initial codes

Once both focus groups had been transcribed and read through, the transcripts were read through systematically, looking for features in the text that were of interest with regards to the research questions (see Table 1).

Each focus group transcript was coded line-by-line manually, and also in ‘chunks’ of meaningful text, where the meaning or importance of a comment only became clear in reference to further responses. These extracts of text were given a label or ‘code’ (see Table 2).

This was a cyclical process, as when codes emerged in one transcript I re-read transcript across the data set for relevant text relating to the new code. The number of codes created is limitless at this stage (see Figure 2). Some extracts of the transcript were given more than one code and I tried to ensure each extract of the transcript was given equal attention by re-checking the codes assigned. The emergent codes were then compared against the research questions in order to ensure that only the codes that significantly contributed towards the research brief were pursued.
# Table 1: Example of initial highlighting of interesting features of the data

<table>
<thead>
<tr>
<th>Example of focus group Transcript</th>
<th>Initial codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>41. AF &gt; Here is a NHS leaflet about breast cancer and its awareness which is in English and Arabic translated, how does this compare to the charity leaflet (breast cancer).</td>
<td>not sure</td>
</tr>
<tr>
<td>42. &quot;as mention before we don't have a clear idea about what is mean by breast awareness&quot;</td>
<td></td>
</tr>
<tr>
<td>43. AF &gt; is it important these leaflets should be available. I need to know why and how to do it so i am not sure about if, I never find like this leaflets anywhere.</td>
<td></td>
</tr>
<tr>
<td>44. &quot;never done this before (breast examination)&quot; (few women had say we agree with her, so idea at all about what does mean by breast awareness)</td>
<td>never knew</td>
</tr>
<tr>
<td>45. &quot;I just have experience&quot;</td>
<td></td>
</tr>
<tr>
<td>46. We can't see these photos it's so embarrassing, look at it it's shame, I don't want to show it to my husband.</td>
<td></td>
</tr>
<tr>
<td>47. &quot;you know our culture restrict us, even it's so embarrassed for us. &quot;</td>
<td></td>
</tr>
<tr>
<td>48. &quot;I don't want a leaflet reminding me about it. But this one (breast cancer care) leaflet, it's nice and enough to look at the photos and illustration and you can understand everything&quot;</td>
<td></td>
</tr>
<tr>
<td>49. &quot;Are the most women doing it — I don’t think, we should see it practically&quot;</td>
<td>Positive view about leaflets</td>
</tr>
<tr>
<td>50. &quot;can't do it either, let us read the leaflets and learn&quot;</td>
<td>Leaflets layout</td>
</tr>
<tr>
<td>51. AF &gt; read both leaflets and I want to hear your opinion about both of them?</td>
<td>Negative view about leaflets</td>
</tr>
<tr>
<td>52. &quot;There's some information in this leaflet (breast cancer care) hand really hard to understand it, it's really good and acceptable. The NHS one is not acceptable, there are no photos and not colourful, they should use a large enough font. Headings:</td>
<td>Unavailability of leaflet</td>
</tr>
<tr>
<td>53. &quot;it should the point list stand out from the main text and be consistent&quot;</td>
<td></td>
</tr>
<tr>
<td>54. &quot;use colour, I mean not many colour, and ensure good contrast need to be maintained between fore and background make the leaflets attractive&quot;</td>
<td></td>
</tr>
<tr>
<td>55. I am sure that the charity one is much better (all women agree) because more detail in it than the NHS one, colorful as well</td>
<td></td>
</tr>
<tr>
<td>56. I never seen it anywhere this leaflets, its unavailable&quot; (Women nod and say yes we never seen it before as well)</td>
<td></td>
</tr>
<tr>
<td>57. I like to read short paragraphs or bullet points to identify key messages, easy and quick to read. The NHS leaflet is not get your attention, it's boring, and all in white and black. all in one paragraph.</td>
<td></td>
</tr>
<tr>
<td>58. &quot;They should put sufficient white space between paragraphs or bullet points to identify key messages, images and photo. I think highlighting the key points is useful. It is important considering our cultural beliefs and tradition in the information&quot;</td>
<td></td>
</tr>
<tr>
<td>59. &quot;... all this information about breast cancer and breast awareness which we are now</td>
<td></td>
</tr>
<tr>
<td>raised before&quot;</td>
<td></td>
</tr>
<tr>
<td>60. That's useful, liked the breast cancer care leaflets, it's encourage you to read it and easy to understand it by looking at image. But it's unavailable, I never seen it before.</td>
<td></td>
</tr>
<tr>
<td>61. I never seen these leaflets before anywhere, no idea at all about the breast awareness and breast cancer.</td>
<td></td>
</tr>
<tr>
<td>62. &quot;... charity one is a good source of information. All the information is interesting and helpful, can't have this leaflets please.&quot;</td>
<td>culturally sensitive information needs</td>
</tr>
<tr>
<td>63. It's not available in Arabic language which takes in to account the Arab culture and sensitively. The whole idea of these leaflets is nice. This leaflet will help breast cancer care. Overall I thought it's very good but where we can find them, it's not available&quot;</td>
<td></td>
</tr>
</tbody>
</table>
Table 2: List of initial codes across data set

<table>
<thead>
<tr>
<th>Breast awareness</th>
<th>Leafllets/NHS and Breast Cancer care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know what is mean</td>
<td>terminology/</td>
</tr>
<tr>
<td>Not sure about meaning</td>
<td>clear &amp; effective message</td>
</tr>
<tr>
<td>It’s mean BSE</td>
<td>Need for motivating message</td>
</tr>
<tr>
<td>Why is important</td>
<td>posters</td>
</tr>
<tr>
<td>Checking the size of breast</td>
<td>too much information</td>
</tr>
<tr>
<td>Never heard about it</td>
<td>having the information increase confidence</td>
</tr>
<tr>
<td>Important during pregnancy</td>
<td>trust in leaflets information</td>
</tr>
<tr>
<td>Keep it clean</td>
<td>sensitive information</td>
</tr>
<tr>
<td>Low awareness</td>
<td>educational classes</td>
</tr>
<tr>
<td>Knew nothing</td>
<td>shows a videos</td>
</tr>
<tr>
<td>How to do it</td>
<td>empowerment</td>
</tr>
<tr>
<td></td>
<td>reassurance</td>
</tr>
<tr>
<td>Leaflets/NHS and Breast cancer care</td>
<td>Community health educator</td>
</tr>
<tr>
<td>Positive comments BCC</td>
<td>Meet another women with similar experience</td>
</tr>
<tr>
<td>spacing &amp; bold heading</td>
<td>Leaflets through the door</td>
</tr>
<tr>
<td>Large font</td>
<td>TV advertise</td>
</tr>
<tr>
<td>Negative comments NHS</td>
<td>cancer incidence within our ethnicity</td>
</tr>
<tr>
<td>Unviability of leaflet</td>
<td>picture of Muslim women</td>
</tr>
<tr>
<td>Information isn’t culturally sensitive</td>
<td>Simple words to understand</td>
</tr>
<tr>
<td>Produce spoken materials (e.g. CDs)</td>
<td>Use more images</td>
</tr>
<tr>
<td>cultural expressions</td>
<td>GP advice and recommendation</td>
</tr>
<tr>
<td>particular to (Arab population)</td>
<td></td>
</tr>
<tr>
<td>Illustrations and colour</td>
<td></td>
</tr>
<tr>
<td>Presentation and dissemination</td>
<td></td>
</tr>
<tr>
<td>Translated by native language</td>
<td></td>
</tr>
<tr>
<td>Speakers simple language</td>
<td></td>
</tr>
<tr>
<td>Cultural appropriateness</td>
<td></td>
</tr>
<tr>
<td>Understandable words</td>
<td></td>
</tr>
<tr>
<td>New nothing (breast cancer)</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Women’s need for information</td>
<td></td>
</tr>
<tr>
<td>Keen to know</td>
<td></td>
</tr>
<tr>
<td>Motivational factor</td>
<td></td>
</tr>
<tr>
<td>Nice information presentation</td>
<td></td>
</tr>
<tr>
<td>Unclear information</td>
<td></td>
</tr>
<tr>
<td>Poor knowledge (breast cancer and its awareness)</td>
<td></td>
</tr>
<tr>
<td>Availability of information</td>
<td></td>
</tr>
<tr>
<td>Cultural competence information (Cultural sensitivity)</td>
<td></td>
</tr>
<tr>
<td>Style of the leaflets</td>
<td></td>
</tr>
<tr>
<td>Language barriers</td>
<td></td>
</tr>
<tr>
<td>Source of information</td>
<td></td>
</tr>
<tr>
<td>Knew nothing about breast awareness</td>
<td></td>
</tr>
<tr>
<td>Audio and video information</td>
<td></td>
</tr>
<tr>
<td>Educational classes</td>
<td></td>
</tr>
<tr>
<td>Dissemination</td>
<td></td>
</tr>
<tr>
<td>Sensitivity of information</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 2:** Initial themes created after first cycle of examining data codes
I started to get feel for the main themes and sub-themes and the ones that felt more significant. The developing mind map allowed me to consider the relationships between codes, sub themes and main themes (see figure 2A).

Figure 2A: Working out themes from focus groups data set
### Stage 3: Searching for themes

Once the data set had been read, re-read, coded and re-coded and all of the codes created were collated into possible themes. Consideration was given to how different codes could combine to create main themes, which was an iterative process. During this stage I tried to refocus the analytical process at a broader level of analysis, once I had coded the focus groups discussion transcripts, trying to identify emerging hierarchical themes that could group codes together.

### Stage 4: Reviewing the Themes

This phase is about reviewing and refining the themes (Braun & Clarke, 2006). Each time created theme was read through with the coded text extracts to check that the themes were grounded in the codes. In order to achieve trustworthiness, one researcher (SA) independently opened coded to make tentative main themes using subjective assessment (Guest et al, 2012), then we met to discuss the similarities and differences and seek clarity and agreement by discussion and consensus (see Table 14) below in this appendix for notes from this process. The themes and subthemes, and the possible thematic maps were also considered. Discrepancies were discussed and any amendments made. Following this, thematic maps were created.
Table 15: Steps taken to achieve trustworthiness

Me and a second independent academic researcher (SA) examined the definitions at all themes.

We considered the location at the subthemes and looked at the content of the subthemes with random selection of quotes.

Examined the overall thematic maps.

Looked at the selection of subordinate themes and quotes within those.

SA. For example looked through my “empowerment” theme and checked quote.

We discussed the wording of some names for themes – for example “breast awareness knowledge” into “making sense of breast cancer awareness” and “empowerment” into “empowerment as motivational factor”.

SA. noticed that towards the theme “motivational factor as empowerment” that the quotes used blurred with other themes.

**Action point**

Suggested using specific quote to really highlight the motivational factor as empowerment the immigrant Arab women for breast cancer awareness.
Figure 25: Final thematic map shows four main themes and their subthemes
Stage 5: Defining and naming the themes

The themes were revisited and re-read several times, creating an opportunity to revise them, ensuring that the story told was clear and reliable. This also aided in developing the names for each theme. Following the reviewing themes stage and producing a thematic map of the data, I was able to determine what each theme was about by writing a description of each theme to outline what the theme entailed to ensure a systematic approach (see Appendix 10). Braun and Clarke (2006, p. 92) suggest identifying the "...story that each theme tells..." that contributes to the detailed analysis of each theme. At this stage, I also considered how each theme fits into the overall 'story' of the data. The thematic map enabled me to be able to see how the different themes related to each other (see Figure 25) above, and potential splitting or merging themes. At this point it was noticed that a small number of modifications were required as the themes were not creating what Braun and Clarke (2006) term a 'coherent and internally consistent account' (p.92). These modifications included collapsing and overlapping some sub-themes.

Stage 6: Producing the report

The final stage of thematic analysis involves the final analysis and write-up of the findings. Thematic maps were created to help provide an overview or story of the data (see figure 25). Coded extracts are included as examples, with the data relating back of the analysis to the research question and literature. The reader will be told a story of the data, which supports the validity of the analysis (Braun & Clarke, 2006).
### Appendix 2.7: Themes and Subthemes with an Example of Supporting Data

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
<th>Supporting extract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making sense of breast cancer awareness</td>
<td>Knew nothing about it (This theme highlights how immigrant Arab women’s breast cancer awareness was unfamiliar issue for them)</td>
<td>“I never knew that we need to be aware about our breasts and if we need to be aware about something serious related to breast cancer, what it is?“</td>
</tr>
<tr>
<td></td>
<td>What, why and how? (The first generation women want to know the definition of breast cancer awareness, the reason for its importance, how they can practice it)</td>
<td>“we I need to know more and more about what you call it ‘Breast Awareness’ what it does mean and is every women need to know about it and how to do it, it’s really interested—we are in need for such information”</td>
</tr>
<tr>
<td>Leaflets format and layout</td>
<td>Positive and negative notes (The format and layout of the information in the leaflets is crucial to the way in which people access the key messages for safe use)</td>
<td>“I like the breast cancer care leaflets rather than the NHS one, it’s colourful and bright and catches your attention, but compared to the NHS leaflets which has nothing that catches my attention”</td>
</tr>
<tr>
<td>Leaflets content</td>
<td>Preferred language (This theme describes the language preferred for breast awareness information leaflets in order to provide culturally sensitive information) (Cultural sensitivity should be taken into account when designing breast cancer and breast cancer awareness information leaflets)</td>
<td>“I need to read it many times to understand it, it’s difficult for me especially it’s containing medical terminology which I never knew about before such as mammogram, we don’t have this name in Arabic”</td>
</tr>
<tr>
<td></td>
<td>Cultural sensitivity information (Cultural sensitivity should be taken into account when designing breast cancer and breast cancer awareness information leaflets)</td>
<td>The one who wrote the leaflets information should know that the embarrassment is one of the main cultural barriers against the breast cancer awareness measurement such as breast screening.</td>
</tr>
<tr>
<td>Empowerment as motivational factors</td>
<td>Preferred source of information (The source of the breast cancer awareness information and dissemination empowered immigrant Arab women)</td>
<td>“I use to get the information from my close friends who they are here now in the focus group, I am not sure if we have the right information, we don’t have the reliable information about breast cancer and how it is important, otherwise you will find us with good knowledge about this subject”</td>
</tr>
<tr>
<td></td>
<td>Accessibility (Availability and Displayed)</td>
<td>“I used to look for any new leaflets in the surgery but every time I looked, I found the same leaflets that have nothing to do with breast cancer or breast cancer awareness. All leaflets talk about pregnancy, diets, eczema and immunization.”</td>
</tr>
</tbody>
</table>
3. Other Appendices

Appendix 3.1: Data Extraction Sheets

1. Administration Details

Review title: ______________________________

Paper title: ______________________________

Paper number: ____________________________

Paper ID:

i. (Surname of first author, Publication Year (Trial Year if other publications present) ______________________________

Other references to which this study may link with:

________________________________________________________________________

2. Characteristics of Included Studies

Methods________________________________________

Design of study: ________________________________

________________________________________________________________________

Method of randomisation: _______________________

________________________________________________________________________

Reliability and Validity:

________________________________________________________________________
Additional notes:

-----------------------------------------

3. Participants

Total eligible for inclusion into study:

-----------------------------------------

Total number enrolled into study:

-----------------------------------------

Numbers of withdrawals or dropouts from the study:

-----------------------------------------

Description of withdrawals or dropouts:

-----------------------------------------

Age:

-----------------------------------------

Sex:

-----------------------------------------

Ethnicity:

-----------------------------------------

Inclusion criteria:

-----------------------------------------

-----------------------------------------

Exclusion criteria:

-----------------------------------------
Baseline characteristics:

Source of participants:

Additional note:

4. Interventions

Setting:

Duration:

Additional notes:

5. Analysis methods

DATA EXTRACTION FORM – OUTCOMES

Outcome description:
Appendix 3.2: Ethnic Category Form

Ethnic Category and Language Spoken
Questionnaire

We are required from the Government to record all Ethnic Category and Main Spoken Language for all our patients.

Please could you take a moment to fill this questionnaire in and return it to reception?

Name………………………………..  DOB……………………

What is your ethnic group?

Choose ONE section from A to E, and then tick the appropriate box to indicate your cultural background.

A. White
- British
- Irish
- Any other white background

B. Mixed
- White and Black Caribbean
- White and black African
- White and Asian
- Any other mixed background

C. Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background

D. Black or Black British
- Caribbean
- African
- Any other Black background

E. Other Ethnic Groups
- Chinese
- Other ethnic category
Appendix 3.3: The Final Approval Letter for Phase 1 & 2 Studies

Dear Afrah

Application to SHSSW Research Ethics Committee: Knowledge, attitudes, beliefs and practice of immigrant Arab women toward breast cancer and breast awareness in England – second phase

Thank you for your response to the School of Health Sciences and Social Work (SHSSW) Research Ethics and Peer Review Committee.

Committee members would now like to give a favourable opinion.

Best wishes and good luck with the project,

Dr Rebecca Stores
Chair of SHSSW Research Ethics and Peer Review Committee
Dear Afrah

Research proposal:
Knowledge, attitudes and practice of breast self-examination among immigrant Arab women in England

Thank you for submitting your research proposal to the School of Health Sciences and Social Work (SHSSW) Research Ethics and Peer Review Committee.

Although your proposal describes Phase 1 and Phase 2 of your research programme, at this stage it is only possible to give an ethical opinion on Phase 1, as insufficient information is presented for Phase 2.

Committee members would require more detail relating to Phase 2 before providing an ethical opinion on this phase. This would include, for example, the proposed recruitment strategy, invitation letter, information sheet and draft questionnaire.

It would seem sensible to submit a second application relating to Phase 2 nearer to the time of starting this phase.

With regards to Phase 1, committee members would like to give a favourable opinion with the following provisions:

- All documentation needs proof reading for grammatical and spelling errors and style.
- The invitation letter and information sheet contains several examples of technical terminology and research ‘jargon’ which may not be fully understood by participants. These documents should be written in layman’s terms wherever possible.
- Will all documentation for participants be available in Arabic as well as English? This would seem advisable given the potential for confusion relating to a subject area that could become easily misconstrued through issues to do with communication.
- In the consent form, you say confidentiality cannot be guaranteed. Can you explain this more fully to help reduce participants’ concerns.
- It may be advisable to clearly reassure potential participants that physical examination would not be taking place as part of this study.
- No information is provided on inclusion criteria. Presumably, it is possible that participants may have had cancer themselves (or their relatives)? Do you have any procedures in place to deal with participants becoming upset as a result of this whilst the interviews are being carried out?

Additional comments of a more general nature include:
There is a lack of references to back up some of your statements within the introductory section of the proposal.

Will recruiting only from the Southampton School of Saudi Arabia introduce bias within the study sample? Will women from all Arab Immigrant groups be represented? Also, will recruiting from only this source limit the potential age range of participants?

Please arrange a meeting with your supervisors to clarify these issues. Once they are satisfied that you have addressed the issues, you can begin collecting data.

If you have any questions in the meantime, please do not hesitate to contact me.

Best wishes,

Rebecca Stores
Chair of SHSSW Research Ethics and Peer Review Committee
Appendix 3.4: The UPR16 Form declaring the ethical conduct of the research

**FORM UPR16**

- Research Ethics Review Checklist
  - Please include this completed form as an appendix to your thesis (see the Postgraduate Research Student Handbook for more information).

<table>
<thead>
<tr>
<th>Postgraduate Research Student (PGRS) Information</th>
<th>Student 378596</th>
</tr>
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<tbody>
<tr>
<td>Candidate Name:</td>
<td>Afrah N. Redha</td>
</tr>
<tr>
<td>Department:</td>
<td>Health science and social work</td>
</tr>
<tr>
<td>Start Date: (or progression date for Prof Doc students)</td>
<td>1st October 2007</td>
</tr>
</tbody>
</table>

| Study Mode and Route: | Part-time [x] | MPhil [x] | Full-time [ ] | MD [ ] | PhD [x] |

<table>
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<tr>
<th>Title of Thesis:</th>
<th>Immigrant Arab Women: Knowledge, Beliefs and Attitudes towards Breast Cancer and Cancer Awareness Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thesis Word Count: (excluding ancillary data)</td>
<td>Word Count: 80,000 (Excluding verbatim quotes and appendixes)</td>
</tr>
</tbody>
</table>

If you are unsure about any of the following, please contact the local representative on your Faculty Ethics Committee for advice. Please note that it is your responsibility to follow the University’s Ethics Policy and any relevant University, academic or professional guidelines in the conduct of your study.

Although the Ethics Committee may have given your study a favourable opinion, the final responsibility for the ethical conduct of this work lies with the researcher(s).
Candidate Statement:

I have considered the ethical dimensions of the above named research project, and have successfully obtained the necessary ethical approval(s)

Ethical review number(s) from Faculty Ethics Committee (or from NRES/SCREC):

Response of the UoP ethics Committee for Phase 1 Study (Application Reference Number 08-02)

Signed: Afrah Redha
(Student)  Date: 27/05/15

If you have not submitted your work for ethical review, and/or you have answered 'No' to one or more of questions a) to e), please explain why this is so:

Signed: Afrah Redha
(Student)  Date: 27/05/15

UKRIO Finished Research Checklist:
(If you would like to know more about the checklist, please see your Faculty or Departmental Ethics Committee rep or see the online version of the full checklist at: http://www.ukrio.org/what-we-do/code-of-practice-for-research/)

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<tbody>
<tr>
<td>a)</td>
<td>Have all of your research and findings been reported accurately, honestly and within a reasonable time frame?</td>
</tr>
<tr>
<td>b)</td>
<td>Have all contributions to knowledge been acknowledged?</td>
</tr>
<tr>
<td>c)</td>
<td>Have you complied with all agreements relating to intellectual property, publication and authorship?</td>
</tr>
<tr>
<td>d)</td>
<td>Has your research data been retained in a secure and accessible form and will it remain so for the required duration?</td>
</tr>
<tr>
<td>e)</td>
<td>Does your research comply with all legal, ethical, and contractual requirements?</td>
</tr>
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