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USING A MIXED DESIGN STUDY TO DEVELOP A BREAST SCREENING INTERVENTION AMONG CHINESE WOMEN IN THE UK

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Doctor of Philosophy

ASTON UNIVERSITY

June 2014

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THESIS SUMMARY

Aston University

Using a mixed design study to develop a breast screening intervention among Chinese women in the UK

Ying Zhang Doctor of Philosophy June 2014

Breast cancer is the most common cancer among Chinese women living in the UK. However the literature suggests that Chinese women are less likely to attend breast screening than white British women. No studies have been conducted to explore reasons for low attendance among this specific population. The purpose of this thesis was to understand the psychosocial factors related to breast cancer prevention and screening among Chinese women in the UK, and then to inform a breast screening intervention design.

Three studies were conducted. The first was a systematic review of interventions to increase breast screening among Chinese women living in Western countries. The second and third studies used focus groups to explore Chinese women's beliefs about breast cancer prevention and screening practices among older and younger generations. Finally, Intervention Mapping was used to synthesise the findings of the focus groups with those of the systematic review to design an empirical and theoretical evidence based breast screening intervention directed at Chinese women who are non-adherent to the NHS Breast Screening Programme.

The qualitative findings revealed that older participants held a more holistic view of health maintenance, and had less knowledge about breast cancer and its causes than younger participants. They showed positive attitudes to breast screening and most had responded to receiving a mammography invitation. Language was a key barrier to older participants using medical care and obtaining health-related information. Younger participants expressed high dissatisfaction with health care in UK and showed a strong 'neo-fatalistic' view of breast cancer prevention, believing the main cause of breast cancer to be genetic predisposition. The synthesis of findings suggest that healthcare providers need to take Chinese cultural and language concerns, but also the differences between generations, into account when designing and implementing breast screening services and educational programmes which target Chinese women.

Key words / Phrases: Chinese-British women, breast health, mammography screening, Intervention Mapping.

DEDICATION

This thesis is dedicated to my son, Ziqin.

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Chapter 1 Introduction

1.1 Foreword

According to global cancer statistics, breast cancer is the most frequently diagnosed cancer and the leading cause of cancer death among women worldwide (Jemal, Bray, Center, Ferlay, Ward, & Forman, 2011). About 48,000 women in the UK develop breast cancer each year (NHS, 2012). Despite Chinese-British women having a lower breast cancer incidence than white British women, breast cancer is still a major health issue among this population (National Cancer Intelligence Network and Cancer Research UK, 2009).

Mammography screening has been identified as the most effective way to promote early detection and has the potential to reduce breast cancer-related mortality and morbidity (AIHW & NBCC, 2007; Elmore, Armstrong, Lehamn, & Fletcher, 2005). In the UK, the NHS Breast Screening Programme provides free regular mammography screening for women aged between 50 and 70 (Bennett & Moss, 2011). However, it has been reported that Chinese-British women are less likely to use this service compared with their white counterparts (Breast Cancer Care, 2005; Hoare, 1996; Liao & McIlwaine, 1995). There is little evidence available on the factors related with lower uptake of mammography screening among Chinese women living in the UK. In addition, no particular interventions to promote breast health and breast screening among this population have been researched.

Therefore the aim of this thesis was to gain an understanding of the psycho-social factors related to breast cancer prevention and screening among Chinese women in the UK. This study complements the research which has been carried out to understand and improve breast health among Chinese women in the other Western countries, and ultimately by synthesizing evidence, enables the development of an educational and motivational intervention for the Chinese-British population.

This chapter provides an overview of breast cancer incidence in the UK, the risk factors related with breast cancer, breast cancer screening methods, a description and introduction of NHS Breast Screening Programme, and the low uptake of breast screening by Chinese women in Western countries. The psycho-social factors which influence breast screening behaviour in Chinese women living in Western countries are reviewed here. In addition, the evidence of the major health psychology models that have been used to predict breast cancer related health behaviour such as breast self-examination and mammography screening are considered.

1.2 Breast cancer

1.2.1 Breast cancer incidence

Breast cancer is the most common cancer among women in the UK. The estimated lifetime risk of developing breast cancer is 1 in 9 for women living in the UK (Cancer Research UK, 2009). Although the European age-standardised breast cancer rates were estimated as from 41.3 to 74.9 per 100,000 for all ages among Chinese women, compared with the range from 122.4 to 125.7 per 100,000 for white women (National Cancer Intelligence Network and Cancer Research UK, 2009), breast cancer is still the most common cancer among Chinese women in England (National Cancer Intelligence Network and Cancer Research UK, 2009). In addition, breast cancer incidence among Chinese women significantly increases after they migrate to Western countries (Kwok & Sullivan, 2006). For example, women who have been in United States for more than ten years have an 80% higher risk of developing breast cancer than those who are newly arrived (Ziegler et al, 1993). Moreover, breast cancer risk increases with successive generations (National Institutes of Health, 2002). The increased risk of breast cancer among Chinese emigrants is found to be related to factors such as dietary changes, Westernization of lifestyle and reproductive patterns (Hoare, 1996). Therefore, more Chinese women living in Western countries are expected to be diagnosed with breast cancer in future years.

1.2.2 Breast cancer causes

1.2.2.1 Risk factors

The exact cause of breast cancer is still unclear (NHS, 2010). However, there are some risk factors that may increase the risk of getting breast cancer. The risk factors include (Cancer Research UK, 2009):

- Gender: Being a female gives a significantly higher risk of developing breast cancer than being a male
- Age: 81% of breast cancers occur among women over 50 years old. Nearly half of breast cancer cases are diagnosed between the ages of 50-69 years
- Family history: having close relatives with breast cancer or ovarian cancer, especially if the cancer was diagnosed when they were under the age of 50
- A breast cancer history
- Having a benign breast lump: such as lobular carcinoma in situ or atypical ductal hyperplasia
- Having dense breasts
- Exposure to estrogen: e.g. starting periods at an early age; entering menopause after the age of 55; having a first child in later life or being childless
- Hormone replacement therapy (HRT): women who are currently using the HRT have a 66% increase in risk of breast cancer than never users, but this risk returns to normal within 5 years of stop taking HRT
- Height: the risk of developing breast cancer increased by 7% for additional 5
 centimetres increase in height for post-menopausal women
- Lifestyle factors: e.g. less physical activity; being overweight or obese after menopause; excessive alcohol consumption; high fat intake; doing night shift work
- Exposure to radiation for a long period of time

1.2.2.2 Family history and breast cancer genes

Family history is a contributor to the increased risk of breast cancer (Cancer Research UK, 2009; NHS, 2010) and accounts for 10-15% of breast cancer cases (Weber & Garber, 1993; Key, Verkasalo, & Bank, 2001). The National Institute for Health and Clinical Excellence (2006) suggests that a woman's risk of breast cancer is higher than the normal population if she has one of the following on the same side of her family: 1) an affected first-degree relative with breast cancer under age of 40; 2) two or more close relatives diagnosed with breast cancer; 3) three close relatives with breast cancer; 4) a male relative with breast cancer detected aged under 50; 6) one close relative with breast cancer and one close relative with ovarian cancer if one of them is a first-degree relative.

Having a strong family history may be due to the mutation in breast cancer genes. Epidemiological studies have shown that the development of some breast cancer is associated with a specific genetic component and that around 5-10% of breast cancer cases are considered to be attributable to this heritable predisposition (Bowcock, 1997). The mutations in BRCA1 (BReast CAncer 1) and BRCA2 (BReast CAncer 2) are the major cause of hereditary breast cancer (Ford et al, 1998; Hemel & Domchek, 2010) and constitute approximately 5% of the total breast cancer cases (Bowcock, 1997). Mutations in one of the two genes result in high risks for developing breast cancer in the lifetime (Ford et al, 1998; Parmigiani, Berry, & Aguilar, 1998; Thompson & Easton, 2004) and high chances of having breast cancer at a young age (≤ 40 years old) as well (Loman, Johannsson, Kristoffersson, Olsson, & Borg, 2001; Parmigiani et al, 1998). Mutations in other genes, such as TP53, PTEN, STK11/LKB1, CDH1, CHEK2, ATM, MLH1, and MSH2, also contribute to an increased risk of breast cancer, but the rates of having mutations in these genes are relatively low compared with BRCA1 and BRCA2 (Ebomoyi, 2011).

1.3 Approaches to breast cancer screening

Because some of the risk factors, such as age and genetics, cannot be modified, early detection enables women to get treatment at the early stage, prohibits breast cancer progressing to an advanced stage, and thus improves chances of survival. The three major approaches to early breast cancer detection are breast self-examination, clinical breast examination and mammography.

1.3.1 Breast self-examination (BSE)

BSE is a screening method in which women themselves systematically feel their breasts for changes, such as lumps. BSE has been considered as an essential screening method for breast cancer early detection, especially for women who are younger than 50 years old because mammography screening is less sensitive to the dense breast tissues of premenopausal women (Vahabi, 2003). In addition, BSE plays an important role in the detection of cancer appearing in the interval between two successive mammograms (Lechner, De Nooijer, & De Vries, 2004). However, BSE is not recommended at present due to a large number of studies that have indicated that BSE did not have an effect on the improvement of breast cancer mortality and even increased the number of women going for a biopsy (Gao et al, 2006; Kosters & Gotzsche, 2003). Therefore, the NHS recommends increasing breast awareness advice involves being familiar with your breasts, knowing what is normal for your breasts, telling your GP once you have noticed changes in your breasts, and attending NHS breast screening programme when you are 50 years old (NHS Cancer Screening Programmes, 2006).

1.3.2 Clinical breast examination (CBE)

CBE is a visual and manual examination of the breasts to identify abnormalities by health professionals. However, this screening method is not commonly in use in clinical practice (Crossing & Manaszewicz, 2003). The reason may be attributed to the fact that there is

limited evidence on the effectiveness of CBE on the reduction of breast cancer mortality (Humphrey, Helfand, Chan, & Woolf, 2002; Pisani et al, 2006).

1.3.3 Mammography screening

Mammography screening is considered as the most effective way to promote early detection and has the potential to reduce breast cancer mortality. It is an x-ray exam to detect small changes in breast tissues that are abnormal. A mammogram can detect changes which are too small to be felt through BSE and CBE (Parker, Tong, Bolden, & Wingo, 1996; The Information Centre, 2008). The Department of Health (2011) reported that approximately one third of breast cancer cases are diagnosed by mammogram at present. The efficacy of mammography screening has been assessed by randomized control trials by comparing the breast cancer mortality between women who received an invitation and those who did not and results showed that mammography screening significantly reduced breast cancer mortality (Tabar et al, 1985; Tabar, Fagerberg, Duffy, & Day, 1989; Tabar et al, 1995; Tabar et al, 2000; Nystrom et al, 2002; Tabar et al, 2011). For example, Swedish randomized trials reported that mammography reduced the breast cancer mortality by around 21% (OR=0.79, 95% CI .70-.89) among women aged from 40 to 74 years old who were invited to screening (Nystrom et al, 2002).

1.4 NHS Breast screening Programme

Free mammography screening is provided in several countries in order to reduce breast cancer mortality nowadays. In 1986, the Forrest Committee, chaired by Professor Sir Patrick Forrest, presented the findings of the effects of mammography screening on breast cancer and recommended the implementation of a NHS Breast Cancer Screening Programme across the nation providing free mammogram to women aged between 50 and 64, every three years (Forrest, 1986). The NHS Breast Cancer Screening Programme, which was the first world national breast screening programme, was brought into operation in England in 1988, with only around 2.5% of the target women going for the screening in that year (Duffy

et al, 2010).

The programme was expanded across the UK in the following years, with the final few breast screening units being opened in 1992 (East Kent Hospital University, 2012). The Health of the Nation White Paper (Department of Health, 1992) estimated that the breast cancer mortality rates among women aged 50-69 would be reduced by 25% if 70% of the target population go for breast screening. Therefore, the target uptake rate was set at 70% in the Health of the National White Paper in 1992 and it remains the national minimum standard for uptake rate for the NHS Breast Cancer Screening Programme (Department of Health, 1992). By 1995, the NHS Breast Cancer Screening Programme had completed the first round of screening (East Kent Hospital University, 2012).

It was reported that the breast cancer mortality in the UK had fallen by 25% by 2000 (Peto, Boreham, Clarke, Davies, & Beral, 2000). Despite the improvement of breast cancer mortality being also attributed to improvements of breast cancer services and treatment rather than the promotion of NHS Breast Cancer Screening Programme only, many researchers argued that these improvements were affected by the introduction of NHS Breast Screening Programme (NHS Breast Screening Programme, 2006). The eligible age range for breast screening was expanded to 50-70 years old by 2004 and has been further extended to 47-73 years old from 2007 (NHS Cancer Screening Programmes, 2011). The age extension is supposed to be implemented across the nation by 2016 (NHS Cancer Screening Programmes, 2011).

With the development of NHS Breast Screening Programme, the number of women receiving breast screening continues to grow year by year. A total number of 1.79 million women aged 45 and over received breast screening during 2009-2010 compared with 1.32 million women who were screened in 1999-2000 (The Health and Social Information Centre, 2011). The breast screening rate has increased by 35.7% during the past ten years (The Health and

Social Care Information Centre, 2011). Among the 2.24 million women aged 50-70 who were invited to breast screening during 2009-2010, 73.2% of them went for the screening. In total, 14,229 women aged 45 and over were detected with breast cancer by attending the screening programme in 2009-2010 (The Health and Social Care Information Centre, 2011).

Population-based breast cancer survival rates are key factors to evaluate the success of health services in breast cancer management. In England and Wales, the evidence indicates the five-year relative survival rates for women with breast cancer have increased to 82% in 2001-2006 compared with 52% during 1971-1975 (Coleman, Babb, & Damiecki, 1999; Rachet et al, 2009). A significant improvement is also observed for the ten-year survival rates as the rates have increased from 41% during 1971-1975 to 73% during 1996-2000 (Coleman et al, 1999; Richards, 2008; Rachet et al, 2009).

Apart from the improvement on the five and ten year survival rates, the rates of breast cancer mortality also have been decreasing since 1989 (Office for National Statistics, 1997). The age-standardised mortality rates for women diagnosed with breast cancer have reduced by 37% from 42 to 26 per 100,000 women during 1989-2008 (Cancer Research UK, 2009). The reduction of breast cancer deaths has applied for various age groups including 40-49, 50-64, 65-69 and 70+ (Cancer Research UK, 2009). The greatest improvement was found among women aged between 50 and 69 which is the eligible age range for attending the NHS Breast Cancer Screening Programme (Cancer Research UK, 2009).

The improvement on both the breast cancer survival and mortality rates during the past decades can be attributed in part to the implementation of NHS Breast Cancer Screening Programme which enables breast cancer to be diagnosed at an early stage and thus be treated effectively (Beral & Peto, 2010). Other factors including the development of breast cancer treatment and care and the promotion of breast health are also contributors to the significant improvement on breast health.

1.5 Chinese population demography

Chinese women have been selected as the target population in this study as there is a lack of knowledge regarding the breast cancer prevention and screening among this community despite the prevalence of breast cancer in this population. The Chinese account for 0.7% of the total population in England and Wales (Office for National Statistics, 2012). The UK census data show that the Chinese community has the fastest growing rate of 8.6% per year between 2001 and 2009 compared to the other ethnic groups (Office for National Statistics, 2011). The latest estimated residence data suggest that Chinese women aged between 50 and 69 constitute 14.68% of the total female Chinese population in England and Wales (Office for National Statistics, 2010).

Chinese are often considered as an 'invisible community' or 'hard to reach' group in the UK (Tran, 2006). The reason may be attributed to the Chinese being widely geographically distributed throughout the UK (Tran, 2006). This is related to the employment patterns among the Chinese population. According to the 2004 Annual Population Survey, the Chinese are concentrated in the distribution, hotel and restaurant sectors, accounting for 45.2% of the UK Chinese population. The catering trade is the number one industry for the Chinese population, as many Chinese families run Chinese takeaways or Chinese restaurants (Office for National Statistics, 2005). In order to avoid keen competition, they need to settle in different places. This scattered settlement pattern among the Chinese population increases the difficulties of getting access into the community.

Another reason for difficulties in access is that the Chinese population is heterogeneous in terms of place of birth, English ability and language. Most Chinese migrants came to the UK through one of three main ways (Wong, 2006). The first phase of migration started in the 1950s when some parts of Hong Kong experienced the collapse of the agricultural industry and the land reforms. Around 30-50,000 Chinese, most of them male farmers and Cantonese speaking, came to the UK during that period. The majority of these migrants worked in the

laundries before starting the catering trade due to their low education level and inability to speak fluent English (Tameside Metropolitan Borough Council, 1995).

The second wave of immigration occurred during the 1970s and 1980s because the catering industry developed rapidly, leading to more workers being required. Therefore, the dependents of the first generation of migrants came to the UK and worked in this business. During the 1980's and 1990's, more Hong Kong people entered the UK. This is mainly due to the Chinese and UK governments entering a dialogue regarding the return of Hong Kong to China in 1997 (Chau & Yu, 2001).

The most recent immigration started in 1990's and continues now that the number of migrants from mainland China has been increased. It includes students and scholars who chose to stay to work and gain permanent citizenship after they had finished their studies. Most of them are Mandarin speakers. At the same time, as many as 80,000 Chinese from the Fujian province also came and work illegally in the UK (Tran, 2006). Despite some people from other Asian countries, such as Malaysia and Vietnam, being the descendants of Chinese and regarded as Chinese, this thesis defines Chinese as people who are originally from Hong Kong and mainland China because they constitute a relatively large proportion of the Chinese community in the UK.

The complex immigration patterns lead to many different places of birth, education level, English ability, dialects and life experiences in the UK among the Chinese community. These differences together with the scattered settlement patterns increase the difficulties in reaching the Chinese community and understanding their health experience. However Chinese societies and Chinatowns can be easily found in major cities in the UK, such as London, Birmingham and Manchester, where there is a relatively higher Chinese population density. These Chinese societies are well organised and not only provide support and help for Chinese community but also hold many activities such as health workshops. Accordingly,

many Chinese, especially those with language barriers and/or strong cultural views, have limited connections with the British community. Therefore, this population is hard for health services and health service researchers to reach.

1.6 Low uptake of mammography screening among Chinese women in Western countries Although a number of strategies have been used to improve the uptake of mammogram screening, prior studies suggest that women from the Chinese community are less likely to use this service compared with white British women (Liao & McIlwaine, 1995; Hoare, 1996). For example, Liao and McIlwaine (1995) carried out a survey among Chinese living in Glasgow, in order to understand their health status and health needs. The results showed that of Chinese women aged 50-65, only 10 out of 55 women (18%) had attended the NHS Breast Screening Programme. Hoare (1996) conducted a review to assess the uptake of breast screening among ethnic minorities in the UK and reported relatively lower uptake rates among this population. However, it should be noted that the two studies reported the findings in the early 1990s, when the NHS Breast Cancer Screening Programme was still in the first round of implementation across the nation. As a result, it is difficult to assess whether Chinese women involved in the two studies has been invited to attend the breast screening programme. Therefore, the low uptake of mammography screening among Chinese women in the two studies might be due to the incompletion of the NHS Breast Screening Programme.

The NHS Cancer Screening Programmes carried out a review on the inequalities in cancer screening access and found that the attendance of mammography screening was lower among women in the Black and Minority Ethnic (BME) groups than in the white ethnic group in both UK and US (Chiu, 2003). Breast Cancer Care (2005) conducted a survey among 861 women from BME communities, including Indian, Pakistani, Bangladeshi, Black African, Black Caribbean, Chinese and Irish, in order to understand breast awareness and breast screening among this population. It was found that nearly half (45%) of women aged between 50 and 70 years had never gone to the NHS Breast Screening Programme.

However, this survey did not provide information on sample size and acceptance rates of mammography screening according to ethnic groups. In contrast to the findings of previous research, a recent study (Moser, Patnick, & Beral, 2009) used the data from National Statistics Omnibus Survey 2005-2007 and reported that women from minority ethnic groups as a whole (n=259) did not differ from white British women (n=2889) on the uptake of mammography screening. This study failed to compare differences between white British women and women from each individual ethnic group on mammography screening attendance because of the small number of women from minority ethnic groups.

The NHS Cancer Screening Programmes (2009) analysed all breast cancer diagnosed in 2006 and reported that 31% Chinese patients were detected with breast cancer through attending mammography screening compared with 33% of patients known to be white. Regarding the invasive tumour grade, evidence showed that Chinese women were more likely to present with grade 3 tumour than white British women (41% compared to 36%). These findings suggest that Chinese women might be less likely to attend breast screening compared with white British women and thus leading them to having more advanced tumours.

Low mammography screening rates are also found among areas with a high proportion of BME groups. For example, the average uptake of mammogram screening was 35.2% for three general practices with a high number of BME groups in inner city Cardiff, which was much lower than the national screening rate target of 70% (Bell, Branston, Newcombe, & Barton, 1999). Similar evidence was also observed in northwest London which consists of mixed ethnic groups, where the uptake of mammography screening was 58.3% (Northwest London Hospital Strategic Health Authority, 2002). The low screening rates in these areas can be partially explained by the diversity of ethnicity. A recent study suggested that 28% of the variation on breast screening uptake between Primary Care Trusts can be attributed to ethnicity (Eilbert et al, 2009). However it must be noted that the low screening rates in these areas may also be influenced by factors such as socio-economic status (Eilbert et al, 2009;

Hoare, 1996). For example, deprivation is found as a significant factor that contributes to the low breast screening coverage (Eilbert et al, 2009). There is evidence that women with a lower monthly income were more likely to have poor breast cancer knowledge and were less likely to attend breast screening (Sim, Seah, & Tan, 2009). In addition, the inaccurate screening register due to the high residential mobility in inner cities is another confounding factor (Eilbert et al, 2009; Hoare, 1996; Millett, Zelenyanszki, Binysh, Lancaster, & Majeed, 2005). For example, a previous study explored the reasons of 93 Asian women who failed to attend mammography screening in inner-city Manchester and indicated that around 49% of interviewed women had already moved away from the invitation addresses (Hoare, Johnson, Gorton, & Alberg, 1992). Recent data show that population mobility accounts for 4% of the variation in breast screening (Eilbert et al, 2009).

The NHS Cancer Screening Programmes report that there is lack of information about the attendance at mammogram screening according to the social status and ethnic group at present (Chiu, 2003). The low breast screening rates among ethnic groups are generally generated through local surveys or the national health lifestyle surveys rather than the record from screening services (Chiu, 2003). Because the Chinese are a relatively small ethnic group in the UK, the majority of the surveys focus on the south Asian population or treat ethnic groups as a whole without reporting the data on each individual ethnic group. At present, the data on ethnic groups is only generated for the cases of diagnosed cancer in England (NHS Cancer Screening Programmes, 2009). Hence, there is insufficient data on the mammography screening among Chinese women in the UK.

Compared with the limited surveys on breast screening among Chinese-British women, relatively more effort has made to explore the utilization of health services and the performance of health behaviour among the Chinese population in the UK. The uptake of mammogram screening may be reflected in these studies. Evidence suggests that the Chinese population experiences inequality in getting access to health care (Rochelle &

Marks, 2011). Previous studies consistently show that the Chinese community makes less use of health services than white people and people from other ethnic groups (Smaje & Grand, 1997; Sproston, Pitson, & Walker, 2001; Watt, Howel, & Lo, 1993). For example, the first large scale national survey (n=1022) of the Chinese population living in England indicates that a lower percentage of the Chinese respondents had used health services than the national population, in terms of having visited a GP or health centre during the past month (6% vs. 28%) and having consulted with a GP within last year (64% vs. 76%) (Sproston et al, 2001). Regarding the use of hospital services within the past three months prior to the survey, the data show that the Chinese people used the outpatient services less often (10%) when compared with the general population (15-16%) (Sproston, Pitson, Whitfield, & Walker, 1999). However, the use of inpatient day treatment was slightly higher for the Chinese population (9%) than for the general population (6-7%) (Sproston et al, 1999).

Morris, Sutton and Gravelle (2005) explored the use of health care among ethnic groups on the basis of the data collected by the Health Survey for England (HSE) between 1998 and 2000. This survey analyzed the data of secondary care utilization over a relatively longer period (1 year) compared with the study which was described above (3 months) (Sproston et al, 1999). It was found that Chinese had a 45% and 41% lower utilization of outpatient visits and inpatient stays, respectively, than the white population (Morris et al, 2005). However, there was no significant difference on the GP consultation and day case model between the Chinese and white ethnic groups (Morris et al, 2005).

With respect to preventive health care services, a survey based in Hull showed that Chinese respondents had a lower utilization of preventative health care services than their ethnic white counterparts, in relation to blood pressure checks (70% vs. 91%) and vision tests (24% vs. 45%) (Watt et al, 1993). As far as women's awareness of screening programmes, such as breast screening and cervical screening, which has been widely recommended and freely available to women aged between 20 and 64 from 1988 (Department of Health and Social

Services, 1988), Chinese women (less than 40%) were half as likely as white women (more than 80%) to have heard of each individual screening programme (Watt et al, 1993). There is no surprise that the engagement in screening behaviours was also lower among Chinese women. Compared with 98% of white women having ever had a cervical smear test, the percentage for Chinese women was only 69% (Watt et al, 1993). In addition, lower performance of breast self-examination was observed in Chinese women, with only 19% of them reporting doing it, compared with a considerably higher figure of 78% for white women (Watt et al, 1993).

On the basis of the data regarding low utilization of health services and uptake of preventive health care services among Chinese population, it could be anticipated that Chinese-British women may still have a lower uptake of mammography screening than white British women at present even though the NHS Breast Screening Programme has been promoted in the recent decades. This assumption may be supported by the evidence on the low mammogram screening among Chinese women in the other Western countries (Kwok, Fethney, & White, 2011; Sun et al, 2010).

The Canadian Community Health Survey reported that Asian immigrant women, including Korean, Filipino, Japanese, Chinese, South Asian, Southeast Asian, Arab, and West Asian, had a lower uptake of mammogram screening within the previous two years compared to non-immigrant general women, with rates of 60% and 72% respectively (Sun et al, 2010). Similarly, the national reports in the US indicated that Asian-Americans, including Chinese, have the lowest uptake of mammogram screening among all the ethnic groups, with only 54% screening rates within the previous two years (American Cancer Society, 2008). Although Chinese is the largest Asian ethnicity in the US, mammogram screening among Chinese women was lower than in the other Asian ethnicities, such as Filipino, Japanese and Vietnamese women (McCracken et al, 2007). It was found that only 52% of Chinese women in California reported having mammography screening in the previous year even though

breast cancer is the most common cancer for them (McCracken et al, 2007).

The national data for Australia showed that English-speaking women aged between 50 and 69 had a higher compliance (59%) with breast screening than those from non-English-speaking backgrounds (45%) (AIHW & NBCC, 2009). However, a recent cross-sectional survey among 292 Chinese-Australian women reported a quite favourable result that around 75% of Chinese women aged between 50 and 69 reported that they have mammogram screening every two years (Kwok et al, 2011). The authors suggest that the high screening rates may be associated with two factors. First, the Chinese organizations that the participants were recruited from may be more likely to promote health than other Chinese organizations. Second, the recruitment did not include those who were geographically isolated and who were newly moved to Australia. Therefore, the data on mammography screening that was generated from that study may be not generalized for the entire population of Chinese-Australian women. Overall, the data from different Western countries evidences that Chinese emigrants have low participation in breast screening.

1.7 Factors-related to low mammography screening among Chinese women in Western countries

Several studies have been carried out to explore factors related to low mammographic screening rates among Chinese women in Western countries, such as US, Australia and Canada, which have relatively large Chinese populations (Jackson et al, 2003; Kwok & Sullivan, 2006, 2007; Lee, Lee, & Stewart, 1996). It was found that the low uptake of mammography screening was influenced by Chinese cultures and women's knowledge of breast cancer. In addition, there were some motivators and barriers contributing to the uptake of mammography screening. These factors are discussed in the following sections.

1.7.1 Chinese cultural beliefs about health and illness

Chinese culture has an important influence on the uptake of mammography screening

among Chinese women (Kwok & Sullivan, 2006; 2007; Liang et al, 2008; Wang et al, 2006; Wang et al, 2008). Chinese cultural beliefs about health and illness are affected by Confucianism, Taoism and Buddhism. Both Confucianism and Taoism suggest that health can be maintained by keeping the physical, the emotional and the social in harmony. Therefore the Chinese emphasise the importance of engaging in regular exercise and eating a healthy diet in promoting health rather than taking regular screening (Kwok & Sullivan, 2007; Liang, Yuan, Mandelblatt, & Pasick, 2004). In addition, there is some evidence that fatalistic views may also contribute to people's perception of illness in this population. For example, people consider that illness is inevitable and nothing can be done to prevent it (Jackson et al, 2003; Kwok & Sullivan, 2006). Therefore, the low screening rates of mammography may be attributed to Chinese cultural beliefs and values about health and illness.

1.7.2 Knowledge and attitudes toward breast cancer and mammography

Limited knowledge of breast cancer and mammography screening may contribute to the low attendance at mammography (Lee et al, 1996; Lee-Lin et al, 2008; Su, Ma, Seals, Tan, & Hausman, 2006). Breast cancer is believed to be a "white disease" (Kwok, Sullivan, & Cant, 2006) by many Chinese women, leading to low perceived susceptibility to breast cancer. For example, Tang, Solomon and McCracken (2000) reported that 72% Chinese-American women perceived themselves to have a smaller chance of developing breast cancer compared to non-Chinese-American women. In addition, many Chinese women stated that breast cancer is a sensitive topic in their community, not only because cancer is a private subject, but also women feel embarrassment when talking about breasts and exposing their breasts to others (Gany, Herrera, Avallone, & Changrani, 2006; Kwok, Cant, & Sullivan, 2005).

As to benefits of taking mammography, although Liang et al (2004) found that many Chinese women believed that mammography is an effective means of early breast cancer detection

and treatment, Gany et al (2006) reported that some Chinese women considered that having mammography can cause breast cancer and other possible side effects. Many women also reported that they do not need mammography if they feel healthy and have no symptoms (Kwok & Sullivan 2007; Liang et al, 2004; Wu, Guthrie, & Bancroft, 2005). Fear of pain or discomfort caused by mammography and a positive result are also prevalent reasons why Chinese women are reluctant to attend mammography screening (Gany et al, 2006; Sadler, Wang, Wang, & Ko, 2000).

1.7.3 Common barriers to mammography

Studies from the other Western countries indicate that language is a key factor influencing breast cancer screening among Chinese women. Inability to speak English may inhibit the Chinese from obtaining health-related information or using medical care (Lee et al, 1996; Liang et al, 2004; Sadler et al, 2000; Tang et al, 2000; Yu, Kim, Chen, & Brintnall, 2001; Yu, Seetoo, Tsai, & Sun, 1998). Even those who understand conversational English, still had difficulties in talking with doctors using English medical terms (Liang et al, 2004). Thus, they delayed visiting a doctor when they had symptoms, leading their illness to progress to an advanced stage. As to breast screening, Lee et al (1996) found that the degree of English fluency is positively associated with uptake of mammography screening.

The lack of health insurance or inability to afford mammography screening is identified as another barrier to mammography screening in countries where the service is not free at the point of need. In a quantitative study, it was found that women with health insurance in the US were more likely to have had mammography screening and to have had mammography at regular intervals than those without health insurance (Lee-Lin et al, 2008). The differences in breast screening participation might also be associated with women's educational levels. It was evident that women with private insurance are more likely to be those with higher educational levels (Esteva, Ripoll, Leiva, Sanchez-Contador, & Collado, 2008). In addition, a common reason given for not taking mammography among women who had never had it or

women who did not have it regularly is lack of time (Gany et al, 2006), inconvenience in taking public transport (Liang et al, 2004; Sandler et al, 2000), and long waiting times (Liang et al, 2004; Wu, West, Chen, & Hergert, 2006).

1.7.4 Motivators to mammography screening

Physician's recommendation has been identified as the most frequently cited motivator for mammography screening among Chinese women in the US and Canada (Liang et al, 2004; Su et al, 2006). Prior studies revealed that a doctor's suggestion encouraged women to have had a mammography in the past, or to activate their intention to do so (Kwok et al, 2005; Liang et al, 2004; Tang et al, 2000; Tu et al, 2003; Yu, Hong, & Seetoo, 2003). Moreover, suggestions from significant others like family members and friends also have an effect on Chinese women's mammography screening. In addition, it was found that women who have a family history of breast cancer are more likely to have regular mammography screening (Liang et al, 2004).

1.8 Applications of health psychology models to early breast detection and prevention Health psychology mainly aims at understanding behaviours that are associated with health and the determinate factors of why some individuals engage in health behaviours and others do not (Conner & Norman, 2005). Several theoretical models have been widely used within health psychology research in order to understand and predict the performance of health behaviours, and screening attendance in particular. These models mainly consist of two categories, social cognition models and stage models (Sutton, 2002).

1.8.1 Social cognition models

Social cognition models assume that behaviour change is determined by several key cognitive variables, beliefs and attitudes (Stroebe, 2000; Sutton, 2002). Within this section, the commonly used social cognition models on the understanding and prediction of women's breast cancer will be reviewed. These models include the Health Belief Model (HBM; Becker,

1974), the Protection Motivation Theory (PMT; Rogers, 1983), the Theory of Planned Behaviour (TPB; Ajzen, 1991), and the Self-regulation Model of Illness Behaviour (SRMI; Leventhal, Nerenz, & Steele, 1984).

1.8.1.1 The Health Belief Model and its application in breast cancer screening

The HBM (Becker, 1974) is most frequently used social cognition model in the health area (Conner & Norman, 2005; Morrison & Bennett, 2006). It focuses on individuals' beliefs and attitudes to health and health-related behaviour. According to HBM (Becker, 1974), behaviour change is a function of perception of threat and behavioural evaluation. An individual's perception of threat of a specific disease is affected by perceived susceptibility to and perceived severity of this disease. Their evaluation of a recommended action is influenced by perceived benefits and barriers of adopting this action. Therefore, individuals are more likely to engage in health behaviours if they have high perceived susceptibility and perceived severity of the disease, and high perceived benefits and low perceived barriers to the health behaviour (Becker et al, 1979). Becker and Maiman (1975) added cues to action as another component to the HBM and suggested that behaviour change may be triggered by internal (e.g. having symptoms) and/or external events (e.g. health promotion campaigns). Finally, health motivation, which refers to the incentive encouraging an individual to perform the behaviour, was added into this model at a later date (Becker, Maiman, Kirscht, Haefner, & Drachman, 1977). In addition, demographic variables (e.g. class, gender, age) and psychological characteristics (e.g. personality) are suggested to have a potential influence on health behaviour through their effect on each of the HBM components except cues to action (Abraham & Sheeran, 2005).

With regard to breast health-related behaviour, HBM has been demonstrated to be a good predictor of whether women participate in the mammogram screening and BSE. Fischera and Frank (1994) applied HBM to the prediction of compliance to mammography screening among 110 nurses aged over 35 years. The uptake of mammography screening was

predicted by perceived barriers, benefits and health motivation. In a study, involving 170 women aged between 50 and 70 years old, intentions to have a mammogram were predicted by perceived susceptibility (Savage & Clarke, 1996).

Regarding the performance of BSE, Champion (1993) applied HBM to the prediction of BSE in 581 women aged between 35 and 88 years. BSE was predicted by all the HBM components. In addition, the frequency of BSE was predicted by perceived barriers, benefits, confidence, health motivation and susceptibility among 380 women aged over 35 years (Champion, 1990). Umeh and Rogan-Gibson (2001) examined the role of HBM in predicting BSE among young women aged 18-35 years and found that perceived severity and perceived barriers were significantly associated with the performance of BSE.

Although HBM has been successfully used in the prediction of health-related behaviour for many years, critics of this model have pointed out a variety of limitations. First, this model has been criticized for not providing a clear explanation of how HBM variables work with each other or combine to affect behaviour (Morrison & Bennett, 2006). Consequently, the six components of the HBM have been generally examined independently on the prediction of health behaviour in many studies (Abraham, Sheeran, Abrams, & Spear, 1996). Second, there is a lack of consistency in the measurement of each HBM component. In other words, not all components have been tested in all studies (Abraham & Sheeran, 2005). For example, it is difficult to identify and to evaluate cues to action in HBM studies because cues are diverse and changeable. Thus, cues to action have not been examined in many studies based on the HBM (Harrison, Mullen, & Green, 1992; Sheeran & Abraham, 1996). Third, this model addresses the effect of individuals' beliefs on the behaviour change, but ignores whether the individuals have the confidence or ability to implement the behaviour change, e.g. such concepts as self-efficacy and perceived behavioural control. In relation to cancer prevention, self-efficacy has been found to be one of the most significant predictors of preventive behaviour (Seydel, Taal, & Wiegman, 1990). The PMT and TPB, however,

address this construct which is discussed in the following sections. Fourth, the HBM does not provide detailed description on how the social factors such as social norms, family and friends influence an individual's behaviour.

1.8.1.2 Protection Motivation Theory and its application in breast cancer screening

PMT (Rogers, 1983) is another social cognition model that promotes behaviour change through persuasive communication, such as health warning messages (Conner & Norman, 2005; Morrison & Bennett, 2006). It has several components in common with the HBM. However, PMT emphasizes the effect of fear on behaviour change. Rogers (1983) states that fear messages stimulate two parallel appraisal processes: threat appraisal and coping appraisal. Threat appraisal consists of perceived vulnerability and perceived severity. Coping appraisal covers response efficacy, self-efficacy, and response costs. According to PMT, people's intention to adopt an adaptive response (protection motivation) or a maladaptive response (avoidance and denial) is a function of an individual's threat appraisal and coping appraisal.

Only limited studies have applied PMT to participation in mammography screening (Naito, O'Callaghan & Morrissey, 2009). Inukai and Ninomiya (2010) reported that mammography screening was predicted by self-efficacy and response costs. A relatively large number of studies have been carried out to explore the relationship between PMT variables and breast self-examination and have provided supportive evidence for PMT variables. Considering threat appraisal, perceived severity has been found to be a good predictor of intention to perform BSE (Rippetoe & Rogers, 1987; Seydel et al, 1990). The combined threat manipulation also has an effect on the intention to engage in BSE (Rippetoe & Roger, 1987). In addition, coping appraisal variables are also found to have a large effect size for BSE practice. For example, Seydel et al (1990) examined the effect of PMT variables in the prediction of cancer-related preventive behaviours and found that response efficacy and self-efficacy were the key predictors of intention toward, and the performance of, BSE practice. In

short, PMT provides a useful theoretical framework to the prediction of breast screening.

However, PMT has been criticized in that the adoption of health behaviour is not only determined by the threat appraisal and coping appraisal, but also influenced the other variables, such as normative beliefs which refer to an individual's beliefs about the levels of other people's approval of their behaviour (Stroebe, 2000). Normative beliefs have been demonstrated to be an important variable influencing women's decision on breast screening. For example, Allen, Stoddard and Sorensen (2008) examined the relationships between social network characteristics and breast screening practices and found that social norms significantly affected women's uptake of regular screening. In addition, the normative beliefs in relation to the physician, family members and close friends have an important influence on women's intention to go for the initial mammography screening (Tolma, Reininger, Ureda, & Evans, 2003). Within social cognition models only TPB explicitly addresses the subjective norm variable, which is one component of normative beliefs (Conner & Norman, 2005).

1.8.1.3 Theory of Planned Behaviour and its application in breast cancer screening

TPB (Ajzen, 1991) suggests that individuals' performance of a behaviour is mainly determined by their intention to engage in this behaviour. Intention reflects individuals' motivation to perform the behaviour. According to TPB, individuals are more likely to enact a behaviour if they have stronger intention to do it. The intention is in turn influenced by attitudes, subjective norms and perceived behavioural control (PBC). Attitudes reflect a person's beliefs and evaluations of the consequences of the behaviour. Subjective norms refer to the perceived social pressure on the performance of the behaviour. PBC means an individual's perceived ability to perform this behaviour. Ajzen (1988) proposed that it is possible to have a direct relationship between PBC and behaviour if the perceived level of control is accurate.

A number of studies have used the TPB as a theoretical framework to investigate

mammography screening. Attitude is consistently found to be a strong predictor of intention to take part in mammography screening in the majority of studies (Drossaert, Boer, & Seydel, 2003; Rutter, 2000; Steadman, Rutter, & Field, 2002; Steadman & Rutter, 2004). The subjective norm is generally considered as the weakest predictor of intention by many researchers (Godin & Kok, 1996). This view is supported by the meta-analysis of Cooke and French (2008) where subjective norm was found to have a statistically weaker correlation with intention to mammography screening than the other components. PBC was found to be a strong and independent predictor of both intention (Godin et al, 2001; Steele & Porche, 2005; Steadman & Rutter, 2004) and mammography screening (Drossaert et al, 2003; Montano & Taplin, 1991) in most studies. The strong predictor of mammography screening was found to be intention in studies either reporting actual attendance (Drossaert et al, 2003; Rutter, 2000; Steadman & Rutter, 2004; Steadman et al, 2002) or self-reported attendance (Steele & Porche, 2005). The application of TPB in breast self-examination has also been supported. Mason and White (2008) used TPB to predict breast self-examination performance among female college students and found that attitude, subjective norm, and PBC were significant predictors of the intentions to engage in breast self-examination. In addition, intention and PBC significantly predicted the performance of breast selfexamination.

As discussed above, HBM and PMT were specifically formulated in the health domain in order to understand health and illness-related issues. Both HBM and PMT assume that individuals' motivation for self-protection can be stimulated by their perceived threat of an illness, which partly reflects the anticipated severity of an illness and the perceived probability of the occurrence of this illness (Ajzen, 1998). TPB was developed in the social psychology domain and aims at understanding a variety of behaviours, including health-related and non health-related behaviours. TPB does not explicitly include threat appraisal, compared with HBM and PMT. Therefore, TPB has been criticized for not taking into account affective or arousal variables in the explanation of health-related intention or behaviour (Oliver & Berger,
1979). As in PMT, although these two theories suggest that an individual's intention can directly lead to the performance of behaviour, it has been found that individuals quite often fail to apply their intention to practice (Sheppard, Hartwick, & Warshaw, 1988).

1.8.1.4 Leventhal's Self-regulatory Model of illness behaviour and its application in breast cancer screening

The Self-regulatory Model of illness behaviour (SRMI; Leventhal et al, 1984) is also known by various terms, such as the Common-Sense Model of self-regulation, the Illness Perception Model, the Illness Representations Model, the Parallel Process Model or Leventhal's model (Hale, Treharne, & Kitas, 2007). This model provides a theoretical framework to understand the procedure of self-regulation of illness and health (McAndrew et al, 2008). According to SRMI, the illness or symptoms are dealt with by individuals through three hierarchical stages: representations, coping and appraisal (Leventhal, Diefenbach, & Leventhal, 1992). Representations refer to how individuals make sense of their illness (Leventhal et al, 1992). They then inform a coping response, which is thought to be appropriate on the basis of their cognitive and emotional representations, to cope with the health threat (Rees, Fry, Cull, & Sutton, 2004). Two broad coping actions are defined in this stage, approach coping and avoidance coping (Leventhal et al, 1992). When individuals suffer from health problems, they develop coping strategies in order to regain their healthy state. The success of a coping strategy is assessed and individuals then amend the coping plan and/or representation of the health threat according to the appraisal (Morrison & Bennett, 2006).

Illness representations are central to the SRMI (Leventhal, Meyer, & Nernz, 1980). Individuals generally develop their illness representations through personal experience, family and friends, and the media (Morrison & Bennett, 2006). The SRMI is also conceptualized as a 'parallel-processing' model in that individuals actively produce both illness cognitions and emotional representations of health threat when they receive an

internal stimulus such as pain or external stimulus such as a diagnosis (Leventhal et al, 1980). When an individual experiences a symptom or is diagnosed with an illness, the illness representations will retrieve the existing illness schemata, enabling them to understand the current situation and also guide coping plans (Petrie & Weinman, 2003). Therefore, health behaviour can be motivated as a result of cognitive as well as emotional representations (Leventhal et al, 1992; Moss-Morris et al, 2002). These findings suggest that the usage of breast screening would be predicated from the cognitive and emotional representations of breast cancer (Adachi, Kitamura, & Ueno, 2013).

The SRMI posits that the illness representations consist of five domains: identity, cause, consequences, timeline, and curability or controllability (Leventhal et al, 1997). The identity refers to the label given to the illness and its related symptoms. The cause is regarding individuals' beliefs about the aetiology of their illness. Previous research identified a variety of different causal factors on illness representations, including biological cause (such as germs; Heijmans, 1998), psychological cause (personality and mental attitudes; Moss-Morris et al, 2002), emotional cause (such as depression and stress; Moss-Morris, Petrie, & Weinman, 1996), genetic or environmental cause (such as pollution; Heijmans, 1998), or individuals' own behaviours (such as smoking; French, Senior, Weinman, & Marteau, 2001). The consequences represent the anticipated outcomes and effects of illness. Timeline refers to individuals' belief on how long the illness will last (e.g. long-term or short-term) and the course of the illness (e.g. chronic or acute). Finally, the dimension of curability or controllability refers to the extent to which individuals believe that the illness can be cured or controlled.

These five components are related with each other logically (Morrison & Bennett, 2006). A meta-analysis of SRMI reported that there is consistent strong negative relationships between curability or controllability and identity, timeline and consequences (Hagger & Orbell, 2003). The positive relationships were indicated between identity, consequences and timeline

(Hagger & Orbell, 2003). In addition, previous research also indicated that illness representations have more direct effect on illness outcomes when individuals considered that the illness outcomes can be influenced by coping strategies. The relationship between illness representations and illness outcomes has been evidenced in a wide range of behaviours, including the utilisation of medical treatment (Leventhal et al, 1992), adherence to treatment (Horne & Weinman, 2002), and engagement in self-care activities (Hampson, Glasgow, & Toobert, 1990).

With regard to mammography screening, several studies have used SRMI as the theoretical framework to predict the uptake of mammography screening. A recent Greek study used the SRMI to explore the impact of illness representations of women's mammography adoption (Anagnostopoulos, Dimitrakaki, Fitzsimmons, Potamianos, Niakas, & Tountas, 2012). In this study, women's illness perceptions of breast cancer were assessed by rating the revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al, 2002). Regarding the mammography utilization, consistent with previous research (Decruyenaere, Evers-Kiebooms, Welkenhuysen, Denayer, & Claes, 2000), the results showed that the higher level of negative emotional representations on breast cancer (e.g. feeling afraid, getting depressed when thinking about breast cancer) resulted in lower mammography screening rates. Concerning regular mammography screening, worry was proved to be a positive predictor for the uptake of repeated mammography screening. This relationship has been evidenced in the other studies (e.g. Adachi et al, 2013, Diefenbach, Miller, & Daly, 1999; McCaul, Schroeder, & Reid, 1996) and in a meta-analysis (McCaul, Branstetter, Schrpeder, Glasgow, 1996). However, the other dimensions of illness representations including consequences, timeline, cyclical timeline, treatment control, personal control, and illness coherence (the extent of how people understand their illness), did not significantly predict the usage of mammography in the Greek study (Anagnostopoulos et al, 2012).

According to SRMI, both cognitive and emotional representations direct individuals'

formulation of coping strategies (e.g. taking mammography) and influence the implementation of their plans (Anagnostopoulos et al, 2012). The non-significant correlations between illness representation dimensions and the mammography adoption might be explained by the findings from a meta-analytic review of the SRMI. Hagger and Orbell (2003) carried out a meta-analysis of 45 empirical studies in health psychology research to examine the intercorrelations between illness representations dimensions, coping strategies and health outcomes. The findings revealed that the correlations between illness representation dimensions and the coping behaviours are of low-to-moderate magnitude (Hagger & Orbell, 2003). They therefore assumed that coping behaviours may only mediate the impact of illness representations focus on illness beliefs rather than coping behaviours, which may consist of a different set of dimensions (e.g. beliefs on the efficacy of mammography) (Hagger & Orbell, 2003). The IPO-R, which was used to measure the illness representations in the Greek study, did not cover the components of coping behaviours representations (Hagger & Orbell, 2003).

The SRMI was originally developed to understand the behaviour of people with health conditions such as breast cancer, e.g. adherence to medication. Despite this SRMI has been used as a framework to study the health-related behaviours such as uptake of mammography, but some criticisms about the use of this model in this context have been raised. Firstly, this model does not describe the perceived barriers and benefits to the performance of health-related behaviours. In terms of mammogram adoption, previous research showed that barriers and benefits significantly determine individuals' decisions about the performance of breast screening (Fischera & Frank, 1994; Savage & Clarke, 1996). Secondly, the SRMI has been criticized for excluding the role of significant others such as family, friends and healthcare providers (Hale et al, 2007). As mentioned in the literature review above, family support and physician's recommendation have been identified as the common motivators that encourage Chinese women to go for breast screening (Liang et al, 2004; Su et al, 2006). By contrast, the HBM addresses the components of perceived benefits,

perceived barriers and cues to action.

Within the social cognition models, the SRMI is essentially different to the other three models in that the SRMI is more interested in beliefs about illness (Sutton, 2011) whereas the HBM, PMT and TPB are more focused on individuals' beliefs on the recommended behaviour. Hagger and Orbell (2003) suggest that compared with the theories which focus on illness beliefs, those which are focused on behavioural beliefs are more effective in the prediction of behaviour. This may explain why the majority of illness representations dimensions of the SRMI did not predict the breast screening behaviour in the recent Greek study (Anagnostopoulos et al, 2012). This is the main reason why SRMI is not an appropriate theoretical framework for this study.

1.8.2 Stage models

As discussed above, social cognition models are continuum models that identify various components that can influence behaviour. These components are combined to predict where an individual is on a continuum of behaviour likelihood (Weinstein, Rothman, & Sutton, 1998). In contrast, stage models suggest that behaviour change occurs gradually and in discrete ordered stages (Lippke & Ziegelmann, 2008; Rutter & Quine, 2002). Stage models emphasise the process that individuals go through during behaviour change. Therefore, the structures of stage models are fundamentally different from social cognition models (Weinstein et al, 1998). Stage models that are relevant to health behaviours include the Transtheoretical Model (TTM; Prochaska & DiClemente, 1984), the Precaution Adoption Process Model (PAPM; Weinstein & Sandman, 1992), and the Health Action Process Approach (HAPA; Schwarzer & Fuchs, 1996). The TTM is discussed in this section as it has relatively more evidence on its application in the field of health behaviours compared with the PAPM and HAPA (Conner & Norman, 2005; Schuz, Sniehotta, Mallach, Wiedemann, & Schwarzer, 2009).

1.8.2.1 The Transtheoretical Model and its application in breast cancer screening

TTM (Prochaska & DiClemente, 1984) postulated that behaviour change includes five stages: precontemplation, contemplation, preparation, action and maintenance. According to TTM, individuals start their behaviour change from the stage of precontemplation, where they lack awareness of health problems and also do not have the intention to change their behaviour in the next 6 months. They then move to the stage of contemplation where individuals begin to consider the behaviour change. In this stage, the awareness of problems, that may be caused by the unhealthy behaviour, and the perceived susceptibility increase. Therefore, individuals plan to change their behaviour in the stage of preparation. In spite of having a strong intention to change their behaviour in this stage, individuals may vary in their confidence in the implementation of behaviour change. In the stage of action, individuals engage in behaviour change. Finally, individuals enter into the stage of maintenance when they keep up the change over time, e.g. for more than 6 months. Although TTM assumes that individuals go through the five stages in order, it also assumes that it is common for individuals to relapse to a previous stage during this procedure (Prochaska & DiClemente, 1984). Therefore, individuals are allowed to cycle and recycle from one stage to another and finally change their behaviour successfully.

Despite the fact that there are considerable differences between the structures of stage models and social cognition models, there are also some similarities in the concepts among these models (Redding, Rossi, Rossi, Velicer, & Parochaska, 2000). Prochaska, Redding and Evers (2002) suggest that the five dependent stages of TTM are influenced by some independent variables such as the pros and cons associated with behaviour change. For example, women are more likely to be in the later stage of mammography use if they perceive more pros than cons towards mammography. In fact, the pros and cons in the TTM are conceptually the same as the perceived benefits and perceived barriers in the HBM. The components of perceived benefits and barriers have been demonstrated to be significant predictors of mammography screening. In addition, the transitions between the successive

stages are also influenced by self-efficacy which refers to confidence and temptation in the TTM (Prochaska et al, 2002). In short, stage models share some concepts with social cognition models, though the former emphasise the stages of behaviour change and the latter suggest behaviour change is a continuous process.

The TTM was initially developed to understand the process of smoking cessation and other addictive behaviour but has been applied to a broad range of health-related behaviours including breast screening (Chamot, Charvet, & Perneger, 2001; Partin, & Slater, 2003; Rakowski et al, 1992; Rakowski et al, 1996; Rakowski, Fulton, & Feldman, 1993). Spencer, Pagell and Adams (2005) reviewed the studies on the application of TTM in relation to cancer screening and reported that findings support the construct validity of the TTM in mammography screening. However, the evidence of the 'stage of change' mechanisms of the TTM is variable, as many studies in terms of systematic review and randomised controlled studies have not provided sufficient evidence for the effectiveness of TTM-based interventions either on health behaviour change or promoting the progression through 'stages of change' (Callaghan & Herzog, 2006; Herzog, Abrams, Emmons, Linnan, & Shadel, 1999; Sutton, 2001, 2005; West, 2005).

There are also some limitations in the TTM. Firstly, a meta-analysis of the application of TTM in physical activity and exercise showed that although the application was supported there was a lack of empirical evidence to support the theory that individuals at different stages differ in terms of intentions and attitudes toward behaviour change (Marshall & Biddle, 2001). Secondly, this model has limited concern regarding the effect of cultural, social, and organizational factors on behaviour (Marks, Murray, Evans, & Willig, 2000; Marshall & Biddle, 2001). It has been evidenced that cultural variables and social factors play an important role in women's attitudes towards, intention to and utilization of mammography screening (Kwok & Sullivan, 2006; 2007; Liang et al, 2008; Wang et al, 2006; Wang et al, 2008). In addition, the uptake of mammography screening cannot be completed personally, as it also depends

on the delivery of the service, interaction with healthcare providers and technology (Rakowski, Dube, & Goldstein, 1996).

1.9 Justification for using the Health Belief Model as the main theoretical framework in this study

As discussed above, social cognition models have been frequently used within health psychology research to understand the determinants of breast screening utilisation and behaviour change. The social cognition models assume that individuals' choices and behaviour are the result of analysing the benefits and costs of the possible consequences of courses of action (Conner & Norman, 2005). They incorporate, to different extents, expectancy-value theory (Peak, 1955), which suggests that individuals' behaviour is the function of their expectation and evaluations of the goal. Therefore, individuals generally prefer to choose the optimal behaviour with the combination of the highest probability of outcome and the best expected value.

The HBM refers to the perceived benefits and barriers on the performance of behaviour, which have been demonstrated to be significant predictors of mammography screening. For example, language barriers have been evidenced to be a factor related to mammography screening among Chinese women living in the US and Australia (Lee et al, 1996; Liang et al, 2004; Sadler et al, 2000; Tang et al, 2000; Yu et al, 2001; Yu et al, 1998). Understanding the benefits and barriers-related to the health behaviour helps researchers address the advantages of behaviour change and particularly target the obstacles that inhibit individuals' engagement in positive behaviours.

HBM contains cues to action, which are not included in the other models. There is evidence that receiving a recommendation from a physician has been identified as the most important cue that encourages Chinese women to go for mammography screening (Kwok et al, 2005; Liang et al, 2004; Tang et al, 2000; Tu et al, 2003; Yu et al, 2003). In addition, support from

significant others is another cue that has been shown to determine the breast screening behaviour among Chinese women (Liang et al, 2004).

In contrast to TPB and TTM, both the HBM and PMT explicitly emphasise the perceived health threat in terms of perceived susceptibility and perceived severity. Previous US and Australian studies (Kwok & Sullivan 2007; Tang et al, 2000) have reported that Chinese women are inclined to underestimate their risks of breast cancer even though breast cancer is perceived as a serious illness. Accordingly, the mammography screening rates are relatively low among the Chinese community in these countries.

Compared with TPB and PMT, HBM has ignored the link between intention and behaviour. A number of researchers have suggested adding the intention component into the HBM in order to mediate the interaction between HBM variables and behaviour (e.g. Beck et al, 1977; King, 1982; Calnan, 1984). However, in a review, Sheeran (2002) found that among the participants who had positive intentions to perform a health-related behaviour (e.g. exercise, condom use or cancer screening), 47% of them did not implement the behaviour. One reason that individuals cannot turn their intention to action is that there is a psychological intention-behaviour gap (Orbell & Sheeran, 1998). Heckhausen (1991) proposed that goal achievement occurs in two phases. First, there is a motivational phase, where individuals form a plan which includes when, where and how they will achieve their intention. Therefore, changing motivation is only the first step to changing behaviour. The performance of a behaviour requires individuals to make specific plans to bridge the gap between intention and behaviour.

As to mammography screening, the invitation letter sent by the NHS in the UK in fact already uses some methods to increase women's implementation intentions to attend mammography screening. For example, women are provided with a scheduled time and the breast screening unit that they would go for the screening. In addition, the invitation letter also offers

the contact information of the screening unit for those who need to change their appointment time or request facilities if they have special needs. Rutter, Steadman and Quine (2006) compared the differences in mammography screening between planners and non-planners and found that women who completed one of the following plans to mammography screening were more likely to attend mammography screening than those who did not plan: changing the appointment time, arranging travel to the screening unit, and planning time off work. This suggests that having the intention to go for breast screening may not be sufficient to initiate the behaviour, but forming a plan can significantly promote mammography screening. Therefore, it is essential for this study to explore the cues that would facilitate Chinese women converting any intention to attend mammography screening into practice.

The HBM, PTM, SRMI and TPB differ in the level of content specificity. The HBM, PTM, and SRMI are considered to be content-specific models as they provide detailed information about factors which are related to health behaviour or illness representations. In contrast, the TPB is one of the content-free models because TPB only has three constructs and also does not define any specific content. The content of the included constructs is filled during the process of using this theory to understand a specific behaviour (Ajzen, 1998). Therefore, the HBM, PMT and SRMI provide a stricter guideline towards the understanding of the performance of health-related behaviour, compared with the TPB. However, TPB can be applied to predict or understand a wider range of behaviours than HBM, PMT and SRMI, as it is relatively lacking in structure (Nejad, Wertheim, & Greenwood, 2005).

Previous research showed strong support for the application of HBM to the understanding of breast screening behaviour (Fischera & Frank, 1994; Savage & Clarke, 1996). Sanderson (2004) suggested that HBM is the best framework to understand infrequent health-related behaviour, such as mammography screening while other models (e.g. PMT, TPB and TTM) are considered to be more predictive in frequent behaviour, such as smoking cessation and alcohol abuse. Therefore, the HBM was chosen as the theoretical framework to understand

the psychological factors related to breast cancer prevention and early detection among Chinese women living in the UK.

1.10 Other factors that contribute to the understanding of breast screening among Chinese women

Despite the impressive evidence for using HBM to predict health-related behaviour, factors other than those included in HBM were also shown to be important in understanding breast screening behaviours. The HBM model focuses on the individual and takes limited account of the effect of social and economic environment on behaviour. Along with mammography screening, especially in the countries where women have to pay for the screening (e.g. USA), the literature review suggests that financial barriers are one reason why women do not go for mammography screening (Lee-Lin et al, 2008). In addition, the uptake of mammography is also influenced by social norms. Previous studies have revealed that women were more likely to go for mammography screening if they perceived that mammography screening is normative among their friends (Allen, Stoddard, & Sorensen, 2008; Kratzke, Garzon, Lombard, & Karlowicz, 2010). According to the literature review, breast cancer is a sensitive topic in Chinese culture, so that Chinese women are reluctant to talk about breasts and show their breasts to others (Gany et al, 2006; Kwok et al, 2005). It could be assumed that the low screening rates among Chinese women may be attributed to the low social acceptability. Therefore, it is important to take into account the social influence when exploring the factors related to breast screening among Chinese women.

Knowledge about breast screening also emerged as a significant predictor. Adachi et al (2013) found that information seeking about mammography was the most significant predictor for the first time uptake of mammography among 412 middle-aged Japanese women. Moreover, women with more knowledge about the frequency of mammograms reported better adherence to breast screening. Women who considered that mammogram interval is longer than 1 year reported lower odds of the utilisation of repeat mammography

(Anagnostopoulos et al, 2012). Similar findings regarding the relationship between knowledge about the mammogram interval and the frequency of taking repeat mammography were also found in the study carried out by Russell et al. (2006).

Past behaviour has been identified to be a powerful predictor of future mammography screening (Sutton, 1996). It was found that women who had gone for the initial mammography screening became more positive to the repeat screening compared with those women who had never had a mammography screening (Drossaert, Boer, & Seydel, 2001; Mayne & Earp, 2003). However, it cannot be ignored that the pain and embarrassment caused by mammography screening have been reported as barriers to repeat screening by some Chinese women in the literature. Therefore, the impact of experience of breast cancer detection should be explored.

HBM does not take into account the role of emotion in decision-making (Henshaw & Freedman-Doan, 2009; Sutton, 2001). The SRMI has made a great contribution to explain the effect of emotional representations on behaviour change. The relationship between these two constructs has been supported in breast screening research (Anagnostopoulos et al, 2012; Decruyenaere et al, 2000). The previous research also indicated that there is a link between family history of breast cancer and recent mammography screening. This might be explained by women with a family history are more worried about breast cancer and thus more likely to participate in breast screening than those women without a family history. Therefore, the emotional representations should be taken into consideration when carrying out research to explore the factors related to breast screening and designing the intervention programme.

On the basis of comparison of the theoretical models-inspired research on breast screening, this thesis used the HBM in combination with the psycho-social factors identified in the previous studies among Chinese women living in Western countries to understand the breast

health and breast cancer prevention among Chinese women in the UK, and thus provide the empirical findings for the development of an educational and motivational intervention to improve breast health and screening among Chinese women. In addition, the HBM was developed and empirically tested among the Western population, only a few studies (e.g. Maxwell et al, 2011; Wang et al, 2008) have applied this model into Chinese population who have different cultural beliefs and medical seeking behaviours than their Western counterparts. In the current study, once the psycho-social factors related to breast screening had been generated, the HBM variables were related to the findings in order to examine whether this model could explain the mechanism of breast screening usage among Chinese women living in the UK.

1.11 Research questions and aims

The previous research has revealed that despite breast cancer being the most common cancer among Chinese women in the UK and the promotion of the NHS Breast Screening Programme, Chinese women are less likely to take part in breast screening, and therefore benefit less from early diagnosis and treatment, than white British women.

The low attendance at mammography screening has also been observed among Chinese women living in other Western countries. The literature review of the psycho-social factors related to the uptake of mammography screening among Chinese women living in Western countries has shown that low attendance rates are associated with perceived costs of screening, a lack of knowledge about cancer, symptoms and risk factors, negative beliefs and attitudes towards cancer and screening behaviour, lower acculturation (the extent to which women are integrated into the local culture), Eastern views of care and a lack of linguistically and culturally appropriate services (Wang et al, 2006; Yu et al, 2001).

As mentioned above, the data on mammography screening practice among Chinese-British women were obtained in the early days of the NHS Breast Screening Programme, so it is necessary to carry out a study to explore the uptake of mammography screening among Chinese community nowadays. On the basis of findings in relation to the low utilization of health services among Chinese-British people (Rochelle & Marks, 2011) and the low uptake of mammography screening among women in BME groups (Breast Cancer Care, 2005), it is assumed that Chinese-British women may still be reluctant to attend mammography screening. In order to improve the participation in breast screening, it is important to understand factors related to mammographic decisions among Chinese-British women, and thus design and implement effective services for them. However, no studies have been specifically carried out to explore the beliefs about breast health and mammography screening among Chinese women in the UK, where mammography screening is routinely available to women aged between 50 to 70 years old through the NHS. This thesis therefore aimed to explore the mammography screening practice and the psycho-social factors related to breast health and breast cancer prevention among older Chinese women aged 50 to 70.

Although breast cancer is less common among young women than among women over 50 years old, it is still identified as the most common cancer among women younger than 35 years old (Cancer Research UK, 2009). Previous studies have indicated that breast cancer in young women is more likely to be diagnosed at a later stage compared with older counterparts (Winchester, Osteen, & Menck, 1996). In addition, young women with breast cancer have a higher recurrence rate and inferior five year survival than older women (Colleoni et al, 2002; El Saghir et al, 2006). Therefore, there is a significant need to promote breast cancer awareness among younger women aged less than 35 years old in order to reduce the breast cancer mortality among this population. The second aim of this study was to gain a comprehensive understanding of the psycho-social factors related to breast health and breast cancer prevention among younger Chinese women living in the UK. It is assumed that younger British-born Chinese women may have different beliefs and knowledge of, and preventive behaviour for breast cancer when compared with older Chinese-British women, because the younger generation may have higher acculturation and fewer language barriers

than the older generation.

In addition, the younger generation also includes Chinese students who came to the UK for study and the new migrants who chose to work in the UK after they had completed their studies. These women are mainly from mainland China where the healthcare services are a fee-for-service based system (Eggleston, Li, Meng, Lindelow, & Wagstaff, 2008), which is different from the healthcare services free at the point of care in the UK. Therefore, these young women are predicted to have different beliefs about and attitudes to breast health and breast cancer prevention than younger British-born Chinese women not only because of the different extent of acculturation but also to the different healthcare systems that they had experienced in the past.

The overall aim of this thesis was to understand the psycho-social factors related to breast health and breast screening among Chinese women living in the UK, and thus develop an intervention to improve the breast health and the adherence to mammography screening among the older Chinese-British women. To achieve this aim, the project used a mixed methods approach and consisted of three studies. The evidence from these three studies then informed the development of educational and motivational interventions within the Intervention Mapping framework (Bartholomew, Parcel, Kok, & Gottlieb, 2006).

As a first step in the development of the breast screening intervention, it is essential to conduct a systematic review to acknowledge the research relevant to breast cancer prevention and screening among Chinese women and to identify reliable evidence for the current study. The specific aim of the first study was to review and evaluate previous interventions that aimed to increase breast screening among Chinese women living in Western countries. The objectives were:

1) To carry out a systematic review of interventions to promote breast health and/or breast screening among Chinese women or minority ethnic groups including Chinese

women in Western countries in the Europe, America and Oceania.

- 2) To review the effectiveness of different types of interventions.
- 3) To compare and contrast the effectiveness of these interventions and determine which intervention format would be effective in enabling Chinese women to increase their breast health-related knowledge and breast screening.

The next step was to collect the empirical evidence for the development of effective intervention strategies to increase breast screening in the Chinese community. The specific aim of second study was to use focus groups, informed by health psychology models, to explore the psycho-social factors related to breast cancer prevention and screening among older Chinese women (aged between 50 and 70). The objectives were:

- To develop an in-depth understanding of older Chinese-British women's knowledge and beliefs about breast cancer, experience of taking mammography, barriers to mammography, and motivating factors related to the uptake of mammography.
- To explore educational modality and format preferences for breast screening interventions.

Similarly, the specific aim of the third study was to use focus groups to investigate the factors related to breast cancer prevention and screening among younger Chinese women aged between 20 and 35. The objectives were:

- To gain an understanding of knowledge and beliefs about breast cancer, experience of breast cancer prevention and early detection, and factors related to breast awareness among a small number of younger Chinese-British women and large number of younger Chinese women living in UK.
- 2) To explore educational modality and format preferences for interventions.

The aim of the final part of the project was to use Intervention Mapping to design a culturally tailored educational intervention to improve breast screening among older Chinese women in

the UK. The objectives were:

- 1) To integrate the findings from the focus groups among older Chinese women with the evidence from the systematic review of interventions to increase uptake of mammography screening in Chinese women living in other Western countries and the factors related to mammography screening suggested by the literature. This would result in a synthesis of the evidence and provide the basis for the design of the intervention.
- 2) To apply theory-based methods to the intervention.
- 3) To design a health psychology theory-based, culturally-tailored educational intervention to increase breast cancer-related knowledge and participation in mammography screening among older Chinese-British women.
- To consult the service users and healthcare providers regarding the intervention programme components.

Chapter 2 Methodology

2.1 Introduction

This chapter provides detailed information about the methodology which guided the research in this thesis. Within this chapter, the application of Intervention Mapping to plan a culturally and linguistically tailored intervention to promote breast health and breast screening among older Chinese-British women is illustrated. A number of research paradigms are discussed and the justification for the use of Pragmatism is provided. An explanation of the mixed methods approach that was used throughout this research is given, which included a systematic review, qualitative studies, and the development of breast screening intervention.

2.2 Research strategy

To fulfil the aim of this study, Intervention Mapping was chosen as the framework for the development of this intervention. Intervention Mapping is a systematic approach to developing evidence and theory-driven health promotion interventions (Bartholomew et al, 2006) and has been widely used in the development of health promotion programmes including asthma management (Bartholomew et al, 2000), risk-taking among adolescents (Tortolero et al, 2005), nutrition (Cullen, Bartholomew, Parcel, & Kok, 1998), HIV prevention (van Empelen, Kok, Schaalma, & Bartholomew, 2003), sun protection (Tripp, Herrmann, Parcel, Chamberlain, & Gritz, 2000), colorectal cancer screening (Vernon, 2004), and cervical cancer screening (Hou, Fernandez, & Parcel, 2004).

Intervention Mapping specifies six fundamental steps in intervention development:

- 1) carrying out the assessment of the health problem and its related factors;
- 2) developing matrices of intervention objectives;
- 3) selecting theory-based intervention methods and practical strategies;
- 4) applying the methods and strategies into the development and organisation of the

programme;

- 5) delivering the programme;
- 6) forming a programme evaluation plan.

(The processes are illustrated in Figure 2.1)



Figure 2.1 Intervention Mapping (adapted from Bartholomew et al, 2006, p. 16)

Intervention Mapping is a tool to help researchers to design and implement health promotion programmes rather than a theoretical model (Kok, Schaalma, Ruiter, van Empelen, & Brug, 2004). Intervention developers are assumed to go through the steps in order, but they may go back or move forward between steps (Bartholomew et al, 2006). Therefore, the process is considered to be iterative rather than linear (Bartholomew et al, 2006). In addition, the process of planning is cumulative in that each step is developed on the basis of previous steps, so that developers need to pay attention at each step in order to ensure their decision on each step is optimally rigorous, and thus to maximise the effectiveness of the intervention (Bartholomew et al, 2006; Kok et al, 2004).

2.3 Research Paradigm

In order to organise this study successfully, it was crucial to acknowledge the underlying paradigm which guided the way in which the research was undertaken (Hiles, 2014). Guba and Lincoln (1994, p. 107) defined a paradigm as "a set of basic beliefs (or metaphysics) that deals with ultimates or first principles". They stressed that "paradigms ... are not open to proof in any conventional sense" (p. 108). Therefore, a paradigm is suggested to be a worldview about the nature of reality or assumptions about the world made by a community of researchers with shared beliefs (Deshpande, 1983; Jacob, 1989; Hinshaw, 1996). Guba and Lincoln (1994) divided the paradigm into three components: ontology, epistemology, and methodology. Ontology refers to an assumption about "the nature of reality" (p. 107). Epistemology is about "the nature of the relationship between the knower or would-be knower and what can be known" (p. 107). Epistemology concerns the ways to obtain knowledge (Bryman, 2001) and how to ensure that the knowledge is valid and legitimate (Maynard, 1994). Finally, methodology is defined as "how can the inquirer (would-be knower) goes about finding out whatever he or she believes can be known?" (Guba & Lincoln, 1994, p. 107). This refers to the methods that are used to collect and analyze data (Cohen, Manion, & Morrison, 2001). The concept of the paradigm therefore directs researchers' understanding of the nature of truth and also influences the ways that the phenomenon is investigated

(Weaver & Olson, 2006; Morgan, 2007). Two common research paradigms have been identified within the social sciences field, namely positivism and interpretivism (Roth & Mehta, 2002).

2.3.1 Positivism

Positivism uses the natural sciences as a model and assumes that the social world can be studied by using methods to explore the natural world (Kura, 2012). Positivists believe in the existence of objective reality which can be systematically investigated through empirical observation (Guba & Lincoln, 1994). Positivists posit that social behaviour is driven by the cause-effect laws rather than occurring randomly (Guba & Lincoln, 1994; May 1997). According to the positivist epistemology, the researcher is assumed to be isolated from the investigated phenomenon and the study should be 'value-free' (Kura, 2012, p. 5). Research directed within the paradigm of positivism therefore is a 'systematic and methodological process' (Koch & Harrington, 1998, p. 884) with the key features of 'rationality, objectivity, prediction and control' (Streubert & Carpenter, 1999, p. 7). The aim of positivists in the social sciences is to establish a hypothesis and then explain the causal relationship between social and psychological phenomena through using structured quantitative approaches (Shankman, 1984a; Lin, 1998). A deductive or theory-test approach is commonly employed to collect the numerical data which are then in turn analyzed by using statistical analyses to explain phenomenon (Cater, 2000a; Jack & Clark, 1998). According to positivism, analyses should be repeatable and testable across different contexts (Roth & Mehta, 2002).

However, it has been questioned whether the positivist paradigm is completely appropriate for social sciences (Hirscheim, 1985) as it fails to realize that the world consists of disorganised units which have their unique characteristics and only can be understood through interactions (Kura, 2012). As mentioned above, positivism focuses on the causal relationships and tries to generalize findings to a larger population through objective facts (Tien, 2009). It has limitations in the prediction of human behaviours which are dynamic and

complex (Kura, 2012) and influenced by many factors, such as emotions, motivations or cultural influences (Johnson & Duberley, 2000). Therefore, positivism has weaknesses in understanding human behaviour in-depth (Crossan, 2003). Lincoln and Guba (1994) suggest that the demerits of positivism could be minimized with the use of some descriptive methods, such as are used in interpretivist methodology.

2.3.2 Interpretivism

In contrast, interpretivism is dependent on a relativist ontology which assumes that reality is perceived through subjective interpretations and social constructions (Carson, Gilmore, Gronhaug, & Perry, 2001; Hudson & Ozanne, 1988). Interpretivists, therefore, disagree with the positivist view that the social world can only be understood through the cause-effect laws (Johnson, 1987). They claim that human behaviours should be explored by "capturing the actual meanings and interpretations that actors subjectively ascribed to phenomena in order to describe and explain behaviour" (Johnson, Buehring, Cassell, & Symon, 2006, p. 132). This implies that human behaviour only can be understood within the context where it occurs (Parahoo, 2006). Interpretivists, therefore, endeavour to enter into individuals' realities, use appropriate ways to understand and interpret their perceptions and behaviours, and view the research problem through a holistic lens (Hoepfl, 1997; Shaw, 1999). Interpretivists use research methods such as in-depth interviewing to investigate human behaviours within the real-life context. It requires that researchers work rather close to participants and are inside the research to understand how and why things happens (Denzin & Lincoln, 2000). In contrast with positivism, interpretivism is associated with an inductive approach that theory is defined on the basis of the observations of phenomena (Weaver & Olson, 2006).

With the goal of the paradigm of interpretivism being to interpret social meanings of phenomena which are influenced by values and cultural beliefs (Roth & Mehta 2002), thus it is useful to gain insight of individuals' experiences on using healthcare services (Foss & Ellefsen, 2002; Kingdon, 2004). Despite its popularity, interpretivism is criticized for the

difficulties in tests of reliability, validity and how to make generalisations within social research (Kura, 2012; Polit & Beck, 2010).

2.3.3 The justification for the use of pragmatism

Pragmatism has emerged as an alternative to the competing debate between positivism and interpretivism in social sciences (Wicks & Freeman, 1998). Pragmatists are less concerned with the issues of reality or truth associated with the paradigm wars, but focus on finding out 'what works' in solving research problems (Creswell & Plano Clark, 2007; Rorty, 1999). This implies firstly that the research questions and consequences of the research are more important than the methods used (Creswell & Plano Clark, 2007; Miller, 2006). Secondly, the problems to be researched determine which types of method is suitable for the research (Tashakkori & Toddlie, 2003b). As a consequence, pragmatism assumes that researchers are free to select the most appropriate tools to meet their research aims and do not have to be restricted to a particular method or type of data (Creswell & Plano Clark, 2007; Creswell, 2009).

Pragmatism is considered as the main paradigm underpinning the mixed methods approach. Jick (1979) argued that using multiple methods to study the same phenomenon can help researchers to develop an enriched understanding of the phenomenon and also improve the quality of the study. For example, within mixed methods research, the researcher can collect both qualitative and quantitative data on the same research question. The comparison of the findings generated from different methods enables the researcher to appreciate the similarities in findings and thus assess whether the research topics have been accurately assessed (Frost & Bowen, 2011). On the other hand, the use of mixed methods allows the researcher to integrate valuable data, which may be neglected in a single research does not include 'unwanted noise' in the data analysis, such as participants' comments scribbled on a questionnaire (Feilzer, 2010). The pragmatist approach therefore provides the

researcher with multiple perspectives on research phenomena which are multi-faceted (Howitt, 2010). The advantages of using a pragmatist approach has been acknowledged in the area of educational, social, and health-related research (Glogowska, 2011).

For this thesis, as stated in Chapter One, the aim was to explore the psychological and social factors related to breast health and breast cancer screening among Chinese women in the UK and then to develop an evidence-based educational intervention to promote breast health and mammography screening among older Chinese-British women. According to pragmatism, an individual's experience is influenced by social, cultural and historical factors rather than any antecedent or underlying causes (Creswell, 2009). This could be the reason why Western health education may not work effectively with minority ethnic groups as the biomedical information presented does not take these factors into account, leading people from minority ethnic groups to feel that the information does not relate to them. In order to organize this study logically, the researcher was required to understand how Chinese women take care of their breast health, to realize the effect of Chinese culture on Chinese women's preventive behaviours, and to gain knowledge on the motivators and barriers to breast screening among Chinese women. Once the information had been generated, this empirical evidence could be integrated with the pre-existing findings in the literature to form the design for the mammogram intervention. Within the paradigm of pragmatism, the researcher has flexibility to select the methods best suited to the research topics and achieve the objectives of this study.

2.4 Research methods

2.4.1 Mixed methods approach for step one of Intervention Mapping

Hiles (2014) has proposed a model of Disciplined Inquiry (Figure 2.2) which suggests that all research consists of five phases of inquiry: paradigm, strategy, method, analysis, and critical evaluation. An important distinction of this model is the recognition of the notion of strategies of inquiry, which provide vital links between research paradigms and methods of data

collection and analysis. According to Disciplined Inquiry, strategies of inquiry direct the researcher's decision on what types of methods will be used to answer the research questions rather than the researcher's personal preference or historical tradition (Hiles, 2014). Therefore, research questions have been given the priority in the list of strategies. In the case of developing a theoretical and empirical evidence-based educational intervention to promote breast screening among Chinese community, it was considered that relying solely on either qualitative or quantitative approach would not sufficiently realize the psycho-social factors related to breast screening and the mechanism of behaviour change. Therefore, a mixed methods approach was used in the design of this project in order to provide the best understanding of research questions.



Figure 2.2 A model of Disciplined Inquiry (adapted from Hiles, 2014, p. 51)

This research included a systematic review of interventions aimed at increasing breast health and mammography screening among Chinese women in Western countries, and qualitative research of psycho-social factors related to breast health and breast screening behaviour among Chinese women living in the UK. The results of this research firstly fulfilled the needs assessment (step 1) of Intervention Mapping, and then fed into steps two, three and four of the Intervention Mapping process, facilitating the development of the breast screening intervention. These methods were considered to be sufficiently flexible to answer the research objectives of each study and finally develop the theory- and evidence-based intervention.

2.4.2 Systematic review

A systematic review of interventions aimed at increasing breast health and mammography screening among Chinese women in Western countries was undertaken. Chalmers (2003) suggested that when professionals intervene in people's lives, they may do more harm than good. Therefore, it is essential to review the existing relevant research in order to reduce the chances of creating adverse effects. A systematic review of research is defined as "a review of research literature using systematic and explicit, accountable methods" (Gough, Oliver, & Thomas, 2012, p. 5). The purpose of a systematic review is to identify the relevant research to specific research questions, evaluate individual studies in a systematic manner and synthesise the findings of all studies, thus providing reliable research evidence for decision-makers (Centre for Reviews and Dissemination, 2008). As the current research aimed to develop an intervention to promote breast health and breast screening among older Chinese-British women, it is critically important to carry out a systematic review to compare and contrast the effectiveness of different types of interventions, thereby providing a guide for the selection of the most defensible intervention method for this research.

In relation to Intervention Mapping, this systematic review formed part of the first step of needs assessment process. Despite the target population being Chinese-British women in current research, it is still worth understanding the breast screening needs and determinants of breast screening among Chinese women living in the other Western countries who share the same culture and language background with Chinese-British women and are also influenced by Western culture. The evidenced factors that might encourage or prohibit Chinese women taking mammogram screening, which are generated from the systematic review, guided the design of the mammogram screening intervention.

During systematic review, the effectiveness and feasibility of various theoretical models and practical strategies of relevant studies were also assessed. There is increasing advocating of integrating theoretical approaches into the design of interventions that focus on behaviour change (Michie, Johnston, Francis, Hardeman, & Eccles, 2008). Theories generally present a causal relationship between determinants and behaviour, so theory-based interventions can ensure that interventions target the causal determinants of behaviour and behaviour changes. thus increasing the effectiveness of interventions (Michie et al, 2008; Michie & Prestwich, 2010). Second, theory-based interventions can offer a good understanding of why interventions are successful or not and of the mechanisms of behaviour change (Jemmott & Jemmott, 2000, Michie & Abraham 2004, Michie et al, 2008). The third step of Intervention Mapping is to identify the theoretically based intervention methods that are considered to be effective on changing breast screening related determinants and also to select the practical strategies that will apply the intervention method into practice. The information gathered from the systematic review helped the researcher to decide whether the intervention programme and/or practical strategies could be replicated in the current population. In addition, the systematic review also pointed out the limitations of the relevant studies and thus highlighted the need of adding additional theories and new strategies that may help to improve the mammogram screening behaviour in the current population.

In summary the systematic review informed Intervention Mapping and its findings guided the design and implantation of breast screening-related educational intervention targeted at Chinese-British women.

2.4.3 Focus groups

Understanding the psycho-social factors related to breast cancer prevention and detection among Chinese women was crucial to successfully design a tailored intervention in this study. Qualitative research methods were considered appropriate in this study to explore how Chinese women make sense of breast cancer and how they experience breast cancer prevention. According to Smith (2003, p. 1), "qualitative analysis is concerned with describing the constituent properties of an entity". Qualitative researchers are interested in obtaining detailed and rich descriptive data of the phenomenon being studied through exploration. Qualitative methods have been widely used in psychology to explore, describe and interpret participants' personal lives and social experiences (Smith, 2003). Participants are investigated in natural settings, where conditions continuously develop and interact with each other to produce a process of ongoing change. This process is determined by participants' and researchers' interpretations of events. Therefore, qualitative researchers tend to understand why and how people make decisions in certain situations rather than just what, where and when. Rossman and Rallis (1998, p. 9) listed four characteristics of qualitative research: it (a) 'takes place in the natural world', (b) 'uses multiple methods that are interactive and humanistic', (c) 'is emergent rather than tightly prefigured', and (d) 'is fundamentally interpretive'.

There are some distinct differences between qualitative and quantitative research approaches. First, they differ in terms of research orientation. Qualitative research tries to explore phenomena through investigation whereas quantitative research seeks to test hypotheses about phenomena (Smith, 2006). Moreover, they differ in terms of data analysis. Quantitative research needs to transform the phenomenon into numerical values so that statistical analyses can be carried out. However, qualitative research collects data from naturalistic verbal reports, such as interview transcripts or written accounts, and analyses the data within textural contexts (Smith, 2006). Therefore, qualitative research tends to focus on interpreting the phenomenon whereas quantitative research tends to focus on exploring the measurable properties of it.

A key difference between quantitative and qualitative methods is their flexibility (Manson, 2006). Compared with qualitative research, quantitative research is less flexible because it generally uses highly structured methods such as questionnaire surveys or experimental

designs to investigate numerical properties, phenomena and their relationships (Crossan, 2003); research hypotheses originating from the researchers and existing theory determine the questions to be asked and the responses allowed to be given (Smith, 2006). Participants are generally asked to rate the scales or choose their responses from closed or fixed categories. The study design of quantitative research is stable in that participants' responses do not affect or determine the following questions that researcher asks and how they ask it.

In contrast, qualitative research captures the individual's perspective and their individuality (Howitt, 2010). Here researchers prefer to use relatively unstructured methods such as focus groups and in-depth interviews to investigate the perspective of individuals (Smith, 2006). Therefore, the interaction between the researcher and participant has more spontaneity and adaptation to the participants' responses in gualitative studies when compared with quantitative studies (Howitt, 2010). Participants are generally asked open-ended questions and are encouraged to express their own views on research questions. In addition, the social relationship between researcher and participant in qualitative research is closer than in quantitative research. Participants have the opportunity to share their stories and points of views rather than simply choosing one of the fixed answers in quantitative research. In turn, researchers can adjust the questions which will be asked next according to participants' responses. Researchers are seen to be insiders in qualitative research whereas they are tend to be the outsiders in the quantitative research (Denzin & Lincoln, 2000). Therefore, it was decided that qualitative methods of data collection, specifically focus groups, should be employed to gain detailed and deep information regarding Chinese-British women's personal beliefs about breast cancer and their own experience of breast cancer prevention.

Focus groups are one method for qualitative data collection and have been much used in health education, health promotion and general health research (Shaw, Wallace, & Bansal, 2003; Shaw, Wallace, Cook, & Phillips, 2004). On the basis of various definitions, Gibbs (1997) summarised four key features of a focus group: 1) organised discussion (Kitzinger,

1994), 2) collective activity (Powell, Single, & Lloyd, 1996), 3) social events (Goss & Leinbach, 1996), and 4) interaction (Kitzinger, 1995). According to Morgan (1997), focus groups rely on "interaction within the group based on topics that are supplied by the researcher" (p. 12). This suggests that the crucial feature of focus groups is the interaction between participants, which is also the most distinct difference between focus groups and individual interviews.

Focus groups are suggested to be very effective in exploring sensitive topics (Kitzinger, 2000; Wilkison, 2004) and to get in-depth information about perceptions and behaviours (Howitt, 2010). As breast cancer has been shown to be a sensitive topic among Chinese women (Gany, Herrera, Avallone, & Changrani, 2006; Kwok, Cant, & Sullivan, 2005; Kwok & Sullivan, 2006), focus groups were considered to be more suitable than individual interviews in the current study. Focus groups enable the researcher to collect data from more naturalistic processes of communication between group participants, which includes "storytelling, joking, arguing, boasting, teasing, persuasion, challenge, and disagreement" (Wilkinson, 2006, p. 185). The interaction offers the opportunities for participants to "discuss, debate and (sometimes) disagree about key issues" (Wilkinson, 2006, p. 185). In focus groups, the interviewer is a 'moderator' whose role is to explain the purpose of the focus groups, introduce participants to each other, ensure participants feel free to express their views and facilitate the interaction between participants rather than asking questions of single individuals in turn (Wilkinson, 2006). Therefore focus groups may generate the deeper and richer data on research topics than individual interviews. The group dynamics may enable Chinese women feel more comfortable talking breast cancer and generate deeper and richer data on research topics compared with individual interviews.

The interaction allows participants to discuss the topics which are important to them rather than the topics that the researcher is interested in. This is particularly important when the researcher is not a member of the specific population being researched e.g. they may be from a different gender, ethnic, or age group. In this case, compared with individual interviews, the data generated by focus groups may have higher "ecological validity" (Willig, 2008, p. 31), which refers to how well the behaviours observed in a study can reflect the behaviours in real life. In addition, the interaction between participants enables the discussion to be more meaningful and culturally salient to them than individual interviews. Consequently, focus groups provide a different level of data gathering and a variety of perspectives on the research issues from that provided by the individual interviews (Fontana & Frey, 1994). Goss and Leinbach (1996, p. 115) state that

"group discussion itself provides valuable insight into social relations and that the "stories" produced in the collaborative performance of a focus group better reflect the social nature of knowledge than a summation of individual narratives extracted in interviews."

Finally, focus groups use relatively fewer resources for collecting rich data, as each group usually consists of 4 to 8 participants (Wilkinson, 2006). Focus groups can generate important insights into the research topics from a small sample size in a relatively short time (Howitt, 2010). It was believed that focus groups should produce richer data than individual interviews on Chinese women's beliefs and knowledge related to breast cancer and their preventive behaviours.

2.4.3.1 Generation of focus group schedules

It is important to clarify the strategy that was used to set up the focus group questions to ensure that these questions were developed logically and participants were allowed to express a variety of viewpoints on breast screening. This section discusses the logic of inquiry that lay at the heart of the development of the focus group schedule.

Hiles (2014) put forward a model of logic of inquiry to specify the relation between theory and data (Figure 2.3) and distinguished three types of relationships: theory-driven, data-driven, and explanation-driven. The theory-driven logic is positioned in relation to "deductive inference" which refers to predicting data (findings) from theory. In contrast, the data-driven

logic is associated with "inductive inference" which is concerned with using data to systematically generate theory. These two approaches are quite commonly used in quantitative and qualitative research, respectively. The explanation-driven logic is related to "abductive inference" which goes from the generation of data on a phenomenon to a hypothesis that provides the best explanation for the data (Josephson & Josephson, 1994). Abduction is also called "inference to the best explanation" (Harman, 1965) and "the explanatory inference" (Lycan, 1988) by philosophers. The explanation-driven approach focuses on testing the degree to which the theory and data could match each other on providing explanations for findings (Hiles, 2014), and it is different from the deductive approach and inductive approach in terms of the role of theory. In studies using explanationdriven approaches, the theory is not being used alone to predict the findings but also not generated solely from the data (Hiles, 2014). Different theories can be used in the theorydriven approach to explain the data that is observed from a phenomenon (Hiles, 2014). In the current study, the explanation-driven logic was chosen as the guideline for development of focus group questions and data analysis as it was believed that this approach could provide the best explanation on Chinese women's breast screening behaviour.



Figure 2.3 The relation between theory and data, and the logic of inquiry (adapted from Hiles, 2014, p. 55)

2.4.3.2 Advantages of using a Chinese researcher

In research among minority ethnic groups, the benefits of matching ethnicities between researchers and communities are stressed repeatedly in previous studies (Blauner & Wellman, 1973; Stanfield & Routledge, 1993). The concept of 'race-of-interviewer-effects' (RIE) has been used to refer to 'response bias' and 'measurement error' meaning that participants are likely to edit their opinions and attitudes in ways that would be expected to be positive in the researcher's ethnic group (Gunaratnam, 2003). A previous literature review indicated that RIE are more like to occur when survey items relate to attitudes, to sociodemographic characteristics or participants' engagement in sensitive behaviours (Davis, Couper, Janz, Caldwell & Resnicow, 2010). However, it was found that the RIE had no effect on the majority of non-racial items in previous studies (Johnson & Parsons, 1994; Webster, 1996; Zimmerman, Caldwell & Bernat, 2002). These results regarding the effects of RIE are consistent with Rhodes' (1994) statement that racial differences between the researcher and participants have a substantial impact on the 'genuineness' and 'accuracy' of how participants respond to research questions, particularly in race-related topics.

Although ethnicity and race are often substituted in psychology research, there are some differences between these two terms. The traditional definition of race relates to "physical features, gene pools, and character qualities" (Spickard, 1992, p. 14). Nowadays, race is a social construct and refers to a group of people who share a common heritage (Helms, 1993). Racial identity is more likely to be used as a frame to divide people into different racial groups especially according to their skin colours (Chavez, Guido-Dibrito, & Mallory, 1996). Therefore, the racial identity focuses on an individual's physical characteristics. In contrast, ethnicity refers to cultural factors such as language, traditions, values and beliefs (Ott, 1989). Ethnic identity is used to categorise people into different ethnic groups on the basis of sharing similar cultural characteristics.

Breast cancer is a sensitive topic in the Chinese community, not only because cancer is a

private subject, but also because women feel embarrassed when talking about breasts and exposing breasts to others (Gany et al, 2006; Kwok et al, 2005). The literature review indicated that the adoption of breast screening among Chinese women is influenced by Chinese culture and health beliefs. The researcher of this study was a Chinese woman from mainland China who speaks Mandarin. Although the researcher cannot speak fluent Cantonese, she was able to understand Cantonese. The majority of the Cantonese speaking participants in this study stated that they had no difficulties in understanding Mandarin as it is the official language in mainland China and Hong Kong. A bilingual interpreter was also employed in this study to translate the researcher's questions into Cantonese. Sharing the same ethnicity and gender between the researcher and participants may allow participants to feel more comfortable talking about their beliefs and experience with breast cancer prevention and screening. Additionally, using a Chinese researcher can eliminate the language barrier, as the majority of elderly Chinese cannot speak fluent English. Participants may also express some beliefs and elements of the Chinese culture, which are not easy to express in English. Therefore, sharing the same cultural background and language between researcher and participants can definitely facilitate focus groups and also help the researcher to get rich and deep information from participants.

2.4.3.3 Data analysis – Inductive and deductive thematic analysis

Thematic analysis was chosen to analyse the data from the focus groups and to explore the factors related to breast cancer prevention among Chinese women. According to Braun & Clarke (2006, p. 79), "thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data". Thematic analysis not only can organize and describe data in detail, but also can interpret various aspects of the research topic (Boyatzis, 1998). Thematic analysis was considered as the appropriate method of analysis in the current study because of the flexibility of this method in analysing qualitative data. Compared with other qualitative methods such as discourse analysis or conversation analysis, thematic analysis is not related to any theory. As a consequence, thematic analysis is applicable in a wide range of

theoretical frameworks (Braun & Clarke, 2006). Thematic analysis can be used with different paradigms, including essentialist or realist method, constructionist method and contextualist method, according to the research purpose. Therefore, thematic analysis was hoped to be flexible enough to explore the psycho-social factors related to breast cancer prevention among older and younger Chinese women as it is a method to identify a number of themes which are important to the description of the phenomenon (Daly, Kellehear, & Gliksman, 1997).

According to Braun & Clarke (2006), thematic analysis can be carried out in two different ways: an inductive way (bottom up) (Frith & Gleeson, 2004) or a deductive way (top down) (Boyatzis, 1998; Hayes, 1997). The inductive thematic analysis approach is suggested as a data-driven approach (Braun & Clarke, 2006) and is similar in concept to the inductive logic of enquiry (Hiles, 2014), as the codings and themes are primarily driven by the participants' discussion on research topics rather than the researchers' theoretical preference (Braun & Clarke, 2006). Therefore, using inductive analysis to identify themes can ensure the findings emerge from participants' data themselves (Patton, 1990). With regard to previous studies that aimed at understanding breast screening behaviours, the majority of them used a datadriven inductive approach (e.g. Im, Park, Lee, & Yuan, 2004; Smyth, 2009). In contrast, deductive thematic analysis is guided by the theoretical background to topics or research areas (Hayes, 1997). The process of coding data, which is similar in concept to the deductive logic of enquiry (Hiles, 2014), aims to fit the data into a pre-existing coding frame or the researcher's analytic interest in this area (Braun & Clarke, 2006). As a result, themes, which are identified by deductive thematic analysis, are more likely to be those which have been expected from theoretical aspects.

As this thesis used a pragmatic, mixed design approach to answer research questions and achieve research aims, a hybrid approach combining both inductive approach and deductive approach was considered to be the most suitable and effective way to understand the
psycho-social factors related to breast cancer prevention and screening among Chinese women. Using the combined inductive and deductive analysis method is also consistent with abductive logic of enquiry which underpinned the generation of focus group questions.

Braun and Clarke (2006) suggest that inductive thematic analysis is an extremely useful way for exploring under-researched topics, or understanding participants' views towards research topics which are unknown. Therefore, the inductive thematic analysis was firstly applied to focus group data in order to understand older Chinese women's experiences of breast cancer prevention and screening. During the process of inductive thematic analysis, themes are 'emerging' or being 'discovered' from the data (Braun & Clarke, 2006). It is undoubtedly the case that the development of the breast screening intervention required a strong empirical evidence base. However, if the intervention is informed solely by the accumulation of the empirical evidence, it might target inappropriate variables or only focus on a few of the variables (Green, 2000). Therefore, it is important to use theory to assess whether all the key determinants of the behaviour change are addressed in the intervention (Green, 2000). In addition, the theory enables the researcher to understand what works and why it works by illustrating a process map regarding the causal relationship between necessary variables and behaviour change (Pingree, Hawkins, Baker, duBenske, Roberts, & Gustafson, 2010). Therefore, the deductive thematic analysis was carried out to connect the themes identified by the inductive thematic analysis with the HBM concepts. It was believed that the combined inductive and deductive thematic analysis would provide valuable empirical and theoretical foundations for the development of the breast screening intervention.

The data analysis was carried out based on the stages of thematic analysis as described by Braun and Clarke (2006) with one extra step (step 6) added.

1. Data familiarization

The transcripts were read several times in an "active way", in order to get familiar with the data. Meanings and patterns in the data were noted down during this phase.

2. Initial coding generation

The interesting meanings and patterns throughout the entire data set were located into different meaningful groups, and thus generated the initial codes which refer to "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998, p. 63).

3. Searching for themes

The codes were formed into the potential themes by thinking about the links between codes, between themes and between different levels of themes. The extracted data related to each code were collated as well.

4. Review of themes

Review of themes includes two levels. During level one, the coded extracts were read again and considered to see if they were examples of the themes. Some extracts, which do not fit the theme, were combined together to form a new theme or discarded from the analysis. Once the themes were adequate to present the contours of the coded extract, a 'thematic map' was created. At the second level, the themes and thematic maps were evaluated in relation to the data set to ensure that they could adequately and accurately reflect the whole data set. Additional data, which may support the themes or form a new code but had been missed in previous stage, were coded at this level.

5. Themes definition and labelling

In this stage, it is important to define and refine the themes and also determine the characteristics of the data that each theme reflects. A detailed analysis for each theme was carried out and written down, including writing a narrative to describe each theme taking into account its relationship with the research topic. This stage also involved the identification of subthemes, which can provide clear structure for the large and complex themes. In this study, the themes and sub-themes were discussed with supervisor and were given names.

6. Corroborating coded themes

This stage presents the process of using the HBM to interpret the identified themes. Corroborating is defined as "the process of confirming the findings" (Crabtree & Miller, 1999,

p. 170). In this stage, therefore, the identified themes were examined to determine their fit with HBM on providing explanations of findings.

7. Report writing

Report writing includes the final analysis and writing up the report. Sufficient data extracts were arranged into brief, attractive and logical stories to illustrate the essence of themes and also to raise the argument in relation to the research topic and the concepts of HBM.

2.4.3.4 Ensuring quality

Despite the many strengths of qualitative methods as noted above, qualitative research has been criticised for a lack of 'scientific rigour' (Plummer-D'Amato, 2008). The frequent criticisms of qualitative methods are concentrated on the reliability, validity and generalizability (Plummer-D'Amato, 2008). However, many researchers have argued that the criteria of reliability and validity that apply to quantitative research are not suitable for the qualitative methods (Sandelowski, 1986; Nyamathi & Shuler, 1990; Leininger, 1994; Holloway & Wheeler, 1996; Yardley, 2008).

Most quantitative research aims to test the causal relationship regarding phenomena and also hope that the causal relationship remains relatively consistent over time and can be replicated into different contexts (Joppe, 2000). However, qualitative researchers are interested in exploring individuals' reactions in different contexts and individuals' differences (Yardley, 2008). For example, people may give different descriptions of the severity of pain that they suffer when they are asked by different people, such as employer, family member or doctor (Yardley, 2008). This suggests that people may produce different responses to the same topic in different contexts in the real world. As a result, the criteria of reliability do not fit most of the qualitative studies.

Additionally, generalizability is a major criterion for assessing the quality of quantitative research (Kerlinger & Lee, 2000; Polit & Beck, 2010). Quantitative researchers try to apply

their observations from a sample to a broader population by conducting research among a randomly selected representative sample (Yardley, 2008). The issue of generalizability, however, is less explicit in qualitative research (Payne & Williams, 2005). Most qualitative studies aim to explore the subtle interactive processes within different contexts rather than making generalizations of their findings (Yardley, 2008). Therefore, qualitative researchers are more interested in carrying out intensive studies among a small number of particularly selected cases (Pilot & Beck, 2010). Although it is very difficult to replicate the qualitative findings in any other context or broader population, the rich and detailed findings that are gained from a particular context can provide very useful information for the studies that are carried out in another similar context. Yardley (2008, p. 238) suggests that "since contexts can share some features even if others are quite dissimilar, generalizability in qualitative research is potentially wide-ranging and flexible".

Lincoln and Guba (1985) put forward the concept of trustworthiness for assessing qualitative research and also suggest that trustworthiness can be evaluated from four standards: dependability, credibility, transferability and confirmability. Other procedures for enhancing the quality of qualitative research include triangulation (Flick, 1992), comparing researchers' coding (Boyatzis, 1998), participants' feedback (Silverman, 1993), disconfirming case analysis (Creswell, 1998; Pope & Mays, 1995) and an 'audit trail' (Flick, 1998). These procedures are quite flexible and can be used in a wide range of qualitative methodologies (Yardley, 2008). However, these procedures have their limitations in increasing the validity of qualitative research as they only can be used as the principles for enhancing the quality of qualitative data analysis (see Barbour, 2001).

Yardley (2008) offers a broad framework for evaluating the quality of qualitative research. This framework consists of four core principles: sensitivity to context, commitment and rigour, transparency and coherence and impact and importance. This framework makes a great contribution on how to carry out and justify qualitative research as it outlines numerous ways

to establish each principle and different studies can achieve the core principles in different ways (Smith, 2008). One should be aware that Yardley also points out that it is difficult for a study to meet all the criteria in practice. The key features of the four principles are listed in Table 2.1.

Table 2.1 Yardley's framework for assessing the validity of qualitative psychology (Adapted from Yardley, 2008, p. 243-244)



Yardley's framework (2008) was used as the guideline for judging the quality of current study and is presented in Chapter Eight.

2.4.4 The development of breast screening intervention for steps two, three and four of Intervention Mapping

At the final stage, the information gathered from the systematic review, focus groups and the literature review was synthesised to develop the culturally and linguistically tailored breast screening intervention by using Intervention Mapping.

The systematic review and the literature review about the factors related to mammography

screening among Chinese women in Western countries (Section 1.7) provided the possible factors that are related to Chinese women's perception of breast health and screening behaviour. The focus group themes generated by the inductive thematic analysis provided insight from Chinese-British women's perceptions of health, and their personal and environmental factors that relate to breast cancer screening and the determinants that can reinforce and prohibit these factors. The empirical evidence provided the needs assessment of Intervention Mapping and also helped to define the goals of this breast cancer screening intervention (See Figure 2.1).

Despite the empirical findings being extremely helpful for the development of interventions, it is suggested that the participants and communities will receive more benefits when the health promotion intervention is designed on the basis of health psychology theories of behaviour and behaviour change (Connor & Norman, 1996; Glanz, Lewis, & Rimer, 1997; Michie & Abraham, 2003; Norman, Abraham, & Connor, 2000). Therefore, a broad review of theories that can be used to provide a better understanding of breast screening was carried out. Firstly, the researcher reviewed the theoretical frameworks that have been used for the development of breast health and breast screening interventions among Chinese women living in Western countries through the systematic review. Secondly, the deductive thematic analysis was carried out to link the theoretical constructs of HBM with the themes that were generated from inductive thematic analysis. Finally, the possible theories of behaviour change techniques that may help to explain and promote the breast health and breast screening were also considered.

By integrating the empirical data and the theoretical evidence, the personal and external factors related to breast health and breast cancer prevention among Chinese women were identified as the first step of needs assessment of Intervention Mapping (see Figure 2.1). In step 2, the objectives of this breast screening intervention were set up through defining what needs to be changed at both individual and environmental levels for the modification of

determinants. In the next step (Step 3), the theoretical and empirical findings were reviewed again in order to select the appropriate theory-based intervention methods and strategies to address the determinants of behaviour change. In step 4, the breast screening intervention was designed and organized on the basis of the theory and evidence produced in needs assessment (Step 1) and the ideas about methods and strategies generated in step 3, in order to achieve the objectives in Step 2.

To ensure the intervention was tailored to the target population, in step 4, two further focus groups were carried out to obtain older Chinese-British women's opinions on the educational and motivational materials that were involved in this intervention and obtain suggestions on the implementation of this intervention. In addition, consultations with Breast Screening service providers were conducted to gain the provider perspective and to determine whether the intervention could be implemented in this step (Step 4). The fifth step of Intervention Mapping is to consider and plan the adoption and implementation of the breast screening intervention. The focus on last step is to formulate an evaluation plan which is guided by the activities and products developed from Intervention, but also exams the process and delivery of this intervention. This project aimed to complete up to Step 4 as Step 5 and 6 were beyond the scope of this PhD level project.

2.5 Summary

The aim of this chapter was to describe the methodology of this thesis. This chapter described the outline of using Intervention Mapping to develop a theory and data based educational and motivational intervention to promote breast health and breast screening among Chinese women living in the UK. A mixed methods approach was chosen for data collection, analysis and synthesis of findings in this thesis based on the stepwise model of Intervention Mapping.

Chapter 3 Interventions to increase breast screening among Chinese women living in Western countries: a systematic review

3.1 Introduction

As discussed in Chapter One, although breast cancer is a common cancer among Chinese women living in Western countries, there is evidence that Chinese women are less likely to attend mammography screening which is the most effective way to detect breast cancer at an early stage. Several interventions have been carried out in order to improve breast health and screening behaviour among Chinese women in Western countries (Atri, Falshaw, Gregg, Robson, Omar, & Dixon, 1997; Hiatt, Pasick, Stewart, Bloom, Davis, Gardiner & Luce, 2008). To the researcher's awareness, no systematic reviews have been conducted to assess the effectiveness of these interventions. Therefore, the objective of this chapter was to conduct a systematic review to assess the interventions that have been carried out to improve breast health and screening behaviour among Chinese women in Western countries and also evaluate the effect of different types of interventions on Chinese women's breast cancerrelated knowledge, beliefs, intentions, and/or screening behaviour, and thus to determine which intervention format may be effective in enabling Chinese women to make informed choices. It was believed that the results of this systematic review could be used as a guideline for the design and implementation of breast screening-related educational interventions targeted at Chinese-British women in the future.

3.2 Methods

3.2.1 Search strategy

A number of sources were used to search the literature from January 1985 to August 2011. These were: PsycARTICLES, PubMed, Sciencedirect, Taylor and Francis, Ingenta, SwetsWise, and Web of Knowledge. The searches used terms referring to breast screening (e.g., breast screening, mammogram, breast self-examination, clinic breast examination, breast cancer preventive behaviour) combined with terms describing Chinese women in Western countries (e.g., Chinese-American women, Chinese-British women, Chinese-Canadian women, Chinese-Australian women, Chinese women, minority ethnic groups, Asian women, underserved women, non-attenders) (see Appendix 1 for the full search strategy). In addition, the relevant citations in articles were also retrieved, in order to make sure the relevant studies were also included in this review. Searches of the internet were carried out using Google Scholar to find grey literature.

3.2.2 Selection criteria

Interventions: Any studies, including quantitative studies, qualitative studies and mixed methods studies, that use interventions to promote breast cancer-related knowledge, beliefs, intentions, and/or breast screening among Chinese women without breast cancer living in Western countries were included in this review. In addition, studies that included Chinese women and also reported the changes in terms of breast cancer-related knowledge, beliefs, intentions, and/or breast screening in Chinese women were included in this review. Studies that assessed the effectiveness of interventions by comparing differences before and after intervention within the same group of participants or between control and intervention groups were all included in this review, as limited studies were expected to be have been carried out in this area.

Outcome measures: Screening rates were used as the primary measurement to evaluate the success of interventions, but studies measuring changes in breast cancer screening related-knowledge, beliefs and intentions were also included.

Exclusion criteria: Studies that just reported Chinese women's knowledge of, and attitudes and intentions towards breast screening, without the use of the intervention being described, were excluded. This review also excluded studies that did not clearly specify the proportion of Chinese women in an overall targeted population. Studies that did not report the effectiveness of the intervention on Chinese women's breast cancer-related knowledge,

beliefs, intentions to breast screening and screening behaviours were also excluded. In addition, this review excluded studies that reported changes among Asian women/minority ethnic groups, but did not specify changes among Chinese women. Studies that only reported the baseline findings were also excluded. This systematic review excluded articles that were not published in English (Please refer to Table 3.1 for the inclusion/exclusion criteria).

| | Inclusion | Exclusion |
|-----------------------------|---|--|
| Study population | Chinese women without breast cancer living in Western countries | Chinese women living in the outside of Western countries. Chinese women with breast cancer |
| Participants information | Providing specific demographic information on Chinese participants | Treating women from minority ethnic groups as a whole and not providing demographic information for each ethnic group. |
| Purpose of intervention | Primarily for increasing the breast screening. Secondary for increasing breast cancer-related knowledge, beliefs and intentions | Studies did not measure the improvement on either breast screening or breast cancer- related knowledge, beliefs and intentions |
| Study design | Between or within group comparison | No comparison made |
| Method | Quantitative, qualitative, or mixed methodology | No |
| Results | Reporting the changes for Chinese women | Not reporting the changes for Chinese women. Only reported the baseline findings. |
| Research | Original journal articles | Epidemiological articles, reviews and book chapters |
| Language | English | Other than English |

Table 3.1 Inclusion/exclusion criteria of journal article selection for systematic review

3.2.3 Data extraction

Initially, the titles and abstracts were reviewed according to the eligibility criteria to identify any studies reporting the effect of interventions on breast cancer-related knowledge, beliefs, intentions, and/or breast screening. Those which did not concur with this aim were excluded. When the titles and abstracts did not provide sufficient information to ascertain whether they were relevant, the full-text was retrieved and an in-depth evaluation was carried out.

A data extraction form was developed following the guidelines for data extraction by the Centre for Review and Dissemination (2009) (Appendix 2). Data were extracted into the data extraction form and then checked by the supervisor in order to ensure the data were detailed and accurate. The data extraction form covered five aspects.

- General information about article: authors, article title, year and country.
- Study characteristics: aim, design, study inclusion and exclusion criteria, recruitment and setting.
- Participants: age, ethnicity, number of participants.
- Intervention and setting: The number of intervention groups, details of intervention and control, and theoretical framework of intervention.
- Outcomes: the time points that data were collected, the ways outcomes were obtained and outcomes at each time point
- Results: number of participants in the intervention groups and control group, withdrawals and lost to follow-up, summary outcome data, type of analysis and results of study analysis.

3.2.4 Quality assessment

The quality checklist of Downs and Black (1998) was used to assess the quality of each included study as this checklist has been developed for the assessment of both randomised and non-randomised studies of health care interventions. Downs & Black's checklist evaluates studies on 27 items from 5 aspects: reporting, external validity, bias, confounding and statistical power. The maximum quality score of this checklist is 32, with 0-1 for 25 items, 0-2 for 1 item, and 0-5 for 1 item (Appendix 3). The score was marked for each study and then was checked by the supervisor. Meta-analysis was planned to be carried out if there were suitable studies retrieved. Otherwise, narrative analysis would be performed to

generate a synthesis of findings of included studies.

3.3 Results

3.3.1 Description of studies

Results of the search

Nine hundred and forty-three potentially relevant published papers were primarily generated according to the search strategy. Once titles and abstracts had been assessed, 30 full published papers were retrieved for detailed examination. Twenty-two papers were excluded after detailed evaluation (information on these is given in Appendix 4). Upon completion of the review, eight studies which met the criteria for inclusion were included in this systematic review. The process of the literature search is shown in Figure 3.1.



Figure 3.1 Flowchart for the process of study inclusion in the systematic review

Population and setting

The characteristics of the eight included studies are shown in Table 3.2. Six studies were carried out in the US and the other two studies were in the UK and Australia. Four studies recruited participants from a general population (Kwok, Koo, D'Abrew, White, & Roydhouse, 2011; Sadler et al, 2000; Sun, Zhang, Tsoh, Wong-Kim, & Chow, 2007; Tu, Taplin, Barlow, & Boyko, 1999), the other four studies targeted women who were non-attenders or non-

adherent to the national mammography screening programmes in the UK and US (Atri et al, 1997; Hiatt et al, 2008; Wang et al, 2008; Maxwell, Wang, Young, Crespi, Mistry, Sudan, & Bastani, 2011).

Five studies targeted Chinese women (Kwok et al, 2011; Maxwell et al, 2011; Sadler et al, 2000; Sun et al, 2007; Wang et al, 2008). The remaining studies also included women from other ethnic groups (Atri et al, 1997; Tu et al, 1999; Hiatt et al, 2008). The number of Chinese women involved in the included studies varied from 26 to 710, with half the studies having fewer than 60 Chinese participants. As concerns the age of participants, only three studies (Kwok et al, 2011; Sadler et al, 2000; Sun et al, 2007) included women below 40 years old, the remaining studies were conducted among women aged 40 or above.

Table 3.2 Characteristics of included studies in systematic review

| Trial location | Design | Population & Eligibility criteria (E) | Setting | Number of participants | Age (years) | Recruitment rate | Intervention type | Theoretical framework |
|--|--------------------------------|--|---|------------------------|------------------------------------|--|---|--------------------------|
| Atri, 1997, London, UK | Cluster randomised study | Subjects: general multiethnic population E: women registered in a breast screening centre who failed to attend | 26 inner city general practices | 2064 (Chinese=26) | 50-64 | 70.27% for selected general practices which agreed | Person- directed intervention | No |
| Kwok, 2011; Sydney, Australia | Before-and- after study | Subjects: Chinese- Australian women E: Cantonese- speaking women, ≥ 18 years old, no breast cancer history, and could read Chinese | Chinese organization | 37 | 23-64 (M=49, SD=8.68) | 74% | Social network directed intervention | No |
| Hiatt, 2008; San Francisco Bay Area, US | Cluster randomised trial | Subjects: underserved & low-income African American, Chinese, Hispanic and white women, 40-75 years old | 8 low-income neighborhoods and 8 public health clinics | 1616 (Chinese=288) | ≥ 40 (60% participants ≥ 50) | Not stated | Multi-strategy intervention | No |
| Maxwell, 2011, Los Angeles County, U.S. | Before-and- after study | Subjects: Chinese American who have not had a MAM within 2 years and have not scheduled a MAM in the following 6 months | Churches, Chinese community-based organizations and private homes | 101 | ≥40 (M=57, SD=10.3) | Half (the exact number not stated) | Multi-strategy interventions | Health belief model |
| Sadler, 2000; US | Before-and- after study | Subjects: Chinese- American women | 19 Asian grocery stores | 302 | 20 – 84 (M=41.46) | Around 75% | Social network directed intervention | No |

| Trial location and dates | Design | Population & Eligibility criteria (E) | Setting | Number of participants recruited | Age (years) | Recruitment rate | Intervention type | Theoretical framework |
|--|-----------------------------|---|-----------------------|--|--------------------------------|------------------|---|--------------------------|
| Sun, 2007; San Francisco, US | Case- control study | Subjects: general Chinese women | Chinese community | 710 | 19 -91 (M=48.4, SD=10.9) | 75% | Social network directed intervention | No |
| Tu, 1999; US | Prospective cohort study | Asian-American women and non-Asian women E: ≥ 40 years old, enrolled with breast cancer screening programme (BCSP), no breast cancer history | Health care system | 3352 (Chinese=495) | ≥ 40 | N/A | System- directed intervention | No |
| Wang, 2008; Metro D.C. area, US | Before-and- after study | Subjects: Chinese American who were non-adherent to the National Cancer Institute's mammography guidelines, E: age ≥40 and non- adherent to the National Cancer Institute screening mammography guidelines. | Chinese community | 52 | 41-75 (M=58, SD=10.19) | 57.78% | Multi-strategy intervention | Health belief model |

Note: N/A = not applicable

Types of interventions

Interventions were allocated into one of the following five types: person directed intervention, system directed intervention, social network directed intervention, mass media directed intervention, and multi-strategy intervention. These five types have been used in previous reviews to describe interventions (Legler, Meissner, Coyne, Breen, Chollette, & Rimer, 2002; Rimer, 1994). The results showed that one study was a person directed intervention, one was a system directed intervention, two were social network directed, one was a mass media directed intervention, and three interventions were in the multi-strategy study category.

Outcomes

Four studies (Kwok et al, 2011; Maxwell et al, 2011; Sun et al, 2007; Wang et al, 2008) measured the outcome on breast screening-related knowledge and three studies (Kwok et al, 2011; Maxwell et al, 2011; Wang et al, 2008) reported on breast cancer-related beliefs. Four studies (Kwok et al, 2011; Maxwell et al, 2011; Sadler et al, 2000; Wang et al, 2008) reported on intention to undergo mammography screening and six studies (Atri et al, 1997; Tu et al, 1999; Kwok et al, 2011; Sun et al, 2007; Hiatt et al, 2008, Maxwell et al, 2011) measured breast screening, including breast self-examination, clinical breast examination and mammography screening.

3.3.2 Study quality

In Downs and Black's (1998) initial validation work, the mean quality score was 14 and 11.7 for randomised studies and non-randomised studies respectively, on the basis of 20 papers. Therefore, the acceptable quality was defined as having a score that is equal or higher than 14 for randomised studies and 12 for non-randomised studies in this systematic review. Table 3.3 presents the performance of included studies on each assessment item and their total score. It can be seen that the score for the two cluster randomised studies was 23 and 18 respectively, and for the non-randomised studies varied from 16 to 20 (mean score = 17.67), reflecting a high methodological quality for the included studies.

Table 3.3 Downs & Black's checklist for measuring included study quality (Down & Black, 1998)

| Included studies | Atri, 1997 | Tu, 1999 | Sadler, | Sun, | Kwok, | Hiatt, | Wang, 2008 | Maxwel, |
|--|---------------|-------------|---------|------|-------|--------|---------------|---------|
| Checklist | 1337 | 1333 | 2000 | 2007 | 2011 | 2000 | 2000 | 2011 |
| 1. Is the hypothesis/aim/objective of the study clearly described? | Y | Y | Y | Y | Y | Y | Y | Y |
| 2. Are the main outcomes to be measured clearly described in the | Y | Y | Y | Y | Y | Y | Y | Y |
| Introduction or Methods section | | | | | | | | |
| 3. Are the characteristics of the patients included in the study clearly | Y | Y | Ν | Y | Y | Ν | Y | Y |
| described? | | | | | | | | |
| 4. Are the interventions of interest clearly described? | Υ | Υ | Y | Υ | Y | Υ | Y | Y |
| 5. Are the distributions of principal confounders in each group of subjects to | Y | Y | Y | Y | Y | Ν | Y | Y |
| be compared clearly described? | | | | | | | | |
| 6. Are the main findings of the study clearly described? | Υ | Y | Y | Y | Υ | Y | Y | Y |
| 7. Does the study provide estimates of the random variability in the data for the main outcomes? | Y | Y | Y | Y | Y | Y | Y | Y |
| 8. Have All important adverse events that may be a consequence of the | Ν | Ν | Ν | Ν | Ν | Ν | Ν | Ν |
| intervention been reported? | | | | | | | | |
| 9. Have the characteristics of patients lost to follow-up been described? | Υ | Ν | Y | N/A | Y | Ν | Y | Y |
| 10. Have actual value probability values been reported (e.g. 0.035 rather | Y | Y | N | Y | N | Y | Y | Y |
| than <0.05) for the main outcomes except where the probability value is less | | | | | | | | |
| than 0.001? | | | | | | | | |
| External validity | | | | | | | | |
| 11. Were the subjects asked to participate in the study representative of the | Y | U | U | U | U | Y | U | U |
| entire population from which they were recruited? | | | | | | | | |
| 12. Were those subjects who were prepared to participate representative of | U | U | U | U | U | U | U | U |
| the entire population from which they were recruited? | | | | | | | | |
| 13. Were the staff places, and facilities where the patients were treated, | Y | Y | N/A | N/A | N/A | Y | N/A | N/A |
| representative of the treatment the majority of patients receive? | | | | | | | | |
| Internal validity – bias | | | | | | | | |
| 14. Was an attempt made to blind study subjects to the intervention they | U | Ν | N | Ν | N | N | N | N |
| have received? | | | | | | | | |
| 15. Was an attempt made to blind those measuring the main outcomes of the | U | N | N | N | N | N | N | N |
| intervention? | | | | | | | | |
| 16. If any of the results of the study were based on "data dredging", was this made clear? | Y | Y | Y | Y | Y | Y | Y | Y |

| Included studies | Atri, | Tu, | Sadler, | Sun, | Kwok, | Hiatt, | Wang, | Maxwel, |
|---|---|---|---------|---|-------|--------|-------|-------------------|
| Checklist | 1997 | 1999 | 2000 | 2007 | 2011 | 2008 | 2008 | 2011 |
| 17. In trials and cohort studies, do the analyses adjust for different lengths of | Y | Y | Y | Y | Y | Y | Y | Υ |
| follow-up of patients, or in care-control studies, is the time period between | | | | | | | | |
| the intervention and outcome the same for cases and controls? | | | | | | | | |
| 18. Were the statistical tests used to assess the main outcomes appropriate? | Y | Y | Y | Y | Y | Y | Y | Y |
| 19. Was compliance with the intervention/s reliable? | Y | Y | Y | Y | Y | Y | Y | Y |
| 20. Were the main outcome measures used accurate (valid and reliable)? | Y | U | Y | Y | Y | Υ | Y | Y |
| Internal validity – confounding (selection bias) | | | | | | | | |
| 21. Were the patients in different intervention groups (trials and cohort | Y | Ν | Y | Y | Y | Y | Y | Y |
| studies) or were the cases and controls (case-control studies) recruited from | | | | | | | | |
| the same population? | | | | | | | | |
| 22. Were study subjects in different intervention groups (trials and cohort | Y | Ν | Y | Y | Y | Y | Y | Y |
| studies) or were the cases and controls (case-control studies) recruited over | | | | | | | | |
| the same period of time? | | | | | | | | |
| 23. Were study subjects randomised to intervention groups? | Y | Ν | N | Ν | N | Y | Ν | N |
| 24. Was the randomised intervention assignment concealed from both | U | N/A | N/A | N/A | N/A | Ν | N/A | N/A |
| patients and health care staff until recruitment was complete and | | | | | | | | |
| irrevocable? | | | | | | | | |
| 25. Was there adequate adjustment for confounding in the analyses from | Y | Y | N | Y | N | Y | Y | Y |
| which the main findings were drawn? | | | | | | | | |
| 26. Were losses of patients to follow-up taken into account? | Y | Ν | Y | N/A | Y | Ν | Y | Y |
| Power | | | | | | | | |
| 27. Did the study have sufficient power to detect a clinically important effect | <n1< td=""><td><n1< td=""><td>N</td><td><n1< td=""><td>N</td><td>Ν</td><td>N</td><td><n1< td=""></n1<></td></n1<></td></n1<></td></n1<> | <n1< td=""><td>N</td><td><n1< td=""><td>N</td><td>Ν</td><td>N</td><td><n1< td=""></n1<></td></n1<></td></n1<> | N | <n1< td=""><td>N</td><td>Ν</td><td>N</td><td><n1< td=""></n1<></td></n1<> | N | Ν | N | <n1< td=""></n1<> |
| where the probability value for a difference being due to chance is less than | | | | | | | | |
| 5% | | | | | | | | |
| Total score | 23 | 16 | 16 | 18 | 17 | 18 | 19 | 20 |

Note: Y = yes, N = no, U = unable to determine, N/A = not applicable;

The maximum quality score of this checklist is 32, with 0-1 for item1-4 and 6-26, 0-2 for item 5, and 0-5 for item 27.

Intervention design

Two studies (Atri et al, 1997; Hiatt et al, 2008) measured the effect of intervention by using cluster randomised trial which is a type of randomised controlled trial in which clusters of people are randomly allocated to intervention groups or control groups rather than individuals. Four (Kwok et al, 2011; Maxwell et al, 2011; Sadler et al, 2000; Wang et al, 2008) were before-and-after studies that compare the differences among the single group of participants before and after the intervention. One (Tu et al, 1999) was a prospective cohort study that followed a cohort of participants over time and compared the outcomes between those who did receive an intervention and those who did not. In a prospective cohort study, participants are recruited before any intervention. One (Sun et al, 2007) was case-control study that aimed at finding out the relationship between outcome and prior exposure to the intervention by comparing a specific outcome of interest between participants who had or had not been exposed to the intervention.

Selection bias

As far as selection bias was concerned, participants in the two cluster randomised trials (Atri et al, 1997; Hiatt et al, 2008) were very likely to be representative of the target population. Participants in three before-and-after studies (Kwok et al, 2011; Sadler et al, 2000; Wang et al, 2008) and the case-control study (Sun et al, 2007) were considered to be somewhat likely to represent the targeted Chinese women as they were recruited through the local Chinese community. Although the health care system based prospective study (Tu et al, 1999) reported that they included all the Asian women and randomly selected non-Asian women as controls, it should be noted that participants were identified as Asian women or non-Asian women according to their surname rather than their ethnicity due to the lack of information. This recruitment method might lead to misclassification, thus participants in this study might not be representative. The other two before-and-after studies (Maxwell et al, 2011; Sadler et al, 2000;) were not likely to be representative though they were carried out among Chinese community, because participants in the Asian grocery store based intervention were

shoppers (Sadler et al, 2000) and in the other intervention were a selected sample of volunteers (Maxwell et al, 2011).

Four studies clearly reported the proportion of selected individuals who agreed to participate in the study, including three before-and-after studies (Kwok et al, 2011; Sadler et al, 2000; Wang et al, 2008) and the case control study (Sun et al, 2007). Among the four studies, except one before-and-after study (Wang et al, 2008) that reported a relative low participation rate (57.78%), the percentage of agreement was quite similar in the other three studies, around 74-75%. Another before-and-after study (Maxwell et al, 2011), that asked trained lay health educators to recruit and carry out breast health educational sessions among Chinese women, only reported that half of the targeted women took part in the educational sessions without providing an exact number. Among the two cluster randomised trials, only one (Atri et al, 1997) reported the proportion of targeted practice clinics which agreed to participate in the study, with a 70% participation. It was considered that the proportion of agreement was not applicable to the prospective cohort study (Tu et al, 1999).

Randomisation and concealment

This systematic review only included two randomised trials (Atri et al, 1997; Hiatt et al, 2008). One study (Atri et al, 1997) was randomised by general practices, and the other one was randomised by neighbourhoods and clinics (Hiatt et al, 2008). However, the latter was not completely random as two clinics were unable to reach the requirements of being the intervention condition. Neither of the two studies clearly reported whether both participants and outcome assessors were unaware of the randomised intervention assignment during the recruitment.

Blinding

None of these studies clearly stated whether they tried to mask participants, healthcare providers, or outcome assessors.

Adjustment of confounders

Among the six non-randomised studies, the prospective study (Tu et al, 1999) reported the adjusted results after taking into account the confounders (age group, enrolment with Breast Cancer Screening Program (BCSP) for at least 1 year, years of enrolment with Group Health Cooperative of Puget Sound (GHC), study year, BCSP risk level, first-degree relative with breast cancer, previous biopsy and prior mammogram). In addition, two before-and-after studies (Maxwell et al, 2011; Wang et al, 2008) and the case-control study (Sun et al, 2007) tested the effects of main confounders, such as age, education level.

Withdrawals and drop-outs

Five studies reported withdrawals and drop-outs. One cluster randomised trial (Atri et al, 1997), aimed at increasing the mammography screening among non-attenders, reported that 78 of the 995 participants (8%) in the intervention groups dropped out or were not eligible for the intervention after randomisation due to moving out of the practice areas, dying, going abroad or being away, and having had a mammogram recently. Therefore, the study analysis was carried out on the basis of intention to treat (Atri et al, 1997). One before-and-after study that (Wang et al, 2008) used a culturally tailored video to promote breast screening among Chinese women reported that 6 of the 52 participants (12%) were lost to follow-up because of getting ill (n=1), being away from home (n=2), telephone disconnection (n=2), or failure to contact (n=1). The Asian grocery store based educational intervention (Sadler et al, 2000) included 302 Chinese women at the baseline, 99 (33%) participants failed to attend the follow-up assessment and most of them were lost to follow up (n=82), 15 participants withdrew from this study, and 2 participants did not reply though contact details were left. The culturally tailored training programme with lay health advisors (Kwok et al, 2011) reported high dropout rates in that nearly half of the participants (n=18, 49%) did not attend the followup assessment. The reasons included being abroad (n=3), having conflict with the assessment time (n=10), or being unable to take time off from childcare (n=5). The peer-led educational video intervention to increase breast screening among Chinese women (Maxwell,

et al, 2011) reported a good follow-up as all participants completed both the baseline and follow-up investigation (Table 3.4).

3.3.3 Effects of interventions

The included eight studies were allocated into five intervention types: person directed, system directed, social network directed, mass media directed and multi-strategy. Each intervention type was assessed from its effectiveness on the uptake of breast screening, breast cancer-related knowledge, beliefs and intentions towards breast screening (Table 3.4).

In this review, six studies tested the effect of interventions on Chinese women's breast screening and three of them (Kwok et al, 2011; Maxwell et al, 2011; Sun et al, 2007) increased the uptake of breast screening. Four studies assessed the effect of intervention on breast health-related knowledge and all showed significant effects on it (Kwok et al, 2011; Maxwell et al, 2011; Sun et al, 2007; Wang et al, 2008). Three studies tested the effect of intervention on breast cancer-related beliefs and all showed improvement on it (Kwok et al, 2011; Maxwell et al, 2011; Wang et al, 2008). Four studies assessed the effect of intervention on intentions towards breast screening and all reported significant improvements (Kwok et al, 2011; Maxwell et al, 2011; Sadler et al, 2000; Wang et al, 2008).

3.3.3.1 Person directed interventions

Person directed interventions refer to interventions that aim to promote the mammography screening among women who are non-adherent, non-attenders, or underserved. Only one cluster randomised trial by general practice fell into this category.

Atri et al. (1997) assessed whether the uptake of mammography screening among the nonattenders could be improved when they were contacted by the trained general practice reception staff through telephone or letter. This study involved participants from multiethnic groups, including white (31%), Indian (17%), black (14%), Pakistani (10%), Bangladeshi (6%), Chinese (1%), other ethnic groups (4%), and non-reported ethnic group (16%). There were 995 women in the intervention practices (14 Chinese), with 1069 women in the control practices (12 Chinese). This study was carried out in inner city of London, UK.

Breast screening

It was found that the proportion of women who presented for mammography screening was significantly higher in the intervention practices than in the control practice (9% vs 4%, p=0.04). However, women from different ethnic groups did not show equal improvement. The greatest increased mammography screening was found in the Indian group, but there was no significant improvement for Chinese women (Odds ratio = 1.0, 95% CI = 1.3-3.8). It suggests that using trained practice reception staff to contact non-attenders has a small but effective influence on uptake of mammography screening. However, this intervention seems ineffective among Chinese women, which might be due to the small number of Chinese women involved in this study and language issues.

3.3.3.2 System directed interventions

System directed interventions focus on the delivery of the service and also try to eliminate the barriers for getting access into the service, such as financial barriers. Only one prospective cohort study was involved in this category.

Tu et al. (1999) compared the attendance of mammography screening between Asian-American women (Chinese, Japanese, Vietnamese and Korean) and non-Asian control in a Breast Cancer Screening Programme (BCSP) that women were all provided recommendations and out-of-pocket expenses for a mammography screening. Eight hundred and fifty-seven Asian-American women (495 of them Chinese) and 1473 non-Asian controls were included in this survey.

Breast screening

After providing a free mammography screening, Asian-American women in aggregate did not differ from the controls on the attendance of mammogram. However, it was noted that Chinese women aged 50 and above had significantly lower attendance rates in the mammography screening than non-Asian women in the subgroup analysis (odds ratio 0.66; 95% CI 0.44, 0.97). It suggests that financial concern might have an influence on Asian-women's utilization of mammography screening, but it was not a determinant, especially for older Chinese women.

3.3.3.3 Social network directed interventions

Social network directed interventions concern studies which are carried out in the social network where people live. Two before-after studies (Kwok et al, 2011; Sadler et al, 2000) were involved in this category.

Kwok et al. (2011) evaluated whether a culturally tailored training programme could increase lay health advocates' breast health-related knowledge and beliefs in Sydney, Australia. Sadler et al. (2000) conducted an Asian grocery store-based health education programme, including bilingual health educators, visual displays and educational materials regarding breast cancer, screening behaviours and access to the breast cancer screening programme.

Breast screening

One study (Kwok et al, 2011) reported improvement of mammography screening among the advocates who had never had a mammography before.

Breast health-related knowledge

One study (Kwok et al, 2011) measured participants' knowledge on breast health and reported positive results. For example, this training programme increased participants' knowledge of how to do BSE (43% to 73%) and their awareness of CBE (81% to 92%) and

mammogram screening (87% to 92%). The portion of participants who could correctly identify the age group of women that should attend the mammography screening increased from 65% to 89% after the programme.

Breast cancer-related beliefs

Only one study (Kwok et al, 2011) measured the breast cancer-related beliefs and found lay health advocates' false beliefs on breast cancer reduced. For example, more advocates were aware that breast cancer is the leading cancer for women in Australia after the training programme (92% to 97%). More advocates disagreed with the statements that women do not need to worry about breast cancer if they feel well (84% to 92%) or have no physical symptoms (54% to 87%). The false beliefs that thinking about breast cancer will cause breast cancer (78% to 84%) and that women with small breasts have a lower risk of breast cancer (73% to 92%) were denied by more participants. In addition, this intervention led women to feel more comfortable discussing breast cancer (70% to 87%) and its related prevention (87% to 89%) with other Chinese women.

Intentions towards breast screening

Both studies (Kwok et al, 2011; Sadler et al, 2000) reported intentions to attend for breast screening and found positive results. Sadler et al. (2000) showed for example, among women who were non-adherent to the breast cancer screening guidelines at baseline, 31% of women aged between 40 and 50 and 41% of women aged 50 and over had arranged a screening appointment after the baseline survey. Kwok et al. (2011) reported increased intentions to take the repeat or initial mammogram and CBE among the advocators over 50 years old.

3.3.3.4 Mass media directed interventions

Mass media directed interventions refer to studies which use media message to promote health behaviours. One case-control study (Sun et al, 2007) fell into this category. Sun et al.

(2007) used a media-based education campaign to promote breast health, including broadcasting two public service announcement (PSAs) on breast health practices on three Chinese television stations and one Chinese radio station, and publishing this information in two Chinese newspapers for six months.

Breast screening

Having viewed the public service announcements was significantly associated with having performed breast self-examination within the past month (OR = 3.12; 95% CI: 2.05-4.74), having a clinical breast examination (OR = 2.98; 95% CI: 1.82-4.90), and having attended for mammography (OR = 1.97; 95% CI: 1.16-3.36) during the last year.

Breast health-related knowledge

There were significant relationships between having viewed the public service announcements (PSAs) and the ability to identify the breast health guidelines (OR = 1.96; 95% CI: 1.35-2.85) and the knowledge of how to perform breast self-exam (OR = 2.25; 95% CI: 1.53-3.29).

3.3.3.5 Multi-strategy interventions

The term multi-strategy intervention, in this review, refers to a combination of person-directed intervention, system directed intervention and social network directed intervention. One RCT and two descriptive studies were included in this category.

Hiatt et al. (2008) evaluated the effect of a community health worker outreach intervention and a clinic-based in-reach intervention by providing education and computer reminders on breast and cervical cancer screening among 25,000 underserved women from multiethnic groups, including 279 Chinese at pre-test and 288 at post-test. However, this study only compared the differences within groups between before and after intervention, but did not compare the differences between intervention and control groups. Wang et al. (2008) used a Health Belief Model (HBM) based culturally tailored educational video, including a soap opera and a section featuring a recommendation by a physician, to improve the nonattenders' breast health-related knowledge, beliefs and intention in the Chinese-American community. On the basis of Wang et al. (2008)'s study, Maxwell et al. (2011) used this video in combination with breast health workshops which was conducted by trained Chinese American lay health educators to improve the receipt of mammography screening among Chinese non-attenders.

Breast screening

Two of the studies measured breast cancer screening. Hiatt et al. (2008) reported no significant improvement for mammography and clinical breast examination, and little improvement on breast self-examination (89% to 92%) in the community health worker outreach intervention. However, participants in the control group showed significant improvements for all breast cancer screening behaviours. The clinic-based in-reach intervention had no effect on any behaviour. In addition, there was no interaction between outreach and in-reach interventions. The same results were also found in the sub-analysis of Chinese women only.

Maxwell et al. (2011) reported improved participants' uptake of mammography screening during the 6 months follow-up period. The utilization of mammography screening was significantly higher among women who had lived in the U.S. less than 10% of their lifetime, who had received a mammography screening in the previous 1 to 2 years, or who did not have health insurance (all p < 0.05). Moreover, mammography screening rates tended to be higher among women who do not have a regular doctor (p = 0.054). The multivariate logistic regression showed knowing the importance of having a mammogram without symptoms was the only significant predictor of uptake of mammogram during the 6 month period (odds ratio = 7.3, p < 0.007).

Breast health-related knowledge

Two studies (Maxwell et al, 2011; Wang et al, 2008) reported outcomes of breast healthrelated knowledge. Wang et al. (2008) reported significantly increased non-attenders' breast cancer-related knowledge with the mean score increasing from 7.36 at baseline to 8.43 at the 1 week follow-up (p < 0.001). Additionally, this intervention was more successful in increasing breast cancer-related knowledge among women who had never had a mammogram before and had low monthly income (\leq \$20,000). The other study that using the same video in combination with breast health workshop also led to a significant improvement on Chinese women's knowledge about breast cancer (mean score was 2.9 and 4.4 for the pre- and post-intervention, respectively, p < 0.001).

Breast cancer-related beliefs

Two studies (Maxwell et al, 2011; Wang et al, 2008) measured participants' breast cancerrelated beliefs and both showed a significant change on the mean score of the cultural beliefs of breast cancer and healthcare between the pre- and post-intervention (3.4 to 3.7 for Maxwell et al.' study; 38.55 to 45.53 for Wang et al.'s study, both p < 0.001). Additionally, Wang et al. (2008) also explored the effect of the intervention on the four variables of the HBM. There were significant increases in perceived susceptibility (10.25 to 12.24), perceived benefits (23.72 to 27.93) and decrease in perceived barriers (44.65 to 31.09) from the baseline to the follow-up (all p < 0.001) but no effect on perceived seriousness.

Intentions towards breast screening

Two studies (Maxwell et al, 2011; Wang et al, 2008) reported improvement in breast cancer screening intentions. Wang et al. (2008) reported a significant increase in participants' intention to obtain a mammography screening from 37% at the pre-test to 88% at the 1 week follow-up (p < 0.001). Additionally, most women reported that watching this video was the direct reason for their intention to take up the offer of screening (89%), and that it affected their intentions extremely or very much (73%). Similarly, use of the combined video and

educational workshop (Maxwell et al, 2011) also increased women's intention to go for a mammography screening to 72% compared to 38% at baseline (p < 0.001).

Table 3.4 Results for included studies

| Trial location and dates | Intervention (I) and control (C) if applicable | Follow-up | Withdrawals and dropouts | Outcome obtained | Outcome measurements | Results |
|--------------------------------|--|-----------|--------------------------------------|---|--|--|
| 1. Person-di | rected intervention | | • | • | | |
| Atri, 1997, London, UK | I: using trained reception staff to contact non- attenders through telephone or/and letter (n=995, Chinese=14) C: reception staff did not receive training (n=1069, Chinese=12) | 12 months | 8% for individual participants | The record of screening services | Overall mammography attendance rate and by ethnic group | This intervention significantly increased the overall screening rates by 5% (control 4% vs intervention 9%), with OR= 2.3 (95% CI, 1.1-5.3). The most significant improvement was found among Indian women (control 5% vs intervention 19%) with OR= 2.2 (95% CI, 1.3-3.8) No significant improvement was found among Chinese women (control 8% vs intervention 7%). |
| 2. System-di | irected intervention | • | | • | - | |
| Tu, 1999; US | I & C both received a mailed BCSP recommendation for a free MAM I: Asian-American (I=636, Chinese =308) C: Non-Asian American women (n=2716) | 1 year | N/A | The record of Breast Cancer Screening Programme (BCSP) | Compared the differences on the uptake of MAM within one year between Asian-American women and controls | 1) Control: 57.4%, Asian-American: 46.4%, OR= 0.93 (95% CI, 0.78-1.11), AOR= 0.95 (0.80-1.14) 2) Control: 57.4%, Chinese: 45.8%, COR= 0.86 (95% CI, 0.68-1.09) AOR by age groups: 40-49: OR= 1.23 (95% CI, 0.84-1.80) 50-64: OR=0.66 (95% CI, 0.44-0.97) \geq 65: OR=0.43 (95% CI, 0.21-0.90). |
| 3. Social net | work directed intervention | | | | | |
| Sadler, 2000; US | A health education programme (n=302 at pre-test, n=203 at post- test). | 2 weeks | 33% | 1) The baseline survey was self-reported; 2) The follow- up survey was self- reported by telephone interview | Setting up a breast cancer screening appointment | 40-49 years old: 36% (34/95) reported setting up a breast cancer screening appointment during the interval and 15 of the 34 women did not have clinical breast examination at the baseline. Age ≥ 50 years, 43% (21/49) set up a screening, 14 of the 21 women did not have annual mammogram at baseline. |

| Trial | Intervention (I) and | Follow-up | Withdrawals | Outcome | Outcome | Results |
|--|--|-----------|-------------|--|--|---|
| location | control (C) if applicable | | and | obtained | measurements | |
| and dates | | | dropouts | | | |
| 3. Social net | work directed intervention | • | | • | | |
| Kwok, 2011; Sydney, Australia | An education training session (n=37 at baseline, n=19 at 6 weeks follow-up, n=15 at 4 months follow-up.) | 4 months | 49% | 1) Breast health-related knowledge and beliefs, and intention to the uptake of MAM were self-reported by questionnaire 2) the uptake of breast screening was self- reported by telephone interview | Breast health- related knowledge Breast health- related beliefs; Intention to the uptake of MAM breast cancer screening including MAM & CBE | No statistical analysis was carried out. 1) The improvements were found on breast cancer related knowledge including how to do BSE, breast health-related beliefs, intention to screening. 2) The intervention increased the uptake of MAM among non-attenders and the participations of CBE. |
| 4. Mass med | lia directed intervention | | 1 | | 1 | |
| Sun, 2007; San Francisco, US | Media-based educational campaign (476 viewers vs. 234 non-viewers) | N/A | N/A | Self-reported by face-to- face interview | 1) Knowledge of breast health guidelines, 2) knowledge of how to perform BSE, 3) breast health practices | Having viewed the PSAs were significantly related with 1) the ability to identify the breast health guidelines (OR = 1.96; 95% CI: 1.35-2.85); 2) the knowledge of how to perform BSE (OR = 2.25; 95% CI: 1.53-3.29); 3) having performed BSE within the past month (OR = 3.12; 95% CI: 2.05-4.74), having a CBE (OR = 2.98; 95% CI: 1.82-4.90), and having attended for MAM (OR = 1.97; 95% CI: 1.16-3.36) during the last year. |

| Trial | Intervention (I) and | Follow-up | Withdrawals | Outcome | Outcome | Results | | | | |
|---|---|-----------|--------------|--|--|---|--|--|--|--|
| location | control (C) if applicable | | and | obtained | measurements | | | | | |
| and dates | | | dropouts | | | | | | | |
| 5. Multi-strategy interventions | | | | | | | | | | |
| Hiatt, 2008; San Francisco Bay Area, US | I: received the Breast and Cervical Cancer Intervention Study (BACCIS) C: No intervention (Pre-test I& C=1599, Chinese =279; Post-test I&C=1616, Chinese=288) | 4 years | Not reported | Retrospective self-reported by interview | Screening behaviours: BSE, CBE and MAM | This study only compared the differences between before and after intervention within the same group. For the intervention group, the significant improvement was only found on ever completed BSE (x^2 =NR, p=0.031). | | | | |
| Wang, 2008; Metro D.C. area, US | A health belief model- based culturally tailored video (n=52 at pre-test, n= 44 at post-test) | 1 week | 12% | Self-reported by telephone interview | 1) Screening intention, 2) knowledge, cultural views of cancer and health cancer, health beliefs, and process evaluation | Screening intention increased from 37.2% to 88.4% (p <.001) The intervention significantly improved breast cancer knowledge (p=.001), cultural views, fatalistic, self-care, perceived susceptibility, perceived benefits, perceived barriers, access barriers, and discomfort (all p<.001). | | | | |

| Trial location | Intervention (I) and control (C) if applicable | Follow-up | Withdrawals and | Outcome obtained | Outcome measurements | Results |
|--|---|-----------|-----------------|--|--|--|
| and dates | | | dropouts | | | |
| 5. Multi-strat | egy interventions | | | | | |
| Maxwell, 2011, Los Angeles County, U.S. | A HBM-based culturally tailored video, peer-led group discussion sessions, and a list of local facilities providing low- or no-cost MAM. (n=101 at baseline, n=101 at the follow-up) | 6 months | 0 | 1) Breast health-related knowledge and beliefs, and intention to the uptake of MAM were self-reported by questionnaire 2) the uptake of MAM was self-reported by telephone interview | Knowledge and attitudes regarding MAM. the uptake of MAM during 6 months after intervention | This intervention significantly increased the total knowledge cancer knowledge score, the health-related cultural beliefs scale, and plan to have MAM in the next three months (all p<.001). 44% of women obtained a MAM within 6 months, including 16 who never had a MAM before. MAM screening rates were significantly higher among women younger than 70, who had lived in the US less than 10% of their lifetime, women who had a MAM 1 to 2 years ago, and women who did not have health insurance (all p<.05). |

Note: BSE = breast self-examination, CBE = clinic breast examination, MAM = mammogram;

OR= odds ratio, AOR = adjusted odds ratio, NR = not reported.

3.4 Discussion

This systematic review is the first to assess the effectiveness of interventions in increasing breast health-related knowledge, beliefs, intentions to breast screening and/or breast cancer screening among Chinese women in Western countries. Because of the limited number of studies in this area, this review imposed no specific restrictions on the study design, in order to include as many studies as possible. Overall, eight studies were involved in this review. Only two studies used a randomised study design though it has been a common and effective evaluation method for interventions. This suggests that RCTs were not widely applied in increasing breast health-related knowledge, beliefs and behaviours among Chinese women.

3.4.1 Summary of findings

In this review, six studies, one person directed study, one system directed study, one social network directed study, one mass media directed study and two multi-strategy directed studies, tested the effect of interventions on Chinese women's breast screening. The social network directed study (Kwok et al, 2011), mass media directed study (Sun et al, 2007) and one multi-strategy directed study (Maxwell et al, 2011) increased Chinese women's breast screening during the follow-up period. This suggests that social network directed interventions, mass media directed interventions and multi-strategy interventions may be more effective than person directed interventions and system directed interventions in changing Chinese women's screening behaviours. This is not to say, however, that the other two types of interventions have no effect on breast cancer screening behaviour. The reasons may be that the person directed study (Atri et al, 1997) and the system directed study (Tu et al, 1999) were not specific to Chinese women and thus lack culturally and linguistically tailored strategies.

One social network directed intervention (Kwok et al, 2011), one mass media directed intervention (Sun et al, 2007) and two multi-strategy interventions (Maxwell et al, 2011; Wang et

al, 2008) tested the effect of interventions on Chinese women's breast health-related knowledge and all showed significant effects on it. In terms of breast health-related beliefs, one social network directed intervention and two multi-strategy interventions reported significant improvements. Two social network directed interventions and two multi-strategy interventions were successful in increasing intention to undergo breast screening. Although these interventions were before-and-after pilots, participants in one study stated that participation in this intervention was the direct reason for their intention to take up the offer of mammography screening (Wang et al, 2008); another study evaluated the effectiveness of intervention by excluding participants who were already familiar with the breast health guidelines prior to participating in this study (Kwok et al, 2007). It suggests that social network directed interventions, mass media-directed interventions and multi-strategy interventions can benefit Chinese women's breast health-related knowledge, beliefs or intentions.

3.4.2 General practice setting

General practice plays an important role in the promotion of breast screening in the UK. In previous studies, it has been found that the health professional's recommendation is the most frequently cited motivator for mammography screening among Chinese women (Liang et al, 2004; Su et al, 2006). Only one cluster randomised trial was based in general practice in this review. The reason may be attributed to the fact that the US has a different healthcare system from the UK and Australia, for example the US does not have general practice available as a primary care system. Overall, training general practice receptionists to contact non-attenders significantly increased the uptake of mammography. However, women from different ethnic groups benefited unequally, as Indian women showed greatest improvement in attendance of mammography screening while Chinese women showed no changes in it. Apart from the limited number of Chinese women in this study, the main reason may be that most health staff were themselves from an Indian background, who shared the same culture and language background
with Indian women. Therefore, Chinese women probably still suffer the common barriers to mammography, such as language and cultural barriers. From this study, there is evidence to suggest that general practice receptionists with the requisite linguistic skills and cultural knowledge are very useful for achieving improvements in breast cancer screening attendance among minority ethnic groups. This suggests that GP centres should earmark resources for breast cancer screening programmes to increase the rate of breast cancer screening among among women in cultural groups with traditionally low attendance.

3.4.3 Media-led intervention

Media campaigns are one of the most common tools in promoting health behaviours. In this review, Sun et al.'s study (2007) demonstrated that a Chinese media-based campaign is effective in increasing knowledge of breast health guidelines and knowledge of how to perform breast self-examination, and promoting breast health practices including mammography. This is consistent with a previous study targeting Vietnamese-Americans, which showed that a Vietnamese language media-based educational campaign significantly increased Vietnamese women's breast cancer-related knowledge, intentions and behaviours (Jenkins, McPhee, Bird, Pham, Nguyen, Nguyen et al, 1999). All this suggests that linguistically appropriate media-led intervention is an effective way to convey messages in breast cancer prevention and early detection among minority ethnic groups. The reason may be that such groups can better understand the information that is delivered by media campaigns once the language barrier has been removed. The role of the Chinese media was tested in a smoking cessation study. The participants stated that the Chinese media were a trustworthy source of information (Ferketich, Wewer, Kwong, Louie, Moeschberger, Tso et al, 2004). Moreover, the media-led intervention is expected to be an effective way for promoting breast health among Chinese women who are hard to reach, as a previous study indicated that most of the elderly Chinese women were homemakers due to low English proficiency (Kwok et al, 2005). Hence, the media-led

intervention may achieve a broad population sample compared to other means of intervention. In addition, a significant relationship between health behaviour changes and exposure to mass media messages has also been found in many studies (Agha, 2003; Hornik, 2002). This suggests that the mass media work well in disease prevention.

3.4.4 Culturally tailored intervention

Compared with non-culturally tailored interventions, culturally tailored interventions are considered to be more effective in health communication (Springton & Champion, 2004). This review includes three culturally tailored studies (Kwok et al, 2011; Maxwell et al, 2011; Wang et al, 2008) and all increased Chinese women's breast cancer-related knowledge and reduced cultural barriers and misconceptions on mammography. Two studies measured breast cancer screening behaviour and both increased the attendance of mammography among Chinese women. This is consistent with previous studies showing that culturally sensitive programmes are effective in improving knowledge of breast cancer and mammography screening (Drindel, Brown, Caplan & Blumenthal, 2004; Yancey, Tanjasiri, Klein & Tunder, 1995). As was mentioned in Chapter 1, Chinese women generally have been reported as perceiving themselves as having low susceptibility to breast cancer and negative attitudes to mammography, and fatalistic views also affect their perception of illness, as they consider that illness is inevitable and nothing can be done to prevent illness, especially cancer. In addition, Chinese prefer to engage in regular exercise and eat a healthy diet to promote health rather than to go for regular screening. Therefore, the Chinese culture should be taken into consideration when designing interventions, in order to achieve greatest effects in promoting breast health among Chinese women.

3.4.5 Free mammography intervention

Although mammography is available at no cost to women over 50 years old in the UK, women in the US still need to pay for it. Therefore, some free or low-cost mammography interventions

were carried out, in order to eliminate the financial barrier to mammography screening. In this review, it seemed that this kind of intervention did not obviously enhance uptake of mammography screening among Chinese women. Tu et al. (1999) found that older Chinese women remained less likely to participate in mammography screening than non-Asian women even in a no cost programme. The same phenomenon also exists in the UK, where mammography screening rates are lower among Chinese women than among white British women when mammography is free to access. This suggests that the financial barrier was not a determinant for the uptake of mammography screening among Chinese women. The screening behaviour among this population may be more likely to be influenced by cultural barriers such as modesty, language barriers and practical issues such as transport. It should be noted that there is a limitation in Tu et al.'s study, as they compared only the differences across population groups. Therefore, all that can be concluded from this study is that non-Asian women benefited more from the free mammography screening programme than Chinese women. To investigate the actual effect of such an intervention, an RCT will be required to in future research.

3.4.6 Possible limitations

Firstly, most studies included in this review are before-and-after studies which compared the differences between one time and a subsequent time within a group of participants but without a control or comparison group. Compared with randomised controlled trials, it is very difficult to conclude if the improvement in outcomes between the pre- and post-intervention is purely caused by the intervention. This type of design may produce a social desirability bias in that participants might report health behaviours and attitudes in a way that they expect to be viewed favourably by researchers (Burgess, Powell, Griffin, & Partin, 2009). This leads to over-reporting of good outcomes or under-reporting of bad outcomes. Second, the participation rates among selected individuals were relatively low in several studies (Maxwell et al, 2011; Wang et al, 2008). Thus, the data were collected only from certain kinds of participants — those who were willing to

follow breast health practices and had less negative attitudes to breast cancer prevention. This creates a biased sample and may have affected and limited the results obtained. Third, the follow-up is another possible factor that influences the effect of the intervention. People who took part in the baseline assessment might very well not attend the follow-up assessment, and not all studies reported the details of the non-returners. They might be women who are less likely to learn knowledge of breast health and to take up screening. The effectiveness of the intervention would be weakened in this situation. Fourth, most studies were carried out only over a short period; thus they did not measure the actual utilisation of mammography. As to the long-term effectiveness of these interventions, that still needs to be explored in future studies.

3.5 Implications for the development of evidence based breast screening intervention

In the UK, evidence for Evidence Based Practice (EBP) is generally produced and disseminated via reviews which are carried out by organizations and agencies such as the National Institute for Health and Care Excellence (NICE), the Cochrane Collaboration, and the NHS Centre for Reviews and Dissemination at the University of York (Marks, 2002). EBP has been tracked back to the concept of evidence-based medicine (EBM) put forward by Guyatt and others in 1992 (Evidence–Based Medicine Working Group, 1992). Sackett, Rosenberg, Grey et al. (1996, p.71) identified EBM as

"Evidence-based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available clinical evidence from systematic research."

EBP has been influenced by positivism (Marks, 2002), which argues that there is an objective reality independent of the human mind (Crossan, 2003). A hierarchy of evidence has been developed in order to evaluate the effectiveness of research according to its validity by agencies such as NICE (Figure 3.2). RCTs are viewed as the best source of evidence and rank above the other approaches.

| 1. Meta-analysis of RCTs | | | | | |
|---|--|--|--|--|--|
| 2. Individual RCTs | | | | | |
| 3. Controlled studies (without randomisation) | | | | | |
| 4. Quasi-experimental studies | | | | | |
| 5. Non experimental studies (comparative, correlation and case control) | | | | | |
| 6. Evidence from expert committee reports or opinions and/or clinical experience of respected authorities and qualitative studies | | | | | |

Figure 3.2 Categories of evidence accepted by the NICE

The hierarchy of evidence has been criticised for simply focusing on effectiveness (Evans, 2003). Marks (2002) claims that clinical decision making is developed based on the combination of three sources of information: "knowledge about the patient's condition, current best evidence about the effectiveness of treatments, and empathy with the patient's values and subjective meanings" (p.19). Therefore, it is also essential to evaluate whether the intervention is appropriate for the target population. The evidence on the appropriateness of an intervention mainly focuses on the psycho-social aspects of the intervention rather than the physiological aspects (Evans, 2003). Good evidence on the appropriateness of an intervention can be provided by the other methods, such as focus groups.

The literature review presented in Chapter One indicated that there is limited knowledge of breast cancer prevention and detection among the Chinese community in the UK. In addition, the majority of studies involved in this systematic review were not specifically targeted at Chinese women. As a result, the systematic review could not provide sufficient evidence on whether these intervention methods and strategies are appropriate for Chinese women living in the UK. In-depth qualitative research is required in order to understand Chinese women's beliefs,

feelings and experiences of breast cancer prevention and early detection and also to help the evaluation of healthcare programs. This systematic review also showed that there was a lack of the use of theoretical framework in the promotion of breast health and breast screening among Chinese women living in the other Western countries, as only two studies identified a theoretical framework (HBM) for the development of interventions. The benefits of involving behaviour theory in the intervention planning have been addressed in the health behaviour promotion area as theories illuminate the mechanisms of behaviour change (Brug, Oenema, & Ferreira, 2005). The findings of the systematic review highlight the urgency to develop a theory-based breast screening intervention to improve the breast screening practice of encouraging more Chinese women to go for mammogram screening.

As was mentioned in the Methodology, pragmatism was chosen as the research paradigm through this thesis. According to pragmatism, the selection of research method depends on the research purpose, thus different research methods can be used in the same study to generate the best knowledge of the research topic (Yardley & Marks, 2003). Therefore, as well as the evidence generated from the systematic review and literature review, the integration of qualitative research would produce detailed and deep understanding of the psycho-social factors related to breast cancer prevention and early detection among Chinese women and so can aid in the development of the evidence- and theory-based breast screening intervention.

3.6 Summary

The findings of this systematic review indicated that culturally and/or language tailored interventions are more effective on the improvement of breast cancer screening adoption than those which were not tailored. In addition, the systematic review highlights that RCTs cannot provide adequate evidence on whether the interventions targeted at other population are appropriate for Chinese women, and thus findings of the systematic review may not provide the

best evidence-base for the development of the breast screening intervention. Also the systematic review alone would not expand the understanding of the psycho-social factors related to breast cancer prevention and early detection among Chinese women living in the UK. Therefore, there is a need to use qualitative research to complement the evidence reported in the systematic review and literature view, and hence to develop an effective breast screening intervention against breast cancer among Chinese women.

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Chapter 4 Psycho-social factors related to breast cancer prevention and detection among older Chinese women in the UK

4.1 Introduction

The public health literature suggests that older Chinese women living in Western countries have a low uptake of mammogram screening and also lack breast health-related knowledge. Focus groups were considered as the most appropriate way to understand the psycho-social factors related to breast cancer prevention and detection among Chinese women aged between 50 and 70 who are routinely invited to attend the breast screening in the UK (Please refer to section 2.4.3 for details). Fifty-two participants aged 50 and 69 (M=58.55, SD=4.99), recruited from Birmingham and Manchester, participated in this study. Nine focus groups were conducted in Cantonese with 4-7 women in each group. Participants discussed their illness perceptions regarding breast cancer, prevention of breast cancer, mammography beliefs and experience, medical help seeking behaviour and interactions with healthcare providers. This chapter describes the development of focus group schedules, the participant recruitment, focus group procedure and also reports the breast cancer screening experience for older participants and the key themes identified during thematic analysis.

4.2 Material

As mentioned in Chapter Two Methodology, the focus group schedule was developed on the basis of explanation-driven logic (Hiles, 2014). Firstly, on the basis of literature review in Chapter One and the researcher's interests, a variety of questions were developed to understand the psycho-social factors that might influence Chinese women's health and breast cancer prevention. As the literature review indicated that the Health Belief Model (HBM; Becker, 1974) has been widely and successfully used in the prediction of breast screening behaviour, it was used as the theoretical framework to check whether the focus group questions related to the variables

included in the HBM, in order to determine whether the questions could reflect the causal determinants of breast screening. Perceived severity was not especially explored in present study because of the lack of variability in perceived seriousness of cancer in previous cancer screening studies (Champion & Scott, 1997). Therefore, the focus group questions consisted of questions related to the HBM constructs and other questions that might affect Chinese women's breast screening behaviour such as emotional feelings about breast cancer, medical care seeking behaviours and the social interaction between Chinese women and healthcare providers. However, the focus group schedule allowed women to raise and discuss any issues they thought were relevant and conversely to dismiss issues raised by the researcher which they did not believe were relevant to them. The focus group schedule (see appendix 5), with openended questions (see Table 4.1), was used to explore the psycho-social factors related to health and breast cancer prevention and screening among older Chinese women.

Table 4.1 Topics and example questions in the focus group schedule for older Chinese women in

English

| Topics | Example questions | | | | | |
|--|--|--|--|--|--|--|
| Health Belief Model constructs-related questions | | | | | | |
| perceived susceptibility | What do you think about your susceptibility of | | | | | |
| | developing breast cancer? | | | | | |
| perceived benefits | What do you think about breast cancer | | | | | |
| | prevention? | | | | | |
| perceived barriers | Are there any factors that reduce your possibility | | | | | |
| | of preventing breast cancer? | | | | | |
| health motivation | What does health mean to you? | | | | | |
| | What do you think are important things for | | | | | |
| | keeping healthy? | | | | | |
| | What do you usually do to keep healthy? | | | | | |
| cues to taking breast cancer | What particular environments could encourage | | | | | |
| preventive behaviour | you to take mammogram? | | | | | |
| Other questions related to variables | found to be important in previous studies | | | | | |
| breast cancer related knowledge | What do you think are the causes of breast | | | | | |
| | cancer? | | | | | |
| | What do you think are effective ways of | | | | | |
| | preventing breast cancer? | | | | | |
| experience of breast cancer | Could you please talk about your experience of | | | | | |
| prevention | taking a mammogram? | | | | | |
| | | | | | | |
| medical care seeking behaviours | What do you usually do if you feel unwell? | | | | | |
| the interaction with healthcare | What do you think about the health services in | | | | | |
| providers | the UK? | | | | | |
| | What do you think about the health care | | | | | |
| | providers in the UK? | | | | | |

4.3 Participant recruitment

Ethical approval was granted by Aston University Ethics Committee (Appendix 7). Older participants were recruited from two major cities in the UK, Birmingham and Manchester, where the size of the Chinese population is similar in these two cities, both on the total Chinese population and the population of female Chinese (Appendix 9). The Chinese population is also more concentrated in these two cities than anywhere else except London (Office for National statistics, 2010). The researcher contacted the Birmingham Chinese Society and Wai Yin Chinese Women Society in Manchester through email and phone call. The researcher explained the purpose of the study and asked if they were interested in participating. Both centres agreed

to help the researcher recruiting participants and provided a place for carrying out focus groups.

The inclusion criteria for this study were that participants did not have a history of breast cancer, identified themselves as Chinese, were aged between 50 and 70, and originally came from mainland China or Hong Kong. Women from other Asian countries, such as Malaysia, were not included in this study, as people in Malaysia consist of Malays (50%), Chinese (25%), Indians (10%) and other minority ethnic groups (Official Website of Tourism Malaysia, 2014). People from different ethnic groups have influenced each other and therefore create an amalgamated Malaysian culture (Official Website of Tourism Malaysia, 2014), which is considered to be different from the Chinese culture. Previous studies have documented that the adoption of mammography screening is associated with cultural beliefs (Mishra, Bastani, Huang, Luce, & Baquet, 2007; Russell, Monahan, Wagle, & Champion, 2007). Therefore, this thesis only focused on people from a Chinese cultural background. This study also did not include UK-born Chinese, because only 2.88% of Chinese aged between 45 and 64 and 5.10% of Chinese aged 65 and over were born in the UK, reflecting the later immigration among the Chinese population (Office for National statistics, 2010).

The Birmingham Chinese Society and Wai Yin Chinese Women Society were informed of the criteria for participant recruitment. They were responsible for delivery of the participant information sheet (Appendix 10) and recruitment of potential participants because local Chinese societies have frequent contact with Chinese women and were considered to be more effective in persuading Chinese women than the researcher would be. The participant information sheet was presented in Traditional Chinese and briefly explained the purpose of the study, its procedure, benefits of the study, potential risks or discomfort, confidentiality and the voluntary nature of participation and withdrawal. Participants were also informed that they would receive £20 to cover their travel costs. In addition, the researcher's contact details were provided if

further information was required. The recruitment of participants was carried out between April and September 2009.

Fifty-two participants were recruited and divided into groups according to the place that they originally came from and the place they were living at the time of the study. Participants were not divided into different categories based on whether they had been to mammography screening. If a focus group is too homogeneous, group members share the similar views and attitudes toward the research topic that might limit the discussion (Howitt, 2010). Therefore, the diversity of mammography screening attendance would produce conflicting opinions on breast cancer prevention and screening. As long as focus group participants respect each other's opinions, the conflicting views are helpful in getting "to the heart of the matter more quickly" (Grover & Vriens, 2006, p. 64).

As this was such an under-researched population it was decided to run as many focus groups as the Chinese societies in Birmingham and Manchester could arrange. They all took place within a relatively short period of time so it was not possible to pick up the level of redundancy in the data before analysis. However running a large number of focus groups does give some confidence in the validity of the data. There were nine groups in this study: three groups of participants who were originally from Hong Kong and currently live in Birmingham (BH1, BH2, BH3), two groups of women who were originally from mainland China and currently live in Birmingham (BC1, BC2), two groups of participants who were originally from Hong Kong and two groups of women who were originally from mainland China and currently live in Manchester (MH1, MH2) and two groups of women who were originally from mainland China and currently live in Manchester (MC1, MC2). It was anticipated that the nine focus groups would be sufficient to produce the range of relevant beliefs, perceptions and preventive behaviours, with the place they originally come from and the current resident place being the main source of variance. The planned size of each focus group was six, as this number allows

the generation of group dynamic and each participant to have an opportunity to share their views and experience. However, one participant in the BH2 group and two participants in the MC2 group dropped out and the MH2 and MC1 groups involved 7 participants in each group. Therefore, the number of participants in each group varied from 4 to 7.

4.4 Demographic data of older participants

Nine focus groups with fifty-two Chinese-British women aged between 50 and 69 years (M=58.55, SD=4.99) were conducted. Twenty-four participants described themselves as originally from mainland China, and the remaining 28 participants came from Hong Kong. Most participants (n=41, 78%) had lived in the UK for more than 15 years. With the exception of six, all were married or had been married. Around 80% (n=42) of the participants had not had more than middle school level of education. Most of the sample did not speak English or spoke very little. The majority of participants were either a housewife (n=16, 31%) or retired (n=21, 40%). Participants were labelled with a unique code to present their demographic data, including current living city and place of birth, and the number of focus group that they were allocated to. For example, BH1P1 means Birmingham, Hong Kong, focus group one and participant one. Table 4.2 includes the demographic data for each participant.

Table 4.2 Demographic information for focus groups among older participants

| Code | Age | Years in the UK | Place of birth | Marital status | Having relatives with breast cancer | English level | Education level | Occupation |
|-------|-----|-----------------------|----------------------|-------------------|---|------------------|--|------------|
| BH1P1 | 50 | >15 | HK | Divorced | No | Little | High school | Housewife |
| BH1P2 | 59 | >15 | НК | Single | No | Ok | Further education after high school | Retired |
| BH1P3 | 63 | >15 | HK | Divorced | Yes | Ok | University | Retired |
| BH1P4 | 51 | >15 | HK | Married | No | Ok | High school | Part-time |
| BH1P5 | 50 | >15 | НК | Married | No | Little | Further education after high school | Part-time |
| BH1P6 | 62 | >15 | HK | Married | No | Ok | Primary school | Part-time |
| BH2P1 | 60 | >15 | НК | Married | No | Ok | Further education after high school | Part-time |
| BH2P2 | 58 | >15 | HK | Married | Yes | Ok | Middle school | Retired |
| BH2P3 | 54 | >15 | НК | Married | No | Little | Middle school | Housewife |
| BH2P4 | 60 | >15 | HK | Divorced | Yes | Ok | Middle school | Retired |
| BH2P5 | 50 | >15 | HK | Married | No | Can't speak | Middle school | Housewife |
| BH3P1 | 65 | >15 | НК | Married | No | Can't speak | Middle school | Retired |
| BH3P2 | 63 | >15 | НК | Married | No | little | Middle school | housewife |
| BH3P3 | 53 | >15 | HK | Married | No | Little | Middle school | Housewife |
| BH3P4 | 65 | >15 | HK | Married | No | Can't speak | Middle school | Housewife |
| BH3P5 | 54 | >15 | HK | Married | No | Little | Middle school | Housewife |
| BH3P6 | 58 | >15 | HK | Married | No | Little | Middle school | Housewife |
| BC1P1 | 56 | >15 | CHN | Married | No | Little | Middle school | Housewife |
| BC1P2 | 62 | >15 | CHN | Married | No | Can't speak | Middle school | Housewife |

| Code | Age | Years in the UK | Place of birth | Marital status | Having relatives with breast cancer | English level | Education level | Occupation |
|-------|-----|-----------------------|----------------------|-------------------|---|------------------|--|------------|
| BC1P3 | 58 | >15 | CHN | Married | No | Little | Middle school | Housewife |
| BC1P4 | 57 | >15 | CHN | Married | No | Can't speak | Primary school | Housewife |
| BC1P5 | 52 | >15 | CHN | Married | No | Little | Middle school | Housewife |
| BC1P6 | 57 | >15 | CHN | Married | No | Can't speak | Primary school | Housewife |
| BC2P1 | 63 | >15 | CHN | Married | No | Ok | Primary school | Retired |
| BC2P2 | 61 | >15 | CHN | Widowed | No | Ok | Middle school | Retired |
| BC2P3 | 65 | 11-15 | CHN | Divorced | No | Can't speak | Primary school | Housewife |
| BC2P4 | 68 | >15 | CHN | Married | No | Can't speak | Primary school | Housewife |
| BC2P5 | 57 | >15 | CHN | Widowed | No | Good | Further education after high school | Retired |
| BC2P6 | 65 | >15 | CHN | Single | No | Little | Middle school | No job |
| MH1P1 | 52 | >15 | HK | Single | No | Little | Primary school | Part-time |
| MH1P2 | 56 | >15 | HK | Single | No | Little | Primary school | Full time |
| MH1P3 | 62 | >15 | HK | Married | No | Ok | Middle school | Full time |
| MH1P4 | 59 | >15 | HK | Divorce | No | Ok | High school | Full time |
| MH1P5 | 58 | >15 | HK | Married | No | Ok | High school | Housewife |
| MH1P6 | 62 | >15 | HK | Married | No | Little | No education | Housewife |
| MH2P1 | 60 | 6-10 | HK | Married | No | Little | High school | Full time |
| MH2P2 | 57 | 11-15 | HK | Married | No | Little | Primary school | Housewife |
| MH2P3 | 65 | >15 | HK | Divorced | No | Little | Primary school | Retired |
| MH2P4 | 61 | >15 | HK | Married | No | Ok | Middle school | Retired |
| MH2P5 | 60 | >15 | HK | Married | No | Ok | Middle school | Housewife |

| Code | Age | Years in the UK | Place of birth | Marital status | Having relatives with breast cancer | English level | Education level | Occupation |
|-------|-----|-----------------------|----------------------|-------------------|---|------------------|--------------------|-----------------|
| MH2P6 | 58 | >15 | HK | Married | No | Little | Primary school | Full time |
| MH2P7 | 61 | >15 | HK | Widowed | No | Little | High school | Housewife |
| MC1P1 | 55 | 6-10 | CHN | Married | No | Can't speak | Primary school | Full time |
| MC1P2 | 69 | >15 | CHN | Single | No | Can't speak | Middle school | Retired |
| MC1P3 | 66 | 11-15 | CHN | Married | No | Can't speak | Middle school | Retired |
| MC1P4 | 66 | 1-5 | CHN | Widowed | No | Can't speak | Middle school | Retired |
| MC1P5 | 60 | 6-10 | CHN | Single | No | Can't speak | Primary school | Working at home |
| MC1P6 | 59 | 6-10 | CHN | Married | No | Can't speak | Primary school | Part-time |
| MC1P7 | 67 | 6-10 | CHN | Married | No | Can't speak | Primary school | Retired |
| MC2P1 | 57 | >15 | CHN | widowed | Yes | Little | Middle school | Working at home |
| MC2P2 | 60 | 11-15 | CHN | Married | No | Little | Middle school | housewife |
| MC2P3 | 51 | >15 | CHN | Married | No | Ok | No education | Full time |
| MC2P4 | 53 | 11-15 | CHN | Married | Yes | Little | Middle school | Housewife |

Note. HK = Hong Kong; CHN = China

4.5 Procedure

All nine focus groups were conducted in Cantonese because these participants were not fluent in English and all commonly spoke Cantonese. The interviewer speaks Mandarin, most participants understood Mandarin and the interviewer also understood Cantonese. However a bilingual interpreter translated the interviewer's questions to Cantonese, in order to make sure that all participants understood. The consent form (Appendix 12), demographic questionnaire (Appendix 13) and debrief (Appendix 14) were written in Traditional Chinese, which are the Chinese characters commonly used by Chinese communities, especially the older generation, in the UK.

Before the focus groups, participants were briefed on the purpose and procedure for this study. They were informed that the focus group would be audio recorded for the purpose of data analysis. Participants were informed that all the information they provided would be confidential and anonymous by code. Additionally, all participants were requested to respect and preserve the confidentiality of others. In order to ensure that their participation was voluntary, participants were informed that they were able to discontinue with their participation at any time. After they had agreed to take part in this research, they gave their informed consent before participation.

Before the focus groups, all participants were asked to complete the demographic questionnaire. The focus groups were guided by the focus group schedule which was described in Chapter Two (Appendix 5). During the discussion, open-ended questions were introduced by the researcher, but the researcher mainly acted as a facilitator who invited and encouraged participants to share their attitudes and experiences. Focus groups lasted between 60 and 100 minutes, depending on how much participants had to say. Following the focus group, a debrief was provided to participants to assure them that identifying information given by them would not be disclosed to any third parties and all data used e.g. verbatim quotations would be anonymous and to thank them for taking time to take part in this study. Each participant received £20 to cover their travel expenses.

4.6 Breast cancer screening experience for older participants

Table 4.3 summarizes breast cancer screening experience for older participants. Nearly half of participants (n=24, 46%) had had a mammogram in the past three years and one third (n=17, 33%) had had a recent mammogram within one year. Most participants (n=38, 73%) had never

had a clinical breast exam or had a recent clinic breast exam (n=49, 94%). Only a few participants (n=10, 19%) had done breast self exam (BSE) every month.

| Breast cancer screening behaviours | No. of participants (N-52) | % Total |
|---|----------------------------|---------|
| Ever had mammogram in the previous three years | (11-52) | |
| Yes | 24 | 46 |
| No | 28 | 54 |
| Had a recent mammogram (within one year) | | |
| Yes | 17 | 33 |
| No | 35 | 67 |
| Ever had clinic breast exam in the previous three | | |
| years | 14 | 27 |
| Yes | 38 | 73 |
| No | | |
| Had a recent clinic breast exam (within one year) | | |
| Yes | 3 | 6 |
| No | 49 | 94 |
| Done monthly breast self exam | | |
| Yes | 10 | 19 |
| No | 42 | 81 |

| Table 4.3 Breast cancer screening exp | perience for older participants |
|---------------------------------------|---------------------------------|
|---------------------------------------|---------------------------------|

4.7 Key themes

All data were transcribed verbatim and were then translated into English by the researcher. Thematic analysis was carried out to analyze the focus group data according to the stages described by Braun and Clarke (2006, p. 87): 1) familiarising yourself with your data; 2) Generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming; 6) corroborating coded themes and 7) producing the report (please refer to section 2.4.3.3 for details). Analysis identified five themes:

- What is health?
- Causes of breast cancer
- Active breast health management
- Contrast with unhealthy British population on keeping healthy
- Accessing health services generally

Table 4.4 displays the themes and subthemes that were expressed by older Chinese women.

These themes will be discussed individually using data extracts.

Table 4.4 Themes and subthemes expressed by older participants

| Themes | Subthemes |
|--|------------------|
| 1. What is health? | |
| 2. Causes of breast cancer | Genetics |
| | Unusual beliefs |
| | Other causes |
| 3. Active health management | Prevention |
| | Fatalism |
| 4. Contrasts with unhealthy British population | |
| 5. Accessing health services generally | Language |
| | Modesty |
| | Lack of time |
| | Practical issues |

4.7.1 What is health?

When talking about the meaning of health, focus group participants commonly described that

health means feelings of well-being or sleeping and eating well. For example,

MH2P1: Some people think being able to eat and sleep well is health.

However, one participant felt confused by the concept of health, she stated,

MH2P7: I think I'm healthy. But I still feel I have many problems. I don't quite understand the definition of health. What is health?... I know my cholesterol is high.... I feel that I already eat these suggested foods everyday... I don't know what health is. I go swimming every day. Am I healthy or not? I don't know whether I'm healthy or not.

This statement reflects that there is a conflict regarding the concept of health between personal

perception and medical diagnosis. This participant perceived herself as healthy. However, the medical diagnosis indicated that she has high cholesterol. Combined with the statements from other participants, being healthy is generally estimated on the basis of participants' personal feeling.

4.7.2 Causes of breast cancer

When talking about the causes of breast cancer, the majority of participants lacked breast cancer related knowledge as they reported that they were unsure about the causes of breast cancer.

Subtheme 1- Genetics

Genetics were the most frequently reported cause of breast cancer among all focus groups, as many participants suggested that breast cancer can be hereditary and is related to family history. For example,

BC2P4: I heard about breast cancer before. I think maybe it is caused by genetics

MH1P4: Some cancers are genetic. It means if you have a family member with cancer, you'll have 70% chance of developing that cancer.

MC1P6: It's a genetic disease

Although genetics were identified as a major risk for developing breast cancer, participants did not realise that eight out of nine breast cancers occur in women without a family history of breast cancer (Cancer research UK, 2009), leading them to have a false perception about their susceptibility to breast cancer. More than half of the participants believed that they would not develop breast cancer or they did not worry about breast cancer because they did not have a family history. For example,

BH1P5: ...but I don't have a family history, so I'm not worried about it. Usually, people say it's a genetic disease
BH1P2: Right, right, genetic
BH1P5: If you have a family history, you are more likely to develop it.

BH1P2: Yes, I agree with her. It's a family history problem, if the family doesn't have, we won't develop it.

Therefore, the low perceived susceptibility may reflect a limited knowledge of breast cancer causes.

The worry about developing breast cancer appeared to be greater among participants who had had relatives die from breast cancer, as these participants felt a high susceptibility to breast cancer and felt a strong sense of fear of developing breast cancer in the future. This suggests that having relatives with breast cancer is a great contributor to these women's perceived susceptibility. For example,

BH1P3: Well, I hadn't thought about this problem before, but my sister, about eight or nine years ago, she died from this cancer. So I worried about myself developing it from that time.

BH2P2: My sister died from breast cancer, so many doctors said that I have the possibility of developing breast cancer. Yes, I might. So I'm worried about it.

Subtheme 2 - Unusual beliefs

Participants, especially the China-born women, also suggested many unusual beliefs about the

causes of breast cancer which do not accord with current scientific evidence, including having

big breasts, physical pressure, sleeping with a light on and the false perception of the effect of

age on breast cancer.

Around one third of focus group participants stated that British women have a higher chance of

developing breast cancer, because they have big breasts. For example,

BH1P1: Because their breasts are bigger than ours (so they have greater risk of developing breast cancer)

BC2P3: And they said it's easier to get breast cancer if your breasts are big. We don't have (big) breasts, so it's not easy to develop it

These statements may reflect that participants have a misconception of the relationship between

breast size and the density of breast tissue. A woman's breasts consist of fat, connective tissues and numerous tiny glands (NHS, 2010). Although breast cancer patients may have different symptoms, the main symptoms are usually shown as a lump or thickening in the breast tissue (NHS, 2010). Participants might have considered that women with big breasts have more dense tissue, leading them to think that having big breasts is one of the causes of breast cancer.

The statements also suggest that participants' identity as a Chinese woman plays a vital role on their perceived susceptibility to breast cancer, as many participants considered that breast cancer is more likely to strike at the British population. This finding is consistent with how Chinese women interpreted breast cancer causes in previous studies which showed that breast cancer was believed as to be a 'white ladies' disease' or a 'Western disease' (Kwok & Sullivan 2007; Liang et al, 2004; Wu et al, 2005). Being Chinese not only has salience in reducing participants' perceived susceptibility to breast cancer, but also lowers their perceived vulnerability to other diseases. According to health psychology models such as HBM and protection motivation theory (PMT) (Rogers, 1983), perceived susceptibility is an important antecedent of engaging in preventive behaviours. If the Chinese identity makes Chinese women feel secure against developing breast cancer, they may reduce their caution toward breast cancer and also pay less attention to breast cancer prevention and detection because they may consider that breast cancer is not relevant to them.

Physical pressure was identified as another potential cause for breast cancer by one participant. Although her comment was disagreed with by other participants, it was still an interesting point.

BC1P4: Pressing, a man pressing your breast ... I mean if the man presses your breast hard, presses it hard. Your breast will get hurt. It would causes blood clots or lumps in your breast. It causes breast cancer.

BC1P3: No, they are not relevant **BC1P4:** No, no relevance

Another participant, who used to work as a cashier in a medical school in mainland China, suggested that the level of light during sleeping can impact on the release of melanin, which can lead to breast cancer.

MC1P5: You must sleep in a dark room without any light. Even if it's a small light, it'll impact on you to release melanin. The melanin can cause breast cancer.

In addition, two participants, who originally came from mainland China, reported that they did not worry about breast cancer as it does not occur in their age. For example,

MC1P2: I didn't know this disease (breast cancer) when I was young. Now, I'm old, so I think I won't develop it.

MC1P3: I don't have to worry about it at my age. Isn't it?

These two statements reflect that participants have a misconception on the relationship between breast cancer and age and believe that the incidence of breast cancer decreases with age. In fact, getting older is the biggest risk factor for breast cancer, as 81% of cases of breast cancer occur in women older than 50 years old in the UK (Office for National Statistics, 2010).

These unusual perceptions on the causes of breast cancer suggest that participants lack specific knowledge of the risk factors related to breast cancer. It should be noted that these beliefs may not be unique to the Chinese community. Women from other ethnic groups may also hold similar views on the causes of breast cancer. More importantly, the identity as older Chinese women reduced their perceived susceptibility to breast cancer which may prohibit their uptake of breast cancer preventive behaviours.

Subtheme 3 - Other causes

Taking female hormones and taking hormonal contraceptives from a young age were considered as other risk factors for breast cancer by several participants. For example,

BH1P4: If you take it (contraceptives) for a long time and you take them when you are young, it can cause breast cancer. Because the contraceptives can produce a hormone,

it can stimulate your breast and produce the (breast cancer) cells.

MH1P1: But as far as I know, people who take hormone pills have higher chances of getting breast cancer.

MC2P2: It may be caused by drugs, yeah, may be Interviewer: Could you please talk in detail about the drugs? MC2P2: Such as the contraceptive pills

These two statements reflect that participants considered that there was a relationship between

hormones and breast cancer. It seems participants considered that hormones can control the

growth and multiplication of normal cells. The exposure to hormones can disrupt the orderly

process of normal cells and stimulate the growth and division of breast cancer cells, eventually

leading to a higher risk of breast cancer.

Other causes that participants reported involving marital status, number of children, breast

feeding, diet, environment, emotion, and harmful behaviours (smoking and drinking). These

points of view were captured in conversations among participants:

BC1P5: I heard women who had breastfed have less risk of developing breast cancer. Women who hadn't breastfed have more risk of developing breast cancer....
BC1P1: I heard women who're not married or not had children have greater risk of developing breast cancer.
BC1P4: Yes, I also heard women who're not married have greater risk

BC1P3: What about smoking and drinking?

Interviewer: Anything else? Is that any other factor related to breast cancer?
MH1P4: Food and air
MH1P2: Smoking
MH1P4: Yes, Smoking and drinking may have an effect on breast cancer
MH1P2: Hormone, and mood
MH1P4: And salty food and vegetables

4.7.3 Active health management

All focus group participants thought that being healthy is very important and hold a holistic view

of health maintenance. They mainly considered that health can be maintained by eating a

healthy diet, engaging in regular exercise but also by maintaining a positive attitude and psychological wellbeing. This view was captured from the conversations among participants.

Interviewer: How do you keep healthy?
BH1P5: Watch the diet
BH1P6: Watch the diet, do more exercise, don't eat too much meat and salt
BH1P2: Eat more vegetables and fruit
BH1P1: Don't eat too much salt and oil
BH1P4: Exercise
BH1P3: But the most important thing is being happy every day

MC1P2: The most important things is diet MC1P3: Diet and exercise MC1P6: Keep a happy mood, sing

Participants in all focus groups repeatedly mentioned the importance of eating a healthy diet either in relation to health maintenance or illness prevention. This may be influenced by Chinese culture as Traditional Chinese Medicine (TCM) suggests that health can be maintained by the normal flow of *qi* (energy) and *xue* (blood) (Koo, 1984, 1987). Food is the main source of getting energy. This may be the reason why participants pay so much attention to their dietary behaviour, such as eating light food and lots of vegetables and fruits. Participants also emphasised that they should not eat too much food at their age as they are unable to digest these foods. In their words,

BH2P2: ... Pay attention to your diet, eat little **BH2P1:** Eating more vegetables

BH2P3: Yeah, eating little is very important ... When you are over the age of 50, you couldn't digest if you eat too much

As to the engagement of exercise behaviour, most participants engaged in regular exercise, such as walking, swimming, and dancing. Overall, participants in all focus groups put much effort into keeping healthy.

Subtheme 1 - Prevention

When talking about breast cancer prevention, most participants stated that they do not know how to prevent it, as they do not know the causes or risks of breast cancer. However, almost all of the focus group participants were aware of mammography and knew that they would receive the invitation to take a mammogram regularly once they had reached a certain age in order to detect breast cancer at the early stage. More than two thirds of them showed a positive attitude to breast cancer prevention and thought taking a mammogram is an effective way of detecting breast cancer. For example,

BH1P4: Prevention is better than the treatment.

BC2P5: It's (taking mammogram) very useful. If we detect the cancer early, we can get the treatment early.

MH1P6: I think early detection and early treatment is the best solution.

MC2P2: Because we heard of many women with breast cancer, we pay much attention to it. Prevention is better than treatment, isn't it?

Participants reported that taking mammography can enable them to know their health status and

also allow them feel relief if the results are negative. For example,

BH2P1: ... You receive the results, If it says 'ok', youBH2P3: ((Cut in)) happyBH2P1: You're relieved

BC2P1: I think only a few people don't go for the screening, it's good for your health
BC2P2: They're [stupid], you don't need to pay for it and also know your
BC2P1: [stupid]
BC2P2: health status
BC2P5: Yes
BC2P2: Yes, women should go
BC2P5: At least, it may set your mind at rest, isn't it?
BC2P1: Yes, yes

This conversation may also reflect that being free of charge is an attractive factor that encourages women towards mammogram. This point of view was also mentioned by participants in other groups. For example,

Interviewer: ... Will you go for the screening if you receive the invitation letter?

BH2P3: Of course, I want to go. Why not? You don't need to pay for it ((laughs))

MH1P5: only very few people don't go for the screening. All my friends took the screening. Women of our age usually go for the screening. It's also free

MC1P4: ... We don't need to pay the medical service

Receiving the invitation letter was the most frequently cited reason why they went for

mammograms when they felt well. Other reasons participants reported mainly focused on having

symptoms. For example,

Interviewer: Have you received mammogram screening before?
BH3P1: [yes]
BH3P2: [yes]
BH3P3: [yes] because I received the letter from the government that asks me to do it
BH3P5: [yes]
BH3P6: [Yes]
BH3P2: [Yes, asked us to go for the screening] over 50 years old
BH3P4: [Yes, asked us to go for the screening]
Interviewer: In addition to the invitation letter, any other factors that encourage you to go for the screening?
BH3P1: [Cuts in] I won't go for the screening if nothing's wrong with me
BH3P3: If I'm fine, I think there is no other reason that makes me to do it

Interviewer: Have you been to the MAM screening before? BC1P3: [yes], I have BC1P5: [yes] BC1P6: [Yes], I have, I have BC1P1: I still haven't received the letter BC1P5: I receive the letter, every three years BC1P6: Yes, every three years

Interviewer: What situation could encourage you to go for the screening?
MH1P4: feeling uncomfortable
MH1P1: The hospital sending me the letter
MH1P4: Or I feel something, feel some symptoms, I'll book an appointment with the doctor

Interviewer: Apart from the invitation letter, what about the other factors that can encourage you to take mammography screening? **BH1P1:** Feeling the lump **BH1P6:** Yes, feeling lumps. Otherwise, I won't go for mammogram if nothing wrong

In this study, it was found that participants are unclear about who sends the invitation to them.

They were likely to use 'government' or 'GP' to describe the provider of the invitation. Because

women will be invited to take their first mammogram between the ages 50 and 53, several

participants in this age range in the current study still had not received the invitation. Among the participants who had received the invitation, only two of them did not go for a mammogram. It may also reflect that participants put much trust on the 'government' or 'GP' services. Participants mainly had learned their mammogram-related knowledge from the invitation letter.

Aspects of the experience of mammogram that participants discussed included the pain involved,

though some did say it is worth the pain, and being embarrassed by exposing themselves.

These points of views were captured among participants' conversations.

BC2P1: It's for you to know whether you have breast cancer, you should endure the pain. I think only a few people don't go for the screening, it's good for your health.

BC2P5: It's very embarrassing, taking off clothes, Chinese women especially don't like to expose their bodies.

BH3P1: I felt embarrassed at the first time
BH3P4: embarrassed
BH3P1: Very embarrassed. It was very painful after the screening ((laughs))
BH3P4: embarrassed at the first time
BH3P2: Yes, because I am nervous showing my body to others

MC1P5: Because I have to show my body to others, I felt shy
MC1P6: I felt shy at the first time
MC1P1: [A little bit of]
MC1P2: [A little bit of]
MC1P3: Yes, a little bit of embarrassment
MC1P6: Felt embarrassed at the first time
MC1P4: Yes, but you still have to take the screening

With regard to BSE, most participants knew that women should do BSE every month and also believed in the benefits of BSE in detecting breast cancer at an early stage. However, only a small percentage of participants (19%) did monthly BSE while the majority of them only did it when they remembered to do so. For example,

Interviewer: Do you have a regular time to do it (BSE)? BC2P3: No, no fixed time BC2P1: No particular time, just do it when I remember BC2P2: Yeah, no particular time.

MH1P2: I usually check my breasts when I remember to do it, I'm talking about myself

MH1P5: Me too. I feel my breasts when take a shower if I remember to do so

Interviewer: Do you have a routine on the breast self exam?
MC2P3: Only do it when I remember
Interviewer: Ok, you do it when you remember
MC2P3: Yes, I only do it when I remember. But most of the time, I don't remember to do it
MC2P1: Me too, I do it when I remember

The low rate of regular BSE performance may be also be attributed to being unfamiliar with the difference between mammogram and BSE. Several participants, who originally came from mainland China, considered that it is not necessary to do BSE as they take a mammogram every three years. The negative results of the mammogram make participants feel secure that they do not need to worry about breast cancer. Participants' responses suggest that they do not realize that the mammogram is a screening tool to detect breast cancer rather than a preventative behaviour and performing BSE can allow them to detect the breast cancer during the intervals between the two mammograms.

Interviewer: Do you do breast self exam often? MC1P1: No MC1P2: No MC1P3: No, we go to the hospital and take the screening every three years. If no problem with the results, it's ok MC1P4: Yes MC1P7: They don't send you the letter if you are fine. So I don't worry about it if there is no letter for me

With regard to the factors that encouraged participants to perform BSE, feeling pain was reported as the main reason to perform BSE. For example,

Interviewer: Do you do breast self exam every month?
BH3P1: No
BH3P3: I don't do it regularly. I only do it when I feel painful with my breasts
BH3P1: Yes, do it when I feel pain. Normally, I don't do it
BH3P5: I couldn't remember to do it if my breasts are not painful, no regular time

Having friends or hearing others with breast cancer was another motivator for the performance

of BSE. For example,

BH1P4: ... I usually check my breasts right away when I suddenly hear someone has breast cancer

MC2P4: I started to do it in recent years, because one of my friends passed away.... We are at the same age. I get nervous when I think about the fact that she died from breast cancer, and then I feel my breasts immediately

As to BSE competency, around two thirds of participants reported that they have some knowledge on how to perform BSE. Most of them had learned the methods of performing BSE from media such as newspaper or TV programmes, or were taught by their GPs.

Subtheme 2 - Fatalism

Fatalistic views also contributed to people's perception of illness, as some participants

considered that illness, especially cancer, is inevitable and nothing can be done to prevent it. A

participant commented:

BC1P1: It's difficult to prevent, like disease which occurs suddenly, such as cancer ... No prevention, it couldn't be prevented at all. It suddenly occurs, life is very difficult to say ... It couldn't be prevented at all. I think there is no way to prevent it. Indisposition can be prevented, but serious illness can't be prevented...I think it's providence. It's written in the stars. It's your bad luck. You have nothing to complain about. I think everyone has the fatalistic view.

Similarly, the fatalistic view concerning cancer as the will of God was also found in another group

when participants talked about a real story in which four daughters in a family were all diagnosed

with breast cancer.

MH2P3: It's your fate at this time. But this situation is rare, isn't it? It doesn't happen in every family. Keeping a good mood, eating a healthy diet, sleeping well and taking exercise is helpful for keeping healthy. But why did everyone in that family have cancer? It's fate. Sometimes, you couldn't beat God.

4.7.4 Contrasts with unhealthy British population

When talking about if there are any differences between them and the British with regard to

keeping healthy, British people were thought of as much less healthy than themselves. The

differences were mainly focused on diet, exercise, harmful behaviour, and wearing enough

clothes.

MC1P1: Big differences, the British lifestyle is different, they don't eat healthy food.MC1P5: British people don't take much exercise.MC2P6: The British like drinking and smoking.

MC2P4: They even wear few clothes at midnight when it's cold.

MC2P4: So much difference, foreigners don't pay attention on their health **MC2P3:** I think they don't pay much attention on their health, because they drink much alcohol. I think they don't pay as much attention as the Chinese in keeping healthy **MC2P4:** They wear little clothes even in the cold midnight, just a t-shirt and shorts. They don't have sense on how to keep healthy

BH1P6: ... Generally, white people, family and students don't pay attention to their health. You know their body shapes, you know they...
BH1P1: I think they are worse than us. They drink lots of soft drinks, eat lots of butter, cheeses, and etc
BH1P6: They are not good. They eat lots of protein and rubbish food
BH1P1: We, Chinese are very careful for health, eat light food and keep good health
BH1P5: Don't eat fried food, like chips

Around two thirds of participants attributed the high incidence of breast cancer among White

British women to their unhealthy lifestyle. In their words,

Interviewer: You just said that we have a lower chance than British women. Why do you think it is lower?
MC2P2: The lifestyle, the eating habits. We do much exercise, but the foreigners don't MC2P3: They like drinking, smoking and night life, and they eat fried food quite often MC2P2: Yes, fried food
MC2P3: Oven cooked, grilled, and deep fried food is more likely to cause cancer, yeah.

BH3P3: Of course, their chances are higher, because their eating habits are different from us
BH3P2: Yes, different, food, smoking and drinking
BH3P1: Yeah, yeah, their eating habits are different from ours
BH3P2: Coffee
BH3P3: They eat too much meat. We don't eat that much

Participants generally thought the Chinese pay more attention to their health and have much

more health-related knowledge than British people. This view was also captured from one

participant, who is a nurse in the UK.

BC2P5: I think we pay more attention to health, but the British don't ... They don't have

as much knowledge as we have ... Generally, they are not very good. I think we are more advanced than them on how to keep healthy.

4.7.5 Accessing health services generally

Participants in this study showed diverse approaches towards health and illness management which are affected by their perceptions of TCM and Western medicine. TCM was considered to be effective in maintaining health, restoration of health and treating minor conditions (such as colds). In contrast, Western medicine was considered to be effective in tackling the symptoms of illness and treating severe diseases such as cancer. Therefore, participants in this study are more likely to use TCM to keep healthy and prevent illness. For example,

BH3P1: It depends on the situation, for example, take some Chinese tonics to reinforce your body when the weather is cold.

BC2P5: But I think although you don't visit the Chinese medicine practitioners, but we use the Chinese medicine to prevent diseases. For example, boil some soup, we all use the Chinese medicine to prevent diseases.

When talking about breast cancer, participants put more trust in Western medicine than TCM both in terms of diagnosis and treatment. Western technology was believed to be more accurate than the diagnosis methods of TCM as it allows people to find out the real problem rapidly especially on distinguishing various types of tumour. TCM theory suggests that the human body is a unitary whole. If dysfunctions of an internal organ occur, the symptoms can be reflected on the surface of the body. TCM practitioners can determine what is wrong with the patient by using the diagnosis methods including *wang* (watching), *wen* (hearing and smelling), *wen* (asking) *and qie* (feeling the pulse). Participants in this study stated that Western technology is more effective than the diagnostic methods of TCM in detecting cancer. For example,

BH2P2: For example, how does the Chinese medicine know whether the tumour is benign or not?
BH2P3: They have no way
BH2P2: Western medicine can know whether it's a cancer
BH2P3: Do the experimental checks immediately
BH2P2: Check it
BH2P3: Yeah, it's very important

Moreover, Western medicine was believed to be more effective than TCM in treating cancers as patients are offered some potentially curative therapies such as surgery and chemotherapy. In participants' words:

BH3P2: Such as breast cancer, the Western medicine is more effective and has more specific medicineBH3P3: ... Breast cancer is a cancer. The tumour is usually removed. Isn't it? Treat the symptoms immediately. Chinese medicine works slowly on this kind of disease.

As to medical help seeking behaviour, almost all participants reported that seeking help from

their GP was the first choice when they experience health problems. They generally considered

that the healthcare service in the UK is better than in other countries, because it is free of charge.

Although participants were quite likely to visit TCM practitioners in their home countries, they

only visited the TCM practitioners in the UK when the Western medicine was not very effective.

These Chinese women put high trust in their GPs.

Interviewer: What's your first choice if you are uncomfortable?
BH1P2: [seeing GP]
BH1P3: [seeing GP]
BH1P4: I don't see the Chinese medical doctor until I have taken the Western medicine for a long time, but it doesn't work very well.

BH2P1: I won't use Chinese medicine unless the Western medicine has no effects
BH2P3: Yes, yes
BH2P1: It's not my first choice
BH2P3: The first choice is seeing the GP. This is the first choice without doubt. But if the GP couldn't help me, I'll look for other treatments
BH2P1: Yeah, yeah

Interviewer: What's your first choice if you have health problems? MC1P5: My GP MC1P6: Yes, I prefer to see my GP MC1P4: GP MC1P7: Your GP will help it MC1P6: It's better to see the GP

MC2P4: Yes, if we couldn't get better after using the western medicine for a long time, and then we visit the Chinese medicine

The reasons for the low usage of TCM in the UK that participants reported included mistrust of

the TCM practitioners, high costs and the ingredients of TCM. In their words:

BC2P5: ... I don't trust the Chinese medicine practitioners in the UK. I don't know whether they are qualified. I'm afraid to visit them, but I use the Chinese medicine to prevent disease.

BH1P1: ... the ingredients. For example, it originally should have ten herbs. However, we couldn't get two herbs here though they are easy to get in China or Hong Kong. So we only get eight out of ten herbs in the UK. If we take the medicine like this, I think the effects might be not very good.

BC2P4: Because it's very expensive, you may think, wow..., it's a lot of money.

In spite of the preference for using GP services in the UK, focus group participants experienced barriers which prevent them from seeking medical care including taking a mammogram. Aspects of the barriers to medical care that participants reported included language barriers, modesty, lack of time and practical issues.

Subtheme 1 - Language

Inability to speak English was cited as the key barrier that prevents participants from seeking medical care, especially those who were originally from mainland China. However, it was not seen as a problem for taking mammogram because women do not have to speak and are shown what to do by the nurse. Despite living in the UK for a long time, the majority of participants needed interpreting help from their relatives or NHS interpreters, as they were unable to communicate with their GP or other healthcare professionals. Participants generally commented that seeing a doctor is inconvenient for them because of the language barrier and are afraid to visit the doctor. As one participant reported,

BC2P4: There is no problem if you can speak English. I'm afraid to visit the doctor, because I couldn't communicate with them.

BH2P5: ... I don't visit the doctor if I only have some minor illness. It's a big trouble. I have to look for someone to help me

MC2P6: It's inconvenient, because we can't speak English **MC2P5:** We're Chinese. Visiting the doctor is a big trouble for me. I always have to go with a relative Even those who have a good understanding of communicational English still have difficulties in

understanding English medical terms used by doctors.

BC1P1: It's very difficult to understand what doctor said, especially the medical terms, very difficult to understand.

BH2P2: My husband and I can understand what they (healthcare providers) said about the symptoms. ... The medical terms are very difficult. So, sometimes, I ask them to write down the words that I don't understand. I can look in a dictionary later. My son can translate for me sometimes

The language barriers reduced the efficacy of communication between doctors and patients, and

even led to misunderstanding. For example, one participant talked of her experience of

unknowingly giving consent for an operation which was conducted while she was under

anaesthetic for an investigation.

MC2P4: Last year, I was 56 and found a little bleeding. I was scared and visited my GP. My GP referred me to the hospital. I had the examinations in the hospital. The doctor told me that it seems something in it and she needed to take an internal screening of me, in order to see it clearly. My English is not good. I only got this sentence, but didn't get the sentence that was 'I'll do the operation for you immediately if there is something in it'. I didn't get this sentence and signed the consent. She really found something in my uterus and did the operation for me immediately. The doctor thought I understood what she said ...But I really didn't get that sentence. I signed the consent, went into the operation room, and then they removed the tumour for me. Thank goodness. I had no problem at all.

Although a couple of participants did not have the language barriers in visiting doctors, they still

thought language is a main barrier for the Chinese population, especially the older generation.

They reported that many older people do not use the medical service, because they do not want

to be a burden for others to be an interpreter for them.

BC2P5: Some people can't speak English and can't describe their symptoms, so how does the doctor know their situation? They even couldn't tell the doctor how many times they cough every day.

BC2P1: I can express that.

BC2P5: You're different. We are not talking about you individually. We're talking about all Chinese. If they only ask me, I don't have any problem at all. So they don't need to ask me again? Isn't it? Overall, we Chinese, yeah, for some Chinese it's really hard, they can't speak English

BC2P1: Especially the older generation. It's horrible. They prefer not to see the doctor. **BC2P5:** Yes, they rarely visit the doctor, don't visit the doctor
BC2P1: Prefer to take some medicine by themselves **BC2P5:** Yes, avoiding bother for others **BC2P3:** Many people in this situation

Although many participants used their relatives as informal interpreters, they still reported that their relatives also have difficulties in using medical terms, even if they had received higher education. For example, one participant commented,

MC2P4: My daughter graduated with a masters degree, but she doesn't know many English medical terms. It's true.

Inability to interpret properly is another issue when using relatives as interpreters. Sometimes,

patients could not receive the appropriate treatment or even were misdiagnosed because of the

inaccurate interpreting. For instance, one participant talked about her friend who died from lung

cancer, in her mind only because her nephew could not explain her symptoms properly to the

doctor at the early stage.

BC2P5: I had a friend, she asked her nephew to translate for her. She had lung cancer, a cough, but he didn't know how to describe the extent of the cough. The doctor only knew about it at the last minute. It was too late. If he could have explained it clearly at the beginning, could have translated it properly, she could have been saved. Because it's difficult to translate, you can't promise that the children can translate it properly.

When talking about the NHS interpreting services, participants from both Birmingham and

Manchester stated that they were dissatisfied with this service. Mistranslating or not being

familiar with medical terms were the common issues reported by the participants with using the

interpreting services.

BH3P1: No, some translators can't communicate as well. They don't know how to say it (English medical terms)

MC1P7: Sometimes, they couldn't translate clearly, not everything they can translate

MC2P1: I'm not satisfied with the translator, because she didn't translate very clearly

Therefore, the doctors could not understand the patients' symptoms. For example, participants

felt a lack of safety with using the interpreting services.

BC1P1: Because my womb, when I was pregnant, it fell down. I don't know the medical

name, just forgot it. I spoke Cantonese with the interpreter. I told her the *rou* (Chinese word) falls down. She translated it directly to the doctor, the meat, the meat that we eat. She told the doctor the meat. **BC1P3:** It's a pain. **BC1P1:** The doctor was very confused. You couldn't translate it into meat. We don't have meat in our body. If you just randomly pass the words to the doctor, I feel it's ... to me and to the patient **BC1P3:** It lacks a sense of safety. **BC1P1:** Yes

The same experience was also mentioned by a participant in another group when talking about

her friend who visited the doctor for a uterus prolapse.

BH3P1: ... I have a friend. She did lots of heavy work after giving birth. She developed a prolapsed uterus ... When she was seeing the doctor, the translator is from China. You don't do the work if you don't have the ability. The translator said the meat, so the doctor was very confused. The translator said the meat drops off. ((laughs)) It's not meat, is it?

Although rou in Chinese can be used to describe human muscle and fat or meat, the interpreter

should appreciate that rou cannot be translated directly into meat when talking about the womb.

In addition to the poor translation, this may also reflect that the interpreter just listened to the

patient and translated word for word directly without thinking about the actual meaning of the

patients' talk.

Not being fluent in Cantonese was an issue reported by one participant. This meant this participant could not communicate with the interpreter. For example,

BC1P3: City hospital, a Vietnamese girl, very slim. It's terrible. I spoke Cantonese, she couldn't understand me. I spoke English with her, but I couldn't understand her.

The absence of an interpreter was another issue that bothered Chinese women. Several participants reported the interpreters sometimes do not attend the consultation although they booked them in advance, leading them to feel helpless and frustrated. The language barrier and poor interpreting services prohibited the participant seeking medical help from their GP and forced them to use self treatment. In participants' words:

BC1P4: She (the translator) didn't come ... I waited there, waited there for several hours

BC2P4: I have the language barrier, so I'm unable to describe my symptoms to the doctor. I am distressed if I couldn't get an interpreter. When I have interpreters, if they couldn't understand me or their English is not good, they couldn't translate my symptoms to the doctor properly. Although I know their English is not good, I fear to speak out. In this situation, I couldn't complain to the doctor. It's not his responsibility. So I bought a book, the book which is used by doctors in China. ... I gained lots of knowledge by reading the book. I don't visit the doctor for minor illness. If it's really hard, I can't endure it, I'll visit the doctor.

This statement gives the impression that this participant is forced to fend for herself and make

sense of medical texts when an interpreter is not available.

One participant, who is a nurse, pointed out the disadvantages of the current interpreting

services in that the interpreters are not provided with professional training before working.

BC2P5: So the interpreters in the UK should receive professional training first ... The problem is that they don't receive any training at all ... People who can speak two languages can be the interpreter.

Participants generally suggested the language barriers can be reduced by 1) involving more

healthcare providers who can speak Chinese and 2) providing more skilled interpreters.

Subtheme 2 - Modesty

Modesty was cited as the main barrier for not attending mammogram by one participant. This

participant stated in a low voice:

BC2P6: I'm shy, because I still haven't got married.

Shyness and embarrassment was also mentioned by another participant when talking about why

her friend had not had mammogram.

BC1P1: I have a friend ... She still hasn't gone for any mammogram at all. She said she is shy ... Just doesn't like, she doesn't like doctors doing the check for her, she feels embarrassed ... She is scared of having male doctors there.

Feeling embarrassed was also mentioned repeatedly when participants shared their experience

of taking mammogram, because they need to take off their tops and bra during the screening.

Subtheme 3 - Lack of time

Lack of time was the main reason given by another participant for not going for a mammogram. She said that,

MC1P1: They (The invitation letter) told me to go, but I didn't have time, so I didn't go. They only told me one time.

After knowing all participants except her all have been to the mammogram screening and the benefits of taking mammogram, this participant said:

MC1P1: Yes, I'll go if they ask me to go again ... because everyone in here has received this screening. I have to go.

This suggests that peers' attitudes and behaviours have a significant influence on this participant's intention to take a mammogram. Additionally, providing detailed information about the benefits of taking mammograms is another motivator to increase the uptake of mammograms.

Subtheme 4 - Practical issues

Inconvenience in taking public transport was mentioned as another barrier that prohibits

participants accessing medical services. For example:

MH2P4: I have a friend, she wants to take the (mammogram) screening, but her children don't have time to take her to the hospital ... Some women don't have a person who can take them to the place.

Actually, the inconvenience in taking public transport was due to the language barrier, which was

captured from participants' comments,

MC1P5: I can book an appointment with the interpreter, but I still need my daughter to take me to there, because I don't know how to take the bus, it's very difficult. **MC1P6:** Yes, we don't know English. **MC1P3:** Yes, don't know English.

4.7.6 Sources of health-related information

Due to the language barriers, most focus group participants stated that they generally get health-

related information from workshops in the local Chinese society, Chinese media and books. For

example,

BH1P4: Sometimes, there are a series of health-related seminars held by this society. We usually attend them.

BC2P5: Or get information from Chinese TV stations or newspapers.

MC1P4: Yes, I read these (health-related) books when I'm free.

Only a few women chose to watch or listen to English media. When asked their attitudes to the educational materials which are provided by the healthcare providers, participants said most of the materials are presented in English, so they could not benefit from it.

Leaflets were the most frequently cited favourite format for receiving health-related information, because it is convenient to take and can be read and reread at any time. In addition, leaflets can be shared with family members. DVDs were also mentioned as a favourite format of receiving information regarding breast health, because it can provide vivid and intuitive information about breast cancer screenings. Participants suggested that the DVD should be spoken in Chinese with English subtitles. Therefore, they could learn the English medical terms by watching the DVD, and thus reinforce the efficacy of the communication with doctors.

Focus group participants suggested three major ways for improving their health-related information: 1) NHS should provide more information available in Chinese; 2) more workshops should be held in the local Chinese society; and 3) healthcare organisations could distribute some educational materials in the local Chinese society, thus women could easily collect them.

4.8 The impact of demographics on breast cancer prevention and early detection among older Chinese women

According to the HBM, demographic factors also have effects on the likelihood that an individual will perform health behaviours (Becker, 1974). Therefore, this thesis also examined whether

demographic factors are associated with older Chinese women's mammography screening and beliefs and attitudes toward breast cancer prevention and early detection on the basis of the focus group interviews. Comparisons and contrasts were made in terms of age, years in the UK, place of origin, marital status, educational level, English ability, work status, and whether having relatives with breast cancer, in relation to each theme.

Regarding 'what is health?', all focus group participants discussed Chinese health beliefs. This reflects that older Chinese women still maintained strong Chinese cultural beliefs and values no matter the variation on demographic factors. The second theme that emerged from focus group discussions was 'causes of breast cancer' where genetics was considered as the greatest contributor to breast cancer by all participants. However, China-born women might have less knowledge on breast cancer compared with Hong Kong-born women, as they reported relatively more unusual beliefs about the causes of breast cancer, including physical pressure, sleeping in a dark room and misconception on the impact of age on breast cancer compared to those without relatives with breast cancer.

As to 'active health management' (third theme), participants hold a holistic view on health maintenance, which was consistent with the TCM holistic theory. The majority of participants showed positive attitudes toward breast cancer prevention and considered that taking mammography screening could help them to detect breast cancer in its early stage. There was no obvious difference on health management among participants from different demographic backgrounds.

The fourth theme was 'contrasts with unhealthy British population', where no effects of demographic factors were observed. Finally, participants discussed the issues related to

'accessing health services' (fifth theme). It seems demographic factors do not have an impact on the uptake of mammography screening. Among the non-attenders, one participant working full time reported the inconvenience of taking the time to attend the screening as the reason for not attending mammography screening. However, it is difficult to assume that work status is associated with mammography adoption as the sample size was quite small. The impact of work status on mammography screening should be further explored. Despite previous studies having identified age, education, and duration of residency in current country as predictors of mammography screening utilization among Chinese women (Lai & Chau, 2007; Yu et al, 2005), the effects of these demographic factors on breast screening were limited through comparing the attenders and non-attenders. The reason probably could be attributed to the fact that all women are invited to attend breast screening regularly once they had reached the eligible age and mammogram is a free service in the UK. In addition, focus group participants did not differ significantly on demographic data as the majority of them were living in the UK for more than 15 years and had limited English proficiency and lower education level.

Limited English proficiency was the most commonly reported barrier to accessing health services. Not surprisingly, older women with higher English ability reported fewer difficulties in seeking medical help compared to those who could not speak English. In addition, the place of birth was found to be associated with English ability, as China-born women reported more language barriers than those who were born in Hong Kong. The disparities in using health care services were more obvious among women who were living in Manchester.

4.9 Summary

To better understand the psycho-social factors related to breast cancer prevention and early detection among older Chinese women living in the UK, nine focus groups with 52 women recruited from Birmingham and Manchester were conducted. The self-reported screening rates

in this sample were relatively higher than the findings from previous studies. Receiving the invitation letter to attend breast screening was the most important influence for attending the mammogram among Chinese women. On the other hand, being free of charge was also associated with the adoption of mammography screening. It appears that pain and embarrassment were the most frequently reported experience associated with mammography screening. However, older Chinese women still showed positive attitudes toward the breast screening program. Barriers to the adoption of mammography screening included modesty, lack of time and practical issues. It should be noted that despite language not being identified as a barrier to breast screening, it was the most commonly reported barrier to obtain health-related information and the use of health services.

Consistent with the results of previous studies, older Chinese women had limited knowledge on breast cancer causes and prevention. The majority of them attributed breast cancer to a genetic disease, and thus reported low perceived susceptibility to breast cancer. It was observed that Chinese health beliefs and the holistic view on health maintenance have an impact on breast cancer prevention, as participants commonly reported eating healthily, doing exercise and keeping a good mood as the ways to prevent breast cancer. Despite fatalistic views on breast cancer prevention also being observed, participants agreed that taking a mammogram is an effective way to detect breast cancer at the early stage when it is more likely to be treated. This suggests that older Chinese women clearly distinguished the difference between breast cancer prevention and detection and also believed in the benefits of mammogram in early detection.

Compared with studies among women from other minority ethnic groups (Karbani et al, 2011; Moy, Park, Feibelmann, Chiang, & Weissan, 2006), Chinese women shared several common themes with their counterparts, including lack of breast cancer-related knowledge, a fatalistic view on breast cancer prevention, language barriers to using health services, modesty, lack of

time and practical issues. Different ethnic groups have diverse cultural beliefs and values about health, breast cancer and breast screening though there are common barriers to mammography screening among women from minority ethnic groups. In the current study, Chinese women showed unique holistic views on health and health maintenance, which are associated with the theory of TCM. In addition, Chinese women showed positive attitudes on breast screening and appreciated the benefits of detecting breast cancer in its early stage.

Breast screening interventions should strengthen the motivators and try to eliminate the barriers related to breast screening identified in the findings. Health service providers must acknowledge the impact of Chinese culture and language barriers on the usage of health care services, and thus provide culturally and language tailored service to better serve older Chinese women. The following chapter will explore the psycho-social factors related to breast cancer prevention among younger Chinese women, because this population is less likely to have a language barrier and higher acculturation than older women. There should be some differences between these two age groups. It is anticipated that the data from these two age groups should be sufficient enough to reflect the breast cancer prevention and screening practices among Chinese community.

Chapter 5 Psycho-social factors related to breast cancer prevention among younger Chinese women in the UK

5.1 Introduction

Although the majority of breast cancer occurs among women over 50 years old, breast cancer still strikes women under the age of 50. In breast cancer patients of known Chinese origin, around 32% were diagnosed with breast cancer under the age of 50, compared to 18% in patients known to be white in the UK (National Cancer Intelligence Network, 2008). In addition, breast cancer is the second most common cancer in women under 35 years old (Cancer Research UK, 2009). Understanding younger women's beliefs related to, and their engagement in, breast cancer prevention has significant meaning for developing effective breast cancer interventions that are targeted at this population. Therefore, the objective of the third study was to explore the psycho-social factors related to breast cancer prevention among younger Chinese women aged between 20 and 35. Focus groups were selected as the most appropriate method to generate insights into the research topic (Please refer to section 2.4.3 for details). The focus group discussion was guided by an interview schedule (Appendix 6), which was developed similarly to the focus group schedule for older participants, to ensure that the important issues of breast cancer prevention were covered. Twenty-one participants (M=27.80, SD=3.89), who were recruited from Aston University, Birmingham Chinese society and Wai Yin Chinese Women Society in Manchester, participated in this study. Participants discussed their health beliefs, breast cancer-related beliefs and knowledge, breast cancer screening behaviours, medical help seeking behaviours, and interactions with healthcare providers. This chapter describes the focus group schedule, specify participant recruitment, focus group procedure and also report the breast cancer screening experience for younger participants and the key themes identified during thematic analysis.

5.2 Material

The focus group schedule for younger Chinese women (Appendix 6) was developed similar to the one used for older Chinese women. It used open-ended questions (Table 5.1) to explore the psycho-social factors related to health and breast cancer prevention among younger Chinese women and also guided the focus group discussion. There was no substantial difference between the focus group schedule for older and younger women as both focus group studies had the same purpose i.e. to understand Chinese women's health beliefs and breast cancer preventive behaviour. However, the discussion points regarding breast cancer screening were different in these two age groups. The discussion among younger women mainly focused on the performance of BSE as it is the most useful method for younger women and mammography is not provided in this age group. In addition, this schedule included questions regarding the experience of being interpreters, as it was noted during the focus groups with older Chinese women that they quite often use their family members as informal interpreters when they visit English-speaking doctors because they spoke limited or no English themselves.

Table 5.1 Topics and example questions of focus group schedule among younger Chinese women in English

| Topics | Example questions | | | |
|--|--|--|--|--|
| Health Belief Model variables-related questions | | | | |
| perceived susceptibility | What do you think about your susceptibility of | | | |
| | developing breast cancer? | | | |
| perceived benefits | What do you think about breast cancer | | | |
| | prevention? | | | |
| perceived barriers | Are there any factors that reduce your possibility | | | |
| | of preventing breast cancer? | | | |
| health motivation | What does health mean to you? | | | |
| | What do you think are important things for | | | |
| | keeping healthy? | | | |
| | What do you usually do to keep healthy? | | | |
| cues to taking breast cancer | What particular environments could encourage | | | |
| preventive behaviour | you to try to prevent breast cancer? | | | |
| Other questions related to variables found to be important in previous studies | | | | |
| breast cancer related knowledge | What do you think are the causes of breast | | | |
| | cancer? | | | |
| | What do you think are effective ways of | | | |
| | preventing breast cancer? | | | |
| experience of breast cancer | Do you perform BSE regularly | | | |
| prevention | | | | |
| medical care seeking behaviours | What do you usually do if you feel unwell? | | | |
| The interaction with healthcare | What do you think about the health services in | | | |
| providers | the UK? | | | |
| | What do you think about the health care | | | |
| | providers in the UK? | | | |
| experience of being interpreter | Have you ever been an interpreter for your | | | |
| | family or friends? Could you please talk about | | | |
| | your experience? | | | |

5.3 Participant recruitment

Ethical approval was granted by Aston University Ethics Committee (Appendix 8). Younger participants were recruited through Aston University, Birmingham Chinese Society and Wai Yin Chinese Women Society in Manchester. Chinese women who originally came from mainland China, Hong Kong, or who were born in the UK or other Western countries aged between 20 and 35 were regarded as potential participants in this study. The Birmingham Chinese Society and Wai Yin Chinese Women Society were informed of the inclusion criteria and responsible for participant recruitment. The study was advertised through flyers at Aston University. Participants

were emailed or sent the participant information sheet (Appendix 11) which stated detailed information about the purpose, procedure, benefits, potential risks and discomfort, compensation for taking part and the voluntary nature of participation and withdrawal. Younger Chinese women were also offered the researcher's contact information if they request further information. The information sheet was written in both English and Chinese.

The researcher originally planned to divide the participants into groups according to their education level and place of birth such as outside UK-born and UK-born. However, the researcher failed to recruit enough UK-born participants despite the effort to recruit those younger Chinese women. It may be attributed to the fact that only 26.09% of the Chinese population aged between 25 and 34 were born in the UK (Office for National Statistics, 2005). As a result, the groups were finally organised according to the women's education level alone. Therefore, there were four groups in this study: one group of women studying at Aston University (AH), one group of women with higher education from the Birmingham Chinese Society (BL) and one group of women with higher education at the Wai Yin Chinese Women Society (MH).

Similarly to the focus group study among the older generation, the planned number of participants in each group was six in order to generate a good group dynamic. However, the BL group had only recruited four participants without higher education. According to the 2011 Census, around 43% of Chinese had degree level qualifications in the UK. This might explain why this study did not recruit the planned number of younger Chinese women without a higher educational level. Among these participants, one participant (BLP2) was originally from Malaysia who was not eligible for the current study, hence her data were removed from the data analysis. In addition, one participant dropped out of the BH group. Therefore, the number of participants in each group varied from 3 to 6. It was anticipated that focus groups among younger Chinese

women would produce a range of detailed information and deep insights on breast cancer related beliefs, perception and preventive behaviours, with level of education being the main source of variance. The recruitment of younger participants took place from March to July 2010.

5.4 Demographic data of younger participants

Four focus groups with 20 Chinese women aged between 20 and 35 years (M=27.55, SD=3.89) were conducted in this study. About 60% (n=12) had lived in the UK for 6 years or longer. Thirteen participants were born in China, 5 in Hong Kong, and 2 in others countries (1 in US and 1 in Germany). Just over half of the participants were single (55%, n=11), while the rest were married or living with a partner (45%, n=9). The majority of participants had received higher education (85%, n=17). About 35% (n=7) had a full time job, 10% (n=2) worked part time, 15% (n=3) were unemployed, 5% (n=1) were housewives, and 35% (n=7) were students. Almost all participants had no relatives with breast cancer (95%, n=19). Participants were labelled with a unique code to represent which focus group they were allocated in and their educational levels. For example, AHP1 means Aston University, higher educational level and participants.

| Code | Age | Years in the UK | Place of birth | Marital status | Having relatives with breast cancer | Education level | Occupation |
|------|-----|-----------------------|-------------------|-------------------|---|---------------------------------------|------------|
| AHP1 | 28 | 1-5 | China | Married | No | University | Student |
| AHP2 | 23 | 1-5 | China | Single | No | University | Student |
| AHP3 | 25 | 1-5 | China | Single | No | University | Student |
| AHP4 | 28 | 1-5 | China | Single | Yes | University | Student |
| AHP5 | 26 | 6-10 | China | Married | No | University | Student |
| AHP6 | 28 | 6-10 | China | Single | No | University | Student |
| BHP1 | 35 | 6-10 | China | Married | No | University | Unemployed |
| BHP2 | 26 | >15 | US | Married | No | University | Full time |
| BHP3 | 29 | 6-10 | China | Single | No | University | Full time |
| BHP4 | 24 | 6-10 | German | Married | No | University | Full time |
| BHP5 | 23 | 6-10 | HK | Single | No | University | Unemployed |
| BLP1 | 35 | 11-15 | HK | Married | No | Further educational after high school | Full time |
| BLP3 | 33 | 11-15 | HK | Single | No | Further educational after high school | Full time |
| BLP4 | 32 | 6-10 | China | Married | No | Left school without qualification | Housewife |
| MHP1 | 25 | 1-5 | China | Single | No | University | Part-time |
| MHP2 | 25 | 1-5 | China | Single | No | University | Full time |
| MHP3 | 27 | 6-10 | HK | Single | No | University | Student |
| MHP4 | 28 | 6-10 | HK | Married | No | University | Part-time |
| MHP5 | 22 | 1-5 | China | Single | No | University | Unemployed |
| MHP6 | 29 | 6-10 | China | Married | No | University | Full time |

Table 5.2 Demographic information for focus groups among younger participants

Note. HK = Hong Kong

5.5 Procedure

Except the BL group of women, the other three focus groups (AH, BH, & MH) were all conducted in English, as participants in these three groups showed high proficiency in English. The BL focus group was conducted in Mandarin, because one participant could not speak English. In this group, the interviewer and two participants spoke Mandarin while one participant spoke Cantonese. Although the participants and researcher could all understand Mandarin and Cantonese, a bilingual interpreter translated the interviewer's questions to Cantonese, in order to make sure that all participants understood. The content form (Appendix 15), demographic questionnaire (Appendix 16) and debrief (Appendix 17) were presented in Traditional Chinese for the BL group whereas the other three groups were provided with the English version.

The procedure was the same as the procedure that was used among the older generation. Before the commencement of the focus group, participants were given an overview of the purpose and procedure of the study and also presented the ground rules. Participants signed the consent form after they had agreed to participate in this study. At the start of discussion, a demographic questionnaire was distributed to each participant to complete. The length of group discussions varied from 70 to 110 minutes. When the focus group was completed, participants were debriefed and received £20 to cover their travel expenses.

5.6 Breast cancer screening experience for younger participants

Table 5.3 summarizes breast cancer screening experience for younger participants. Only four participants had consulted a healthcare professional about breast cancer (n=4, 20%). Almost all of the participants had never had a mammogram (n=19, 95%) or had not had a recent mammogram (n=19, 95%). Only two participants had ever had clinic breast examination (10%) and three participants had had a recent clinic breast examination (15%). As to breast self-examination, the majority of participants had never done any breast self-examination (n=12, 60%). Only 5% (n=1) and 10% (n=2) participants respectively performed breast self-examination every month or more frequently.

Table 5.3 Breast cancer screening experience for younger participants

| Behaviours | No. of participants | % Total |
|---|---------------------|---------|
| | (N=20) | |
| Had consulted about breast cancer before | | |
| Yes | 4 | 20 |
| No | 16 | 80 |
| Ever had mammography in previous three years | | |
| Yes | 1 | 5 |
| No | 19 | 95 |
| Had a recent mammography within one year | | |
| Yes | 1 | 5 |
| No | 19 | 95 |
| Ever had clinic breast exam in previous three | | |
| years | | |
| Yes | 2 | 10 |
| No | 18 | 90 |
| Had a recent clinic breast exam within one year | | |
| Yes | 3 | 15 |
| No | 17 | 85 |
| Had experience of breast cancer screening | | |
| Yes | 5 | 25 |
| No | 15 | 75 |
| How often perform breast self exam | | |
| Never | 12 | 60 |
| 3 or 4 times a year | 5 | 25 |
| Every month | 1 | 5 |
| More often than frequently | 2 | 10 |

5.7 Key themes

Focus group data were transcribed verbatim. The Chinese transcript was translated into English by the researcher. Thematic analysis was conducted to analyze the focus group data based on the stages described by Braun and Clarke (2006, p. 87): 1) familiarising yourself with your data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming; 6) corroborating coded themes and 7) producing the report (please refer to Section 2.4.3.3 for details). Table 5.4 displays the themes and subthemes that were expressed by younger Chinese women.

These themes will be discussed individually using data extracts from the focus groups among

younger Chinese women.

| Themes | Subthemes |
|--|--|
| 1. What is health? | |
| 2. Causes of breast cancer | Genetics |
| | Using female hormones and medication |
| | Lifestyle |
| | Psychological factors |
| | Age |
| | Menstruation retained in the body |
| | Unusual beliefs |
| 3. Active breast health management | Neo-fatalism |
| | Breast cancer prevention |
| 4. Contrast with British population on keeping | |
| healthy | |
| 5. Healthcare seeking behaviours | |
| 6. Barriers to seeking medical help in the UK | Inconvenient referral system |
| | Long waiting time |
| | No accessibility out of the normal work hours |
| 7. Interaction with healthcare providers | Prescribing |
| | Lack of confidence in using GP services |
| | Different body constitution |
| 8. The experience of being an interpreter | Lack of proficiency in Chinese |
| | Difficulties in translating Chinese concept of |
| | illness |
| | Not familiar with English medical terms |

5.7.1 What is health?

All focus group participants, regardless of their education level, stated that being healthy is very

important to them. Participants frequently reported that being healthy means the whole world or

life to them. They even stressed that being healthy is not only important for themselves, but also

has a significant meaning for their family. For example,

Interviewer: What does health mean to you?
MHP1: It means the world. If you don't have health, you can't live every day, you can't enjoy the sunshine, you can't go outside work, you can't study, and you can't do anything. ... And I would like to treat everything with health really
MHP2: Yeah, for me, I thought it's everything, it's, it's I can put an equal side to life. Yeah, it's your life...
MHP3: It's important. ... But also you are affecting your family as well, like if you don't

¹ "Neo-fatalism" was a term coined by Professor Helen Pattison. Personal Communication.

have the health, then they might have to suffer things they might need to take care of you

Participants generally assessed their health status on the basis of their personal feelings. For example, participants in all groups perceived health as the absence of illness, feeling fine, mentally and physically well-being, or having enough energy. Health is part of their daily life experience. For example:

Interviewer: Ok. What do you think health is?
HLP4: No illness, no pain
Interviewer: Ok, no illness, no pain
HLP4: Yeah, I think health means you can eat well and sleep well

MHP3: I eat well, sleep well, don't drink, don't smoke, I feel I'm very healthy. I also don't have silver hair and wrinkles **MHP1:** I think health mentally and physically. Mentally means you have to have a positive attitude and you need to face survive everyday with a good mood. And physically you need to be healthy...

AHP5: Have fairly enough energy to do your normal life. ... If you are feeling fine, that's that's health

Several participants mentioned that they sometimes assess their health status according to the diagnostic methods of the Traditional Chinese Medicine (TCM), such as *Wang* (observation). TCM suggest that the human body is an organic entity, so local pathological changes may have an influence on the whole body. In addition, the pathological changes of the internal organs may reflect on the body surface. *Wang* is one of the methods to examine the patient by observation of the expression, appearance, colour, and abnormal changes of secretion and excretion in Chinese medicine. Using *Wang* to estimate their health status was captured from the conversation among participants who are currently studying at Aston University.

AHP3: I think it's Chinese medicine. You can always see some, er, maybe if you really have some problem, it will appear in front of your body. In Chinese medicine, if you have some inside problems, your body will show some symptoms outside

AHP5: Yeah, like you can see if you are healthy of your digest system from your tongue **AHP2:** Yes, from your hand

When talking about health management, participants believed in a holistic approach to health

maintenance and suggested that eating healthy food, taking regular exercise, leading a regular

life, having good habits and keeping mentally healthy are important components in keeping

healthy. For example,

AHP6: Leave the junk food ((laughs)). Have a regular life cycle, like sleep, sleep early, get up early

AHP1: Do some exercise, make yourself happy **AHP2:** Have a positive attitude to your life

BHP5: Do more exercise
BHP1: And eat wisely
BHP2: Yeah
BHP3: Eat balance diet
BHP2: [Yeah]
BHP5: [Yeah]
Interviewer: Ok. Any other ways?
BHP2: Ideally don't smoke, ideally don't drink
BHP1: Sure, sure
BHP5: happy everyday
Interviewer: ok
BHP1: Yeah, emotion plays a very important part ...

BHP3: And sleep, don't stay up too late

BLP4: I think the most important thing is your mood, having a happy mood. If you are in a good mood, you can eat well and sleep well. This is health **Interviewer:** Except the good mood, any other important things for keeping healthy? **BLP1:** exercise, moderate exercise.

MHP1: ... live your life positively, like eat proper food, like have a good habit, and do exercise regularly, and so that you can keep up with your health

When asking what the proper food means, participants explained it as a balanced diet and also

emphasised the importance of having a balanced diet. For example:

Interviewer: You just mentioned the balanced diet. Could you please talk about it in detail? BHP1: Alright, fish, meat, vegetables, salad, good. No fried, especially deep fried BHP2: ((Cut in)) En, steam food is good BHP1: chips, not very good, just occasionally BHP3: Have rice BHP1: Rice is ok BHP2: Yeah BHP3: Rice, noodles, that's great BHP1: Yeah, yeah, yeah, that's good

BLP1: The food... Yeah, and don't fry food, don't eat the food which is too hot, too salty

and too sweet... I don't have any particular standard, just eat some light food. But it shouldn't be too overemphasised. Otherwise we are going to lose our immunity.

BLP4: I'm not over strict on my diet. For example, telling myself I can't eat this or can't eat that. I think I'm ok, just eat some light food. I think it's abnormal if you over care about your diet **BLP1:** Yeah, if you over care about your diet, there will be no difference with an

unhealthy diet

Food is considered as a vital way for keeping healthy in the Chinese culture, as TCM suggests that health depends on the normal flows of *qi* (energy) and *xue* (blood) and food is seen as an important source of energy (Koo, 1984, 1987). Eating a balanced diet and having meals on disciplined timing were mentioned as very useful ways for staying healthy. Koo (1984, 1987) pointed out that nowadays almost all Chinese families are still using the manipulation of nutrition intake as their first choice to maintain good health and prevent or cure illness. In the current study, eating light and moderate amounts of foods was considered as essential in maintaining good health, as participants believed that dietary behaviour is associated with the immune system. Not caring or over caring about the diet could also lead to health problems. Therefore, participants emphasized the importance of eating a balanced diet.

Regarding their activities for keeping physically healthy, participants in all groups stated that they make some efforts to eat a healthy diet, avoid harmful habits (like smoking and drinking) and to have a regular life (e.g. regular eating and meal times), but they do not engage in regular exercise because of laziness, no-one to accompany them and time. In their words:

Interviewer: Do you usually do exercise? AHP1: No AHP5: No AHP3: I plan, I hope I can have that habit, but I can't, I'm lazy AHP5: Me too

AHP1: I quite happy to do the exercise, but I I, maybe I need someone to accompany me, I don't want to do exercise only alone

Interviewer: Do you exercise? **BLP1:** No, I don't.

BLP4: Very little. Most of the time, I just take the kid to the park for a walk. That's all
BLP1: Er, I don't know if climbing stairs can be counted in or not. I only do that
Interviewer: You all said keeping exercise is good for health, but you don't do it regularly
BLP1: We don't have time
BLP3: And we don't have company
BLP1: Yeah, yeah, have no company
BLP3: I wouldn't do exercise if I'm alone

These statements reflect that lack of motivation was the intrapersonal barrier that inhibited younger Chinese women to participate in regular exercise. Zhang and Cooke (2012) suggest that changing motivation is the first step of changing exercise behaviour. The positive relationship between motivation and exercise behaviour has been documented in many studies (e.g. Thogersen-Ntoumani & Ntoumanis, 2006). Lack of peer support was identified as a common interpersonal inhibiting factor for performing exercise regularly. This implies that social support is an important motivator to participation in regular exercise. Another barrier was a lack of time, which reflects that physical activity is not a competing priority when compared with other activities in younger Chinese women's daily life.

Participants stressed that mental health is as important as physical health, and believed that having a positive attitude or keeping a good mood is not only helpful in maintaining health, but also useful for fighting diseases. For instance:

MHP3: I think your mood is very important. Like I have heard so many case, ... people get very like terminal illness like cancer or things like that. But because they have got the, I don't know, you know the encouragement, they got a positive attitude and they, you know beat the disease itself. I think it's very important for you to have a positive attitude whatever happened. Yeah, like she said, you need to deal with things that you know doesn't go your way

BHP2: ... I think the mind is a very powerful thing. If you know you ill, you got to think I'm ill, I'm going to die, er, I'm ill. oh.. But if you think ok, I get illness, but I'm going to fight against it. I er... I'm not going to think about it. I just carry on life as normal. I think you do feel a little bit better

The need for annual checks was also put forward by several participants with higher education at Aston University. For example:

AHP3: Do annual check... your body need to be checked every year
Interviewer: So did you do it or not? ((laughs))
AHP3: I just think about it. No, no. ((laughs))
AHP2: I like to do it and from now on, check my body every year
AHP6: I check every two years. Because every summer holiday, I back to China, I'll be checked about, not every year, twice, er... no, two years, yeah, just two year time

It is thought that younger women with a higher education level probably were more aware of the benefits of having regular medical check-ups. However, the low participation in regular medical check-ups may reflect that younger Chinese women's personal experiences of health maintenance and illness prevention are still grounded in Chinese cultural beliefs and values as the regular check-ups are not recommended by the TCM.

5.7.2 Causes of breast cancer

Subtheme 1- Genetics

Genetic susceptibility was mentioned as the main cause of breast cancer in all groups, as

participants believed that breast cancer is an inherited disease and related to genes. For example,

BHP4: ... the genes, like DNA, just some people are more likely, some people are less likely to have it, so it could be caused because your family... it likes some cancers come up, keep coming up with your family
BHP5: [Yes]
BHP2: [Yes]
BHP4: It likes some cancers come up, keep coming up with your family. That's mean BHP2: In your DNA

Interviewer: What do you think causes breast cancer? BLP3: I never thought about it BLP4: I think it's inherited...

BLP3: I never thought about it. I think if someone in your family has breast cancer, you might be easily to develop breast cancer

The genetic view of breast cancer causation was also captured from participants in other groups.

For example, participants in Manchester reported that men can develop breast cancer if they

have a family history of breast cancer. In their words,

MHP2: Personally I think most of the reasons from the genes, I never heard any bad habit will cause breast cancer, but I don't know, I'm not sure about it, yeah, I think it's the genes problem
Interviewer: Ok. Can you talk about detail about the genes problem?
MHP2: I don't know. It's just like normal, normal cancer, so when you, when they want change, they change. So I have no idea why, so I'm
MHP1: ((Cut in)) Youh, also I have no idea why, so I'm

MHP1: ((Cut in)) Yeah, also I heard one of the story that the family have high risk of breast cancer even a man can get a breast cancer **MHP2:** Yeah, definitely

Several participants with higher education believed that white British women have a higher risk

for developing breast cancer than Chinese women and attributed the main reason to the genes.

For example,

MHP1: It's like most of the white women they easy to get breast cancer and Asian women I think probably less, but I'm not saying they don't get, but less risk
MHP3: Ur
Interviewer: Why do you think white women are more likely to get breast cancer?
MHP1: Er I presume their er living habit and their genes and their living like the environment, these kind of things, but mostly because of their genes I think
Interviewer: Ok. Anything you want to talk about?
MHP4: I think the most reason is from the genes...

BHP4: ... I think that could depends on what you have in your genes and what you do with, yeah

Interviewer: Ok. Why do you think they have the higher rate?

BHP2: Er I'm both terms I think. I think eat differently to us, the lifestyles different, and like you said in the DNA as well, from like their grand grand grandmother or something

Although there are specific genetic groups (such as BRCA1, BRCA2) that have a higher risk of

developing breast cancer than the rest of the population only 3% of breast cancer patients have

the known genes (Cancer Research UK, 2009). Around half of the participants, regardless of

having high or low education, over evaluated the effect of breast cancer genes on breast cancer,

leading them to consider that they will not develop breast cancer or have a low risk of

developing breast cancer because they do not have a family history. In their words:

BLP3: So far, no one in my family has had breast cancer, so I think I won't have that as well. ... Actually, I think women developing breast cancer only when someone in her family has breast cancer. There is no point you develop breast cancer without a family history

AHP6: I think I won't have that the chance to get breast cancer. It's not 100% sure you are not going to get that

AHP5: Yeah, me too. Because I don't have relatives have that

Subtheme 2 - Using female hormone and medication

Around one third of the participants mentioned that using female hormones for long periods can

cause breast cancer. One participant talked about her friend's auntie who had taken female

hormones for a long time but felt unwell. In her words:

AHP6: Because some of the medicine, they have the female hormone. When you eat a lot and every day, they will affect your breast, and they can cause breast cancer **Interviewer:** Do you have any idea what kind of medicine could cause breast cancer? **AHP6:** I think it's the primrose oil, the evening primrose oil. ... Because I saw my friends, he, she always bought some that kind of medicine for her auntie, and she ate quite a lot for the 5 years already, but she feels not really good now. She just stops it

A similar statement was reported by another participant, by considering celebrities who are more

likely to develop breast cancer as they use too many female hormones. For example,

BLP4: Usually, celebrities are more likely to get breast cancer. I think maybe because they use too much hormone, they are more easily to develop some diseases

Additionally, another participant reported high perceived susceptibility to breast cancer, because

she is taking medicine regularly. She also considered that taking the contraceptive pill may also

increase the possibility of developing breast cancer.

MHP3: I think I do think I'm likely to get the breast cancer though because I'm taking medicine regularly, so it's one of the, I do believe one of the reason why people get breast cancer as well if they take er medication regularly or er they, you know like those er, those tablets for you to prevent you to get pregnant, those or hormones, and I think it causes high possibility to get breast cancer

These statements reflect that participants strongly believe that hormones have an effect on

breast health. They might think taking hormones for a long time may disrupt their hormone levels,

and thus lead to the increased risks of breast cancer. These beliefs were generally generated

from participants' personal experience or the observation of others.

Subtheme 3 - Lifestyle

Another of the most frequently mentioned causes of breast cancer in all groups was lifestyle, which mainly concentrated on harmful habits, unhealthy diet and exercise. For example, several participants reported that there is a link between breast cancer and harmful habits such as smoking and drinking as they considered that the likelihood of developing breast cancer increases with the amount of cigarettes and alcohol consumed. In participant's words:

MHP4:... but also their living habit, ... and maybe someone some ladies smoking, the chance get the breast cancer will be higher than the, the ladies or people who don't have the bad ha, bad ha, bad habit

Interviewer: What do you think causes breast cancer? **AHP1:** Smoking, drinking alcohol...

Unhealthy diet was reported as another contributing factor to breast cancer. For example, one

participant stated her view regarding the effect of salty food on breast cancer. In her words,

BLP4: People said eating too much salty food may have the influence (on breast cancer)

Another participant stated that eating junk food regularly can disrupt the balance of hormone

levels, leading to the increased risk of developing breast cancer.

BHP5: They eat too much junk food, they not eat healthy. The Chinese women eat healthy

AHP5: Maybe junk food, ... some food will cause the imbalance of hormone levels, probably will cause breast cancer

These statements reflect beliefs that dietary behaviour can influence the risk of developing breast cancer. Participants considered that an unhealthy diet could disrupt the balance of hormone and thus cause breast cancer. The statement from AHP5 confirms other participants' views of the relationship between hormones and breast cancer which was discussed above (theme 2.2).

Physical activity was also considered to play a role in the causes of breast cancer as one

participant stated that the low level of physical activity can increase the risks of breast cancer.

For example,

AHP1: Smoking, drinking alcohol, and er...er... do not exercise quite often

Subtheme 4 - Psychological factors

Psychological factors were also reported as having an impact on breast cancer. Participants

considered that long term exposure to negative emotions can increase a woman's risk of

developing breast cancer. For example,

Interviewer: Anything else (for the causes of breast cancer)? **AHP2:** I think stress and bad temper, don't have a very normal life **AHP3:** ... I think the mood cause cancer a lot

A similar view on emotional causes of breast cancer was stated by another group of participants when they attributed the high rates of breast cancer among white British women to negative emotion. In their words,

BHP1: So I think British women maybe a little bit more emotional than Chinese women.
BHP2: Yeah, yeah, yeah, I agree
BHP1: More, I think it's easier for them to get stressed even
BHP2: En.
BHP1: you know the same issue, if it happens to a Chinese woman, maybe it's nothing, but if it happens to a British girl, maybe it's an issue

These statements are consistent with one of the TCM views of breast cancer aetiology. TCM suggests the function of human organs is influenced by 'seven emotions': *xi* (joy), *nong* (anger), *you* (worry), *si* (pensiveness), *bei* (grief), *kong* (fear), and *jing* (fright) (Sun, 1991). According to TCM, the accumulation of the negative emotions can cause stagnation of *qi* (energy) and the *xue* (blood) stasis, and thus cause a lump in the breast. This lump can eventually progress to breast cancer (Sun, 1991). Participants' view regarding the influence of emotions on breast cancer might be affected by TCM. This point of view can also be linked with participants' statements about the importance of keeping a good mood in health maintenance (theme 1). Despite participants not explaining the effect of emotions on the causes of illness from the TCM theory, their statements indeed reflect that TCM guides young Chinese women's health beliefs.

Subtheme 5 - Age

Around a quarter of participants identified age as a strong risk factor for breast cancer, as breast cancer was perceived as being common among women over 50 years old. However, several participants considered that breast cancer does not strike at younger ages, thus they perceived low susceptibility to breast cancer. For example, one participant with higher education stated that although women have a high risk of developing breast cancer, she felt that she has no chance of getting breast cancer at a young age. In her words:

AHP2: ... I didn't always think about it, think about I'll get this cancer later. I didn't think about it. But I think for female, you should consider about it, because maybe one day you will get it. We know it, it is really a high risk for female...
Interviewer: You just mentioned women have a high risk for developing breast cancer, but you said you don't think you have a big chance
AHP2: Because I think I'm very health. Yeah, I don't have that kind of problem with me, so just no, not very worry about it. Maybe later, when I get married, maybe it'll be a problem

The same view was also captured in the statements of another participant in Manchester. For example,

MHP6: ... I think women will get breast cancer after like they have children, they have like after they give breastfeeding. Yeah, so I'm not married, so I don't think I'll get breast cancer

Subtheme 6 - Menstruation retained in the body

Having menstruation retained in the body was identified as another cause of breast cancer. For example, one participant explained the causes of breast cancer according to the TCM that health depends on the normal flows of *qi* (energy) and *xue* (blood). In TCM, one of the most common causes for breast cancer is that if the *qi* and *xue* are deficient, they cannot flow smoothly, and thus lead to *qi* stagnation and *xue* stasis, which finally causes the formation of tumours in the breast. This participant stated that the breast cancer was caused because of menstruation retained in the body. She explained:

AHP3: I heard that Chinese medicine and Chinese doctor said that when woman in period, the wasted blood if that can't go out totally, it may stay in the, I don't know the

word, stay in the body for a er short time, it may cause cancer, breast cancer. ... I think that's probably right in Chinese medicine. We talk about the bad thing, but, and the qi. How to say it? Yeah, that's it

Although this participant did not clearly state the causes of breast cancer from the theory of TCM, it still could be seen that her statement mainly focuses on the flow of *xue*. Combined with the statement regarding the effect of psychological factors on breast cancer, it suggests that the theory of TCM contributes to younger Chinese women's beliefs about the causes of breast cancer.

Subtheme 7 - Unusual beliefs

It should be noticed that one participant without higher education put forward some other unusual beliefs on breast cancer causes which seem have not been supported by any scientific evidence at present. For example, she considered that breast cancer can be caused by using antiperspirants. In her words:

BLP1: I have read it online that using the antiperspirants might cause breast cancer. ... Or we'll be absolutely safe if we don't remove the armpit hair

In addition, when talking about the risk factors for breast cancer, she considered that compared with Chinese women, white women have a higher risk for breast cancer due to them having more hair.

Interviewer: Compared with white women, what do you think about the rates for Chinese women getting breast cancer? Higher, lower or same? **BLP1:** I think it's lower... They have more hair

Interviewer: Why do you think they have the high rates because they have more hair? **BLP1:** I have no idea. I just think so

These statements suggest that this participant lacked knowledge on breast cancer. In addition, it

should be aware that these views might be held by women from other ethnic groups.

5.7.3 Active breast health management

Subtheme 1 - Neo-fatalism

The neo-fatalistic view regarding breast cancer prevention might be attributed to the genetic

beliefs regarding breast cancer causes, which were mentioned above (theme 2.1). Participants

strongly believed that inherited breast cancer is not preventable. Although having a healthy

lifestyle was suggested as one of the possible ways to reduce the risk of developing breast

cancer, it was not considered having much effect on inherited breast cancer. For example,

MHP2: I don't think this is called you prevent this happen, it can minimise the chance to get this happen, because yeah if your genes got some problem, and or then your grandma, grandma's grandma got this breast cancer, and then even you got a healthy life, you can't stop this happens. So that's why I said I don't think there is a way to prevent or stop it happen.

BHP2: I'm a nurse, so I know medically you can't do anything to prevent it. It just happens **BHP3:** Yeah, I agree

Additionally, nearly half of participants considered that breast cancer is inevitable and nothing

can be done to prevent it so there is no incentive for it. For example,

Interviewer: What do you think breast cancer can be prevented or not?
BHP1: I, I, I don't think you can prevent it. ... It just like some other cancer, it just happens, maybe you can, it's better if you can detect in an early stage. That would be lucky you know
BHP2: I think breast cancer, you can't prevent it. It's not like lung cancer, you may smoking a lot, then, yes, you are putting the health at risk. But breast cancer, you can't do anything bad to trigger the disease
BHP1: Yes

The finding of neo-fatalistic view among younger participants is different with findings of previous

studies which showed that Chinese women have fatalistic beliefs related to breast cancer (Kwok

& Sullivan, 2006). Fatalism generally refers to the beliefs that life events are predetermined and

individuals have little or no power to change their fate (Perez-Stable, Sabogal, Otero-Sabogal,

Hiatt, & McPhee, 1992). Younger participants in this study considered that breast cancer is not

preventable because it is mainly caused by the breast cancer genes rather than fate. This neo-

fatalistic view is not influenced by any religious beliefs or cultural beliefs but only to do with their

perception that breast cancer is an inherited disease.

Subtheme 2 - Breast cancer prevention

When talking about breast cancer prevention, nearly two thirds of the participants showed

positive and optimistic attitudes to breast cancer prevention. It appears contradiction to their

neo-fatalistic view on breast cancer prevention. Having a good lifestyle was suggested as one of

the useful ways in preventing breast cancer by several participants. For example, one participant

with higher education stated that genetics is not the only risk of developing breast cancer, and

strongly believed that maintaining a good lifestyle can help one to stay healthy. In her words:

AHP1: I quite er believe er ourselves, so I don't think it's the fate. ... And genetics,... not every cancer can get from genetics. So I think ... the good lifestyle can really really keep your health, so I think our health can be handled by ourselves

MHP1: ... I have my way of presume can prevent breast cancer, like not drinking, not smoking, not sleep er in the morning, and regularly in a good habit, and not go waste, the things that eat healthily, these kind of things, but er, nothing more

MHP1: Yeah, I'm not saying prevent like definitely won't get eventually, I'm just saying to reduce the risk of having it
MHP3: En
MHP2: ((Cut in)) Yeah, yeah, that's I agree with you

Breast self-examination (BSE) was suggested as an effective means of detecting breast cancer at an early stage by most participants, even including those who have neo-fatalistic view. For example,

AHP4: ... When you have the symptoms, it's too late. But if you feel your breast quite often and notice the symptoms in its early stage, it would be better

BHP4: ... It's to have regular check, if possible to, er... if you notice it early, then to get a treatment.

These statements reflect that participants clearly understand the difference between prevention

and early detection. Although many participants showed neo-fatalistic views of breast cancer,

participants in all focus groups appreciated the benefits of finding breast cancer early as the

early detection can allow women to receive effective treatment at the early stage and increase

their rates of survival.

When asking whether they practise BSE regularly, only one participant with higher education reported that she is familiar with the method for BSE and performed it regularly, because she had a lesson regarding how to perform BSE in school. The majority of participants, regardless of whether they had received higher education or not, reported that they do not perform BSE on a regular basis though they are aware that BSE can help women to ensure their good breast health. Unfamiliarity with the method for performing BSE was the common reason for failure to practise BSE regularly. For instance:

BHP1: Not regularly, very seldom. ... I didn't have any education like you (the participant who had received the education on how to perform breast self exam) had before, I didn't have any education, you know, regard to this. I don't really do it. Even if you know maybe we should do it, but we don't know how to do it. Just I don't know the proper way or any. I don't know how to do it

MHP2: (I did breast self exam) Just, just once. I don't know (the way to do it) and I find that I fail, and then I stop doing it

A few participants even doubted the efficacy of BSE, because they perceived an inability to

identify the symptoms of breast cancer. In their words:

BLP3: Yes, I think it's useless to check by yourself. I think it's more likely to detect the problems by doctors. ... And I can't recognize what a lump is and how hard it should be

MHP1: Even I'm doing for myself, I don't know what is wrong and what are the symptoms, the thing that you need pay attention to, I know nothing. If I check, I don't know whether it is going to be a risk or not. So I just, because I'm not the person who knows what is a lump or is that the hurting things that will be a symptom that you got breast cancer. I don't know. I don't have this kind of information, so check is useless

This suggests that uncertainty about the method for performing BSE and having no confidence

in their capability to perform the procedure correctly were perceived barriers, leading participants

not to do or to give up practising BSE regularly.

As mentioned above, some participants did not think breast cancer could occur at a young age

(subtheme 5 age in Section 5.7.2). As they perceived a low risk of developing breast cancer, so

they tended to think that they do not need to perform preventive behaviours. For example,

MHP6: So I never do that (BSE). I don't think I need to. So well, in my opinion, I think women will get breast cancer after like they have children, they have like after they give breeding. Yeah, so I'm not married, so I don't think I'll get breast cancer

However, it was found that participants' perceived susceptibility of breast cancer and their breast

cancer screening behaviours can be increased by exposure to breast cancer patients, having

peers with breast diseases, or having relatives with breast cancer. For example, one participant

with higher education stated that she was quite concerned about developing breast cancer in the

future due to her mother having several friends with breast cancer. In her words,

Interviewer: Have you ever thought about it, your possibility (of developing breast cancer)?

AHP1: Er... yes, I, I was thought about this problem, because I have, my mother has some friends have this breast cancer, so I just worried about it. To be a female maybe have a very high ability to get this cancer in the future, so I quite concerned about this problem

Attention should be paid to the fact that this participant used 'some friends' in her statement. By

observing the high rate of her mother's friends with breast cancer might provide the information

to this participant that breast cancer is a common disease among women. This could be the

reason why this participant showed high perceived susceptibility to breast cancer. It suggests

that exposure to breast cancer patients can increase women's awareness of breast cancer.

The high perceived susceptibility to breast cancer was also found in another participant who has

friends with hyperplasia of mammary glands. In her words,

AHP3: I actually I really worried about it (breast cancer). I just worried about people, I may get that hyperplasia of mammary glands, because I have three friends got that when they are just 20 years old... maybe it can become cancer later... I mean it may be a very serious thing

This statement reflects that having friends with breast disease is a trigger to increase individual's

perceived susceptibility to breast disease and to think about whether this breast disease can progress to breast cancer. This peer effect might be attributed to this participant being at the same age as her friends and may also have the same lifestyle. As a result, this participant was alarmed by having friends with breast disease.

It was also observed that participants increased their vigilance to breast cancer if they have relatives with breast cancer. Some of them had already gone for breast cancer screening every year in order to detect breast cancer in the early stages. For example,

AHP4: I thought about it (breast cancer), and I do the screening regularly, like once per year, because my auntie has breast cancer

BHP2: I need do it (BSE) because when I was at school, they taught me. And then my mum found a lump on her breast, she didn't feel it. My dad feels it. That's then why she went to get check. So, it seems that I'm doing more regularly now. Conscious thing

These statements reflect awareness of disease in others plays an important role in increasing

women's perceived susceptibility to breast cancer and also in determining their engagement in

breast cancer screenings. Participants might consider that they have a high risk of developing

breast cancer because they share the same or similar genes or lifestyles with their relatives.

5.7.4 Contrast with the British population on keeping healthy

When asked about whether there are any differences between them and British women on

keeping healthy, the majority of the participants considered that the Chinese pay more attention

to their health than British people. The differences were mainly concentrated on dietary

behaviour, exercise, bad habits and wearing warm clothes. For example,

BLP2: British people like take away and the fried food, such as fish and chips, which are not healthy.

BHP2: They don't really exercise you know

MHP4: Probably also the habit, they, I think one of the custom of them is going to clubbing, and drinking, and smoking. I found lots of white women they smoke. And which is not common in China

AHP3: I notice is that British, they wear er thinner clothes than us and they wear little clothes in the winter even. Most Chinese I think we, we really need keep warm and we were told we need to wear warm clothes to keep healthy

Previous studies have indicated that cultural beliefs about health maintenance and disease prevention have a significant influence on the engagement of health behaviours among the Chinese community (Tang et al, 2000; Yu et al, 1998). According to TCM, health can be maintained through the normal flow of *qi* (energy) and *xue* (blood), which can be achieved by good living habits (Koo, 1984, 1987). In addition, the *Yin-Yang* theory is central to the treatment of TCM, which suggests that the universal can be divided into two opposite characters *Yin* and *Yang* (Mo, 1992). The basic properties of cold, dark, passive and weak belong to Yin, whereas the properties of hot, light, active and strong belong to Yang (Mo, 1992). Keeping a balance between *Yin* and *Yang* is considered as an important way to achieve health. This can be used to explain why Chinese women emphasized the importance of keeping warm during winter in order to keep the *Yin* and *Yang* balance in their body. The findings of focus groups reflect that participants compared and contrasted Chinese and British people on keeping healthy based on their cultural understanding of how to maintain health and prevent disease.

5.7.5 Healthcare seeking behaviours

It was observed that participants' health beliefs are affected by the traditional Chinese beliefs. Meanwhile, the neo-fatalism on breast cancer prevention and beliefs about a genetic cause for breast cancer reflected that younger participants' beliefs about and attitudes towards breast cancer and its prevention are also influenced by the theory of Western medicine. Therefore it is not surprising that participants may integrate Chinese medical treatment and Western medical treatment together and choose the best way that they think to manage health and illness.

Focus group participants stated that Chinese medicine differs from Western medicine either in

the medical theories or illness treatment. It was found that participants choose healthcare services and treatment methods according to their personal perception of the severity and nature of the illness. Chinese medicine was advocated in the case of minor conditions (such as colds), to tackle the 'root' of the disease and to maintain health. By comparison, Western medicine was advocated to tackle the symptoms of illness. For example,

BHP1: You know for certain problem, Chinese medicine does work much better than the (Western) medicine. It's different medical system and different approach to human health. Western medicine more for the symptoms, superficial, Chinese medicine go to the root **BHP2:** Yeah, I agree

BHP3: It works better. And Western medicine they treat one thing, they bring other problems, the side effects. But herbs, nature herbs, you know compared with Western medicine, you don't really need to worry about side effects

BHP2: Yeah, I think nature medicines much better than the drugs

Chinese medicine was also believed as effective in maintaining health and preventing illness

rather than curing serious diseases.

BLP2: I think Chinese medicine is mainly to maintain your body and to prevent illness.

MHP3:... If you go to a Chinese doctor, it's usually for things that to make you or, to keep your health better. ...Yeah, and to keep your health better. That's slowly in a way rather than curing you

Regarding medical seeking behaviours, one participant mentioned that she put more trust in

Chinese doctors compared with British GPs as Chinese doctors share the same knowledge. In

her words,

BHP5: I trust Chinese doctor than British doctor. They better than them I think, because they have your knowledge, they know what's your problem, so they can help you to solve out. But British, but I don't know so, just ask you to wait to see the specialist

This statement suggests that Chinese women's confidence in using healthcare providers is also

influenced by the cultural background as they are more likely to trust Chinese doctors who share

the same cultural background as them.

Consistent with the previous statement about using Chinese diagnostic methods to assess their

health status, participants in this study also reported the advantages of TCM compared to
Western medicine in terms of diagnostic methods. It implies that participants' attitudes to medical

systems are associated with their cultural beliefs.

BHP2: ... He felt my pulse. He knew straight away, I didn't say anything, I didn't tell him what pain or what problem I had. He just done it and knew where the problem was... Just touching the pulse
BHP1: You know actually, if you see your Chinese doctor, they had apart from this, they also check your tongue, your tongue does tell a lot of information definitely...
BHP2: Well, British, western doctors they won't know it. I don't think they know it
BHP1: No
BHP5: They just ask you to scan, x-ray
BHP2: Yeah, yeah, [yeah]
BHP1: [yeah]
BHP5: the test and wait

However, it was noticed that in spite of the advantages of using Chinese medicine and frequently

using Chinese medicine in their home countries, only a few participants had visited Chinese

doctors in the UK. When asked the reasons for not visiting Chinese doctors or using Chinese

medicine in the UK, participants commonly reported that they do not trust the Chinese doctors in

the UK and were suspicious as to whether these doctors are qualified. The high cost of seeing

Chinese doctors and the authenticity of Chinese medicine were the other common reasons that

prohibited participants from seeking help from Chinese doctors in the UK.

Interviewers: Do you trust the Chinese doctors here?

BHP3: Not really. I haven't seen the Chinese doctors here, I don't think they help me much Because I don't know where they come from or whether they are really qualified, so

BHP5: ((Cut in)) Yeah, they just ask you to pay

BHP3: Yeah, yeah, you spend a lot of money, and the medicine, there is not a lot of medicine here, you don't know whether they are the real one

Interviewer: Ok. Besides your GP, have you ever visited Chinese medicine doctors in the UK?

BLP4: It's very expensive to see the Chinese doctor

BLP3: No, I haven't.

BLP2: No.

BLP1: Chinese medical doctor? No. They even don't have high skills

BLP4: Yeah, the Chinese medical doctors don't have high skills

BLP1: Yeah, I agree

BLP4: They also charge a lot

BLP1: Yeah, very expensive

When discussing their priority when they are unwell in the UK, participants reported that it depends on the severity of the illness. The majority of participants used self treatment, buying non-prescription drugs from pharmacies or using Chinese herbal drinks, for minor illnesses such as colds. If they considered that the illness is serious and beyond their awareness, some participants reported that they rely on their GP. For example,

BHP2: if something I can, if I got headache or cold, I'll take some tablets by myself, and then if something else, I don't know what to do, then I go to GP first

Interviewer: Ok. If you have health problems, what do you usually do?
BLP3: Go to my GP
Interviewer: Go to your GP. Ok
BLP4: Depends on what it is. Yeah, if it's a temperature, I'll take care of myself, it's not a serious thing. But if I don't know what happens, so, yeah, I'd like to wait for several days before going to see the GP. Such as my skin problem, I waited for about two weeks before I decided to go to see the GP, because I didn't think whether it would heal itself. So when I have no idea on how to treat it, I'll go to see the GP
BLP3: I usually go to the pharmacy, get some medicine firstly
Interviewer: ok
BLP3: If it's not serious. If something I have no idea on what's happening, then I definitely go to see the GP

Apart from seeking help from the GP, it was noticed that many participants would prefer to go back to their home countries and seek medical help if they suffered severe illness in the future, which was further discussed in Section 5.7.6. A few participants even reported that they had never visited their GP since they came to the UK. Participants reported negative experience of using health services including barriers to using the health services in the UK and communication issues with the health professionals. The low satisfaction of the health services in the UK might due to the differences in the health system and treatment methods between China and UK. Almost all the participants had been born in China, they are accustomed to the health services in China. They might assume that the health system in the UK is the same or similar as the health system in China. Their previous experience of seeking medical help might influence their perceptions and satisfaction with the health systems in the UK. When talking about using the health services in the UK, focus group participants reported some barriers that prevent them from seeking medical care in the UK.

5.7.6 Barriers to seeking medical help in the UK

Aspects of the barriers to medical care that participants reported, included inconvenient referral systems, long waiting times before getting treatment and no accessibility out of the normal work hours.

Subtheme 1 - Inconvenient referral system

Compared with the health care system in China, most participants described the health care system in the UK as inconvenient. In China there is no primary care system, in particular general practice. Only parts of urban China have General Practice (GP). The healthcare service is a fee-for-service based system in China (Eggleston et al, 2008). Accordingly, people can visit their preferred hospital and healthcare providers, including medical specialists, without booking an appointment when they suffer from health problems. Therefore, participants complained that the referral system in the UK is inconvenient, because it takes a long time before they can visit specialists. For example,

BHP3: ... maybe they (GPs) couldn't find out what the problem is, you have to get transfer to, refer to another specialist, you have to book the appointment yourself and then get to wait for the appointment for month before you get to see the specialist

AHP1: Recently, I got my low back pain ... I think 3 months ago, I just go to GP to make appointment and to report my details and symptoms, and I go there for 3 times for GP check. After the 3 times check, GP just told me en maybe you need a specialist at hospital. After 2 months, I was sent to hospital, to hospital to go to again for the normal check. ... So today I just got my x-ray this morning.... I think it's quite long way. ... I don't know how long I need to waiting for my final results. So maybe in the summer holiday, I can go back to China to get one day check to get my results. So I think it's really really inconvenient

Subtheme 2 - Long waiting time before getting treatment

Participants also complained that the waiting time for the next available appointment is too long

and even for emergencies. As a result, some participants considered that health providers do not

work efficiently and are not very helpful. This view was captured from the conversation among

participants in Birmingham:

BLP1: ... you can't see the doctor immediately when you are sick. You have to wait
BLP2: Right, right. Very annoying
BLP1: Maybe you have already died before your appointment
Interviewer: Do you have this problem as well?
BLP4: Yes, quite the same. And they work very slowly, not efficient
BLP2: Even the Emergency is also not efficient. You still have to wait for hours
BLP1: Exactly
BLP2: So it's not helpful
Interviewer: Ok. Do you have any inconvenience in visiting your GP?
MHP2: Yeah, there's lots

MHP3: Yeah, they usually take ages MHP4: [Yeah] MHP5: [Yeah] MHP2: [Yeah]

The long waiting time even led a few participants to feel that GPs do not care about them.

Participants were quite worried that their illness may progress to an advanced stage during the

waiting time. Therefore, some participants stated that they would prefer to go back to China and

get the medical help if they suffered from severe diseases. For example,

BHP5: Even I get the family doctor, but I don't want to see the GP here because ... waiting time it too long. ... You think that's a problem, I don't think they'll see this is a problem. Yeah, I just think they not care about you.... Maybe in the er in the early time, ... it's just simple things, so you can solve it out every quickly. ... but if the waiting time is too long, the simple would become to the serious, worse, so on that time, you, I don't know they can help me to do anything. So why not, why I am not back to China to do it, to solve it out quickly?

MHP3: ... I won't go to them. Because I know they will just not care, because it doesn't happen yet. If you go to them and say you want a check, it might take a year at least (laugh)
MHP5: Yeah
MHP2: Yeah...
MHP3: Yeah, seriously, if I do get the breast cancer, I'll fly back home straight away, I won't stay here anymore although it's free here
MHP2: Yeah, it's the only way to solve the problem
MHP3: Yeah
MHP3: Yeah

These statements reflect that younger Chinese women were unfamiliar with the health system in

the UK where urgent appointments are available if conditions become more severe.

Subtheme 3 - No accessibility out of normal work hours

No accessibility out of normal work hours was another barrier for seeking medical help for people who could not easily to take time off from work. For example, one participant, who has a full time job, complained that the opening hours of the medical centre do not fit her work time. This participant stated:

BLP1: I think the major problem is that you have to see the doctor during work time, because they only work during work time. You need to get off from work if you want to see the doctor. Otherwise, there is no way to see the doctor.

5.7.7 The interaction between patients and healthcare providers

When talking about participants' experience of seeking medical help, half the participants reported negative experiences or attitudes towards healthcare providers. The dissatisfactions were mainly divided into three aspects: prescribing, lack of confidence in using GP services and different body constitution.

Subtheme 1 - Prescribing

As to the illness treatment, many participants complained that they are not prescribed antibiotics

when they suffer from a cold, which are commonly used to treat colds in China. The overuse of

antibiotics is a common issue in China. Previous studies have indicated that 75% of patients

suffering with colds are prescribed with antibiotics in China (Ying & Tao, 2008). The expectation

of being given antibiotics for a cold was captured from the conversation among participants. For

example,

AHP5: I didn't visit my GP, but I once went to hospital because I got cold. And I cough last a month and went to hospital. I thought I need some medicine, some *antibiotics* (speaking in Chinese), because I worried about having the lung, lung.. **AHP1:** Inflammation, lung inflammation

AHP5: Yeah. I worried about that, so I went to hospital. But finally, they didn't give me anything, any pills, any medicine, they just let me go home and drink hot water and put lemons in the water

BLP4: ... I don't go to see the doctor when I've caught a cold, because they always said to drink more water and didn't give you the medicine

BLP1: That's true **BLP4:** They always said that

MHP3: ... if I got a cold or you know like small things, I don't need to go to the GP, because all they would say is go back home, drink more water and go to sleep
MHP4: Yeah
MHP3: I found them quite useless actually
MHP2: [Yeah]
MHP4: [Yeah]

The statement reflects that women's perception of illness treatment in the UK is largely influenced by their previous experience in their home countries.

Subtheme 2 - Lack of confidence in using GP services

Three participants stated that they lacked confidence in the competence of the GP, because their

GP failed to explain the side effects or some issues related to their illness. For example,

MHP2: They not knowledgeable enough I think, ... I remembered I asked her for my illness, and I just asked something extra, because sometimes you are wondering or thinking maybe you got another problem, it causes the side effects or anything. And then she told me she doesn't know... They even cannot answer the simple question

As it was mentioned above that people generally seek medical help from medicinal specialists

directly if they have health problems in China. This statement may reflect this participant's lack of

understanding of the structure of NHS which consists of primary care and secondary care. She

may not understand the role of GP and the difference between GP and medical specialist, and

thus leading her to expect that GP should be as knowledgeable as the medical specialist who

can provide sufficient information regarding her illness and treatment.

Not being trustworthy was another issue that prevented a few participants from seeking help from their healthcare provider. For example, one participant reported that she distrusted her GP, as her GP did not provide proper treatment for her stomach ache. In her words:

BLP3: I only went to see the doctor for stomach pain twice, and he always said it's because of homesickness. And after that, I never saw the doctor again. ... So I don't want to waste time anymore

Another participant talked about her experience of being presumed to have cancer due to inaccurate blood test results, which reduced her confidence in seeking medical help from doctors in the UK.

MHP3: Yeah, I got a ridiculous case recently... And, but they do the examination once, in the blood test, they found that my red blood cells decrease than, much less than normal people. Because the normal weights maybe 4 points something, and I just got zero point zero something. So it's ridiculous, and then they found me maybe I got the cancer or or tumour something like that. Then they scare me off, and then I wait for 3 or 4 days, then they said that yeah, your blood test is go to normal today. And then he he directly tell me I think it's as a normal person, it's not possible to, er, the blood cells is go back from zero point something to 4 point something in a day, so should be our problem

One participant, who is working in a Chinese society, reported that some of her clients complain about their GPs losing their children's blood samples, leading them distrust the healthcare providers. In her words:

MHP1:... I realize that the GP here is not trustworthy. And lots of clients in Wai Yin, they said their children get test, they get blood test, so but the GP lost their blood. That's not one case. So they have to go again, and they lost again

Subtheme 3 - Different body constitution

Different body constitution was identified as another barrier that influences Chinese women's

medical help seeking behaviour. For example, one participant without higher education doubted

Western doctors' competence in treating Asians' illness and believed that doctors in Western

countries do not know how to treat Asians' illness, because the Chinese have a different body

constitution. She talked of her friends who prefer to go back to China and get treatment when

they are sick. In her words,

BLP4: I guess those foreign doctors know nothing about our Asian disease. I don't think they have high medical skills. ... I have many friends in USA and Canada, they also prefer to go back to China when they are sick, because the local doctors can't cure them. Maybe because we have a different body constitution, we need to see Chinese doctors

The efficacy of Western medicine on Chinese people was also suspected by one participant who considered that Western medicine does not work for the Chinese, because the Chinese have

different genes from Western people. In her words,

MHP3: I think there is another reason why Chinese don't usually trust the GP here or the GP don't usually work well with us because I do think we have different, how should I put it, like we got different genes, and we react to the medicine differently. Er, because, I, for example, I take some herbal drinks, like Chinese herbal drinks, then it works for me. But for, if you give them to the west, like the British women, I don't, I don't think it works for them. This is some medicines work for certain people. And it just happen we are not in our own country and medicines are not really for us

As a consequence, these participants prefer to go back to China if they suffer from serious illness, because they believe that they have a different body constitution or genes from Western people. They considered that they can get better treatment in China, as Chinese doctors know their body constitution or /and Chinese medicine works better for them.

5.7.8 The experiences of being an interpreter

In the previous focus group study, the majority of older Chinese women stated that they use their children as interpreters when they use health services as they do not have English skills to communicate with healthcare providers. Therefore, younger women's experience of interpreting was also explored in this study. Among the focus group participants, only a few participants reported having the experience of being interpreters in healthcare settings because most participants are living in the UK without older relatives. Apart from one participant who reported that she has worked as an interpreter for the NHS previously, others predominantly interpreted for their parents and friends. In general, these participants reported that they are able to interpret in the medical consultation. However, some of them experienced some less successful situations in interpreting the communication between healthcare providers and their relatives. Three issues were mentioned in accounts of less successful interpreting.

Subtheme 1 - Lack of proficiency in Chinese

In this study, only two participants had been born in Western countries (one in Germany and one

in the US) and migrated to the UK at a young age. While one participant talked about her experience of being an interpreter, the other participant did not have this experience because her parents do not have communication problems. Lack of Chinese skills in explaining the illness was the major issue for this participant who received her education in English from childhood. She reported that she is more fluent in English than in Chinese and has difficulties in translating words into Chinese though she is a nurse and has no difficulties with the medical terms. She had to draw pictures for her parents when she was unable to translate the words. Although her parents could understand from the pictures, she still considered that it is better to have a skilled interpreter. In her words,

BHP2: Yeah, because my Chinese is not that brilliant, so sometimes I don't understand how to translate the words, but I would solve it out liking drawing pictures for my mum or my dad to see where, what's wrong and what's happening **Interviewer:** Ur, so can they have a good understanding of you? You draw pictures **BHP2:** Yes, but I think it's better if there is a proper interpreter coming in, a medical interpreter I think

Subtheme 2 - Difficulties with translating Chinese concept of illness

The difficulty in interpreting the Chinese concept of illness into English was another barrier that influences the effective communication between doctors and patients. One participant reported that older people are more likely to use traditional Chinese terms to describe their symptoms. TCM is based on the cosmological conception of *Yin* (cooling, nourishing) and *Yang* (warming, activating) and the Five Elements, the functions of *qi* (energy), *xue* (blood), emotions, essence and body fluids, as well as their relationship to each other (WHO, 1999). According to the concept of *Yin* and *Yang*, the human body should be kept in balance. Health is a product of the flow of body energy. If the energy is imbalanced, people might feel excessively 'hot', 'cold', wet' or 'dry' (Koo, 1984). In the current study, this participant stated that the older people, who she has interpreted for, usually use the Chinese concepts to describe their health. For example, some older people used the concept of *shang huo* (rising hot) and *tou feng* (dizziness caused by

'wind' inside the body) to describe their health problems to healthcare provider. This participant

felt that it is extremely hard to interpret and explain these concepts to doctors.

MHP3: I think the problem for translating between English and Chinese is about medical issues is er, the concept is different. Our concepts are different. Because, from er, for example, in Chinese, we say shang huo, that's no way you can translate into English. I know there is a term, but they don't, they just don't have the idea in English
MHP2: up fire (shang huo)... And the cultural difference, the name we used to call and the Chinese concern we say it as a sickness, and local people may think that this is a normal thing, because they drink a lot of beer and they don't know about, don't understand what is up fire mean
MHP3: Yeah, for example, like tou feng. They don't have concept like that. So yeah, I think it's the main problem
Interviewer: Ok. So is that from your experience?
MHP3: Yeah, when I have to translate from my, you know especially elder friends,

like the elderly. You usually say things like that to us... But how can I explain that to the doctor? I don't know

Using traditional Chinese terms to describe illness symptoms actually is parallel to some of the themes that were discussed above, such as menstruation retained in the body, and contrasts with the British population on keeping healthy. All these findings indicate that the concepts of health and illness and the body deeply rooted within the Chinese culture, which play an important role in the accounts of the causes of disease, engagement in preventive health behaviours, and medical decision making by patients.

Subtheme 3 - Familiarity with English medical terms

Not being familiar with English medical terms was not reported as a barrier by the participants in current study. However, one participant who had worked as an interpreter for NHS before talked of her previous colleagues' experience when they were unable to interpret the healthcare providers' words for the patients due to the fact they cannot understand some of the medical terms. In her words,

BLP1: My friends did this many times (being an interpreter in NHS). Sometimes when there was a new word, they usually told the doctor that the patient wants to know more about his illness and could you please explain it in detail. Then the doctor used some easier words. So they could understand the doctor

When talking about the NHS interpreting services, only one participant had used this service and

reported that some interpreters were not familiar with medical terms. However, the quality of

consultations could be improved if the interpreter had a medical background. For example,

BLP4: Actually, some interpreters are not very good at English. Some of the medical terms are really difficult for them. My husband has lumbar disc, it's very hard for them to translate. But if the translator once was a nurse in China, things went better

The lack of proficiency in English medical terms for interpreters might be due to the fact that they

have not received any training before working and even their English ability in interpreting health

and illness are not assessed when recruiting. This was evident from the participant who was

recruited as an interpreter for NHS through an agent. In her words,

BLP1: I was not recruited by NHS, but by an agency who was recruiting interpreters for NHS. So I handed in my CV
Interviewer: Did they have any special requirements?
BLP1: No, just an interview. They asked me a few questions, like age, where I live, something like that, just an informal interview to see your English level
Interviewer: Before you went to work, did NHS provide any training for you?
BLP1: No, they didn't. Just the NHS needs a translator, they inform the agency, and the agency contact us. That's it

As was evident in the focus groups with the older generation that Chinese women with low English proficiency are less likely to use medical services. In addition, the literature review also indicates that language barriers inhibit the use of breast screening among Chinese women, which has a significant impact on early breast cancer detection and effective treatment. Health service providers should be aware of language barriers and thus provide trained medical interpreters to meet the linguistic needs of patients who come from different ethnic groups.

5.7.9 Source of health-related information

With regard to the ability to speak English, apart from one participant without higher education who had a language problem, the remainder spoke competently. Language was not perceived to be a major barrier to obtaining health-related information among these participants. Although a few participants were not familiar with some medical terms, it did not affect them much in receiving health-related information in English. The internet, media and healthcare providers were identified as the three major sources of getting health-related information by most participants in all groups. For example,

MHP2: Yeah, usually I, I get the information from internet, yeah definitely you can get everything on internet, and then another way will be the TV programme, yeah there's lots of health information TV programmes plays regularly ...
MHP3: I do read the leaflets in the clinics, hospitals, I found it's quite useful, they are usually quite easy to read, quite you know short and clear
MHP6: Well, I think you can get the information from the GP as well, you just tell them I need some information about breast cancer, they will like send you like regularly

Many participants reported that the health-related information, which is provided by the healthcare providers, is quite useful. When talking about the breast cancer-related information, it was apparent that participants did not have sufficient knowledge about breast cancer and prevention. For example,

MHP2: ... the government raise this awareness in women, but not giving enough information for us telling about how it's causes and how it's happen, and how to prevent it, and how to check everything. You just realise that you can easily to get this happen, yeah, but nothing else you can know about this. Yeah, the GP always said that it's so easy you can check it, ... it sounds very easy but it's difficult to practice I think. ... It's all about lack of information about this.

This statement reflects that there is a gap between motivation and behaviour. Young Chinese women perceived that breast cancer is a common disease among women and have the intention to prevent breast cancer and detect it at early stage. However, due to lack of knowledge about breast cancer and prevention, participants had difficulty carrying out the prevention in practice.

Therefore, participants suggested breast cancer prevention programmes should also pay attention to increasing people's knowledge of breast cancer causes, symptoms and prevention rather than just raising people's awareness on their susceptibility to breast cancer. Participants also suggested that healthcare providers should promote breast cancer treatment as well, because most people might consider that removing the whole breast is the only way to treat breast cancer, leading them afraid to face and fight breast cancer. For example:

MHP2:... because most of people think that cut cut, it is the only way to solve this problem and then people may be scared and afraid to fact it. You know people always get the real word, then skip that all the problems that they are facing. So if you tell them it's just a, just can take some medicine or any other ways.... I think people maybe more willing to face it...

Participants' responses regarding the favourite format for receiving health-related information fell into three major ways, leaflets, letters and TV advertisement, because these ways are convenient to reach most of the population. Health service providers could use these approaches for breast cancer knowledge and treatment dissemination among younger Chinese women.

5.8 The impact of demographics on breast cancer prevention and early detection among younger Chinese women

Similarly to the focus groups among the older generation, the effect of demographic factors on breast cancer prevention and early detection will be assessed among the younger generation. Despite the differences in educational level, all participants held similar views on the concept of health. They described health as no illness, eating well, sleeping well, and feeling energetic. The perception of being healthy was generally based on their personal feeling. However, it should be noted that several participants with higher education talked about using Chinese diagnostic methods from TCM to assess their health status. In addition, all participants showed a strong holistic view on health maintenance.

Regarding the causes of breast cancer (second theme), it was observed that genetics, using female hormones and lifestyle were the three common causes reported by all participants. However, participants with a higher educational level also reported other causes of breast

cancer including psychological factors, age and menstruation retained in the body. In contrast, one participant without higher education had some unusual beliefs regarding the causes of breast cancer. For example, she considered that using antiperspirants and having more hair could increase the risk of breast cancer. Data from this study is consistent with findings of previous research that breast cancer screening knowledge is affected by educational level (Rasu, Rianon, Shahidullah, Faisel, & Selwyn, 2011).

The third theme was active health management. Regarding breast cancer prevention, a prominent attitude among the younger generation, especially those with a higher educational level, was neo-fatalism which means that nothing can be done to prevent inherited breast cancer. Despite those participants showing the belief that having a healthy lifestyle could reduce the risk of breast cancer, they strongly believed that it has no impact on breast cancer genes. The sense of neo-fatalism is a novel finding and has not been studied in relation to breast cancer preventive behaviour in previous research. This highlights that future research should further explore the relationship between neo-fatalism and breast cancer prevention. There was no attitudinal difference among participants regarding early detection and early treatment as they all acknowledged that early detection of breast cancer can improve the survival rates. The impact of educational level on BSE performance was not evident as almost all participants did not do monthly BSE. Lack of knowledge on the BSE methods was reported as the main barrier to BSE.

Regarding the fourth theme of contrast with British population on keeping healthy, difference was not found among participants as they all believed that the Chinese care more about their health and have a healthier lifestyle than white British. Participants also discussed the healthcare seeking behaviours (theme 5) and barriers to seeking medical help in the UK (theme 6). From the literature reviewed in Chapter One it is evident that the level of acculturation is an important determinant of accessing Western medical care systems. It appears that the data generated in

the current study supports previous findings. It was found that participants who were born in China or Hong Kong were more likely to use both TCM and Western medicine to manage health and illness than the two participants who were born in Western countries. In addition, the Chinaborn and Hong Kong-born participants were less satisfied with the medical service in the UK. There is no surprise that these participants reported more issues regarding the interaction with healthcare providers (theme 7). This might be due to the lack of familiarity with the UK health care system. A comparison was also made among the China-born and Hong Kong-born participants in terms of years in the UK and educational level and did not identify obvious differences among these populations regarding the three themes. The final theme was the experience due to living alone in the UK, the comparison and contrast among participants was not carried out on this theme.

5.9 Summary

The chapter provided valuable insights into breast cancer prevention and early detection among young Chinese women living in the UK. The Chinese concept of health was still dominant in their perception of being healthy. Participants showed a holistic view on health and health maintenance and emphasized the importance of healthy diet, regular sleep and exercise, and emotional harmony to keep healthy. It was found that participants were more likely to focus on health maintenance rather than illness detection when they talked about health promotion. Participants rarely engaged in regular preventive medical check-ups despite several participants with a higher educational level mentioning them as ways for keeping healthy. The reason might be attributed to the fact that the concept of using screening to detect asymptomatic disease does not exist in TCM. However, it should be noted that participants integrated TCM with Western medicine and selected the most suitable method to maintain health and treat disease. Participants talked about breast cancer causes in terms of both Western medical concepts and

TCM concepts. Genetics was considered as the main cause of breast cancer by all participants, leading some participants showed strong neo-fatalism on breast cancer prevention and considered that inherited breast cancer is not preventable. There was poor performance of regular BSE despite most of participants believing that doing BSE regularly is an effective way to detect breast cancer early. The main reason was due to inadequate knowledge about BSE performance.

Previous medical help seeking experience plays an important role in women's attitudes toward the medical services in the UK. Participants who were born in China or Hong Kong reported high dissatisfaction with the NHS health care system in terms of inconvenient referral systems, long waiting times and no accessibility out of normal hours. The cultural influence on medical help seeking behaviour was also evident. Several participants considered that they have different body constitution from white British and thus GPs do not understand Chinese diseases and the Western drugs do not work effectively on Chinese patients. Accordingly, they were lacking in confidence in using GP services. Language was not identified as a barrier to health-related information and medical services access.

The findings of this qualitative study highlight that it is essential to develop culturally tailored promotions because the interventions for the general UK population would not address the issues reported by the younger Chinese women. Efforts should address breast cancer awareness among this population. Health service providers should also provide information about the structure of the NHS health and care system, thus to improve the understanding and utilization of the medical services among younger Chinese women. Meanwhile, practitioner training should be carried out among health care providers in order to increase cultural awareness and provide services tailored to their local community.

The following chapter will integrate the findings from older Chinese women with the younger generation to identify the similarity and differences among these two age groups.

Chapter 6 Synthesis of qualitative research findings and comparison with other ethnic groups

6.1 Introduction

The aim of this chapter is to integrate the qualitative research findings from the focus groups with older and younger Chinese women. This chapter will firstly compare and contrast the differences and similarities emerging between the two age groups on health beliefs, breast cancer prevention and healthcare seeking behaviour and then use deductive thematic analysis to connect the HBM variables and the themes generated by inductive thematic analysis. How the findings of this study add to the body of literature on mammography screening among Chinese women living in Western countries will be considered. The findings of this study will also be contrasted to the evidence on breast health and breast screening that have been generated from studies among South Asian women in the UK as the largest ethnic minority group in the UK. Finally, implications for the use of the empirical evidence generated from the focus groups to form the basis for breast screening interventions now and in the future among the Chinese community will be discussed.

6.2 Comparison of findings from focus groups among younger and older groups

Thirteen focus groups were conducted separately with 52 older (over 50) and 20 younger (under 35) participants. In terms of the length of living in the UK, most of the older generation had lived in the UK more than 15 years, whereas the majority of younger generation had stayed between 1 to 10 years. In contrast with the older generation who had nearly equal numbers of participants originally from Hong Kong and mainland China, most of the younger generation came from mainland China. In addition, younger participants had received higher education and were more proficient in English when compared to their older counterparts. In line with the work status, while the majority of older participants were housewives or retired, all the younger participants

except four were students or employed. The findings from focus groups among the two generations revealed some similarities and differences in health beliefs, breast cancer prevention and detection and the ways of seeking healthcare, which are discussed in the following sections.

6.2.1 Health beliefs

Traditional Chinese health beliefs were found in common among the younger and older groups. Participants held a holistic view towards health maintenance and believed that health could be maintained by doing regular exercise, eating a healthy diet, and keeping a good mood. The holistic view was more apparent among the older generation than in the younger generation. Since all participants had been exposed to dual sources of health care, they reported that they integrated Traditional Chinese Medicine (TCM) with Western medicine on health maintenance and illness treatment. For example, TCM was considered to be more effective in reinforcing health, tackling the 'root' of illness and treating minor illness, whereas Western medicine was suggested to be more useful in tackling the symptoms of illness and treating severe conditions. Accordingly, younger participants mentioned ways of using the diagnostic methods of TCM to assess their health status and also explained the causes of breast cancer according to the theory of TCM. Older participants were observed to use Chinese tonics and food therapy to maintain their health. When talking about breast cancer treatment, Western medicine was considered to be more effective than TCM. It seems that these participants did not feel that there is a conflict between the beliefs of TCM and the Western medicine though the two medical models propose different theories towards aetiology and different methods to illness treatment.

6.2.2 Breast cancer prevention and detection

With regard to breast cancer causes and its related risk factors, participants' responses concentrated on three aspects: genetics, using female hormones, and lifestyle. Younger

participants had more beliefs about breast cancer than older participants. Younger participants mainly attributed the high breast cancer incidence among white women to genes, lifestyle and environment, whereas several older participants were inclined to consider that having large breasts is one of the reasons why white women are more likely to develop breast cancer in addition to lifestyle, particularly dietary behaviour. Younger participants also described other risk factors for breast cancer, including psychological factors and menstruation retained in the body. Older participants, in contrast, mentioned more unusual beliefs on the causes of breast cancer such as physical pressure and sleeping with the light on. Despite older participants identifying age as a risk factor for breast cancer, some of them did not realize that the risk of getting breast cancer-related knowledge among the two age groups may be due to education levels, as the overall education level was lower among the older generation than the younger generation.

The effect of educational level on breast cancer knowledge has been documented among women across different ethnic groups. For example, a UK national study indicated that professional women had more knowledge of risk factors and symptoms of breast cancer than women who were unskilled or never worked (Grunfeld, Ramirez, Hunter, & Richards, 2002). As similar as the Chinese women, family history was identified as the most common risk factor of breast cancer by British women in this national study. Other risk factors that British women reported including previous breast cancer, smoking, oral contraceptives and older age. The false belief regarding the relationship between age and breast cancer was also evident in this national study as around 25% of participants perceived low susceptibility to breast cancer due to getting old. These findings suggest that although Chinese women showed some cultural beliefs on breast cancer causes, they shared some beliefs with the general British population.

Regarding breast cancer prevention, the two generations showed entirely different attitudes. The

majority of older participants were unfamiliar with breast cancer prevention due to the limited knowledge on the causes and risk factors for breast cancer. However, they were aware of mammography screening and believed that having mammography screening enables them to detect breast cancer at an early stage and receive efficient treatment. Accordingly, almost all of them had responded to receiving a mammography invitation letter, which is contrary to the low screening rates reported by previous studies (Breast Cancer Care, 2005; Kwok et al, 2011; Sun et al, 2010). However, many younger participants showed a strong "neo-fatalistic" view in relation to breast cancer prevention as they put great emphasis on genetic causes of breast cancer and considered that nothing can be done if women have breast cancer genes. Regarding breast selfexamination (BSE), younger participants including those having neo-fatalistic views all showed positive attitudes and agreed on the effectiveness of BSE on breast cancer early detection. This reflects the fact that younger participants conceived of BSE as a detection method rather than a way to prevent breast cancer. However, only a small number of them were compliant with BSE on a regular basis though they were aware that they should be so. The most frequently cited reason for the low practice was inadequate knowledge on how to perform BSE. In addition, low perceived susceptibility was another contributor as several participants considered that breast cancer usually strikes older women so that they did not have to worry about breast cancer at their current age. Despite Chinese women having a lower risk of breast cancer compared to white British women and the risk increases with age, younger Chinese women should realize that the low susceptibility is not the same as zero susceptibility.

6.2.3 Healthcare seeking behaviour

In this study, participants reported using practitioners of Chinese medicine, however they did not believe that their care was very effective and considered that they are expensive. The majority of older participants said that they put trust in their GP services. However, in the context of healthcare access, older Chinese women felt difficulties in communicating with their GP.

Participants also reported problems with interpreters not being available, not speaking fluent Cantonese, or poor interpreting services. Therefore, doctors could not understand their illness, and thus led them to feeling distressed and frustrated. Some participants even learnt medical knowledge from books and used self treatment when they had minor illness rather than go to the GP. This study supports the finding of previous works that the ability to speak English is a predictor for Chinese people's medical help seeking behaviour and cancer screening (Gany et al, 2006).

Compared with the older generation, language barriers were not an issue for the younger generation especially those who had received higher education. However, younger participants were highly critical of health care in the UK, especially the referral system. This may be due to the different healthcare systems between China and UK. Britain's health services consist of primary and secondary care (NHS, 2012). According to the NHS structure, most people are firstly treated by primary care providers such as GPs when they suffer normal health issues. If the condition is serious, they will be further referred to the secondary care by their GPs for specialized services (NHS, 2012). In China, the healthcare delivery system is also hierarchically organized (Eggleston et al, 2008). The healthcare system in urban areas consists of three tiers, city hospitals, district hospitals and community services, whereas the system in urban areas includes county hospitals, township health centres and village clinics (Eggleston et al, 2008). However the economy of China has experienced a transformation from a planned system to a market-oriented system since 1980. The previous referral system has been changed to a fee-forservice based system (Eggleston et al, 2008). Eggleston et al (2008) suggests that around 60% of the payment for healthcare providers are from out-of-pocket payment, 20% from social insurers, and the rest from government. Because of the fee-for-service based healthcare system, patients can self-refer to any healthcare providers including specialist services that they can afford (Eggleston et al, 2008). As a result, residents living in urban areas prefer to go to city

hospitals even for a minor illness such as a cold and gastroenteritis, because city hospitals have more skilled doctors and advanced equipment compared with lower grade hospitals and clinics (Lim et al, 2011). In addition, the fee-for-service based healthcare system gives an incentive to healthcare providers to provide high profitable services such as using high-tech diagnosis and to over prescribe drugs rather than provide regulated, evidence-based services (Eggleston et al, 2008; Yu et al, 2011).

In contrast with the older generation who had mostly lived in the UK for more than 15 years, most of the younger participants had stayed for a relatively shorter time. Therefore, younger participants might be less familiar with the healthcare system in the UK than the older participants. In addition, as mentioned previously (Section 1.5) the older generation was mainly from rural areas and came to the UK during the first (1950s) and second waves (1970-1980) of immigration when the healthcare services in China was far behind that in the UK. Consequently, older participants were all very appreciative of the fact that the healthcare services are free at the point of care and considered that the British National Health Service is much better than the health service in the other Western countries where patients have to pay. By comparison, most of the younger participants were temporarily in the UK to study. These participants were from high socioeconomic families as they were able to afford the high tuition fees and living costs in the UK, so they might benefit a lot from the fee-for-service based healthcare system in China. This may help to explain why the younger generation perceived the referral system in the UK as an inconvenience. They even considered that the referral system could prevent patients receiving treatment efficiently and thus lead to illness progressing to an advanced stage. Thereby, some of them stated that they would prefer to go back to China to seek medical help if they suffered serious illness in the future.

6.3 Findings of the deductive thematic analysis

As mentioned in Chapter Two methodology, the findings of focus groups were firstly analysed by using the inductive thematic analysis to identify the themes related to breast cancer prevention and screening among Chinese women that come from the data. Once the empirical evidence had been generated, it is important to use the health psychology theory to understand the mechanism of behaviour change. Therefore, deductive thematic analysis was conducted to connect the themes identified by the inductive thematic analysis with constructs of HBM, which has been documented as the most suitable theoretical framework to understand breast screening behaviour by previous research (Fischera & Frank, 1994; Sanderson, 2004; Savage & Clarke, 1996).

HBM consists of six variables: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and health motivation. According to HBM, women engage in breast screening because they firstly perceive themselves at a high risk of breast cancer and anticipate the serious outcomes caused by breast cancer. In turn, the threat serves as a motivation for them to undertake health promoting activities. In addition, women have to perceive more benefits than barriers towards to the uptake of mammography screening. In the meantime, there are internal and/or external events that may give them an incentive to engage in mammography screening. The engagement in mammography is also influenced by their health motivations, such as cultural beliefs.

The qualitative study among older Chinese women reported positive results on breast screening as the majority of participants had gone for mammography screening. The HBM suggests that the perceived chances of getting breast cancer are a prerequisite for the adoption of breast screening. In the current study, however, when talking about the perceived susceptibility to breast cancer, older participants reported that Chinese women were less likely to develop breast

cancer than white British women and attributed the differences to lifestyle and physiological differences (e.g. larger breasts). Despite participants being aware that breast cancer is a serious disease and may even lead to death, the majority of older participants did not perceive that they were at the risk for breast cancer as they did not have a family history of breast cancer. It was perceived that participants who had relatives with breast cancer showed more sensitivity and worries to getting breast cancer than those without a family history. Therefore, the application of perceived susceptibility becomes questionable within the Chinese community.

On the barriers to mammography screening, participants' concerns included inability to speak English, embarrassment, pain caused by mammography screening, practical issues (e.g. being too busy with work), and access barriers which were in part related to language barriers (e.g. transportation). The HBM proposes that an individual's performance of health promoting behaviour is also driven by their health motivation (Becker et al. 1977). Participants paid much attention to their health in this study. However, the lack of the concept of regular screening within Chinese health beliefs on health maintenance might be a potential barrier to mammography screening. On the point of mammography screening, participants highlighted the benefits of having mammography screening on the early diagnosis of breast cancer, receiving treatment at an early stage, and the improvement of breast cancer mortality. According to HBM, the perceived benefits of mammography screening weighed against the perceived barriers, and thus resulted in the high participation in mammography screening among older participants. However, what should not be ignored is the vital role of the invitation letter and the free service on the influence of women's decision on mammography screening because they were the two frequently mentioned factors that encouraged Chinese women to go for screening. In addition, having relatives with breast cancer and receiving family support were the other cues to mammography screening.

According to HBM, demographic variables also have an effect on individuals' health behaviour. In this study, the older participants were allocated into different groups according to two demographic variables: the place that they originally come from and the city that they are living in at present. However, no obvious differences have been identified in themes raised by these different clusters on the variables related to mammography screening and mammography screening rates among older participants. The reason may be ascribed to participants sharing the same cultural background and living in two major cities in the UK alongside similar levels of education and English ability.

It is believed that the breast screening intervention which was developed on the basis of the combination of the empirical and theoretical evidence could not only address the barriers and motivators to breast screening among Chinese women but also provide a deliberate matching of the theoretical causal relationship between beliefs and behavioural change.

6.4 The findings of the present study in relation to the literature

The findings from this study complement and also add new evidence to the literature on mammography screening among Chinese women in Western countries. The published research has demonstrated that Chinese women living in Western countries had a low mammography screening rate (American Cancer Society, 2008; AIHW & NBCC, 2009; Breast Cancer Care, 2005). Therefore, beliefs about mammography screening and screening rates among the older participants were predicted to be less positive than they were. This study indicates high mammography screening rates in that all but two older participants had attended the initial mammography screening when they received an invitation. For those who had received the invitation for their second or further screening, all of them reported that they had returned to the repeat mammography screening. They also offered some suggestions as to why other Chinese women would not attend mammography screening e.g. shyness, male healthcare staff being

used, fear that they would not be able to communicate with the healthcare provider. This qualitative study was not intended to be simply generalizable. The high mammography rates in this study may not be representative of all older Chinese women in the UK as the sample size was quite small and participants were recruited from two major cities in the UK. However the study does provide valuable information on which aspects of Chinese women's beliefs impact on their screening behaviour and therefore could be targeted in future interventions.

Previous studies have revealed that Chinese women's mammography screening behaviour was significantly predicted by physician's recommendation (Tang et al, 2000; Yu et al, 2001; Yu et al, 2003). This effect is not only found among Chinese women, but also observed among the general population (Mickey, Vezina, Worden, & Warner, 1997). In accordance with the findings of the prior research, participants in this study also reported that receiving the invitation sanctioned by their GP greatly influenced their decision on whether go for a mammography screening. In contrast with other Western countries where women have to pay for mammography screening, the financial barrier to the mammography screening was eliminated for Chinese women as mammography screening is a free service in the UK. Accordingly, no charging was reported as another great contributor to the high rates of mammography screening in this study.

Although the literature review had suggested that fatalistic views towards illness was identified as a major barrier for mammography screening among Chinese women (Kwok & Sullivan, 2006), participants in this study emphasised the importance of keeping healthy and believed in a holistic approach to health management. In contrast to previous research which has found negative attitudes towards mammography screening (e.g. having mammography can cause breast cancer and other possible side effects, Gany et al, 2006), older participants in this study indicated very positive attitudes to mammography screening and early detection and had strong intentions to go for mammography screening on a regular basis.

As seen in previous studies, several barriers to mammography screening were also identified in Chinese-British women. First, inability to speak English was the prominent barrier to receive health-related information. Although older participants expressed high advocacy of mammography screening, they had limited knowledge of breast cancer and reported some misconceptions regarding the risk factors for this disease. This is consistent with the previous research that lack of understanding of breast cancer is a common feature among Chinese women and women from other minority ethnic groups (Breast Cancer Care, 2005; Karbani et al, 2011; Lee et al, 1996; Lee-Lin et al, 2008; Su et al, 2006; Yu et al, 2001) and suggests that knowledge is a significant predictor of the uptake of mammography screening among Chinese women. In addition, older participants who were not fluent in English were reluctant to use health services as they have difficulties communicating with healthcare providers. Previous studies have indicated that language emerges to be a significant barrier of mammography screening use (Lee et al, 1996; Sadler et al, 2000; Yu et al, 2001). In this study, however, mammography screening was often thought to be easier because participants were shown what to do by the nurse and did not have to talk about their health. This suggests that it is important to inform women what happens during the screening before they undergo mammography and thus improve their participation in breast screening programme.

The literature also has suggested some cultural barriers to mammography screening. For example, Eastern views of health care are considered to be a potential barrier to mammography screening among Chinese women, as TCM proposes different approaches to health management and illness treatment when compared to Western medicine (Yuan & Lin, 2000). Studies suggest that Chinese women may prefer not to use Western screening if they hold traditional Chinese beliefs (Lum, 1995; Tang et al, 2000). In this study, although older participants hold a holistic view of health maintenance, they combined TCM and Western medicine and showed diverse approaches to health maintenance and illness management

according to their assessment on their conditions. However, it cannot be ignored that older participants did not mention the importance of having regular medical screenings when they talked about the ways to keep healthy though they showed positive attitudes to mammography screening. This may reflect that their current health beliefs are still influenced by the traditional Chinese health beliefs which do not include the notion of regular medical check-ups in health management. Garcia and Lee (1989) reported that the Chinese showed a strong preference for using healthcare service for acute illness rather than regular physical examinations. Regarding BSE, forgetting or/and lack of symptoms were the main reasons that older participants did not perform regular BSE though they were somewhat aware of the methods to do it. This may reflect that to a certain extent, breast screening behaviour among Chinese women is still influenced by the traditional Chinese beliefs on health maintenance.

Modesty has been found to be another salient cultural barrier for the low mammography screening rates among Chinese women (Gany et al, 2006; Kwok et al, 2005). The literature review demonstrated that the Chinese women feel embarrassed to communicate the issues concerning their breast as it is a private topic for them (Gany et al, 2006; Kwok et al, 2005). There is evidence that older Chinese women with reproductive organ related cancers usually seek medical treatment from the practitioners of TCM in order to avoid exposing their bodies to Western doctors (Vu, 1996). By comparison, modesty was not an important barrier to mammography screening among Chinese women in this study despite some of them feeling embarrassed during mammography screening. However, healthcare providers should still give their attention to the concerns of modesty when they promote breast cancer prevention among Chinese-British women as one of the older participants reported that modesty was the main reason why her friend did not go for mammography screening.

In line with the findings of previous studies (Liang et al, 2004; Sandler et al, 2000), older

participants also suggested other barriers that might reduce Chinese-British women's willingness to take mammography screening, such as transportation. In fact, it was found that the difficulties in using public transport are actually associated with participants' English ability. As a result, participants who had limited or no English proficiency had to rely on their family members when they used healthcare services including mammography screening, as their family members could provide some facilitation such as transportation and interpretive services for their communication with healthcare providers. In addition, older participants also commented that some older Chinese even delayed their visit to doctors so as not to burden their children. It suggests family support plays an important role on Chinese-British women's mammography screening use.

Compared to previous studies, one advantage of this study was that it not only explored the psycho-social factors related to mammography screening among old participants, but also examined breast cancer prevention among young participants. With respect with BSE, younger participants in this study reported a low screening rate, with only around 38% of the younger participants reported that they had ever done BSE. This figure is slightly higher than the number obtained from a previous study which found that the percentage of Asian-American University students who had ever practiced BSE was around 27% (Tang et al, 1999). As discussed above, compared with older participants, younger participants' attitude towards breast cancer prevention was strongly influenced by the "neo-fatalistic" view that breast cancer cannot be prevented due to genetic causes rather than the Chinese beliefs and cultural views. The main reason for the low performance of regular BSE was attributed to the low perceived susceptibility and lack of knowledge on the methods of BSE performance. In addition, younger participants' alertness to breast cancer was perceived as having increased by having relatives with breast cancer or other breast illness. This suggests that the educational programmes targeted at young Chinese women should emphasis the risk factors for breast cancer, increase their breast cancer

awareness and in line with current policy emphasise breast awareness rather than BSE. The most important thing is to inform Chinese women that despite being less susceptible to breast cancer compared to white British women, their susceptibility to breast cancer rises with acculturation. It means that the longer time that they live in the UK the more risk that they have for developing breast cancer.

6.5 The findings of this study contrasted with qualitative studies among South Asian women in the UK

As with the prevalence of breast cancer in Chinese women, breast cancer is the commonest cancer and the leading cause of death among South Asian women (Bhopal & Rankin, 1996; Hoare 1996; Selby, 1996). According to the 2011 Census, South Asian, which consists of Indians, Pakistanis and Bangladeshis, is the main ethnic minority group in England and Wales and accounts for 5.3% of the total population (Office for National Statistics, 2012). Therefore, relatively more studies have been conducted to understand breast health and breast screening among South Asian women (Bottorff et al, 1999; Karbani et al, 2011; Rajan, Lim, & Haq, 2011). As to the uptake of mammography screening, it seems that Chinese women in this study reported higher attendance when compared to the findings from studies among South Asian women (Karbani et al, 2011; Rajan et al, 2011). For example, Rajan et al. (2011) conducted a survey among 36 South Asian women diagnosed with breast cancer and found that majority of symptomatic patients (n=19, 66%) did not go to breast screening even though they were in the eligible age group.

In line with the knowledge of breast cancer, a qualitative study among South Asian patients reported that most of these patients were unaware of the term cancer before they had been diagnosed with breast cancer (Karbani et al, 2011). Accordingly, they lacked breast cancer-related knowledge and indicated strong cultural beliefs towards to the causes of breast cancer.

The themes that were generated regarding cancer were "cancer was a taboo subject, cancer was contagious, cancer was stigmatised and cancer in the family had ramifications on children's marriage prospects" (Karbani et al, 2011, p. 1621). Karbani et al. (2011) suggest that the cultural views and false beliefs about breast cancer and its treatment delay South Asian women's presentation of breast cancer treatment. In contrast, Chinese women in this study were aware that breast cancer is a common female disease and attributed the main risk factors to genetics and dietary behaviour. As to health management, the majority of older participants showed positive attitudes on breast cancer prevention and believed in benefits of early detection and early treatment. However these Chinese women did not see themselves as at significant risk unless they had relatives or friends with breast cancer. As was mentioned above (Section 6.2), Chinese cultural beliefs also have a significant impact on Chinese women's health beliefs and the uptake of mammography screening. Some cultural views, such as modesty and lack of a concept of prevention for specific diseases in Chinese culture, might be potential barriers that prohibited breast screening practices among Chinese women.

As to access to health services, in accordance with findings in the current study, previous studies among the South Asian community also identified that cultural views and language were the two main personal factors that influenced the use of health services and receiving health-related information (Szczepura, 2005). Family and social community were reported as the common ways of gaining cancer–related information by South Asian participants in a qualitative study (Randhawa & Owens, 2004). The same statements were reported by older Chinese women in this study.

The findings suggest that there are some similarities but several differences between Chinese women and South Asian women on their beliefs about breast cancer and its causes, attendance at breast screening, factors-related to healthcare seeking behaviour and channels of learning

health-related information. In short, cultural differences and language barriers are the common issues for Chinese women and South Asian women in understanding breast cancer and utilization of breast screening, but the impacts are different in the two groups.

6.6 Implications for the qualitative findings as evidence in designing the breast screening intervention

In recent decades, the use of evidence-based programmes and interventions has grown in prominence in public health practice and health promotion practice (Teutsch et al, 2009). Such programmes and interventions are developed on the basis of an application of scientific reasoning and credible scientific data and evidence (Brownson, Gurney, & Land, 1999; Brownson, Baker, Leet, & Gilespie, 2003). The effectiveness of an evidence-based programme or intervention on behaviour change has been documented (Bartholomew et al, 2011). Therefore, the aim of this thesis was to develop an evidence-based breast screening intervention to promote breast health and breast screening among Chinese women.

The qualitative findings expand the understanding of breast cancer prevention and early detection among Chinese women living in the UK. From the focus group discussions, older Chinese women showed positive attitudes to mammography screening and high participation in the screening. However, they had limited knowledge about breast cancer and its causes. They over emphasised the impact of genetics on breast cancer causality and also reported some misconceptions of breast cancer causes. Compared with the older generation, the younger generation had more accurate knowledge on breast cancer causes and believed that breast screening can detect early breast cancer. However, strong neo-fatalistic view toward breast cancer prevention and low participation rate of BSE were observed among younger generation. Future breast cancer educational programmes among the Chinese community should realize the diversity of breast cancer knowledge, attitude and behaviours between the two generations and

create age-specific promotion programmes.

There is evidence to suggest that cultural values also contribute to breast screening among Chinese women e.g. Chinese beliefs on health and holistic views of health maintenance. Minkler, Thompson, Bell, Rose and Redman (2002) point out that it is essential to involve the meaningful target population in designing and implementing health promotion programmes. This may explain why an intervention for Western women would not be suitable for the Chinese community and highlights the importance of the development of an evidence-based breast screening intervention among the Chinese community. The next chapter will use Intervention Mapping to integrate findings from the literature review, systematic review and focus groups to develop a culturally and linguistically tailored breast screening intervention, which addresses issues important to the Chinese community. It is believed that such an intervention would raise mammography screening attendance among Chinese women compared with interventions focused on the general population.

6.7 Summary

The findings of qualitative studies indicate that there are some similarities and differences between the older and younger generations of Chinese women, and between Chinese women and South Asian women, in terms of health beliefs, breast cancer prevention and detection, and healthcare seeking behaviour, which suggests that Chinese women cannot be treated as a whole, nor can ethnic minorities, when promoting breast health and breast screening but groups should be provided with tailored interventions to meet their needs.

Chapter 7 Using Intervention Mapping to develop a breast cancer educational programme for Chinese women living in the UK

7.1 Introduction

Since the establishment of the NHS Breast Screening Programme, there has been a significant improvement in breast cancer related mortality and morbidity (Cancer Research UK, 2009), which was partly attributed to the increased screening rates. However, not everyone benefits equally from this screening programme. Previous studies have shown that women from the Chinese community are less likely to get access to breast screening (Breast Cancer Care, 2005; Hoare, 1996; Liao & McIlwaine, 1995). In order to develop and carry out effective interventions to increase the mammography screening among Chinese women, it is essential to understand the psycho-social factors related to the uptake of mammography screening among this population. The focus groups among older women provided insights into the Chinese women's breast health-related knowledge, cultural views towards health management, perceived benefits and barriers to mammography screening, the channels for gaining health-related information and the preferred educational modality (Please refer to Chapter 4 for details). The systematic review revealed that despite several interventions having been carried out to improve the attendance of mammography screening among Chinese women living in Western countries, no specific studies have been conducted to explore the reasons for the lower uptake of mammography among Chinese-British women when breast cancer is the most prevalent cancer among this population (Please refer to Chapter 3 for details). This highlights the necessity to promote the NHS Breast Cancer Screening Programme among Chinese-British women in order to improve breast screening rates, and thus reduce the breast cancer-related morbidity and mortality among them.

The aim of this chapter was to use Intervention Mapping (Bartholomew et al, 2006) to integrate the findings from the focus groups among older women, the literature review on psycho-social factors related to mammography screening among Chinese women and the systematic review of interventions aimed at increasing breast health and mammography screening among Chinese women in Western countries in the development of a culturally and linguistically tailored intervention for increasing mammography screening among Chinese-British women who are non-adherent to the NHS Breast Screening Programme.

7.2 Methods

As discussed in the methodology chapter (Chapter Two), Intervention Mapping (Bartholomew et al, 2006) was used to develop a breast cancer educational programme among Chinese-British women. Following the guide to Intervention Mapping, the following steps were carried out during the intervention development: 1) the needs assessment; 2) the development of matrices of intervention objectives; 3) the selection of theory-based intervention methods and practical strategies; 4) the design of the intervention (Bartholomew et al, 2006) (Please refer to Section 2.4 for details). Step 5 specification of adoption and implementation and step 6 creation of programme evaluation were not carried out as they were outside the scope of this thesis. Intervention Mapping enables intervention developers using theory and evidence to 1) identify personal and external factors related to a special health problem; 2) guide the selection of intervention methods and strategies to focus on the identified factors. The following sections provide a summary of the process of the plan, development, implementation and evaluation of the culturally and linguistically tailored breast screening educational intervention for Chinese-British women according to the steps of Intervention Mapping.

7.3 Results: Intervention development and status

7.3.1 Step1 Needs assessment

The first step of Intervention Mapping is needs assessment, which is a comprehensive problem analysis to specify the health problem that the researchers are interested in (Hou et al, 2004). In
this thesis, a variety of methods have been used to understand breast cancer prevention and screening behaviour among Chinese women. The methods included the literature review on the factors-related to mammography screening among Chinese women in Western countries (Section 1.7). The literature review suggested that low attendance rates are associated with perceived costs of screening, a lack of knowledge about cancer, symptoms and risk factors, negative beliefs and attitudes towards cancer and screening behaviour, language barriers, Eastern views of care and a lack of linguistically and culturally appropriate services (Wang et al, 2006; Yu et al, 2001).

A systematic review of interventions targeted at increasing breast health and screening among Chinese women in Western countries was also carried out in order to determine which intervention method would be effective in enabling Chinese women to make informed choices (Chapter 3). The results have shown that the culturally and/or linguistically tailored social network directed interventions and multi-strategy directed interventions are more effective in terms of increasing the uptake of mammography screening.

Because the target population was Chinese-British women in this intervention, the needs assessment also included focus groups with Chinese-British women so that the psycho-social factors related to low uptake of mammography among Chinese women, even though breast screening is free of charge for them, could be understood. Chinese women in focus groups showed positive attitudes and behaviours on keeping healthy and taking mammography. However, they lacked accurate knowledge about breast cancer and its causes. Despite the fact that Chinese women have lower risk for developing breast cancer compared to white British women, some of them failed to realize that low susceptibility does not mean zero susceptibility. Inability to speak English was a key barrier to obtaining health-related information or indeed using medical care more generally (please refer to Chapter 4 for details). All this work informed

the choice of the intervention methods and strategies and the plan of the implementation of the intervention.

7.3.2 Step 2 Matrices of proximal programme objectives

Step 2 provides the foundation for the development of the intervention by specifying the detailed information about who and what will change as a result of this intervention (Bartholomew et al, 2006). The aim of step 2 is to develop the proximal programme objectives that are the statements about what needs to be learnt at the individual level and what needs to be changed at the environmental level for the modification of the determinants and thus achieve the performance objectives (Bartholomew et al, 2006).

Step 2.1 Performance objectives

The aim of this intervention was to increase breast screening among Chinese-British women who are non-adherent to the NHS Breast Screening Programme. The literature reviews have shown that the uptake of mammography screening was not only affected by the individual factors, but also influenced by the environmental factors such as the recommendation from the healthcare providers (Kwok et al, 2005; Liang et al, 2004; Tang et al, 2000; Tu et al, 2003; Yu et al, 2003). This finding has also been observed in the focus groups, as participants reported that receiving the invitation letter sanctioned by their GP was the most common reason why they went for mammography screening. Despite women not being invited through their GP, actually they get a standard letter sent by Breast Screening Service with their GP's name on it. Therefore, it is vital to involve Breast Screening Service in this intervention.

Due to their inability to speak English, Chinese women could not benefit from the health-related information in English. Although the NHS provided some educational materials in Chinese, these materials are generally not culturally sensitive. Accordingly, Chinese women might be less likely

to be motivated to attend the mammography screening by the existing educational materials. In addition, inaccessibility is another issue that might prohibit Chinese women from gaining the culturally tailored information (further exploration in Section 7.3.4). The focus groups with older Chinese women revealed that they generally received health information through the workshops held by local Chinese society, Chinese media and friends and family. It is therefore important to get the local Chinese society involved into the breast cancer educational programmes to ensure that the breast cancer-related knowledge and information regarding breast screening could reach into a wider population especially those who cannot speak English. The systematic review (Chapter 3) demonstrated that using trained Chinese lay health workers-led workshop is an effective way to improve the breast screening among Chinese women. Synthesis of the findings from the focus groups and systematic review suggests that the NHS could engage with local Chinese societies by providing training to Chinese lay health workers and then implement lay health worker-led workshops among Chinese women who have failed to follow the breast screening programme, and thus improve the screening rates among this population.

On the basis of the needs assessment, the performance objectives, which are the more specific and detailed behavioural objectives, were developed for three groups in the current intervention: individuals, healthcare providers, and local Chinese societies.

The performance objective for individuals was:

Performance objective 1: Non-attending women will attend for breast screening within 6 months of a missed appointment.

The performance objectives for the environmental factors were:

The performance objective 2: Healthcare providers will send culturally and linguistically tailored invitations and educational materials to Chinese women.

The performance objective 3: Local Chinese societies will carry out breast cancer-related workshops targeted at women who are non-adherent to the NHS Breast Screening Programme.

Step 2.2 Specifying determinants of behavioural and environmental factors

Compared with the findings from the literature, Chinese women among the focus groups indicated high engagement in mammography. However they did provide information on why other women may not engage and why engagement may be lower in particular circumstances. Participants felt that barriers to screening in the UK were reduced because it is free at point of care and because all women receive invitations automatically. However, there are some problems that healthcare providers should pay attention to in this population. Although many participants believed that mammography is an effective means of early breast cancer detection and route to successful treatment, they lacked specific knowledge about breast cancer and its causes. For example, most of participants strongly believed that having a family history is the main cause of breast cancer. As a result, many participants reported that they did not worry about breast cancer due to having no relatives with it. In addition, breast cancer was labelled as a 'white women's disease' by some participants because white women have bigger breasts. This point of view was consistent with findings of previous studies (Tang et al, 2000). Not having the genetic component and being Chinese were the two major contributors of the low perceived risks of developing breast cancer among Chinese women. In turn, Chinese women might consider that it is not necessary for them to attend mammography screening as they are not at risk of developing breast cancer. The research literature has revealed that the low uptake of mammography screening is associated more generally with the low estimated risk of breast cancer (Neise, Rauchfuss, Paepke, Beier, & Lichtenegger, 2001; Polednak, Lane, & Burg, 1991).

Inability to speak English was a key barrier to obtaining health-related information or indeed using medical care more generally. Several women reported problems with translators not being available or not speaking fluent Cantonese. Mammography screening, however, was often thought to be easier because they were shown what to do by the nurse and did not have to talk about their health. It cannot be ignored that for women who had never attended mammography

screening, they might be not aware the procedure of mammography screening and may still be concerned about the communication difficulties with healthcare providers, and thus would be reluctant to go for mammography screening. This view has been supported by the statement from one participant when she talked about her friend refusing to go for mammography screening due to the language barrier. Therefore, it is important to inform Chinese women what will be involved during the mammography screening in order to reduce the potential barriers to their participation in breast screening.

Chinese women indicated that they put high value on their health and believed in a holistic approach to health maintenance through diet, exercise, and maintaining a positive attitude, which is consistent with the traditional Chinese health beliefs. As food is considered as the main source of getting energy in Chinese medicine, it is not a surprise that participants in the current study repeatedly emphasised the importance of eating a healthy diet either in keeping healthy or in breast cancer prevention. It should be noted that when participants talked about health management, they focused on health maintenance rather than disease prevention. Participants seldom mentioned the importance of using screenings to detect asymptomatic disease. This finding might be attributable to that the concept of preventive measures for specific diseases not being familiar in traditional Chinese culture (Kwok & Sullivan, 2007). Therefore, this might be one of the reasons why Chinese people are less likely to follow the recommendation of the screening programmes in Western countries (Chan & Quine, 1997; Kwan & Bedody, 2000). This study supported the findings of previous studies in the other Western countries that traditional Chinese health beliefs are still central to the Chinese despite them having lived in the Western countries for many years (Kwok & Sullivan, 2007). In brief, Chinese culture plays an important role in informing individuals' health beliefs and influencing their preventive health behaviour, including mammography screening (Kwok & Sullivan, 2007).

A fatalistic view was observed among a few participants. For example, getting breast cancer was considered as fate and nothing could be done to prevent it. In addition, participants who had relatives die from breast cancer showed high vigilance and fear of the development of breast cancer. This might reflect that having breast cancer is considered equivalent to death in these participants. Participants might not be fully informed of breast cancer curability if it is detected at the early stage. Women with fatalistic views towards breast cancer might perceive fewer benefits of mammography, consequently, they might be less likely to follow the national screening programme. The literature review has suggested that fatalism is one of the factors that prohibits Chinese women from going to mammography screening (Kwok & Sullivan, 2006). However, a fatalistic view of cancer is not unique to Chinese women and it has also found among women from other ethnic groups in Western countries (Perez-Stable et al, 1992; Salazar & Walsh, 2006). For example, getting breast cancer is considered as God's will (Powe & Weinrich, 1999; Barroso et al, 2000).

The literature has revealed that there is no agreed definition on fatalism (Shen, Condit, & Wright, 2009) and suggested that the concept of cancer fatalism consists of one or more of the following health beliefs: 1) pessimism, which refers to the state of helplessness and hopelessness that an individual perceived due to their overestimation of negative health outcomes (Scheier & Bridges, 1995); 2) predetermination, which means that individuals believe that health is determined by external events and they have nothing to do to control these events (Chavez, Hubbell, Mishra, & Valdez, 1997; Davison, Frankel, & Smith, 1992); and 3) the operation of luck (Davison et al, 1992; Straughan & Seow, 1998). Powe (1996) proposed that cancer fatalism is determined by culture, history and socioeconomics. In this study, it appears that older Chinese women were more likely to believe that they have less control of breast cancer as developing breast cancer is a matter of fate or luck. There is evidence that the culturally tailored intervention significantly decreased participants' cancer fatalism and also increased their screening behaviour (Powe &

Weinrich, 1999). This implies that healthcare providers must realize the role of cancer fatalism in breast cancer prevention and have to interpret the fatalistic views on breast cancer in a cultural context.

Although the literature review has suggested that breast cancer is a sensitive topic among the Chinese community, participants in this study reported that they were comfortable talking about breast cancer with their friends. However, modesty still influenced the uptake of mammography for a few Chinese women. In addition, the modesty issue has been observed in women from other minority groups (Tang, Solomon, Yeh, & Worden, 1999). Generally, women from Asian countries are reluctant to expose their breast to others. Aspects of the experience of mammography that women discussed included the pain involved and being embarrassed by exposing themselves, but these were not major problems. Participants in this study stated that it is worth enduring the embarrassment and pain. Chinese women in previous studies stated that the embarrassment can be overcome by using female staff to carry out mammography (Kwok, et al, 2005). It is therefore essential for breast screening educational materials and programmes to emphasise the fact that mammography screening is conducted by female health care professionals in the UK in order to encourage the participation of mammography screening among women from minority groups.

Being unable to take time off from work was identified as a barrier by one participant for not going for mammography screening. However, this barrier was found to be easily overcome when the participant was aware that the other participants in her group all received mammography screening. This suggests that perceived social norms are another factor that can encourage women to go for mammography screening. It implies that Chinese models could be used in breast cancer campaigns or educational programmes aimed to improve the breast health and screening among the Chinese community, as Chinese women might be more likely to take part

in mammography screening by observing the performance of their compatriots.

Family members also play an important role in the women's decision to use medical services. Many participants in this study stated that family members accompanied them when visiting a doctor, as they could provide the transportation and facilitate communication with physicians,. In addition, participants who cannot speak English usually asked their family members to translate the English health information or screening invitations such as mammography screening for them. The use of medical services was also determined by whether their children are able to take time off work to take them to the appointment. Therefore, it is important to involve the family members in NHS services such as mammography.

Having completed the focus groups, the results of the focus groups were synthesised with the literature review of other researchers' findings. A list of determinant factors for behaviour were identified, including knowledge, Chinese beliefs, perceived susceptibility, perceived benefits, perceived barriers, perceived norm and some facilitators such as family support and receiving breast screening invitations (Table 7.1).

The findings of the focus groups suggest that healthcare providers need to take Chinese cultural and language concerns into account when designing and implementing breast cancer screening services which target Chinese-British women. Therefore, health providers firstly have to acknowledge the psycho-social factors related with mammography among Chinese-British women and thus provide the tailored services to improve the availability and accessibility of breast screening services among this population. With regard to the Chinese community, organisers have to realize the prevalence of breast cancer among the Chinese and appreciate the importance of conducting breast screening promotion among the Chinese community. In this thesis, some determinants of the environmental conditions were suggested (Table 7.2). However,

in-depth interviews with healthcare providers and organisers in local Chinese communities should be conducted in future studies in order to identify the specific determinants that have an influence on them.

Step 2.3 Developing a matrix of proximal programme objectives

The final point of step 2 is to develop a matrix of proximal programme objectives by the combination of the performance objectives and the key determinants. The determinants are presented on the first row of the matrix and the performance objectives are listed on the left column. The learning objectives for Chinese-British women and the change objectives for the environmental factors were written within each matrix cell. The matrix of the learning objectives and change objective provide a guide for the selection of methods and strategies towards behavioural change (Table 7.1 & 7.2).

| Behaviour: Non-adherent Chinese-British women will go for mammography screening | | | | | | | | | | |
|--|--|---|--|--|--|--|---|---|--|--|
| Personal determinants External d | | | | | | | | ternal determinants | | |
| Performance objectives | Knowledge (EL, FG & FCW) | Chinese beliefs (EL, FG & FCW) | Perceived susceptibility (EL, FG & FCW) | Perceived benefits (EL, FG & FCW) | Perceived barriers (EL, FG & FCW) | Perceived norm (EL, FG & FCW) | Availability and accessibility (EL, FG & FCW) | Family support (EL & FG) | | |
| 1. Non-adherent women will attend the breast screening after they have received the intervention. | 1. Understand what breast cancer is and its related risk factors (EL, FG & FCW) 2. Describes the NHS Breast Screening Programme (EL, FG & FCW) | 1. Realize the importance of screening in health promotion (EL, SR, FG & FCW) | Identify themselves at risk of developing breast cancer (FG, SR & FCW). Aware that the risks of developing breast cancer increase with successive generations | State benefits of having mammography screening (FG & SR). Understand that mammography screening can detect breast cancer which is unable to be detected by CBE and BSE 3. Mammography is an effective means of early breast cancer detection and route to successful treatment (EL, SR & FG) | Know that the mammography screening was carried out by female practitioners (EL, FG & FCW) Describe that pain caused by taking mammography is durable (FG) Can book an appointment with trained interpreter if they can't speak English. Realize that having mammography screening does not cause breast cancer (EL & FG) | 1. Indicate that most Chinese women go for mammography screening and the high screening rates among white British women (EL, FG & FCW) | 1. Breast Screening Service will send the invitation every three years to women aged between 50-70 (EL, FG & FCW) | 1. Family members' encouragement to go for the mammography screening (EL & FG) 2. Family member can provide some facilitation such as providing transportation and interpreting (EL & FG) | | |

Table 7.1 Matrix of proximal programme objectives for Chinese women

Note. Sources that have been used throughout the intervention mapping exercise are given in brackets. EL = extant literature, SR = systematic review, FG = focus groups, FCW = feedback from Chinese women

Table 7.2 Matrix of proximal programme objectives for healthcare providers and Chinese communities

| Environment: Breast Screening Service providing the culturally and linguistically tailored mammography screening services to Chinese women. | | | | | | | | |
|---|--|--|--|--|--|--|--|--|
| Personal Determinants | | | | | | | | |
| Performance objectives | Knowledge (EL, FG & FCW) | Outcome expectations | | | | | | |
| 2. Healthcare provider will send cultural and language | 1. Understand the Chinese cultural beliefs on health and | 1. The culturally and linguist tailored invitation | | | | | | |
| tailored invitations and educational materials to Chinese | health maintenance (EL, SR & FG) | and services will increase Chinese-British | | | | | | |
| women. | 2. Recognize the barriers to mammography screening | women's breast cancer-related knowledge | | | | | | |
| | among Chinese-British women (EL, FG & FCW) | and the uptake of mammography screening | | | | | | |
| | 3. Realize that Chinese women lack breast cancer | (SR, FCW & FHP) | | | | | | |
| | related knowledge (EL, FG & FCW) | | | | | | | |
| 3. Local Chinese societies will carry out the breast | 1. Realize that the uptake of mammography screening is | 1. Carrying out breast cancer-related | | | | | | |
| cancer-related workshops targeted at women who are | lower among Chinese women than white British women. | workshops will increase Chinese-British | | | | | | |
| non-adherent to the breast screening programme | 2. Chinese women are more likely to be diagnosed with | women's breast cancer-related knowledge | | | | | | |
| | an advanced stage of breast cancer. | and the uptake of mammography screening | | | | | | |
| | 3. Chinese women do not have sufficient breast cancer- | (SR & FCW). | | | | | | |
| | related knowledge (FG & FCW) | | | | | | | |
| | 4. Workshops held by local Chinese societies are one of | | | | | | | |
| | the importance source for Chinese women to get health- | | | | | | | |
| | related information (EL, FG & FCW) | | | | | | | |

Note. Sources that have been used throughout the intervention mapping exercise are given in brackets. EL = extant literature, SR = systematic review, FG = focus groups, FCW = feedback from Chinese women, FHP = feedback from healthcare provider

7.3.3 Step 3 Theory-based intervention methods and practical strategies

The aim of this step is to develop an inventory of theoretical methods and practical strategies to achieve the proximal programme objectives which are defined at step 2. To do this, the question 'how can the learning and change objectives be achieved?' was firstly considered. The methods and strategies were selected based on 1) the findings from the systematic review of breast cancer interventions among Chinese women in Western countries (Chapter 3), 2) the findings of focus groups in this thesis (Chapter 4), and 3) the resources available.

In accordance with the recommendations of the literature (Abraham & Michie, 2008; Batholomew et al, 2006; Michie, Johnston, Francis, Hardeman, & Eccles, 2008), a variety of methods have been selected to modify changes in determinants. Kok et al. (2004) suggest that individuals' perceived risks to an illness may be influenced by providing the information about the causes and outcomes. In addition, their attitudes toward to the target behaviour may be also improved by receiving the information about the benefits and costs of an action (Abraham & Michie, 2008). Department of Health (2000) proposed that information plays a pivotal role throughout the cancer screening and also points out that women in general are not provided with adequate information about cancer screening, especially those from minority ethnic groups who are disadvantaged with respect to accessing health information. Breast Cancer Care (2005) stresses that breast health information should be available in different formats and languages and be culturally sensitive to ensure people from minority ethnic groups could benefit equally. Therefore, the priority for promoting breast screening among the Chinese community is to provide breast cancer-related preventative health information thereby providing information about the behaviour and outcomes (Michie et al, 2008). The information-motivation-behavioural skills model (Fisher & Fisher, 1992), was therefore selected as the first theoretical method to influence the learning objectives regarding knowledge, perceived severity and perceived benefits. The qualitative data in this research identified Chinese society, media, family and friends as the

main sources of getting health-related information, and hence it is essential to work closely with local Chinese societies for the sake of making sure that breast awareness and breast screening information could reach the targeted population. In addition, the benefits of involving breast screening users in the breast screening campaigns have been emphasized by the National Health Service Cancer Screening Programme (Chiu, 2002). According to the Social Cognitive Model (Bandura, 1977, 1986), people's attitudes may be changed by observing the behaviour of others either in their social networks or in the media. Hence modelling has been suggested to be an effective method to influence individuals' beliefs and values (Bandura, 1986). Accordingly, modelling was selected as another theoretical method to influence the determinants of beliefs and perceived norms.

The systematic review demonstrated the effect of lay health worker-led educational interventions on breast health-related knowledge and beliefs, and intention towards breast screening among the Chinese community. Chiu (2002) suggested policymakers and practitioners should realize the fact that the interpersonal communication between community health educators and target women is more effective than mass media for reducing the misconception and myths of the breast screening programme. Therefore, persuasive communication, which is another method derived Social Cognitive Model (Bandura, 1977, 1986), was used to improve Chinese women's beliefs on breast cancer prevention and mammography screening in this intervention as it has been agreed as a useful technique to change people's beliefs about consequences, motivation and goals (Michie et al, 2008). In addition, barrier identification was selected to identify the potential barriers to mammography screening and also aim to find out the ways to overcome the barriers (Abraham & Michie, 2008). Department of Health (2004) suggested that communication organisations and the voluntary sector have more advantages than the public sector in distributing health information to those who are less likely to use public services. This highlights the need for the Breast Screening Service to develop a partnership with local Chinese

organizations to ensure the NHS Breast Screening Programme is implemented in a more effective way.

The results from focus groups together with evidence from the literature review suggest that the uptake of mammography screening among Chinese women is also influenced by some environmental factors. Despite the qualitative study in this research indicating that a majority of older Chinese women showed positive attitudes and behaviour on breast screening, they still faced some difficulties on making an informed choice or getting access to breast screening. Chinese women who are new arrivals, disabled, socially isolated may suffer greater difficulties in the uptake of breast screening than Chinese women involved in the current study. The National Health Service Cancer Screening Programme report has suggested that it is crucial to inform women of the procedure and purpose of NHS Breast Screening Programme as the lack of information has an influence on women's decision about mammography screening adoption (Chiu, 2003). Therefore, this intervention involved sending a culturally and linguistically tailored breast screening leaflet alongside the invitation letter.

Apart from the accessibility of information, the necessary facilitations for Chinese women in accessing breast screening should be provided once they have made the informed choice, such as providing high quality interpreting services. The focus groups and literature review revealed that communication between Chinese women and healthcare providers significantly affects the usage of health care services including breast screening. The findings of this study revealed that the NHS did not provide high quality interpreting services to meet the needs of Chinese women who cannot speak or speak little English. Lack of proficiency in medical terms, not sharing the same language with Chinese patients and the absence of interpreters were reported as the common issues related to the interpreting services that discouraged Chinese women from using the health services. It is important to realize that the language barriers and poor interpreting

services may enable Chinese women to delay visiting their GPs when they have symptoms of breast cancer. Consequently, they may be more likely to present at advanced stage of breast cancer and thus reduce the effectiveness of treatment. Although language was not reported as a major barrier to breast screening, the limited proficiency in English would become a big issue when the screening result was positive and further treatment was needed. Therefore, it is essential for the NHS to provide more professional training to interpreters in order to improve the quality of health services among the Chinese community.

Family support also was an impact on the uptake of mammography screening among Chinese women. Besides providing the transportation and language support, family members' attitude towards breast screening also affect women's intention to attend the screening (Rutter, 2000). Breast Cancer Care (2005) has recommended that the promotion of breast awareness should target the whole population because family members even the male relatives can be the source of obtaining health-related information among women from minority ethnic groups. Family members were included in this intervention accordingly for the purpose of providing accurate messages on breast cancer risk and screening when they communicate with their female relatives.

Michie, van Stralen and West (2011) put forward the behaviour change wheel which is a systematic method for designing behaviour change interventions. According to the behaviour change wheel, enablement, which is defined as "increasing means/reducing barriers to increase capability or opportunity" (Michie et al, 2011, p. 42), has been suggested as an effective method to reinforce an individual's motivation to perform a behaviour change. Therefore, enablement was chosen as the theoretical method to increase the availability and accessibility of breast screening and family support.

The theory-based methods were then operationalized into practical strategies which included sending breast screening invitations and educational materials, carrying out Chinese lay health worker-led educational workshops, increasing breast cancer information accessibility and availability, NHS providing high quality interpreting services, inviting family members to the prevention programme and encouraging them to provide support. Table 7.3 presents the process of how to deliver the theory-based methods to practical strategies, and the programme components.

| Learning objectives | Theory-based method | Practical strategies | Programme component |
|--|---|---|--|
| Knowledge determinate, perceived susceptibility, perceived benefits. | 1. Provide information about behaviour and outcome (IMB) | 1. Mail communication (FG, SR & FCW) 2. Chinese lay worker-led workshop (FG, EL, SR & FCW) | The modified NHS breast screening leaflet The video 'Breast screening, your health, your choice'. |
| Chinese beliefs, perceived barriers, perceived norm | Modelling (SCogT) Persuasive communication (SCogT) Prompt barrier identification. (SCogT) | Model stories (EL) Chinese lay worker-led educational workshop among women who have failed to attend the mammography screening (FG, EL & SR) | Role-model stories in the video 'Breast screening, your health, your choice'. The modified NHS breast screening leaflet Group discussion on the benefits of mammography screening and how to overcome the barriers to mammography screening |
| Change objectives | | | |
| Availability and accessibility of breast screening | 1. Enablement (BCW) | Increase breast screening accessibility (EL & FG) NHS providing high quality interpreting services (EL & FG) Provide trainings on healthcare providers (EL, SR & FG) | Sending invitation letter in Chinese Informing Chinese women that screening will be taken by female practitioners (EL, FG & FCW) Provide training for healthcare providers on Chinese cultural beliefs and the skills on how to communicate with Chinese women (EL & SR) Using trained Chinese receptionist to remind non-attending women and to answer women's questions regarding mammography screening (SR) Provide high quality interpreting services with specialist training (EL & FG) |
| Family support | 1. Enablement (BCW) | Invite family members to attend the Chinese lay worker-led educational workshop (EL) Discuss the importance of family support (EL & FG) Set up support goals, such as providing transportation, interpretation and accurate information (EL & FG) | |

Table 7.3 Determinants of learning and change objectives and the associated methods and strategies

Note. Sources that have been used throughout the intervention mapping exercise are given in brackets. EL = extant literature, SR = systematic review, FG = focus groups, FCW = feedback from Chinese women, FHP = feedback from healthcare provider, IMB = information-motivation-behavioural skills model, SCogT = social cognitive model, BCW = the behaviour change wheel

7.3.4 Step 4 Programme

In this step, the intervention was developed and organized on the basis of the findings of the assessment needs (step 1) and the theoretical methods and practical strategies generated in step 3 in order to increase the mammography screening among Chinese women who are non-adherent to the NHS Breast Cancer Screening Programme. The intervention was divided into two parts: a Breast Screening Service setting-based in-reach intervention and Chinese lay health worker-led outreach intervention.

The Breast Screening Service setting-based in-reach intervention consists of using trained Chinese receptionists in primary care to contact non-attenders through sending invitation and educational materials, and making phone calls. During the training, Chinese receptionists would be informed about the NHS Breast Cancer Screening Programme, Chinese beliefs, benefits and barriers of taking mammography among Chinese women, and communication skills with Chinese women. As was assessed in the systematic review, using trained receptionists to contact non-attenders significantly improved the uptake of breast screening.

The Chinese lay health worker-led outreach intervention consists of using trained Chinese lay workers to carry out a video educational workshop among Chinese women who have failed to attend the mammography screening. The effectiveness of this kind of intervention on increasing breast health and the uptake of mammography was supported in the systematic review. In addition, older Chinese women in focus groups also suggested that more workshops should be held in the local Chinese society in order to improve their health-related information.

Step 4.1 Designing programme materials

The existing educational materials about breast screening in Chinese developed by NHS were incorporated into the intervention. There are three existing NHS breast cancer-related leaflets available in Chinese: Breast Screening (2010), Be Breast Aware (2006), and Breast

Screening over 70? You are still entitled to Breast Screening (2007). The audio CD sets of the three leaflets also available from the NHS are website http://www.cancerscreening.nhs.uk/breastscreen/publications/audio-cd-set.html. Among the existing educational leaflets, Breast Screening (2010) is the leaflet that is currently enclosed with the invitation letter sent to women who are eligible for the breast screening. By reviewing these leaflets, it was found that the Breast Screening (2010) leaflet already provided clear and detailed information about the NHS Breast Screening Programme. It addressed the benefits and limitations of mammography screening, the importance of mammography screening for early detection and treatment, breast awareness and also provided some data about breast cancer incidence, mortality and information about breast cancer treatment. In addition, the leaflet also notified women that the mammography screening is taken by female health professionals. However, this leaflet was developed for the general population, it did not take the Chinese cultural and language issues into consideration. And unfortunately the only part of the invitation letter which is in Chinese is a message saying that if the recipient has any questions about mammography, they should ask their GP. Poor communication with GPs was highlighted as a barrier to care amongst the participants. According to the findings from focus groups, Chinese-British women lacked breast cancer-related knowledge and that is probably one of the reasons why Chinese women were more likely to stay away from mammography screening. Thus, it is essential for the breast screening educational materials targeted at Chinese-British women to include the risk factors of breast cancer and the data about breast cancer prevalence among them, and also emphasize the increased risk of developing breast cancer after they have moved to Western countries even though they have lower risks of developing breast cancer when compared to White British women. In addition, the leaflet also has to address the facilities that the NHS provide for reducing the potential barriers that may prohibit the uptake of mammography screening among Chinese women. Therefore, a culturally and linguistically tailored breast screening leaflet was developed on the basis of the NHS Breast Screening (2010) leaflet and covered the issues that Chinese women concern with their breast health

and breast screening (Appendix 18).

Participants from focus groups stated that in addition to leaflets, DVDs were the second favourite format of receiving health cancer-related information and also suggested that it is better to have the DVD in Chinese with English subtitles. Hence, in addition to gaining the knowledge on breast cancer, they also learn the medical terms in order to improve their communication with healthcare providers. According to participants' recommendations, the outreach intervention is a video intervention which would be carried out by trained Chinese lay health workers. There are two existing DVDs regarding breast cancer prevention developed by NHS available in Chinese: Remedica Breast Screening DVD and the video 'Breast screening: your health, your choice' (NHS Cancer Screening Programme, 2006). The Remedica Breast Screening DVD is accessible through NHS website: http://www.cancerscreening.nhs.uk/breastscreen/publications/video/index.html. As in the Chinese leaflets, this DVD was considered not tailored to Chinese women as they were just translated versions of the English one. In addition, the way of using online video to prompt breast screening among Chinese women might be less effective as the majority of older participants stated that they did not know how to use a computer. Therefore, using the Internet was not a common source for older Chinese women to gain health-related information. With this finding, Breast Screening Service providers must realize the main sources of information seeking among Chinese women and thus use these channels to disseminate the knowledge on breast cancer and information regarding mammography screening to reinforce the acknowledgement of the NHS Breast Screening Programme within Chinese community.

In contrast, the video 'Breast Screening: Your Health, Your Choice' (NHS Cancer Screening Programmes, 2006) was specially developed for Chinese and South Asian women in order to improve the uptake of mammography screening among the two ethnic groups. This video is available in Cantonese and Mandarin and also provided with English subtitles, which fulfilled the expectations of participants in focus groups. Despite the advantages of this DVD on the

cultural and linguistic sensitive, Chinese women may have difficulties on getting access to this video resource. The NHS breast screening programme website states that this DVD can be ordered for those outside of NHS via Department of Health website. However, when Aston University has tried to order this DVD for the research use of this study, it was notified that this DVD is only for NHS use. Finally, the researcher contacted the administrator of the NHS Cancer Screening Programme and got a copy. It is essential for the Breast Screening Service providers to ensure that the educational materials should be widely available to the public. Otherwise, people cannot benefit from health information even if it is culturally and linguistically tailored. The video 'Breast screening: your health, your choice' (NHS Cancer Screening Programme, 2006) was adopted in this intervention because it addressed Chinese women's concerns about breast cancer and its prevention and the issues related to the access of mammography screening apart from providing the general information about NHS Breast Screening Programme (Chiu, 2009). In addition, this video also provides guidance for training health workers to present this video and facilitate discussion on breast health (Chiu, 2009). Therefore, Chinese lay health workers would be trained under the directions of this video. The effectiveness of the lay health worker-led educational video intervention on increasing breast health and the uptake of mammography was supported in the systematic review (see Chapter 3). Detailed information about the intervention components are presented in Table 7.3.

Step 4.2 Consult intended participants

Prior to the implementation of this intervention, it was necessary to test whether the educational materials developed for the intervention are culturally appropriate and the target population can understand the message provided. Therefore, two focus groups with six participants in each group were carried out among older Chinese women in Birmingham Chinese Society to obtain feedback on involvement, acceptability, comprehension, understandability and the overall effects of the educational materials. Participants were provided with the information sheet during the recruitment (Appendix 19). Before the

commencement of the focus groups, they completed the demographic data questionnaire (Appendix 20) and signed the consent form (Appendix 21). Participants received a debrief (Appendix 22) and £20 for their travel expenses after the focus groups. Among the 12 participants, three of them previously attended the focus group study. There were no significant differences between participants in this consultation and the older Chinese women in the focus groups reported in Chapter Three in terms of demographic background and breast screening practice.

Regarding the culturally and linguistically tailored breast screening leaflet, participants gave positive comments on the content. In participant's words:

FG1P3: I think it's very good. I think it's very comprehensive. We sometimes missed the every three years check due to going back to China or missing the appointment, this leaflet told us how to book another appointment, such as contacting GP or calling the breast screening centre. The other thing is that most Chinese women don't think they would develop breast cancer. I had the same view. But after reading this leaflet, I have realized that breast cancer is also common in Chinese women, the incidence is not related to breast size.

When talking about the limitations of this leaflet, participants pointed out that it does not provide sufficient information on breast self-examination (BSE). Although participants believed in the effectiveness of BSE for detection breast cancer signs and symptoms at the early stage, they had limited knowledge on how to perform BSE and suggested that such information especially pictures of BSE should be included in breast screening leaflet. As the purpose of the current study was to promote mammography screening, it was considered that too much information on BSE might shift the emphasis from mammography screening to BSE, leading participants to develop the erroneous belief that BSE can substitute for mammography screening. As mentioned above (Section 1.3.1), routine BSE is no longer recommended by NHS as a primary screening procedure because mortality from breast cancer is not significant reduced by performing BSE (Gao et al, 2006; Kosters & Gotzsche, 2003). Women, however, are recommended to become more 'breast aware'. The Be Breast Awareness leaflet (NHS Breast Screening Programme, 2006) was therefore developed by

the NHS to promote the awareness of breast health and encourage women to be more familiar with their bodies. This leaflet provides the information on how to feel the breast and what to look for, but does not include pictures of performance. According to Chinese women's feedback, women might benefit more from the Be Breast Awareness leaflet if pictures of how to perform the screening and what changes to look out for would be added to it. This leaflet would be sent together with the culturally and linguistically tailored breast screening leaflet and the breast screening invitation letter so that Chinese women are not only encouraged to take the mammography screening but also to be more aware of their breast health.

In line with the educational videos, apart from the video 'Breast Screening: Your Health, Your Choice' (NHS Cancer Screening Programmes, 2006), the 'Remedica Breast Screening' (NHS Cancer Screening Programmes, 2006) was also checked in this study as this is the video that is current available to the Chinese community. Participants compared and contrasted these two videos in terms of content and cultural sensitivity. Participants reported that both videos focus on breast screening and do not have numerous differences on the content. However, participants were more satisfied with the 'Breast Screening: Your Health, Your Choice' DVD as this video uses Chinese images and addresses the common concerns related to breast screening among the Chinese community, making the content more relevant to Chinese women's experience. For example, one participant stated:

F1P4: Because it mentioned the misconceptions about breast screening among the Chinese, where Chinese can seek help, the procedure of the screening. It is clearer than the first video and gives me more confidence

Participants also reported that watching this video increased their knowledge on breast screening and also reduced the culturally related barriers on the uptake of mammography screening. In their words:

F2P6: It showed the procedure of the screening. The screening will be taken by the machine. Not like what you thought. Someone said that the doctor will touch your breasts and pinch your breasts, so you don't want to go. It's not like that. ...It eliminated the psychological barriers

F2P6: After watching this video, I feel that taking breast screening is not as embarrassing as we thought. Women will intend to go for the appointment

(speaking in English). The most important thing is taking the first step. You know Chinese are ...

F2P3: Conservative

F2P6: Yes, conservative. Chinese are conservative and afraid to be touched by others. This video would eliminate their psychological barriers ... Western people are not aware of the weak point of Chinese. Accepting breast screening is the first step to making Chinese women going for breast screening

This statement illustrates one reason why Western educational messages do not work effectively in the Chinese community because the generic messages for the general population are not culturally tailored to Chinese women. It suggests that promoting breast health and the breast screening programme among Chinese community requires the healthcare providers to realize the cultural components related to behaviour change, and thus develop culturally and language sensitive educational materials to address the facilitators and eliminate the culturally related barriers to breast screening.

The consultation results indicated that the educational materials used in this intervention are appropriate to older Chinese women as the messages increased participants' breast screening-related knowledge and also motivated them to go for the mammography screening. During the focus groups, the interviewer also described the intervention to participants and asked them for comments. Participants indicated positive responses to the intervention method so it was believed that the Breast screening Service setting based in-reach intervention together with the Chinese lay health worker-led outreach intervention would be an effective way to promote breast awareness and breast screening among older Chinese women. The feedback from the consultation served as guideline for intervention developers to improve the intervention so that the intervention would be appropriate to most of the target population.

Step 4.3 Consultation with breast screening service providers

Apart from asking for feedback from the target participants, consultation with breast screening service providers is an essential part of Intervention Mapping as it enables the

exploration of whether the Breast Screening Service setting-based in-reach intervention and Chinese lay health worker-led outreach intervention could be applied into practice and maintained over time. Public Health England was initially approached by email with an explanation of the aims of this research by the researcher. Public Health England suggested the researcher contact local breast screening services directly for help with the research project. The researcher then contacted through email the City, Sandwell & Walsall Breast Screening Service and South Birmingham Breast Screening Service, which are the Breast Screening Units located in Birmingham. The researcher explained the purpose of this research and asked if they were interested in participation. The Breast Screening Services manager in South Birmingham Breast Screening Service, which is the Breast Screening Unit that Chinese women usually go for their screenings, agreed to take part in this survey. An initial meeting was set up among the service manager, researcher and her supervisor during March 2014 to discuss the most feasible way of accessing service providers for comments and feedback on this intervention. Finally, an agreement was made on conducting this consultation via email, which was considered as the most practical way to collect data in a relatively short period.

Results

Nine service providers, including a health services manager, four breast radiographers, one specialist mammographer and three mammography practitioners, working at the Breast Screening Service in Birmingham evaluated the two breast screening interventions. They were sent a cover letter (Appendix 23), information sheets on the in-reach intervention and outreach intervention (Appendix 24), the culturally and linguistically tailored breast screening leaflet in English highlighting which parts of the original breast screening programme leaflet have been modified and the reason for doing that (Appendix 25), and some questions regarding the two interventions (Appendix 26). Once they had completed the questions, they sent them back to the researcher by email.

Regarding the Breast Screening Service setting-based in-reach intervention, service providers believed in the effectiveness of this intervention on increasing the breast screening uptake among Chinese women. However, under the evaluation of cost effectiveness, the majority of service providers considered that this intervention would be difficult to adopt or implement for long term use because of the high costs and time consuming nature of training Chinese receptionists. In addition, service providers were concerned that providing Chinese receptionists would cause inequality in accessing breast screening as women for other minority ethnic groups are not provided with the same services. In their words:

This is something that sounds really good but with regards to cost effectiveness might be quite an issue. Also, there is an issue here where if we have a dedicated Chinese receptionist that we should also provide the same to all other ethnicity. (Participant 1, advanced practitioner).

No... it's not cost effective, and very time consuming, to employ Chinese receptionists for minority of patients that may call in with enquiries. (Participant 2, radiographer)

It (training programme for Chinese receptionists) sounds like a good idea but might be difficult budget wise. It (the intervention) will be very helpful and effective if budget will be provided. (Participant 3, trainee assistant practitioner)

I think this could be quite expensive to set up and may not be cost effective. The principle is good though. (Participant 6, radiographer)

Service providers were also asked to review the culturally and linguistically tailored breast

screening leaflet in English to determine whether this leaflet is well enough modified. Service

providers reported that this leaflet is easy to understand and provided culturally tailored

information for the Chinese community so that women could benefit from it. In addition,

distributing a tailored leaflet was considered as a cost-effective way to improve women's

knowledge on breast cancer and breast screening. For example,

Clear, well presented, easy to understand (Participant 4, screening services manager)

I think tailor made leaflets is a really good idea aside from the fact that it will be cost effective and does not require much work or training. (Participant 1, advanced practitioner)

This is a cheap and easy way to get the leaflets and required information to the ladies. It means that if they do attend for breast screening, they are fully informed as to what they should expect to happen, when they attend for breast screening. ... only that it is in a language they understand, this is a good method to

use. (Participant 5, senior radiographer)

In contrast, the Chinese lay health worker-led intervention was advocated by all service providers as it was considered as a cost effective way to increase Chinese women's awareness of breast cancer and breast screening adherence by using limited resources. Therefore, this intervention was considered as an effective intervention that they would adopt,

implement, and sustain long-term. In their words,

I think this is a brilliant idea because it is focused on the Chinese people and also it is easily attainable. (Participant 1, advanced practitioner)

Excellent, comprehensive approach to delivering the message. (Participant 4, screening services manager)

I think that the DVD is a really good idea, it would be cost effective, as you could have a lot of women watching the DVD at the same time and would only need one trained lay-worker to deliver the DVD. (Participant 5, senior radiographer)

I think it is a good idea and any promotion of health awareness should be tested out even if it just prompts a few people to come or be more aware then it has worked, then its word of mouth that will pass on the information, so yes I think it is worth trying. (Participant 7, breast screening senior ATO)

The feedback and comments from breast screening service providers suggest that under the consideration of costs, how to promote breast screening with limited resources is the key factor to determine whether an intervention would be applied in practice. Therefore, the Chinese lay health worker-led intervention seems more likely to achieve program adoption, implementation and sustainability compared to the Breast Screening Service setting-based intervention.

Step 4.4 Scope and sequence of the programme

This intervention programme would last for six months. Chinese women who are registered with breast screening centres but not adherent to the recommended mammography screening would be eligible for this intervention. As regards the in-reach intervention, the trained receptionists would be asked to send invitation letters and the modified NHS breast screening leaflets to the Chinese non-attenders during the first three months. The invitation letter would include the scheduled time for the mammography screening and the contact number of the trained Chinese receptionists for further enquiries about the breast screening programme. In addition, Chinese women would be provided with the contact number for booking the interpreter services. In the fourth month, Chinese women who still have not gone for mammography screening will be contacted by the trained receptionists by phone and be persuaded to take the mammography screening by addressing the benefits of mammography screening and also discussing the reasons why they fail to attend the mammography screening. The trained receptionists would help the non-attenders to schedule another screening time.

With regard to the outreach intervention, Chinese women who are non-adherent to mammography screening and their family members would be invited to the Chinese lay health worker-led educational workshop. First, the lay health worker would present the video 'Breast screening, your health, your choice'. After watching the video, participants would be encouraged to discuss their beliefs and attitudes towards breast screening, their perceived barriers to breast screening and the possible strategies to eliminate these barriers. Finally, participants would be provided with the culturally and linguistically tailored breast screening leaflet.

The name of the educational video 'Breast screening, your health, your choice' was also used as the theme of this programme as it conveys a significant message that women can manage their health by taking breast screening. It refutes fatalistic views on breast cancer and also emphasises the importance of taking screening on health maintenance. It provides complementary information to Chinese cultural views on keeping healthy. The development of the breast screening intervention finished at this step as it fulfilled the aim of thesis.

7.3.5 Step 5 Programme delivery

This step consists of the development of the adoption and implementation plans to ensure

the programme will be employed and applied into practice for a long time (Bartholomew et al, 2006). This step was not fulfilled as the purpose of this thesis was to design a breast screening educational programme. The adoption and implementation of this programme would be planned according to the guideline of step 5 in further post-doctoral research. The programme delivery would include training receptionists and lay health workers, identifying Chinese women who are non-adherent to breast screening through the NHS Breast Screening Service, using trained Chinese receptionists to contact non-attenders, and recruiting the non-adherent women to the educational workshop through posting recruitment posters at local Chinese societies and on their website.

7.3.6 Step 6 Programme evaluation

Intervention Mapping not only specifies the steps for the development and delivery of the programme, but also directs the evaluation of the programme. The aim of programme evaluation is to assess whether intervention developers have made the right decisions on change objectives, methods, strategies, and implementations through the evaluation of the effect and process of the programme. In addition, carrying out the programme evaluation enables intervention developers to decide if further changes are needed to be made on the intervention. As the systematic review indicated that there is a shortage of RCTs used to evaluate the effectiveness of breast cancer-related interventions among Chinese women living in Western countries, the effectiveness of this intervention would be assessed through an RCT.

The outcomes of the intervention consist of primary outcome and secondary outcomes. The primary outcome would be the attendance of breast screening and the secondary outcome variables including knowledge, cultural views towards to breast cancer, health beliefs, self-efficacy, perceived susceptibility, perceived benefits and barriers to mammography and intentions to go for mammography. The effect of the lay health worker-led workshop on the second outcome would be measured by using questionnaires. The questionnaires would be

allocated to the participants before and after the workshop. The uptake of breast screening would be obtained by phone call around six months after the intervention. The effect of the in-reach intervention would be measured by the actual utilisation of mammography. This measurement would be completed by viewing the breast screening record at the breast screening services.

Process evaluation was also developed in this step on the basis of the products of step 3 (theory-based methods and practical strategies) and step 4 (programme). Semi-structured interviews would be carried out among receptionists and lay health workers to assess whether the outreach intervention and in-reach intervention had been carried out according to the protocol, the possible issues related to programme delivery, and suggestions for future programmes.

7.4 Conclusion

The aim of this chapter was to develop a culturally and linguistically tailored educational programme in order to improve the uptake of the breast screening among the Chinese community. Chinese women in the focus group studies showed positive attitudes and behaviours on keeping healthy and taking mammography. Too much emphasis has been placed on concerns about modesty and fatalism in previous studies. Interventions need to overcome the real language barriers to increase and sustain the use of services. Interventions also need to recognise Chinese-British women's beliefs about health, which are likely to lead to good health maintenance but which are not informed by knowledge of breast cancer causes, treatment and progression. Therefore, healthcare providers need to take Chinese cultural and language concerns into account when designing and implementing breast cancer screening services which target Chinese-British women.

The use of Intervention Mapping enables us to map the findings from the literature review, systematic review and focus groups. As it was suggested by Hou et al. (2004), Intervention

Mapping empowers the design and development of the intervention to be guided by the synthesis of the theories, extent and new empirical and evidence. The needs assessment not only identified the factors that influenced breast screening at an individual level, but also examined the environmental factors that determined Chinese women's decision on the utilisation of breast screening. Therefore, this programme also included some strategies to improve the availability and accessibility of mammography screening at the healthcare providers' level and to enhance breast cancer promotion in Chinese communities, besides planning strategies to increase Chinese-British women's knowledge on breast cancer and intentions to attend mammography screening.

Intervention Mapping provides clear guidance on setting up intervention goals, designing theory-based methods and practical strategies, developing educational materials, planning programme dissemination, and the evaluation assessment for the development of the breast screening educational programme. It was anticipated that this educational and motivational programme would significantly improve Chinese women's breast cancer-related knowledge, cultural views on breast cancer and screening behaviour, reduce the perceived barriers to mammography screening, increase their intention to screening, and finally increase adherence to the NHS Breast Screening Programme.

Chapter 8 Discussion

8.1 Introduction

The aim of this study was to understand Chinese-British women's beliefs about breast cancer and its prevention and then develop an educational intervention to increase breast health awareness and breast screening among the Chinese community. The three studies presented in this thesis aimed to answer specific research questions. A pragmatic mixed methods approach was used in this thesis to ensure the most appropriate methods were selected to answer the research questions of each study. The purpose of this chapter is to bring together the findings of the three studies and consider the project as a whole. First the findings of each study will be summarized. The whole thesis used an innovative mixed design to collect data, analyse data, synthesize findings and inform the educational intervention. Consequently the contribution of this thesis in terms of its mixed design will be discussed in relation to health psychology theory and the development of evidence based practice. This chapter will evaluate the quality of this study by using Yardley's framework (Yardley, 2008) and also consider the possible limitations and comprehensiveness. Finally, a number of recommendations will be made to healthcare providers on the design and implementation of culturally and linguistically tailored health promotion and educational interventions among the Chinese community. This chapter will also provide some directions for future studies.

8.2 Summary of findings

8.2.1 Systematic review

The first study aimed to identify interventions designed to increase the breast health and breast screening among Chinese women living in Western countries and also examine the extent of effectiveness of breast cancer preventive health promotion strategies. Eight papers were included and allocated into one of five types of interventions: personal directed intervention, system directed intervention, social network directed intervention, mass media directed intervention and multi-strategy intervention. The findings showed that social network directed interventions, mass media directed intervention and multi-strategy directed interventions were more likely to be successful than personal directed interventions and system directed interventions in enhancing breast screening uptake. The reason may be attributed to the fact that the studies within the latter two categories also included women from other minority ethnic groups so that these interventions were not culturally sensitive and linguistically tailored for Chinese women. The effectiveness of social network directed intervention strategies took Chinese cultural and language barriers into consideration. The systematic review highlighted that it is essential to consider the impact of cultural and language factors on mammography screening adoption when designing an intervention programme specifically targeted at Chinese women.

Training general practice receptionists to contact non-attenders was likely to improve mammography screening adoption. However, the intervention effectiveness varied with ethnic groups, as the highest increase in the uptake of mammography screening was in Indian women while no change was observed among Chinese women. Besides limited numbers of Chinese women being involved in the study, the most plausible reason was that the cultural and language barriers among Indian women were overcome as the majority of the receptionists were from an Indian background. This suggests that the race or ethnicity match between healthcare providers and patients may be particularly helpful in the elimination of these barriers for women in minority ethnic groups. The effectiveness of this intervention may be also due to the fact that non-attenders were informed that the receptionist contacted them on behalf of the GP centre, which is the medical team that women were familiar with and trusted. The findings highlighted that involving staff from GP centres may be a usual approach to encourage non-attenders to go for mammography screening.

The effectiveness of media-led interventions on breast screening uptake was also demonstrated in the systematic review, suggesting that it was an effective format to provide meaningful and pertinent message to Chinese women. There was a lack of evidence to show that removing the financial barrier, such as providing free mammography screening, influenced the uptake of mammography screening among the Chinese community. This suggests that financial barriers are not a key factor for screening uptake among the Chinese population as a whole, but rather is confounded with socio-economic status in ethnic minority groups.

8.2.2 Qualitative study among older Chinese women in the UK

The second study aimed to explore the psycho-social factors related to breast cancer prevention among older Chinese women in the UK. The findings revealed that Chinese women put a high value on their health and believed in a holistic approach to health maintenance through diet, exercise, and maintaining a positive attitude. Participants lacked knowledge about breast cancer and its causes. The majority of participants over-emphasised the effect of genetics on causing breast cancer. The identity of being older Chinese women made participants feel secure against developing breast cancer. Chinese women in this study indicated high engagement in mammography. Receiving the invitation letter from a GP was the most frequently cited motivator for mammogram screening. Being free of charge is another reason why participants went for screening. Aspects of the experience of mammography that women discussed included the pain involved and being embarrassed by exposing themselves, but they were generally very positive about the service. Although participants appreciate the benefits of performing monthly BSE in detecting breast cancer at an early stage, only a few of them performed BSE every month. The low rate of BSE may be attributed to forgetting to do it, lack of symptoms and unfamiliarity with the differences between BSE and mammogram. The factors that inhibit Chinese women taking a mammogram including modesty, lack of time and practical issues. Inability to speak English was a key barrier to obtaining health-related information or indeed using medical care more

generally. Participants draw upon both Western medicine and Traditional Chinese medicine. However, seeking medical help from GPs was reported as the first choice when suffering health problems by most of the participants. A variety of ways to obtain health information was identified, including workshops in the local Chinese community centres, Chinese media and books. This study highlighted the importance of acknowledging the Chinese health beliefs and cultural and language barriers when promoting breast screening service for older Chinese women.

8.2.3 Qualitative study among younger Chinese women in the UK

The third study aimed to understand the psycho-social factors associated with breast cancer prevention and early detection among young Chinese women in the UK. Like the older Chinese women, younger participants' health beliefs were also influenced by the Chinese culture. Participants held a holistic view of health maintenance that health can be maintained by eating a healthy diet, engaging in regular exercise and maintaining a positive attitude. Participants put great emphasis on genetic causes of breast cancer, leading some of them to consider that breast cancer cannot be prevented. Although many participants showed high intention to prevent breast cancer, they lacked specific knowledge about breast cancer and its causes. Participants were highly critical of health care in UK. Aspects of the experience of seeking medical help in the UK that participants discussed included the inconvenient referral system, long waiting times and no accessibility out of normal hours. The previous medical seeking experience in their home countries influenced their satisfaction with the GP services in the UK. The lower satisfaction with the medical services in the UK might also be due to the participants being unfamiliar with the health system in the UK. Language was not a problem for participants using medical services or receiving health-related information in English. Participants identified the main sources of getting health information as the internet, media and healthcare providers. Some participants interpreted the medical consultations for their families or friends. However, participants who grew up in Western countries and spoke English from childhood, suffered the difficulties in interpreting the English words into Chinese.

Participants also reported difficulties in interpreting the Chinese concept of illness into English. The lack of professional interpreters was also pointed out by participants. This study highlighted that it is essential to provide sufficient information about breast cancer and preventive behaviour for younger Chinese women in order to reduce their false beliefs on perceived susceptibility to breast cancer and the neo-fatalist view towards breast cancer prevention which are due to overestimating the genetic causes of breast cancer. In addition, service and healthcare providers should understand the differences on the structure of healthcare system between China and UK in addition to the Chinese cultural beliefs in order to provide effective healthcare practices for younger Chinese women.

8.2.4 The development of an educational intervention

Finally, Intervention Mapping was chosen to synthesize findings from the literature, systematic review and focus groups to design an educational intervention in order to promote breast health and mammography screening among Chinese women who are non-attenders to the NHS Breast Cancer Screening Programme. The intervention was a multi-strategy intervention that combined a Breast Screening Service setting based in-reach intervention with Chinese lay health worker-led outreach intervention. The in-reach intervention would use trained Chinese receptionists to contact non-attenders by sending an invitation letter and the culturally and linguistically tailored breast screening leaflet and making phone calls to encourage them to attend the screening. The outreach intervention would use trained Chinese lay workers to conduct educational workshops, including playing a tailored breast screening video, discussing the concerns about breast health and screening practices, exploring how to overcome the possible barriers to mammography screening, and distributing a culturally and linguistically tailored breast screening leaflet. The educational materials and intervention method were pre-tested among the targeted population and health service providers and received positive comments from both groups. It was anticipated that this intervention would be an effective approach to increase the knowledge of breast health and encourage Chinese women to go for mammography screening.
8.3 Contributions to health psychology theory

In order to gain a comprehensive understanding of how the psycho-social factors work together to influence Chinese-British women's mammography screening behaviour, it is necessary to apply the findings of this study to theoretical models in Health Psychology. US National Cancer Institute (2005, p. 4) put forward that

"A theory presents a systematic way of understanding events or situations. It is a set of concepts, definitions, and propositions that explain or predict these events or situations by illustrating the relationships between variables".

Therefore, theoretical models can help us to appreciate the mechanisms that underlie the uptake of mammography screening among Chinese-British women.

As was mentioned in the introduction (Section 1.8), Social Cognition models have been widely used as theoretical frameworks to understand and predict breast screening in Health Psychology. The theoretical contribution of this study was that the factors related to the utilization of mammography screening among Chinese women were explored in relation to the Health Belief Model (HBM, Becker et al, 1977) by using deductive analysis. Lancaster (1992) suggests that

"the [Health Belief] Model is useful in looking at health-protecting or diseasepreventive behaviour. It is useful in organizing information about clients' view of their state of health and what factors would influence them to change their behaviour." (p. 187)

Despite the prevalence of using HBM to understand the beliefs related to behaviour change among Western population, there is limited knowledge on its application to the Chinese population. Therefore, the findings of this study provided the evidence on whether the HBM, which was developed on the basis of the empirical findings of Western population, could be used to understand the causal relationship between health beliefs and breast screening behaviour among Chinese population.

The HBM argues that a woman's decision to attend mammography screening is determined by considering the following psychological dimensions: perceived susceptibility to breast cancer, perceived severity of breast cancer, perceived benefits of and perceived barriers to mammography screening. In addition, the HBM proposes that the uptake of mammography screening is also influenced by cues to action and health motivation. The findings of the deductive thematic analysis showed that Chinese women's making-decision process regarding breast screening adoption covered all the HBM variables.

However, the findings of the focus group study also indicated the fact that alternative factors influence the uptake of breast screening among women from the Chinese community in addition to the constructs of HBM. For example, it was evident that the economic environment was an important reinforcement factor of mammography screening behaviour among older Chinese women as the free screening service was reported as one of the most common reasons for mammography utilization. Previous research has documented that inability to afford mammography screening is a general barrier for Chinese women living in the other Western countries where there is not a national health insurance system (Lee-Lin et al, 2008). These results suggest that eliminating the financial barriers to mammography screening may contribute to the high self-reported breast screening uptake among older Chinese women in the current study.

The HBM has been criticized for its relative neglect of social environment, such as social norms (VanLandingham, Suprasert, Grandjean, & Sittitrai, 1995; Ogden, 2012). It was found in the current study that embarrassment was identified as one of the barriers to mammography screening; this factor is associated with the social norms relating to female modesty. In addition, there is substantial empirical evidence that social norms are significant reinforcing factors of mammography use (Kratzke, Garzon, Lombard, & Karlowicz, 2010). For example, Kratzke et al. (2008) examined the prediction of social network characteristics on breast cancer screening practices among employed women and reported a positive relationship between the perception that screening is normative among one's peers and the recent mammography among women aged 52 and above. The peer group influence was

also observed in this thesis and was illustrated specifically in the case of one participant who had failed to attend mammography screening but indicated strong intentions to go for the screening after knowing other participants in her group had been. The findings suggest that social factors make a contribution to mammography adoption among Chinese women and thus the breast screening promotion programmes should consider these factors when targeting the Chinese community.

In the performance of breast self-examination (BSE) there was a substantial number of either older or younger women who did not perform regular BSE. The majority of participants attributed their poor performance of BSE to the lack of confidence in their ability to perform the screening correctly. This thesis documented that emotional factors, such as worry, were associated with the performance of BSE among older Chinese women. The qualitative findings indicated that breast cancer worry was a common reason for BSE performance among older Chinese women. Numerous studies have revealed that there is a significant positive relationship between cancer worry and mammography screening (Hay, Buckley, & Ostroff, 2005). Despite this, a positive relationship was not explicitly observed through the current qualitative study, participants reported that negative results of breast screening enabled them to feel relieved. These findings suggest that emotional factors influence Chinese women's breast screening behaviours.

The findings of this thesis illustrate that the HBM is helpful in understanding the mechanism of breast screening behaviours among Chinese women, but other factors, such as economic environment, social environment and emotional factors, also made great contributions to breast cancer prevention and screening among Chinese women.

8.4 Contributions to the use of mixed methods to inform evidence based practice

This thesis has demonstrated the benefits of using a pragmatic approach to combining mixed methods of data collection in order to develop an empirical and theoretical evidence based

educational intervention. In this study, the qualitative data were analyzed using thematic analysis not only because it is in accordance with the pragmatic approach of this thesis, but also flexible enough to specify the similarities of a group of participants and individual experience because it aims to identify all salient themes across the data corpus (Braun & Clake, 2006). In addition, thematic analysis is essentially not dependent to any theoretical framework (Howitt, 2010). The findings, which are generated by thematic analysis, are easily understood by health service providers and police makers.

A distinguishing feature of this study is that the focus group data were analyzed using thematic analysis from a realist perspective involving both inductive and deductive processes (Braun & Clarke, 2006) when compared with other qualitative studies which generally used an inductive approach to analyze findings (e.g. Malik & Coulson, 2008; Pehlke II, Hennon, Radina, & Kuvalanka, 2009). The analysis started in an inductive way, prioritizing the data and giving voice to participants. Once themes had been identified, the ways in which they were clustered, and therefore interpreted, was informed by the HBM and the pre-existing findings arising from the literature review.

The inductive thematic analysis firstly provided a rich thematic description of the entire data set and helped to define five main themes related to breast health and breast screening among older Chinese women: what is health?; causes of breast cancer; active health management; contrasts with unhealthy British population; accessing health services generally. These themes emerged from the focus group data rather than the questions that participants were asked during focus group discussion. In addition, these themes were not influenced by the researcher's theoretical orientation in this topic. Therefore, the inductive thematic analysis provided the empirical evidence for the development of the breast screening intervention.

However, the inductive thematic analysis fails to take into account the influence of

researchers' role during the process of analysis (Taylor & Ussher, 2001). Researchers have their own theoretical position and values, which more or less affect the identification of themes (Taylor & Ussher, 2001). Therefore, the deductive thematic analysis was also used in order to facilitate the interpretation of identified themes and patterns of behaviours within the researcher's theoretical interest (e.g. HBM) and previous literature. The findings suggest that the HBM can explain the majority of themes related to breast health and breast screening behaviours among Chinese women living in the UK. However, it cannot be ignored that other factors such as social factors also influenced Chinese women's breast cancer prevention and early detection. The deductive thematic analysis also enabled the integration of theory into the design of the breast screening intervention, which increases the validity of the causal pathway between the determinants and behaviour change.

In the context of the current study, the combined inductive and deductive thematic analysis was consistent with the abductive logic of inquiry (Hiles, 2014) that explored the explanatory relationship between data and theory regarding the breast cancer prevention and early detection among Chinese women. In addition, this thesis has demonstrated how both empirical evidence and theory can be used to guide the design of breast cancer screening intervention and also direct the selection of appropriate intervention methods and practical strategies.

8.5 Quality assessment

As mentioned in the methodology chapter (Section 2.4.3.4), Yardley's framework (2008) was used to evaluate the quality of this study. This framework includes four principles: 'sensitivity to context', 'commitment and rigour', 'transparency and coherence', and 'impact and importance' (Yardley, 2000; Yardley, 2008, p.243-246). Yardley's framework is considered to have a wide applicability and can be used to evaluate the qualitative studies in any area of psychology (Smith, 2008). Therefore, this quality assessment method is also suitable for the current study.

With the respect of sensitivity to context, this study has been developed on the basis of the existing literature including the review of psycho-social factors related to mammography screening among Chinese women in Western countries (Section 1.7), the evaluation of the health psychology models in the prediction of breast screening (Section 1.8), and the systematic review of the interventions aimed at promoting breast cancer health and screening behaviour among Chinese women in Western countries (Chapter 3). Therefore, the researcher was aware of the literature in relation to the topics, theoretical context and interventions throughout this study and the intervention development was informed by them.

Yardley (2000, 2008) suggests that researchers should be sensitive to their relationship with participants. In this study, because the researcher was from the same cultural background as the participants, the 'race-of-interviewer-effects' (Gunaratnam, 2003) and language barrier were eliminated. The use of a Chinese researcher also created a comfortable environment for participants to talk about breast cancer which is a sensitive topic in Chinese culture. In addition, the researcher was very sensitive to the Chinese health beliefs and cultural views expressed by participants.

Commitment and rigour is evident through this thesis. First, the researcher had identified the specific research fields, older and younger Chinese-British women, and then a very well organized participant recruitment through the Birmingham Chinese Society, Wai Yin Chinese women society in Manchester, and Aston University (Sections 4.3 & 5.3). Second, the focus group questions were developed on the basis of HBM, without limiting the scope of discussion, to ensure the possible variables related to the research topic were fully explored during focus groups (Section 2.4.3.1). Third, thirteen focus groups were conducted separately with 52 older and 20 younger participants. Therefore, the researcher collected rich data on the factors related to breast cancer prevention and detection among Chinese-British women. Fourth, all data were transcribed verbatim and analysed by using thematic analysis (Braun & Clarke, 2006). The final themes and subthemes were discussed between the

researcher and her supervisor. All these factors demonstrate that the researcher has had prolonged engagement in the design of this study and data collection and also interpreted the data carefully.

In order to meet the criteria of transparency and coherence (Yardley, 2000, 2008), sufficient information on the methodology of this study, especially the data collection and data analysis, have been provided (Chapter 2). In addition, the researcher has tried to provide detailed description of findings and also presented the findings in a logical way in the write-up in order to help the readers to get into the inner world of the participants (Chapters 4 & 5). The researcher also had regular meetings with her supervisor to discuss the difficulties experienced during the participant recruitment, issues of being a Chinese researcher (e.g. the influence of the researcher's pre-understanding and assumption on the interpretation of focus group data) and the progress of the study. The reflective diaries are available on request.

The last principle is impact and importance (Yardley, 2000, 2008). To our knowledge, this is the first qualitative study that comprehensively explored breast cancer prevention and detection among both older and younger generations of Chinese-British women. It has revealed the distinctive determinants of behavioural and environmental factors related to mammography screening among older Chinese-British women (Chapter 4). In contrast with other ethnic minority groups, older Chinese women showed positive attitudes to breast screening and actively participated in it. However, lack of knowledge of breast cancer and language barriers were still considered as the common issues that prohibited the uptake of mammography screening among Chinese women. The strong neo-fatalism and lack of knowledge on breast awareness contributed to the low performance of BSE among younger Chinese women (Chapter 5). On the basis of the findings, a breast cancer psycho-educational intervention has been proposed with the aim of improving adherence to

mammography screening among Chinese-British women (Chapter 7).

The findings have also highlighted some issues that health services have to pay attention to when they provide health care to the Chinese community (Section 8.7). It is believed that too much emphasis has been placed on concerns about modesty, fatalism and use of traditional medicine by previous research. The main problems to overcome are real language barriers and a lack of recognition of Chinese women's beliefs about health and their lowered risks of developing breast cancer. Another distinctive finding of this study was that the older Chinese women were able to read Chinese, which contrasts with the findings of research among South Asian women many of whom cannot even read their own language (Johnson, Owen, Blackburn, Rehaman, & Nazroo, 2000; Modood et al, 1997; Rudat, 1994). It is worth the NHS providing the linguistically tailored health-related information in order to break down the language barriers in the promotion of breast screening among Chinese community.

This thesis has implications for health service providers. The findings indicate that ethnic minority groups cannot be regarded as an amorphous group. Understanding the needs and providing culturally and linguistically tailored information and services is essential for the NHS to ensure people from minority ethnic groups can benefit equally from the health services. In short, this study has addressed the four principles of Yardley's framework (Yardley, 2000; 2008) for quality assessment.

8.6 Limitations of current study

There are some limitations in this study that future research needs to overcome. First, almost all the participants studied had been born in China and had experienced a Chinese health system. This study failed to include a group of young British-born Chinese women (Parker, 1995) though efforts have been made to do this. As a result, this study was unable to assess whether there are differences between the immigrant older generation and their British-born children who grew up in the Western culture but were also influenced by Chinese culture

through their parents. As culture plays an important role on shaping individuals' health beliefs and has an influence on their health practices (Rochelle & Marks, 2011), the British-born Chinese may be more likely to adopt the Western values on health care than their immigrant parents and those who recently came to the UK for education. Therefore, future qualitative study is needed to develop an understanding of the factors that may contribute to the breast cancer prevention among British-born Chinese women.

Another limitation is that the findings from the older groups may be not generalizable to the entire population of the older Chinese-British women. Because participants were recruited through local Chinese societies which is a relatively convenient and low cost recruitment method when compared to the recruitment through telephone or households (Tang, 2000), participants in this study were those who have a strong affiliation with the local Chinese community. This is evidenced during the focus group discussions as older participants mentioned that attending the workshops held by local Chinese society was one of the main sources of gaining health related information. Therefore, the older participants in this study may be more likely to hold Chinese beliefs, cultural views and use TCM than those who have limited or no connection with the local Chinese community. In addition, the findings of this study may be not be applicable to new immigrants because the majority of participants (89%) had lived in the UK for more than 10 years. However there were similarities between the older groups and the younger groups who were, for the most part, new immigrants, giving some confidence of the relevance of this work. Previous studies have revealed that the number of years in the host country is significantly associated with mammography screening use (Hoare et al, 1992; McPhee, Stewart, Brock, Bird, Jenkins, & Pham, 1997; Sun et al, 2007; Yu et al, 1998; Yu et al, 2003). For example, one study reported that the percentage attending mammography within the past two years were nearly twice as high among Chinese women who had lived in the US more than 10 years (Yu et al, 1998). Therefore, the high rates of mammography screening among the older participants may be due to the long residence in the UK in addition to the different health care systems between the two

countries. Although the findings have limitations in generalization, it has to be acknowledged that the aim of a qualitative study is to explore the interaction between variables within a certain context rather than provide generalization of the findings (Krueger & Casey, 2000; Yardley, 2008). Thereby, the results of this study fulfilled the purpose of the methodology.

During the focus groups, knowledge about breast cancer symptoms was not particularly explored. Leventhal, Prohask and Hirschman (1985) suggest that perception of symptoms is the direct reason for engagement in health-related behaviour. Previous studies indicated that lack of knowledge of breast cancer symptoms prevent South Asian women from the engagement in preventive health behaviours (e.g. Karbani et al, 2011). However, participants in this study mentioned the symptoms of breast cancer when they talked about the motivators to adopting breast screening behaviours. The common symptoms that participants reported mainly focus on pain and lumps. The extent of Chinese women's awareness of breast cancer-related symptoms could be further explored in future study.

8.7 Recommendations for the healthcare system

The findings from this study hold important implications not only for breast cancer prevention among Chinese-British women but also for the improvement of utilization of health services generally among the Chinese community. Although older participants in this study showed positive attitudes to mammography screening and also highly participated in the screening, they lacked breast cancer-related knowledge. This suggests future breast health campaigns need to promote breast cancer awareness and related knowledge among this population. The majority of the older participants in this study were not proficient in English. As a result, they are unable to benefit from the NHS breast cancer-related information in English. The unavailability of language tailored health information might lead to poor understanding of breast cancer and use of the breast screening service. It is, therefore, vital to provide the bilingual health-related information to meet the communication needs of the Chinese community.

In this study, participants also reported some cultural barriers that may potentially influence the uptake of mammography screening, such as Chinese beliefs on health management, the low perceived susceptibility and modesty. Apart from providing the bilingual health-related information, the key is to ensure that the information is culturally tailored to the Chinese community. By reviewing the NHS breast cancer-related leaflets available in Chinese, it was noted that all the leaflets were directly translated from the English version. It can be supposed that these health materials may be less effective for Chinese women as the content does not take the Chinese beliefs and cultural views of breast cancer into consideration, leading Chinese women to feel that they are not being involved in the breast screening programme. The systematic review showed that the language and culturally tailored educational interventions had more impact on the improvement of breast cancerrelated knowledge, beliefs, intentions and breast screenings when compared to the interventions that target the general population. Therefore, it is essential to provide the linguistically and culturally tailored information to ensure women from minority ethnic groups can benefit equally from the NHS Breast Screening Programme.

Similarly, understanding the language barrier and Chinese beliefs towards health maintenance and illness management is helpful for the improvement of the communication between healthcare providers and Chinese patients, and thus to improve the utilization of health care services among the Chinese community. Despite their long length of residence in the UK, language was still identified as a prominent barrier for the majority of older Chinese women in using health services in the UK. Although interpreting services are available in the NHS, participants were dissatisfied with this service. Unfamiliarity with medical terms was a common issue for the interpreting services that was reported by the participants besides lack of availability or lack of fluency in Chinese. The reason for the poor interpreting service may be attributed to the NHS not providing any professional training to the interpreters before they were employed. This view was confirmed by an older participant who is a nurse working in the NHS and another younger participant who had worked as an interpreter for the NHS.

Many older participants expressed that they were afraid to visit their GP, delayed their visit or even used self treatment due to an inability to have effective communication with their GP about their health problems. A similar phenomenon has been reported by GPs working in Hull in that Chinese patients tried to avoid or delay medical consultations unless their health problems must be treated (Watt & Chui, 1994). Sproston et al. (2001) reported that the levels of GP consultation were lower among the Chinese ethnic group when compared to white and to other minority ethnic groups. English proficiency is a significant predictor for the usage of GP consultation among the Chinese community (Sproston et al, 2001). In addition, Chinese patients are more likely to give negative feedback on their communication with doctors than the other ethnic groups and the main reason for this is the language barrier (Healthcare Commission, 2008). Therefore, there is an urgent need for the NHS to provide trained medical interpreters in order to overcome the negative effect of language barriers on the use of health care services among the Chinese community, particularly older members of this community. In addition, healthcare providers need training in dealing with patients who cannot speak English, because the health provider is perceived as an authority figure in Chinese culture and greatly influences the uptake of cancer screening among the Chinese (Lee, 1998). Healthcare providers should try to use fewer medical terms and spend more time trying to understand patients' needs, thus to improve the interaction with Chinese patients. Such an approach would benefit all patients whether or not they speak English as a first language.

In this study, participants commonly held traditional Chinese health beliefs, and thus their health behaviour was also influenced by Chinese culture. As TCM is a holistic model, participants showed strong holistic views of health maintenance and also emphasised the importance of eating a healthy diet in health management. However, Western medical theory also has an impact on their perceptions of illness. For example, participants were more likely to attribute the main risk factor of breast cancer to genetics, especially the younger generation. This suggests that the Chinese have a complex knowledge of health and illness.

With regard to health care, the majority of participants rarely visited the practitioners of TCM as they were concerned about whether these practitioners were qualified, whether their treatments were effective given the quality of materials available in the UK and the high cost of visiting TCM practitioners. As a result, they relied on Western medicine but also used TCM as an alternative approach to health care. This is consistent with the findings of previous studies that it is common among the Chinese community to use both TCM and Western medicine (Rochelle & Marks, 2011). However, lack of confidence in the usage of Western health care services also has been perceived among younger participants in this study. The reason for this seemed to be due to the cultural beliefs. For example, a few younger participants considered that doctors of Western medicine were not familiar with their illness or that Western medicine did not have a significant effect on their illness because the Chinese have a different body constitution. These findings imply that healthcare providers should be aware of the diversity and alternative healthcare seeking behaviour among the Chinese community. In addition, they have to be sensitive to the Chinese beliefs and cultural views when they serve Chinese patients.

Although using the NHS was the first choice for many participants, it cannot be ignored that the healthcare delivery system has been criticized by many participants, especially the younger generation. The different health care systems in China and UK could partly explain the negative appraisal of the NHS services. The China-born young women might expect that they would receive the same or similar health care in the UK as they had in China, such as visiting doctors without making an appointment, receiving high-tech medical examinations and being prescribed antibiotics even for a cold. The high expectation on primary care among Chinese patients was also perceived by GPs in a previous study (Watt & Chui, 1994). Therefore, it is important to provide information to explain the structures of the NHS healthcare services in the UK to ensure Chinese people understand the difference between primary care and secondary care. In addition, GPs should be informed about the structures of the health care system in China and the high expectations from Chinese patients, so that

GPs can provide a better explanation to their Chinese patients when they request examinations and prescriptions which are perceived to be unnecessary. In short, the utilization of health care services among Chinese community was mainly influenced by Chinese beliefs and cultural views, communication between healthcare providers and patients, and familiarity with the heath care system in the UK.

The findings of this study also identified some similarities and disparities between the older generation and younger generation on breast cancer-related knowledge, attitudes to prevention, and the use of NHS health care services (Section 6.2). The two generations also reported a variety of sources of gaining health-related information. The major ways for older participants were Chinese media, local Chinese community and word of mouth, whereas media, the internet and healthcare providers were frequently reported by the younger group. The variations between the two age groups may be caused by several factors, including the levels of acculturation to Western culture, educational attainment and previous experience of receiving health care. It suggests that health promotion including breast health should not treat the Chinese as a whole, because there are different factors related to the health behaviour among these two generations. Therefore, it is important for healthcare providers or programme developers to realize the similarities and differences among generations, and thus provide tailored services according to the needs and concerns of different age groups.

8.8 Future studies

Firstly, the researcher plans to complete the step 5 and 6 in the Intervention Mapping in further study. The educational intervention to promote breast health and mammography screening among Chinese women who are non-attenders to the NHS Breast Cancer Screening Programme could be revised according to the feedback and comments from the intended program participants and health service providers to ensure the intervention materials are culturally relevant and the program could be well enough implemented to achieve the change objectives. Then, the final programme could be applied into practice and

to assess whether this program could increase Chinese non-attenders' breast cancer-related knowledge, intention to go for mammography screening and actual behaviour change. This would require an RCT to establish the evidence for the efficacy of the intervention.

The findings of this study provide insight into the psycho-social factors related to breast cancer prevention for Chinese women living in the UK. Health professionals can use the findings of this study as a guideline to develop the culturally and linguistically appropriate intervention and educational programmes to promote the breast health and screening among Chinese-British women. In addition, the results can help to evaluate whether the existing educational materials and programmes that aimed at increasing breast screening for Chinese women are suitable.

In order to have a wider understanding of mammography screening among Chinese women, similar studies need to be carried out among Chinese women living in other areas because the Chinese are geographically scattered across the UK, mainly in order to avoid the competition in the catering industry (Section 1.5). This study was conducted in two major cities, Birmingham and Manchester, which have a large number of Chinese. Therefore, the Chinese community centres in these two cities are very well organized and also provide a wide range of services including health advocacy. Chinese people in these two cities may be more likely to gain health-related information from local community centres and be more aware of the health care systems in the UK. In contrast, Chinese people living in small towns, particularly in rural areas with no local Chinese community centre available, may be more socially isolated than the participants in this study, and thus less likely to use the health services.

Another suggestion is that it would be worth conducting a quantitative study in the future to reach a larger population and provide further views of breast cancer prevention among Chinese women as well as testing the hypotheses regarding the causal relationships

between the psycho-social factors related to breast screening generated by this project and the uptake of mammography screening. In addition, the quantitative study could also help researchers to evaluate the effects of socio-demographic characteristics on screening behaviour and the causal relationship between variables and the uptake of mammography screening. It is believed that the findings from a quantitative study would be generalized to a wider range of the Chinese community.

In order to improve communication between healthcare providers and Chinese patients, a focus group study could be carried out among healthcare providers, especially GPs, to explore the issues that they have encountered during their interaction with Chinese patients either on health promotion or illness treatment. The findings from healthcare providers together with barriers reported by Chinese participants would provide richer data on the development of training targeted on healthcare providers for the purpose of providing effective services for Chinese community.

Finally, the qualitative findings suggest that Chinese women hold different understandings and beliefs of health from white British women. The Western medical models advocate dualisms in constructs, such as body and self, and physiological and psychological (Bulbeck, 2001). However, these constructs do not exist in TCM, which holds a holistic view of treating human body as a unitary whole and integrating psychological and physiological health (Bulbeck, 2001). The holistic belief in health was observed in this thesis in that participants commonly reported that health means sleeping and eating well and feelings of well-being. Accordingly, there is no surprise that Chinese women hold different beliefs on health maintenance and illness prevention when compared to Western discourses. These disparate beliefs about health and illness between Chinese and Western systems may explain why interventions for Western populations are not effective for the Chinese community. However, it should be noticed that the younger generation showed fused beliefs on health and reported being healthy means being physiologically and psychologically healthy. This reflects that the

health beliefs among the younger generation draw upon both medical systems. Future research could investigate in-depth the contrast between the Eastern and Western health beliefs, which could assist to understand the barriers and facilitators to providing culturally appropriate information and health services to Chinese community.

8.9 Conclusion

Breast cancer is a common health issue among Chinese women in the UK even though Chinese women have lower risk of breast cancer than white British women. Despite the benefits of mammography screening in early detection and the improvement in breast cancer related mortality and morbidity, the literature has indicated that the uptake of mammography screening is relatively low among Chinese-British women. However, the psycho-social factors related to the utilization of mammography screening among the Chinese community still have not been comprehensively explored. Therefore, this study used focus groups to gain insights of Chinese-British women's belief about breast cancer and its prevention. In contrast to the findings of previous studies, older participants in this study reported high participation in mammography screening. The findings suggest strong cultural influences and language concerns but differences between age groups. It is believed that too much emphasis has been placed on concerns about modesty and fatalism in relation to mammography screening in prior studies. Interventions need to overcome the real language barriers and can make use of Chinese media and work with local Chinese community centres to increase and sustain the use of services among older generations. Culturally tailored health campaigns may also need to be conducted among younger generations as they put great emphasis on genetic causes of breast cancer and disliked using healthcare services in the UK.

Intervention Mapping was used in this study to integrate the findings from literature review, systematic review and qualitative study among older Chinese women to form an empirical and theoretical based educational breast screening program. It was anticipated that this intervention could increase the breast health-related knowledge and adoption of breast

screening among the Chinese community.

Finally, people from different ethnic groups usually have their own health beliefs, and these beliefs shape their ways of health maintenance and healthcare seeking behaviour. This thesis will enable healthcare providers to have a deeper understanding of the real issues that prevent Chinese people using the healthcare services other than mammography screening. The data from these studies will be helpful for intervention developers to provide culturally and linguistically appropriate health intervention and educational programmes for the Chinese community.

Chapter 9 Reflections on the research journey

Reflexivity is an essential concept in qualitative research as it is a commonly used method that enables researchers to continually examine how their social backgrounds, assumptions, positioning and behaviour might affect the research setting, data collection and analysis (Finlay, 2003a). In addition, reflexivity can help researchers to acknowledge that it is impossible for them to put their own fore-understandings and prejudgements aside during the research process (Finlay, 2003b). However, by considering the ways in which these personal factors have an impact on the research, researchers can develop a deeper understanding of the research phenomenon and thus ensure that the research findings can accurately reflect participants' experiences (Morrow, 2006).

Apart from personal reflexivity, reflexivity also includes the process of reflecting on the epistemology that underpins the research. Bourdieu (1994) put forward the notion of 'epistemic reflexivity' to refer to "critical reflection on social conditions under which disciplinary knowledge comes into being and gains credence" (Kensella & Whiteford, 2009, p. 251). Willig (2001) which suggests that researchers engage in epistemological reflexivity to consider questions including: how was the research question developed and what is the influence of this on the research outcomes; how has the design of the study and the method of analysis impacted on the data and findings of the research; how could the research question have been made, and what is the impact of these on the understanding of the research phenomenon. Therefore, epistemological reflexivity tries to investigate the effect of epistemology on knowledge generation (Bourdieu, 1994).

Lynch (2000) proposes that reflexivity plays an important role for the development of the theory on which research is based. Britzman (1999) argues that theory "lives in the practical experiences of us all and ... must be interpreted as a form of intervention" (p. 55). Therefore,

reflexive practices enable us as researchers to examine the application of theory in practice and also provide opportunities for revising and even re-framing this theory.

In this chapter, I will discuss my personal reflexivity in terms of my motivation to conduct this research, and of becoming and being a researcher during the research process. Being reflexive on epistemology involves reflecting upon the literature review and design of this study while considering the epistemology-methodology-method in relation to the paradigm wars, pragmatism, the logics of inquiry and intervention mapping. Reflection on theory consists of how the theoretical framework infuses the research and how the research findings in turn ground theory. Reflection on the implications of the findings among younger Chinese women is also presented, in terms of public health strategies to improve breast awareness in this population and prepare them to make informed decisions on mammography screening when they reach the eligible age.

9.1 The research purpose and literature review

Prior to conducting research, it is important to choose the most suitable research topic (Denzin & Lincoln, 1998; Glesne, 1999). Russell and Kelly (2002, p. 5) state "good research questions spring from [a researcher's]...values, passions and preoccupations". I had been very interested in breast cancer prevention and early detection since I started my Masters degree in Health Psychology. During my Master's studies, I became aware that there is health inequality in the UK in that people from minority ethnic groups are less likely to benefit from the health services. However, limited numbers of studies have been carried out to understand the factors related to reported low usage of the health services among minority ethnic groups. Part of the reason for this is the cultural and linguistic barriers to British researchers conducting research in this area. As a novice Chinese researcher these barriers were easier for me to overcome and I was motivated to improve Chinese-British people's health. Therefore, I chose as my PhD research area the promotion of breast health and early breast cancer detection among Chinese women in the UK. I started with a literature review

on factors related to low levels of mammography screening that have been reported among Chinese women in Western countries.

According to Boote and Beile (2005), a literature review identifies and evaluates studies, and models, related to the researcher's field and thus helps to define the research topics or questions. The literature review provided evidence that the low uptake of mammography screening was affected by Chinese cultural beliefs and women's knowledge and attitudes toward breast cancer and mammography screening. In addition, the literature review uncovered some motivators (e.g. physician's recommendation) and barriers (e.g. language, modesty and health insurance) to the uptake of mammography screening specifically among Chinese women living in Western countries. However the literature review highlighted that the factors related to mammography screening among Chinese women in the UK still have not been systematically explored. Studies in this area were largely confined to countries other than UK or had been conducted at a time before a universal screening service had been established in UK. It seemed reasonable to cautiously accept that the findings from the review would apply to Chinese-British women, but by identifying a gap in knowledge regarding the reasons why Chinese women were reluctant to attend mammography screening even though it is a free service in the UK; I was confident that I had chosen a worthwhile topic to research.

Glesne and Peshkin (1992, p. xiii) suggest that "conducting research, like teaching and other complex acts, can be improved; it cannot be mastered". Throughout this PhD project, I felt that the literature review was more like a work in progress than a finished chapter as relevant studies keep being published. It has become clear that much of the research has made assumptions about ethnic minority groups that should be questioned. The reflective journal I kept enabled me to reconsider my views on the research topic and re-examine the relationship between the current investigation and relevant studies and health psychology theories. After the thesis was examined, when I came back to the literature review, I realised

that the focus of my literature review was rather narrow from the outset on breast cancer screening only rather than learning from evidence about other types of screening on issues related to uptake to screening, such as cervical cancer screening.

Cervical cancer is the third most common cancer among women worldwide. In England, women between 25 and 49 years old are invited for cervical screening every three years, and women between 50 and 64 years old are invited every five years. Contrasting with breast screening, cervical screening is an effective test for preventing cervical cancer rather than a diagnostic test. It is important for women to go for this screening in order to spot the abnormal cells in the cervix and stop them developing into cervical cancer. However, participation levels in cervical screening (54%) among Chinese women were found to be lower than the national level (79%) in a recent survey carried out in North West England (Conway, Clamp, Hasan et al, 2014). Previous studies suggest that the low attendance at cervical screening among Chinese women is attributable to the lack of knowledge on cervical screening, language barriers and cultural beliefs (Kwok, White, & Roydhouse, 2011; Chang, Woo, Yau, Gorzalka, & Brotto, 2013), which also seem to be the common barriers for attending breast screening.

There are some similarities and differences between the process of breast screening and cervical screening. Unlike breast screening where women receive an invitation letter with the time, date and location of the screening appointment, women have to make an appointment for cervical screening themselves using the contact details in the invitation letter. The findings of this thesis showed that language was a major barrier that prohibited older Chinese women using health services. This is not just because the women themselves are not fluent in English but also because interpreter services do not meet their needs. Therefore, it is anticipated that Chinese women may be less likely to attend cervical screening because of the difficulties of using English to book an appointment. This assumption may be supported by the findings of the North West England study in that only half the Chinese women who

received breast screening had also gone for cervical screening (Conway et al, 2014). The participation disparity between breast screening and cervical screening suggests to me that providing a scheduled appointment is an effective way to reduce the language barriers for Chinese women in attending mammography screening, and thus increasing the participation rates. These could be further reduced by offering written information in Chinese as, unlike some other ethnic minority groups, older Chinese women tend to be highly literate in their own language.

As in breast screening, women need to expose their bodies during cervical screening. However, compared to breast screening, which is always carried out by a female nurse in UK, cervical screening may be done by a male doctor or nurse if the patient does not request a female service provider when she makes an appointment. Under this circumstance, Chinese women may have a male service provider to conduct the screening due to their limited English proficiency and understanding of the English invitation letter and educational leaflet which informs them that they can specify their preference for a female service provider. Chinese women may be more likely to feel embarrassment or even refuse to take part in the cervical screening if a male service provider does the screening. There is evidence that embarrassment is a common barrier for Chinese women attending a cervical screening due to the culturally bound perceptions of sex and sexuality in cervical screening (Kwok et al, 2011).

Apart from cervical screening, I have subsequently also considered the relationship between other types of cancer screening (e.g. colorectal cancer screening) or preventive screenings (e.g. screening for type 2 diabetes), and mammography screening among Chinese women. However, the findings on other types of screening may have limitations in understanding the issues associated with breast screening because women in other screening programmes do not have to show intimate parts of their bodies to service providers. Previous studies indicated that Chinese women are reluctant to participate in mammography screening for

reasons of modesty (Mo, 1992; Gany et al, 2006; Kwok et al, 2005). In the studies in this thesis, the effect of modesty on the uptake of mammography screening was also observed, but also that this could be mitigated by information about the gender of service providers.

Carrying out a literature review on factors related to the uptake of cervical screening among Chinese women would have implications for developing a deep and better understanding of the mechanisms, motivations and barriers behind breast screening among Chinese women living in the UK. However, conducting a limited literature review on cervical screening after completing the set of studies in this thesis makes it possible to use this literature to further support the findings and conclusions on breast screening.

The eligible age for cervical screening (25 to 64) is lower and relatively wider than for breast screening (50 to 70). A review of cervical screening would provide substantial empirical evidence about the role of social-demographic factors (such as age, education level and years in resident countries) on Chinese women's cervical cancer related knowledge, intention and screening behaviour. These findings could be integrated with the focus group findings among younger and older Chinese women in this study to generate a better explanation of the differences between these two age groups in terms of health beliefs, breast cancer prevention and detection, and healthcare seeking behaviour.

9.2 Reflections on health psychology theory

One of the aims of this study was to understand the psycho-social factors related to breast cancer prevention and early detection among Chinese women. Before data collection, it was felt to be more effective to choose a theoretical framework that underpinned and to some extent guided the study. Health psychology models have been commonly used to explain, predict and understand breast screening behaviours. In the literature review, I compared and contrasted the frequently used health psychology models and their applications in breast screening. These models included the Health Belief Model (HBM), the Protection Motivation

Theory (PMT), the Theory of Planned Behaviour (TPB), the Self-regulation Model of Illness Behaviour (SRMI) and the Transtheoretical Model (TTM). The literature review showed that HBM has been suggested to be more effective in the prediction of infrequent health-related behaviours, such as mammography screening, than the other models (e.g. PMT, TPB and TTM) (Sanderson, 2004). In addition, the literature review revealed that SRMI has limitations in the prediction of breast screening behaviour as this model focuses on beliefs about illness rather than individuals' beliefs about a target behaviour. Therefore, without excluding other models and other variables entirely from consideration the HBM was considered to be the most appropriate theoretical framework to fit the purpose of this study. The HBM attempts to explain an individual's health-related behaviour or decision-making process from a cognitive perspective (Bolton & Britain, 1994). According to the HBM, a health-related behaviour is a product of six concepts: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, health motivation and cues to action (Becker et al, 1979). Despite this model having been successfully used to predict women's participation in mammography screening and BSE, the literature review showed that alternative factors, such as social influence, knowledge about breast cancer, past behaviour and emotion, are also great contributors to the understanding of breast screening. Therefore, the HBM was integrated with these factors in the investigation of breast health, breast cancer prevention and early detection among Chinese women to ensure that the important components of behaviour change and decision making were covered. It is important to note that the focus group discussion was not limited to the variables suggested by the theoretical framework (HBM) and the literature review, as participants were encouraged to mention and expand on the discussion points that were important to them and the data were initially analysed purely inductively.

The findings of this thesis suggest that apart from the components advocated by the HBM, Chinese women's decision-making processes on adherence to breast screening were also influenced by the concepts from other health psychology models. For example, the empirical

evidence showed that free mammography screening was reported as one of the most common facilitators for the screening utilization. Similarly, previous studies identified that an inability to afford the costs of mammography screening is a common barrier to breast screening among Chinese women living in the other Western countries where there is a lack of free screening services (Lee-Lin et al, 2008). The component of costs of the adaptive behaviour is addressed in the PMT (Rogers, 1975) in that individuals are more prone to adopt an adaptive behaviour if they perceive low response costs. According to the PMT, the free screening service can reduce women's perceived costs of mammography screening, and thus increase their intention to engage in mammography screening, which subsequently promotes the performance of this screening. Therefore, removing the financial barrier to mammography screening is one of the reasons why Chinese women in the UK reported a higher participation rate in mammography screening than would be expected from the literature.

The TPB suggests that subjective norm is a determinant of behavioural intention, which in turn is a cause of behaviour change. Subjective norm refers to the perceived social norms and perceived social pressure to carry out a target behaviour (Ajzen, 1991). In this study, the influence of subjective norm on Chinese women's decision on whether or not to perform a breast screening was evident. For example, female modesty was reported as a barrier to mammography screening by older participants. In addition, the peer group influence was also observed in action in one focus group when a non-adherent participant was motivated to go for the breast screening by the other Chinese women in her group. This reflects that Chinese women live within a social world so that both individual factors and social environments influence their adherence of breast screening.

The findings of this thesis imply that emotional components should be included in the understanding of breast screening among Chinese women because it was found that breast cancer worry facilitated the performance of BSE. The role of emotional response to health

threat on behaviour change is emphasised in the SRMI, which proposes that health behaviour is determined by both illness cognitions and emotional representations. However, the relationship between emotion and health behaviour is ignored in the HBM.

As this study drew on abductive inference, that moves from a set of evidence to a theory that can best explain the set of evidence (Josephson & Josephson, 1994), a new health psychology model of behaviour change was developed, informed by the findings of this study (Figure 9.1). This model consists of two phases, a motivational phase and a volitional phase. The motivational phase emphasises the cognitive mediation process of behaviour change and consists of perceived susceptibility, perceived severity, health motivation, perceived benefits, perceived barriers, costs, subjective norm and emotion.



Figure 9.1 A model of Health Behaviour Change

According to Gollwitzer (1993) and Heckhausen (1991), changing motivation is the first phase in the process of behaviour change, with a second, volitional, phase required to complete the behaviour change process. In this volitional phase individuals make specific plans, called 'implementation intentions', which link the specific cues (where, when) with a specific response (how). These connections lead to the performance of the behaviour when the individual meets the specific cues. As discussed in the introduction chapter, creating implementation intentions have been found to be effective in increasing the uptake of mammography screening as there is evidence that women who made plans to attend mammography screening showed higher participation than those who did not (Steadman & Quine, 2006). In the context of breast screening in the UK, the invitation letter sent by the NHS already gives the details of the appointment date, time and venue, so that it increases Chinese women's implementation intentions to attend mammography screening and also eliminates the language barriers to booking an appointment. This can be used to explain the differences on participation rates between mammography screening and cervical screening among Chinese women in the UK as women have to book a cervical screening appointment by themselves rather than being given a scheduled appointment. In addition to implementation intention, Chinese women, especially those who are not fluent in English, may still need to make a coping plan that outlines how to deal with the anticipated barriers to mammography screening such as transportation. The results of this thesis have demonstrated that motivational and volitional phases are two essential and qualitatively different stages in the process of behaviour change for breast screening. In the future, this new model can be applied into the understanding of other screening behaviours, such as cervical screening, among Chinese women and also be tested in women from other minority ethnic groups, and indeed majority ethnic groups.

9.3 Epistemology, methodology and method

This study aimed at developing an educational intervention to improve the uptake of mammography screening among Chinese women living in the UK. Intervention Mapping

(Bartholomew et al, 2002) was used as a guide to ensure that the intervention was developed on the basis of a combination of theoretical and empirical evidence.

Within the context of healthcare, the majority of research is influenced by the paradigm of positivism (Johnson & Onwuegbuzie, 2004; Parahoo, 2006). Positivist researchers believe that there is an objective reality independent of the researcher's beliefs or perspective. context and time (Crossan, 2003). Researchers are hence supposed to be neutral and detached from the phenomenon being studied (Guba & Lincoln, 1998). Positivist researchers suggest that social phenomena can be studied in the same way as natural phenomena by using the methods of natural science (Carson et al, 2001). Thus, they believe that human behaviours can be predicted objectively, and use structured quantitative approaches to test theories or hypotheses regarding social phenomena (Carson et al, 2001). Therefore, much research conducted within healthcare has used quantitative approaches to explore the causes of diseases and/or used Evidence Based Practice (EBP) to promote health or provide healthcare. However, results from the systematic review, which is generally regarded to provide the best source of evidence for EBP, indicated that the majority of included studies were not specifically targeted at Chinese women and thus can have no or limited influence on the improvement of breast health and/or screening behaviours among Chinese women specifically as they are not culturally and linguistically tailored. This implies that the quantitative approaches taken so far have limitations in research of relevance to Chinese women. Therefore, designing a breast screening intervention targeting Chinese women requires establishing an understanding of Chinese women's health beliefs, attitudes to breast cancer prevention and early detection and experiences of breast screening in a naturalistic setting that could then explain the process of decision making about breast screening and action. This only can be achieved by using a qualitative approach utilising the paradigm of interpretivism.

In contrast to positivism, the paradigm of interpretivism argues that reality is multiply

constructed and made sense of through subjective interpretations (Garson et al, 2001). Individuals may have different interpretations of a social phenomenon because their experiences are socially constructed and cannot be context or time free (Polit & Beck, 2010). Interpretivism therefore focuses on understanding the meaning that individuals attach to their experiences rather than testing cause-effect laws. Interpretivist researchers claim that it is impossible for a researcher to achieve complete neutrality and objectivity, as the phenomenon is understood through the interaction between researcher and participants (Guba & Lincoln, 1998). Qualitative approaches are commonly adopted by interpretivist researchers.

It has been argued that the use of a single research methodology may lead the researcher to lose or ignore some valuable information and thus constrain their understanding of phenomena (Chamberlain, 2000; Patton, 2002). Marks (2002) suggests that effective EBP requires the combination of best evidence about the effectiveness of an intervention with patients' values and experiences. Therefore, a mixed design approach utilising the paradigm of pragmatism was considered as an appropriate approach to achieve the research purpose. The paradigm of pragmatism focuses on the objectives and aims of the research and enables the researcher to employ different methodologies in order to have a more holistic understanding of the 'true value' of the phenomenon under investigation (Yardley & Bishop, 2008). This thesis has demonstrated that using a pragmatic, mixed design approach can take advantage of the merits of one approach in compensating for the demerits of the other approach, and thus ensure that healthcare practice is developed on the basis of the best available evidence.

The logic of inquiry (Hiles, 2014) was used to guide the choice of the appropriate research approach for each research question. Hiles (2014) suggests three fundamental relationships between data and theory: theory-driven logic (deductive inference), data-driven logic (inductive inference), and explanation-driven logic (abductive inference). Quantitative

approaches are dominant in deductive inference, qualitative approaches are dominant in inductive inference, and a mixed design approach is central to abductive inference. The pragmatic, mixed design approach in this study is consistent with explanation-driven logic. The systematic review of interventions to increase breast screening among Chinese women living in Western countries was a quantitative approach, which provided the evidence on the effectiveness of different types of intervention on increasing breast health and/or mammography screening. On the other hand, the focus group studies, as a form of qualitative research, generated deep insight into breast cancer prevention and early detection among Chinese women and also assisted the researcher in choosing the most appropriate type of intervention for Chinese women. Finally, the combination of the results from the mixed methods approach and the findings from the literature review produced the best available empirical evidence for the development of a breast screening intervention, which fulfilled step one (needs assessment) of Intervention Mapping and also provided the foundation for steps two, three and four.

Intervention Mapping provides an explicit guide for developing a theory and evidence driven intervention in health promotion (Kok et al, 2004). The importance of incorporating a theoretical framework into the development of complex interventions to improve health has been emphasized by the UK Medical Research Council's (MRC) guidelines (Campbell et al, 2000). There is evidence that theory-based interventions tend to be more effective on behaviour change than interventions that are not based on any theory (Webb, Hoseph, Yardley, & Michie, 2010). The reason is attributed to the fact that theories directly address the key constructs that promote behaviour change (Bartholomew et al, 2002). Intervention Mapping bridges health behaviour theory and learning and change objectives, developed in step two, by using theory-based method and practical strategies, identified in step three (Corbie-Smith et al, 2010). In this study, the information-motivation-behavioural skills model (Fisher & Fisher, 1992), social cognitive model (Bandura, 1977, 1986) and the behaviour change wheel (Michie et al, 2011) guided the choice of intervention methods and practical

strategies to improve both personal determinants and external determinants related to mammography screening.

This thesis has described the detailed process of how the Intervention Mapping was used as a research strategy to integrate the evidence collected by using a pragmatic, mixed design approach and health behaviour and behaviour change theory to develop a breast screening intervention for Chinese women living in the UK. Intervention Mapping provided a more systematic and inclusive approach to the design of the intervention than that provided by the MRC guidelines for complex interventions. Both Intervention Mapping and MRC guidelines address the need to combine theory and evidence in the development of interventions to promote health behaviour. However, Intervention Mapping provides detailed guidance about determinants of behaviour change in terms of personal and environmental factors. With a population which has been little studied and where detailed analysis was needed of how current theoretical models mapped on to the experiences and behaviour of that population, Invention Mapping seemed to enable better use of all evidence than the MRC framework. For example, both the systematic review and the results of the inductive and deductive analysis of focus group data indicated that ineffective breast screening interventions for Chinese women might be due to the lack of cultural and linguistic sensitivity. The breast screening intervention, which was developed in this study, addressed the psycho-social factors related to the uptake of mammography screening among Chinese women living in the UK using theoretically underpinned behaviour change methods and strategies. It is anticipated that this empirical and theoretical evidence-based breast screening intervention would maximize intervention impact for non-adherent Chinese-British women.

9.4 The relevance of findings from focus groups among younger Chinese women

To my knowledge, this is the first study that has explored the health beliefs, knowledge about breast cancer, attitudes toward and practice of breast cancer prevention and early detection among younger Chinese women living in the UK. The results revealed that the younger generation had more knowledge about the risk factors for breast cancer than the older generation. All younger participants identified genetics as the most common risk factor. The term "neo-fatalism"² has been used in this thesis to describe the way that strong beliefs about the genetic origin of breast cancer led the younger participants to believe that nothing can be done to prevent most breast cancer. Fatalism is often used to explain behaviour, particularly of ethnic minority groups, in health research. It is traditionally assumed to be an indicator of poor education, lack of understanding of science or superstitious beliefs. It is interesting that modern genetics can give rise to similar beliefs in a relatively well-educated group of young women. The prevalence of these neo-fatalistic beliefs in other ethnic groups is unknown. Once again this shows the importance of detailed, in-depth understanding of the beliefs of populations for whom interventions are targeted.

In contrast to their beliefs about prevention most of the younger participants showed positive beliefs about early detection. It was found that a good proportion of them, including those with strong neo-fatalistic views, considered that BSE is an effective screening method for breast cancer. This indicates that participants understand that early detection is different from prevention. The performance level of regular BSE was very low as only one participant performed this examination monthly. The common reasons for not doing this screening test were lack of knowledge about the method for performing BSE and having no confidence in their ability to perform the procedure correctly. These findings suggest that the NHS Breast Awareness campaign has failed to reach younger Chinese women. In addition, low perceived susceptibility was another contributor to the poor practice of BSE as several participants believed that breast cancer is also observed among women in other ethnic groups (Johnson & Dickson-Swift, 2012). The inaccurate perception of the risk factors has highlighted the need to provide adequate information on breast cancer among younger Chinese women.

² See¹ above for the origin of this term

The National Breast Cancer Centre (2004) reported that the five-year breast cancer mortality rate was 72.4% for women aged 20-29 years old and the main reason for the high mortality rate is lack of breast awareness (Anders et al, 2008). Therefore, it is essential to improve breast awareness among younger generations in order to reduce their breast cancer mortality. Being breast aware can encourage young Chinese women to become more familiar with their own breasts and know the normal appearance and thus increase their confidence to identify the abnormal changes at an early stage.

The results of the focus group studies also showed that Chinese cultural beliefs were still central to Chinese women's beliefs on health maintenance and illness prevention among both younger and older generations. Participants held a strong holistic view on health maintenance. The reason for the low practice of BSE may be partly attributed to fact that regular screening is not recommended by TCM. Healthcare providers have to acknowledge the Chinese cultural influences on performing breast screening behaviours and provide culturally salient information for young women. Promoting breast awareness could help Chinese women to appreciate the benefits of regular screenings and eliminate the cultural barrier to breast screening so that they will be more likely to accept and participate in mammography screening when they reach the eligible age in the future. The results of the focus group study among older Chinese women indicated that family members play an important role in their decision to go for mammography screening, by providing health-related information, transportation and informal interpretive support. Thereby, increasing breast awareness among the younger generation can help them to provide accurate information on breast cancer and positive advice and support on breast screening when their mothers ask their opinion on mammography screening.

As was mentioned in the introduction chapter, the breast cancer incidence for Chinese women significantly increased after they had moved to Western countries due to the adoption of a Western lifestyle (Ziegler et al, 1993). The risk of developing breast cancer continues to

increase in the second and later generations (National Institute of Health, 2002). According to the UK Office for National Statistics (2005), the majority of young Chinese in the UK were born in Asia, with 62.35% for 16-24 years old and 70.56% for 25-34 years old. Most of them are students who come to the UK for higher education and scholars who migrated to the UK after they had finished their studies (Tran, 2006). As new arrivals, they gradually integrate the Western lifestyle (e.g. dietary habits) into their Eastern lifestyle and then establish a new lifestyle which has a great impact on the risk of breast cancer. Therefore, information regarding the influence of Western lifestyle on the increased risks of developing breast cancer among Chinese women needs to be disseminated among younger Chinese women. There are long term implications of promoting breast cancer, reduce their false beliefs, and increase their intention of making informed choices on risk reduction behaviours and breast screening. The findings of this study can be used to design and organise evidence-based and culturally sensitive educational programmes to enhance younger Chinese women's knowledge on breast cancer causes, prevention and early detection.

9.5 Reflexivity on the use of focus groups

This study used focus groups to explore the psycho-social factors related to breast cancer prevention and early detection among Chinese women because of the group dynamic generated by focus groups. Older Chinese participants were recruited from local Chinese Societies. The majority of them knew each other personally, indeed they were friends before they participated in this study. Despite heterogeneity of the uptake of mammography screening among participants, there was homogeneity among them to some extent as the focus groups were developed on the basis of pre-existing peer groups. It was found that the focus group discussion was close to an everyday conversation as participants interacted with each other naturally. They discussed their health beliefs and attitudes on breast cancer prevention and early detection, and also explored their shared and unshared experiences on mammography screening. However, they also debated and sometimes disagreed on some

issues. For example, when one participant considered that physical pressure was one of the causes of breast cancer, her view was denied immediately by other participants in her group.

I had had the experience of conducting individual interviews before, and considered that the crucial feature which distinguishes focus groups from individual interviews is the group dynamic, which allowed Chinese women to ask guestions of one another, comment on others' responses and explain their attitudes and behaviours. Therefore, the focus groups resulted in extended discussion and generated a variety of perspectives on breast cancer prevention and early detection that might have not have been thought of in an individual interview. In addition, the group dynamic enabled participants to raise the issues that were salient for them. For example, participants talked about the language barriers in receiving breast cancer-related knowledge and using health services. In this study, focus groups worked well and research issues were discussed in an interactive group setting where participants developed trust and felt comfortable talking with other group members. It was observed that the dynamic conversational interactions between group members reinforced them to work as a unit rather than as individuals when they tried to find out solutions to a particular problem. For example, all participants talked about the possible barriers to mammography screening among Chinese women and also made suggestions on improvements.

As an interviewer or researcher, I felt the power difference between Chinese women and I was reduced in focus groups as the group dynamic allowed Chinese women to 'determine their own agendas' (Schlesinger et al, 1992, p. 28-29). I had less control over the data generated by participants than in an individual interview (Morgan, 1988). My major role was to facilitate the group discussion, to ask Chinese women to elaborate further on some interesting points, and to ensure participants focus on research topics.

Despite the advantages of using focus group in collecting data, I realized that there were
some limitations with this research method through engaging in reflexivity. In one focus group (BC2 group), when I asked participants whether they had been to mammography screening before, only one participant (BC2P6), who was a 65 year old single women, in that group had never attended screening despite having received the invitation letter. During the focus group discussion, I noticed that BC2P6 was silent when other participants in her group shared their experiences of mammography screening. In order to ensure that every participant was offered an opportunity to talk about her experience, I turned to BC2P6 and asked her directly regarding her experience. Here is the conversation:

| Interviewer: | ((Turned to BC2P6)) Have you been to the screening? |
|------------------|--|
| BC2P1: | ((Turned to BC2P6)) Have you been to the screening? |
| BC2P5: | (BC2P6's name), have you been to the screening? |
| BC2P6: | No° |
| BC2P1: | NO? WHY? You're very old |
| BC2P2: | Yeah, why? Why haven't you? |
| BC2P6: | (I'm fine, so I don't need to take the screening)° |
| | |
| Interviewer: | ((Spoke to BC2P6)) This means you received the letter, but you |
| didn't go for th | ne screening. Why you didn't go for the screening? |
| BC2P6: | (l'm shy)° |
| Interviewer: | Any other reasons? |
| BC2P5: | Many areas have the mobile vans |
| BC2P6: | (Because I still haven't got married)° |

This extract may illustrate that power relations were established within that group due to the heterogeneity of mammography screening behaviours among participants. When talking about the attitudes toward, and experience of, mammography screening, it was observed that the conversation was dominated by participants who had received mammography screening. These participants were more vocal than BC2P6 as they were aware of the NHS Breast Screening Programme and appreciated the benefits of mammography screening. In this situation, these participants' knowledge and experience might have created power differentials within that group, resulting in BC2P6 feeling uncomfortable and reluctantly expressing her opinions. BC2P6 answered the questions in a low voice maybe suggesting that she felt intimidated into not participating in the discussion by the interviewer and other group members. In addition, this extract may reflect the limitation in using pre-existing peer

groups. BC2P6 might be worried that her behaviour was not approved of by the other group members and criticized for deviation from group norms (Kitzinger 1994; Smithson 2000; Stokes & Bergin, 2006).

In the following discussion, a few participants stated that not going for mammography screening is a 'stupid' behaviour as it is a free service and also enables women to know their health status. This reveals that the uptake of mammography screening is considered as a shared norm by the majority of participants in that group. Undoubtedly the power relations and group norms have an influence on participants' contributions. As a researcher, it is important to assess the interactions between participants, how their responses may influence the other's participation in the discussion, and the impact of homogeneity or heterogeneity on the interaction between participants (Gronkjaer, Curtis, de Crespigny, & Delmar, 2011). During the focus group discussion, I made greater effort to control the conversation as a moderator, including inviting BC2P6 to participate in the discussion through direct questioning (Myers, 1998) and diffusing the feeling of offence directed towards her.

Reflective exercises on the use of focus groups revealed that focus groups may prevent some participants like BC2P6, whose behaviour is not normative among their peers, from speaking openly about her views and experience on breast cancer prevention and early detection due to the power relations and social norms within the group. Under these circumstances, an individual interview may provide a more comfortable environment for them to talk about sensitive topics. If I were given a chance to carry out this research again, I think using individual interviews alongside focus groups would be a more effective approach to collecting qualitative data.

9.6 Reflexivity on becoming and being a researcher

As a researcher, it is essential for me to consider how my role has an influence on the research process of data collection, interpretation, analysis and reporting findings. Husserl

(1927) advocated that in order to gain knowledge of the phenomenon as it is in itself, researchers must bracket off their pre-understanding about the phenomenon. The term 'bracketing' refers to the belief that it is possible for researchers to 'cut off' their individual, subjective perception during the processes of data collection and interpretation (Porter, 1993). Van Manen (1990) argues that our "pre-understandings, our suppositions, assumptions and the existing bodies of scientific knowledge, predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological questions" (1990, p.46). Existential-phenomenologists argue that researchers are part of the phenomenon that they explore (Finlay, 2003a). Therefore, it is impossible for researchers to completely bracket off their understanding, experience and historical background when conducting research (Heidegger, 1962). What they can do is to identify the fore-understandings and pre-judgements and try to bridle their influence on their understanding of the phenomenon being studied, in order to maximize the fidelity of the phenomenon (Dahlberg, Dahlberg, & Nystrom, 2008). It is therefore important for me to be reflexive on my experience of being a Chinese researcher, who shared a similar cultural background with participants, studying other Chinese women's attitudes and behaviours related to breast cancer prevention and early detection.

The reflexivity on my role was conducted by using the Gadamerian terms 'horizon' and 'fusion of horizons' (Gadamer, 1975). A horizon refers to the 'range of vision that includes everything that can be seen from a particular vantage of point' (Gadamer, 1975, p. 269). All individuals have their own horizon that consists of values, experiences and forestructures (Gadamer, 1975). Gadamer uses the term of 'fusion of horizons' to illustrate how a researcher's horizon merges with the horizons of participants to generate a new interpretation of the phenomenon (Gadamer, 1975). Therefore, I carefully considered my horizon, including health beliefs, cultural views and knowledge on breast cancer prevention and early detection, my experiences of using medical services in the UK, and preconceptions about the breast cancer screening behaviours among Chinese women before conducting the

research, to ensure that my horizon would not dominate the direction of focus group discussion and data analysis.

During the process of data collection, I found that sharing the same cultural background and language with participants helped me to easily understand participants' opinions, beliefs, experiences and some Chinese concepts that participants used during the focus group discussion. Meanwhile, my female Chinese identity reduced the 'race-of-interviewer effects' (Gunaratnam, 2003) and enabled participants to feel comfortable and talk honestly about their feelings and experiences on some sensitive topics. In addition, I felt that my educational background and the purpose of this research also encouraged participants to express their opinions, as participants hoped I would report the actual issues that prohibited Chinese women from going for breast screening in the NHS and improve the breast screening services targeted at Chinese women. It is clear that I built rapport with my participants thanked me for conducting this research and also stated that they were happy to be contacted if I needed participants in future research.

However, reflexivity also revealed some disadvantages of matching ethnicity between the interviewer and participants. Because sharing the same culture might prevent me from identifying some tacit assumptions in Chinese beliefs and making further investigations. For example, during the first focus group discussion, I felt that it was taken for granted when participants emphasized the importance of eating a healthy diet on maintaining their health as it is a Chinese cultural universal, so I did not ask them why they felt this and what was the meaning of a healthy diet for them. Discussion about the focus group transcript with my supervisor who came from different cultural background highlighted this distinctive feature of the Chinese ethnic group and the value older Chinese women tended to put on keeping healthy. After realising the drawbacks of my Chinese identity, in subsequent focus groups, I tried to bracket off my Chinese cultural views and frequently asked participants why they had

such beliefs or performed certain behaviours, in order to gain insights into the reality of the phenomenon from participants' points of view.

Before conducting the focus groups, on the basis of the literature review, I anticipated that the mammography screening rates among Chinese-British women would be low and participants would show more negative attitudes than positive attitudes to breast screening. Surprisingly, after the first few focus groups it became clear that older Chinese women were reporting a high mammography screening rate and believed in the benefits of mammography screening in early detection and early treatment despite their limited knowledge of breast cancer and low perceived susceptibility to breast cancer. The findings of this study were in opposition to the previous studies among Chinese women in the other Western countries. I reflected on the unexpected findings and realized that the reality may be something different from a researcher's expectations which are generated from reviewing the literature. Although the women had volunteered to talk about this subject and could have been unusually positive about mammography, their explanations of why they went for mammography did suggest that some of the barriers to screening seen in other countries or at different times did not apply to women living in the UK at this time. Furthermore, understanding the behaviour of women who do attend mammography screening is essential in designing interventions to encourage those who do not go to make informed choices. Therefore, as a researcher, it is essential to give voice to participants and listen carefully to how they have responded to the research questions. In addition, participants' responses should be explored in a non-judgmental way to ensure that the research findings are drawn on participants' own perceptions and experiences (Patton, 2002).

In conclusion, this chapter has illustrated that both personal and epistemological reflexivity hold great value for research and are essential parts of the research process by revealing my reflexive account while conducting this study. The personal reflexivity helped me to acknowledge my preconceptions, values, cultural beliefs and experiences and consider how

these might have influenced the data collection, interpretation and analysis, in order to ensure that the research outcomes were rooted in participants' account. In addition, the reflective journal was critical not only in enabling me to explore the relationship between me as a researcher and my participants, but also the interaction between focus group participants, focusing on issues related to power relationships and social norms. The epistemological reflexivity reviewed how the decisions were made on using pragmatic, mixed design approach to answer the research questions and achieve the research purpose, and how this impacted the research and research findings. Intervention Mapping provided the guideline for integrating the empirical evidence and theoretical framework to develop a culturally and linguistically tailored breast cancer intervention among Chinese women. The reflection on health psychology theory helped me to realize the limitations of HBM in understanding breast screening among Chinese women and also provided an example of how practice informs theory. This study has demonstrated the need for and benefits of reflexivity when conducting research to explore individuals' health behaviour.

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Systematic review search strategy

- 1. Breast screening
- 2. Mammogram
- 3. Breast self-examination
- 4. Clinic breast examination
- 5. Breast cancer preventive behavi*
- 6. (#1or #2 or #3 or #4 or #5)
- 7. Chinese-American women
- 8. Chinese-British women
- 9. Chinese-Canadian women
- 10. Chinese-Australian women
- 11. Chinese women
- 12. Minority ethnic groups
- 13. Asian women
- 14. Underserved women
- 15. Non-attenders
- 16. (#7or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15)
- 17. (#6 and #16)

Data extraction form for systematic review

Study reference_____

First author and year of publication_____

Country of origin_____

a. Study characteristics

- 1. Aim/objective of the study
- 2. Study design
- 3. Study inclusion and exclusion criteria
- 4. How were participants recruited to the intervention
- 5. Setting
- b. Participant characteristics
 - 1. Age (means and SD)
 - 2. Ethnicity
 - 3. Total number of participants recruited

- c. Intervention(s)
 - 1. Number of intervention groups
 - 2. Describe all the specific elements of the intervention
 - 3. Describe all the elements of the control
 - 4. Did the intervention explicitly derive from a theoretical framework, and if so, what was the theoretical framework used
 - 5. How the intervention was developed
- d. Outcome and results
 - 1. Duration and specific of follow-up period
 - 2. Number of participants withdrawals and lost to follow-up and reasons
 - 3. Describe the specific outcome and how data were obtained

- 4. At what point(s) following the intervention was the outcome assessed
- 5. Events at baseline
- 6. Number available at follow up 1
- 7. Events at follow up 1
- 8. Number available at follow up 2
- 9. Event at follow up 2
- 10. Was the analysis carried out on an intention to treat basis
- 11. Statistic analysis

12. outcome

Downs and Black checklist for quality assessment

Reporting

1. Is the hypothesis/aim/objective of the study clearly described?

| Yes | 1 |
|-----|---|
| No | 0 |

2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?

In the main outcomes are first motioned in the Results section, the question should be answered no.

| Yes | 1 |
|-----|---|
| No | 0 |

3. Are the characteristics of the patients included in the study clearly described? In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source of controls should be given.

| 163 | I |
|-----|---|
| No | 0 |

 Are the interventions of interest clearly described? Treatments and placebo (where relevant) that are to be compared should be clearly described.

| yes | 1 |
|-----|---|
| no | 0 |
| | |

5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?

A list of principal confounders in provided

| yes | 1 |
|-----------|---|
| partially | 1 |
| no | 0 |

6. Are the main findings of the study clearly described?

Simple outcome data (including denominators and numerator) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).

| yes | 1 |
|-----|---|
| no | 0 |

7. Does the study provide estimates of the random variability in the data for the main outcomes?

In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.

| answereu yes. | | |
|---------------|---|--|
| yes | 1 | |
| no | 0 | |
| | | |

8. Have All important adverse events that may be a consequence of the intervention been reported?

This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided)

| is provided). | |
|---------------|---|
| yes | 1 |
| no | 0 |

9. Have the characteristics of patients lost to follow-up been described? This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.

| yes | 1 |
|-----|---|
| no | 0 |

10. Have actual value probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?

| yes | 1 |
|-----|---|
| no | 0 |

External validity

11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?

The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

12. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?

The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

13. Were the staff places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?

For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

Internal validity - bias

14. Was an attempt made to blind study subjects to the intervention they have received? For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

15. Was an attempt made to blind those measuring the main outcomes of the intervention?

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

16. If any of the results of the study were based on "data dredging", was this made clear? Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in care-control studies, is the time period between the intervention and outcome the same for cases and controls?

Where follow-up was the same for all study patients the answer should yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

18. Were the statistical tests used to assess the main outcomes appropriate?

The statistical techniques used must be appropriate to the data. For example nonparametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

19. Was compliance with the intervention/s reliable?

Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

20. Were the main outcome measures used accurate (valid and reliable)?

For studies where the outcome measures are clearly described, the question should

be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

Internal validity – confounding (selection bias)

21. Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population? For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case control studies where there is no information concerning the source of patients included in the study.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

22. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time? For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

23. Were study subjects randomised to intervention groups?

Studies which state that subjects were randomised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

24. Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?

All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?

This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In nonrandomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

26. Were losses of patients to follow-up taken into account?

If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.

| yes | 1 |
|---------------------|---|
| no | 0 |
| Unable to determine | 0 |

Power

27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%? Sa

| | Size of smallest intervention group | |
|---|-------------------------------------|---|
| А | <n1< td=""><td>0</td></n1<> | 0 |
| В | n ₁₋ n ₂ | 1 |
| С | n ₃₋ n ₄ | 2 |
| D | n ₅₋ n ₆ | 3 |
| Е | n ₇₋ n ₈ | 4 |
| F | n ₈ + | 5 |

Characteristics of excluded studies

| Study References | Reasons for exclusion |
|--|------------------------------|
| Yu M Song L Seetoo A Cai C Smith G & Oakley | Only reported lay health |
| D (2007) Culturally Competent Training Program: A Key to Training | advisors' ability on how to |
| Lav Health Advisors for Promoting Breast Cancer Screening Health | carry out breast cancer |
| education and behaviour 24 928-41 | prevention |
| Sadler G.R. Ryujin I. Nouven T. Ob. G. Paik G & Kustin B. | Reporting the same results |
| (2003) Heterogeneity within the Asian American | reporting the same results |
| community International Journal for Equity in Health 2 12 1-9 | |
| Bell TS Branston I K Newcombe R.G & Barton G.R. | Not including Chinese |
| (1999) Interventions to improve untake of breast screening in inner | women |
| city Cardiff general practices with athnic minority lists. Ethnicity & | women |
| Hoalth A 277-84 | |
| Burack RC Gimotty RA George I Simon MS Dews R | Not including Chinese |
| 8 Moncrosso A (1006) The effect of patient | women |
| a monorease, A. (1990). The effect of patient | women |
| and physicial reminders on use of screening manimography in | |
| a nealth maintenance organization. Results of a randomized | |
| Controlled Indi. Cancer, 70, 1700-21. | Not including Chinago |
| Districtly, A.J., Tobilit, J.N., Sox, C. \Box , Cassels, A.N., Negron, | Not including Chinese |
| F., Younge, R.G., Demby, N.A. & Tosteson, I.D. (1998). Cancer | women |
| the undergeriged A rendemized controlled trial Archives of Comily | |
| Madiana 7 200 7 | |
| Medicine, 7, 320-7. | National value of Ohiona and |
| FOX, S.A., Stein, J.A., SOCKIOSKIE, R.J. & Ory, M.G. | Not including Chinese |
| (2001). largeted mailed materials and | women |
| the Medicare beneficiary: increasing mammogram screening among | |
| the elderly. American Journal of Public Health, 91, 55-61. | |
| Herman, C.J., Speroff, I. & Cebul, R.D. | Not including Chinese |
| (1995). Improving compliance with breast cancer screening | women |
| in older women. Results of a randomized controlled trial. Archives of | |
| Internal Medicine, 155, 117-22. | National Part Officer |
| Hoare, I., Thomas, C., Biggs, A., Booth, M., Bradley, S. & Friedman | Not including Chinese |
| E. (1994). Can the uptake of breast screening by Asian women be | women |
| increased ? A randomized controlled trial of a linkworker intervention. | |
| Journal of public health medicine, 16, 179-85. | |
| Manfredi, C., Czaja, R., Freels, S., Trubitt, M., Warnecke, R., & | Not including Chinese |
| Lacey, L. (1998). Prescribe for health. Improving cancer screening in | women |
| physician practices serving low-income and minority populations. | |
| Archives of Family Medicine, 7(4), 329-337. | |
| Nattinger, A.B., Panzer, R.J. & Janus, J. (1989). Improving | Not including Chinese |
| the utilization of screening mammography in primary care practices. | women |
| Archives of internal medicine, 14, 2087-92. | |
| Ornstein, S.M., Garr, D.R., Jenkins, R.G., Rust, P.F. & Arnon, A. | Not including Chinese |
| (1991). Computer-generated physician and patient reminders. Tools | women |
| to improve population adherence to selected preventive services. The | |
| Journal of Family Practice, 32, 82-90. | |
| Roetzheim, R.G., Christman, L.K., Jacobsen, P.B., Schroeder, | Not including Chinese |
| J., Abdulla, R. & Hunter, S. (2005). Long-term results from | women |
| a randomized controlled trial to increase cancer screening | |
| among attendees of community health centers. Archives of Family | |
| Medicine, 3, 109-14. | |
| Taylor, V., Thompson, B., Lessler, D., Yasui, Y., Montano, | Not including Chinese |
| D., Johnson, K.M., Mahloch, J., Mullen, M., Li, S., Bassett, G. | women |
| & Goldberg, H.I. (1999). A clinic- | |
| based mammography intervention targeting inner-city women. | |
| Journal of General Internal Medicine, 14, 104-11. | |

| Study References | Reasons for exclusion |
|--|-----------------------------|
| Wagner, T.H., Hu, T., Duenas, G.V., Kaplan, C.P., Nguyen, B.H. | Baseline findings only |
| & Pasick, R.J. (2001). Does willingness to pay vary by race/ethnicity? | G 7 |
| An analysis using mammography among low-income women. Health | |
| Policy (Amsterdam, Netherlands), 58, 275-88. | |
| Nattinger, A.B., Panzer, R.J. & Janus, J. (1989). Improving | Only reported including |
| the utilization of screening mammography in primary care practices. | Asian women |
| Archives of internal medicine, 14, 2087-92. | |
| McPhee, S.J., Bird, J.A., Jenkins, C.N. & Fordham, D. | Only reported including |
| (1989). Promoting cancer screening. A randomized, controlled trial | Asian women |
| of three interventions. Archives of Internal Medicine, 149, 1866-72. | |
| Ahmed NU, Haber G, Semenya KA, Hargreaves MK. | Unclear the ethnicity of |
| (2010). Randomized controlled trial of mammography intervention | participants |
| in insured very low-income women. Cancer Epidemiology, | |
| Biomarkers and Prevention, 19, 1790-8. | |
| Bankhead, C., Richards, S.H., Peters, T.J., Sharp, D.J., Hobbs, | Unclear the ethnicity of |
| F.D., Brown, J., Roberts, L., Tydeman, C., Redman, V., Formby, | participants |
| J., Wilson, S. & Austoker, J. (2001). Improving attendance | |
| for breast screening among recent non-attenders: | |
| a randomised controlled trial of two interventions in primary care. | |
| Journal of Medical Screening, 8, 99-105. | |
| Brown, J., Welton, N.J., Bankhead, C., Richards, S.H., Roberts, | Unclear the ethnicity of |
| L., Tydeman, C. & Peters, T.J. (2006). A Bayesian approach | participants |
| to analysing the cost-effectiveness of two primary | |
| care interventions aimed at improving attendance | |
| for breast screening. Health Economics, 15, 435-45. | |
| Kearins, O., Walton, J., O'Sullivan, E. & Lawrence, G. (2009). | Unclear the ethnicity of |
| Invitation management initiative to improve uptake | participants |
| of breast cancer screening in an urban UK Primary Care Trust. | |
| Journal of Medical Screening, 16, 81-4. | |
| Lyncn, F. L., Whitlock, E. P., Valanis, B. G., & Smith, S. K. (2004). | Unclear the ethnicity of |
| Cost-effectiveness of a failored intervention to increase screening in | participants |
| HIVIO women overdue for pap test and mammography services. | |
| Prevenuve iviedicine, 36(4), 403-411. | l la clear tha athricity of |
| Sharp, D.J., Peters, I.J., Bartholomew, J. & Shaw, A. | Unclear the ethnicity of |
| (1990). Diedst screening. a randomised controlled that | participants |
| to increase uptake, Journal of Enidemiology and Community Health | |
| | |
| Stoad M L Wallie M C & Wheaton M E (1009) Improving untake | Lincloar the othnicity of |
| in non-attenders of breast screening; selective use of second | participants |
| appointment Journal of Medical Screening 5 69-72 | participants |
| Tinkler C Pegington K & Baldwin R | Unclear the ethnicity of |
| (2001) Breast screening attendance making better use of | participants |
| an appointment system Journal of Medical Screening 8, 36-8 | |
| Pruthi S Shmidt F Sherman M M Neal I & Wahner-Roedler D | Not reported the results on |
| (2010) Promoting a breast cancer screening clinic | Chinese women |
| for underserved women: a community collaboration <i>Ethnicity</i> & | |
| Disease, 20, 463-6. | |

Focus group schedules for older participants

Introduction

Recap on purpose of project, procedure, ground rules

Questions (used in all groups)

- 1. What do you think causes breast cancer?
- 2. What do you know about breast health practices?
- 3. Have you ever thought about the possibility to develop breast cancer?
- 4. Do you think breast cancer can be prevented? What effective ways do you think about preventing breast cancer?
- 5. Do you have any intentions to prevent breast cancer? What do you usually do?
- 6. Have you taken mammography in the past?
- 7. What set of circumstances would encourage you to go for a mammography?
- 8. Where and how do you get health-related information?
- 9. Which kind of educational modality you prefer to get information about breast health?

For women who had been for mammography:

10. What was your experience with mammography and would you go again?

For women who have not been for mammography:

11. Why you did not uptake mammography?

Supplementary questions (used in some groups, when time)

- 12. What do you think are important things for keeping yourself healthy?
- 13. Why do you think these things are important for your health?
- 14. How different are your views of health compared to White British in general?

Conclusion

Summary, thanks and debriefing

Focus group schedules for younger participants

Introduction

Recap on purpose of project, procedure, ground rules

Questions (used in all groups)

- 1. What do you think causes breast cancer?
- 2. Have you ever thought about the possibility of developing breast cancer?
- 3. Do you think breast cancer can be prevented? What effective ways do you think there are for preventing breast cancer?
- 4. Have you suffered any breast problems before?
- 5. Do you have any intentions to prevent breast cancer? What do you usually do?
- 6. What do you know about breast health practices?
- 7. Do you perform breast self exam regularly?
- 8. Do you know the correct way of performing breast self exam?
- 9. What do you think about breast self exam?
- 10. What set of circumstances would encourage you to perform breast self exam?
- 11. Where and how do you get health-related information?
- 12. Which kind of educational modality you prefer to get information about breast health? For women who do not perform breast cancer regularly
 - 13. Why you do not perform breast self exam regularly?

Supplementary questions (used in some groups, when time)

- 14. What does health mean to you?
- 15. What do you think are important things for keeping yourself healthy?
- 16. What do you do to maintain health?
- 17. How different are your views of health compared to White British in general?
- 18. What do you usually do if you suffer any health problem?
- 19. Compared with the health service in your home country, what do you think about the health service in the UK?
- 20. Have you ever suffered difficulties or inconvenience in seeking medical help in the UK?
- 21. Have you ever been an interpreter for your family or friends? Could you please talk about your experience?

Conclusion

Summary, thanks and debriefing

Ethic approval for study among older participants



MEMORANDUM

- DATE: March 26th 2009
- TO: Dr Helen Pattison
- FROM: Professor Paul Furlong, Life & Health Sciences

SUBJECT: Ethics submission 267: Development of an intervention to promote breast screening uptake in Chinese-British women

I am pleased to inform you that a Sub-Group of the School Ethics Committee has approved the above project.

The details of the investigation are placed on file. You should notify me of any difficulties experienced by the volunteer subjects, and any significant changes which may be planned for this project in future.

Professor P.L.Furlong Chair to the LHS School Ethics Committee

Ethic approval for study among younger participants



Aston Triangle Birmingham B4 7ET United Kingdom Tel +44 (0)121 204 3000

www.aston.ac.uk

Memo

| To: | Dr Helen Pattison; Dr Rachel Shaw; Ms Ying Zhang | | |
|----------|---|--|--|
| | Cc: LauraKing, administratortotheLifeandHealthSciencesResearchEthicsCommittee;Gemma | | |
| | Stanley (covering for Laura during her absence) | | |
| From: | Dr Rachel Shaw | | |
| | Chair of the Life and Health Sciences Research Ethics Committee | | |
| Date: | 25/3/2012 | | |
| | | | |
| Subject | Project 474: Psycho-social factors related to breast cancer preventive behaviours | | |
| Oubject. | among younger Chinese women | | |

The amended documentation and additional information for the above proposal has been considered by the Chair of the LHS Research Ethics Committee.

Reviewer's recommendation: Approved.

Reviewer's comments: Reviewers were happy for this study to proceed but require two minor additions to the Participant Information Sheet: please inform volunteers how long they will have to think about whether they wish to take part before giving their consent; and please inform volunteers who will be taking consent, i.e. name the researcher who will be responsible for this process.

Yours sincerely,

tis -

Dr Rachel Shaw Chair of the LHS Research Ethics Committee

| Area | Number of Chinese | Female | Female | Female | Female |
|------------|-------------------|--------|--------|--------|--------|
| | | | 0-15 | 16-59 | 60+ |
| Birmingham | 12,300 | 6,000 | 800 | 4,900 | 400 |
| Manchester | 12,300 | 5,400 | 700 | 4,500 | 300 |

Estimated Chinese population in Birmingham and Manchester for 2007

Source: Office for National Statistics, 2010

Participant information sheet for older Chinese women (Chinese)

乳腺癌防治活动

为什么做这个研究?-我们是阿斯顿大学的科研人员,并兴趣在华人妇女中开展一项乳腺癌的 预防活动。现在,我们需要收集一些信息,以了解您在乳腺癌方面的知识和观念,在预防中遇 见的困难,以及您认为那些因素可以促进预防活动的开展。

实验过程-您将被邀请参加一个我们的讨论小组。首先,您需要填写一份简单的问卷,比如年 龄之类的一些问题。之后,您将和其他 4 至 5 位女士一起讨论一下你在乳腺癌防治方面的看法 和经历。这个讨论将会被录音,以作为我们以后资料分析所用。讨论结束时,我们将给您一些 乳腺癌防治方面的详细资料,以及一些我们本次研究的资料。

所需时间 – 此小组讨论大概需要您一至一个半小时的时间。

这项研究的好处-通过参加这项研究,可以帮助我们理解哪些因素影响华人妇女在乳腺癌方面 的防治。因此,我们可以设计和实施更有效的服务,以改善华人妇女的乳房健康状况。此外, 您将获得一些关于乳腺癌防治方面的有用信息和有效途径。

参加此活动可能出现的不适 - 通常, 您不会有任何不适感。在罕见情况下, 您或许会有轻微的 压力感。如果您出现此情况, 我们将为您提供详细的咨询服务, 以消除您的不适感。

酬金 - 您将获得现金 20 磅,以作为参与此项研究的感谢。

保密性 · 您所提供的所有资料将完全保密。录音记录将在我们完成资料分析后被销毁。此外, 所有参加讨论的女士都要求尊重和保护其他人的信息。

自愿性 - 你有权在任何时候退出此研究,并且不必作出解释。我们将依旧付给您 20 镑以示感谢。另外,您可以在任何时候,自由地询问任何问题。

问题 - 如果您有关于参加此研究的疑问,请致电张颖 0121 204 4205 或发送电子邮件至 zhangy18@aston.ac.uk。

阿斯顿大学心理系

Participant information sheet for older Chinese women (English)

Why do this study? - We are the investigators at Aston University, and interested in developing an intervention to promote the breast cancer prevention among Chinese women living in the UK. Therefore, we need to collect some data to understand the Chinese women's knowledge and beliefs about breast cancer, barriers to mammography, and motivating factors related to the uptake of mammography.

Procedure – You will be allocated into one of the focus groups according to the main language that you usually speak. At first, you will be asked to complete a questionnaire regarding some demographic information such as your age. After that, you will be encouraged to discuss your views and experiences about breast cancer prevention with other 4 to 5 women in your group. This conversation will be audio recorded for the purpose of data analyses. A debrief will be provided once the conversation has finished. In this, you will get detailed information about this study and the breast cancer prevention programme.

How long will participation take? – This conversation will last approximately one to one and half hours.

Risk or discomfort – Usually, you will have no risks or discomfort in participation in this study. In rare cases, for some of you the questions could be distressing. You will be give details of counselling services that are available to help you.

Benefits of this study – By taking part in this study, you can help us to understand factors associated with screening decisions among Chinese women, thus to design and implement effective services to improve breast health among Chinese women. In addition, you will be provided some useful information about breast cancer and the effective ways to prevent it.

Compensation – You will be awarded 20 pounds for participation in this study.

Confidentiality - All information will be completely confidential and anonymous. The audio record will be destroyed as soon as the data transcription have finished. In addition, all participants are requested to respect and preserve the confidentiality of others.

Voluntary participation and withdrawal - You have the right to withdraw at any stage without having to give an explanation and without loss of payment. You are free to ask any questions at any time.

Questions - If you have any questions about this research project or concerns about your rights as a research participant in this study, please call Ying Zhang at 07500807227 or email at <u>zhangy18@aston.ac.uk</u>.

Psychology Department, Aston University

Participant information sheet for young Chinese women

Why do this study? - We are researchers at Aston University, and interested in developing an intervention to promote the breast cancer prevention among Chinese women living in the UK. Therefore, we need to collect some data to understand Chinese women's knowledge and beliefs about breast cancer, barriers and motivators to breast cancer preventive behaviours.

为什么做这个研究? -我们是阿斯顿大学的科研人员,并兴趣在华人妇女中开展一项乳腺癌的预防活动。现在,我们需要收集一些信息,以了解您在乳腺癌方面的知识和观念,在预防中遇见的困难,以及您认为那些因素可以促进预防活动的开展。

Procedure – You will be allocated into one of the focus groups according to the place of residence. At first, you will be asked to complete a questionnaire regarding some demographic information such as your age. After that, you will be encouraged to discuss your views and experiences about breast cancer prevention with other 4 to 5 women in your group. This conversation will be audio recorded for the purpose of data analyses. A debrief will be provided once the conversation has finished. In this, you will get detailed information about this study and the breast cancer prevention programme.

实验过程-您将被邀请参加一个我们的讨论小组。首先,您需要填写一份简单的问卷,比如年 龄之类的一些问题。之后,您将和其他 4 至 5 位女士一起讨论一下你在乳腺癌防治方面的看法 和经历。这个讨论将会被录音,以作为我们以后资料分析所用。讨论结束时,我们将给您一些 乳腺癌防治方面的详细资料,以及一些我们本次研究的资料。

How long will participation take? - This conversation will last approximately 1 to 1.5 hours.

所需时间 – 此小组讨论大概需要您一至一个半小时的时间。

Risk or discomfort – Usually, you will have no risks or discomfort in participation in this study. In rare cases, for some of you the questions could be distressing. You will be give details of counselling services that are available to help you.

参加此活动可能出现的不适 - 通常,您不会有任何不适感。在罕见情况下,您或许会有轻微的 压力感。如果您出现此情况,我们将为您提供详细的咨询服务,以消除您的不适感。

Benefits of this study – By taking part in this study, you can help us to understand factors associated with breast cancer preventive behaviours among Chinese women, thus to design and implement effective services to improve breast health among Chinese women. In addition, you will be provided some useful information about breast cancer and the effective ways to prevent it.

这项研究的好处-通过参加这项研究,可以帮助我们理解哪些因素影响华人妇女在乳腺癌方面的防治。因此,我们可以设计和实施更有效的服务,以改善华人妇女的乳房健康状况。此外,您将获得一些关于乳腺癌防治方面的有用信息和有效途径。

Compensation – You will be awarded 20 pounds for participation in this study.

酬金 - 您将获得现金 20 磅,以作为参与此项研究的感谢。

Confidentiality - All information will be completely confidential and anonymous. The audio record will be destroyed as soon as the data transcription have finished. In addition, all participants are requested to respect and preserve the confidentiality of others.

保密性 - 您所提供的所有资料将完全保密。录音记录将在我们完成资料分析后被销毁。此外, 所有参加讨论的女士都要求尊重和保护其他人的信息。

Voluntary participation and withdrawal - You have the right to withdraw at any stage without having to give an explanation and without loss of payment. You are free to ask any questions at any time.

自愿性 - 你有权在任何时候退出此研究,并且不必作出解释。我们将依旧付给您 20 镑以示感谢。另外,您可以在任何时候,自由地询问任何问题。

Questions - If you have any questions about this research project or concerns about your rights as a research participant in this study, please call Ying Zhang at 0121 204 4205 or email at <u>zhangy18@aston.ac.uk</u>.

问题 - 如果您有关于参加此研究的疑问,请致电张颖 0121 204 4205 或发送电子邮件至 zhangy18@aston.ac.uk。

Psychology Department, Aston University

阿斯顿大学心理系

Informed consent form for older participants (English)

School of Life and Health Sciences, Aston University

<u>Why do this study?</u> - We are the investigators at Aston University, and interested in developing an intervention to promote the breast cancer prevention among Chinese women living in the UK. Therefore, we need to collect some data to understand the Chinese women's knowledge and beliefs about breast cancer, barriers and motivating factors related to the breast cancer prevention.

<u>What will participation involve?</u> – At first, you will be asked to complete a questionnaire regarding some demographic information, such as your age. After that, you will be encouraged to discuss your views and experiences about breast cancer prevention with other women in your group. This conversation will be audio recorded for the purpose of data analyses. All information will be completely confidential and anonymous. The audio record will be destroyed as soon as the data transcription have finished. You have the right to withdraw at any stage without having to give an explanation and without loss of payment of your expenses. You are free to ask any questions at any time.

<u>Is there any risks or discomfort?</u> – Usually, you will have no risks or discomfort in participation in this study. In rare cases, for some of you the questions could be distressing. You will be give details of counselling services that are available to help you.

How long will participation take? – This conversation will last approximately one to one and half hours.

Researcher's Signature:_____ Date:_____

As an informed participant of this experiment, I understand that:

- 1. My participation is voluntary and I may cease to take part in this study at any time.
- 2. I am aware of what my participation involves.
- 3. All my questions about the study have been satisfactorily answered.
- 4. I should respect and preserve the confidentiality of other participants.

I have read and understood the above, and give consent to participate:

| Participant's Signature: | Date: |
|---------------------------------------|-------|
| · · · · · · · · · · · · · · · · · · · | |

Informed consent form for older participants (Chinese)

同意書

阿斯頓大學生命健康學院

<u>為什麼做這個研究?</u>-我們是阿斯頓大學的科研人員,並有興趣在華人婦女中開展一項乳腺癌的預防活動。現在,我們需要收集一些信息,以了解您在乳腺癌方面的知識和觀念,在預防中遇見的困難,以及您認為哪些因素可以促進預防活動的開展。

實驗過程 - 您將參加一個我們的討論小組。首先,您需要填寫一份簡單的問卷,比如年齡之類的一些 問題。之後,您將和其他几位女士一起討論一下你在乳腺癌防治方面的看法和經歷。這個討論將會被錄 音,以作為我們資料分析所用。討論結束時,我們將給您一些乳腺癌防治方面的資料,以及一些我們本 次研究的資料。

<u>參加此活動可能出現的不適</u> - 通常,您不會有任何不適。在罕見的情況下,您或許會有輕微的壓力 感。如果您出現這種情況,我們將為您提供詳細的諮詢服務,以消除您的不適感。

所需時間 - 此小組討論大概需要您一至一個半小時的時間。

研究者的簽名:_____日期:____日期:____

作為一名參與者,我理解:

- 1 我的參與是自願的,並且可以在任何時候退出。
- 2 我已經了解參加此項活動的過程。
- 3 我所有的關於參加此活動的問題,已得到令人滿意的回答。
- 4 我將尊重其他參與者,並不洩漏他們的資料。

我已經閱讀並了解上述情況,並同意參加:

參與者的簽名:______日期:____日期:_____日期:_____

Demographic data questionnaire for older participants (English)

To complete this questionnaire, please state your answer on line, or tick the appropriate box(es). Your responses are completely anonymous and will be treated in the strictest confidence.

- 1. Your age
- 2. How many years have you been in UK?
 - A. 1-5 years
 - B. 6-10 years
 - C. 11-15 years
 - D. 15 years or more
- 3. Place of birth
 - A. Mainland China
 - B. Hong Kong
 - C. Tai Wan
 - D. Other countries _____ (Please state your answer on line)
- 4. Marital Status
 - A. Married / other live-in relationship
 - B. Divorced /separated
 - C. Widowed
 - D. Single
- 5. Do you know any relatives who have breast cancer?
 - A. No
 - B. Yes
- 6. Are you able to speak English?
 - A. Not at all
 - B. Somewhat
 - C. Moderately
 - D. Very or extremely well
- 7. Education Level
 - A. Never attended school
 - B. Attended primary school
 - C. Attended middle school
 - D. Attended high school
 - E. Attended further education / college / technical school after high school
 - F. Attended university
- 8. Employment status
 - A. Employed outside the home/full time
 - B. Employed outside the home/part time
 - C. Homemaker
 - D. Employed at home
 - E. Retired
 - F. Not working

9. What is your breast cancer screening experience? (Tick all that apply)

- A. Had a mammography in the past
- B. Had a recent mammography
- C. Had a clinical breast examination in the past
- D. Had a recent clinical breast examination
- E. Do breast self examination every month

Demographic data questionnaire for older participants (Chinese)

人口數據調查问卷

请您将答案写在横线上,或者標出適合你自己的答案。您的回答是完全匿名的,將被絕對保 密。

- 1 年齡_____
- 2 您在英國生活了多少年?
- A 1-5年
- B 6-10 年
- C 11-15 年
- D 約15年或以上____ (请写出具体年数)
- 3 出生地點
- A 内地
- B 香港
- C 邰灣
- D 其他國家,請寫出國家名稱_____
- 4 婚姻狀況
- A 已婚/同居
- B 離婚/分居
- C 喪偶
- D 單身
- 5 您是否有親人患乳腺癌?
- A 沒有
- B 有, 請寫出與您的具體關係_____
- 6 您的英語能力
- A 一點都不會

- B 不好
- C 一般
- D 非常好
- 7 教育水平(選中一個框其中最密切的描述您的教育水平)
- A 從未上過學
- B 小學畢業
- C 初中畢業
- D 高中畢業
- E 高中畢業後,參加過一步教育,如技校等
- F 大學
- 8 就業狀況(選中一個框其中最密切的描述您的就業狀況)
- A 全職
- B 兼職
- C 家庭主婦
- D 在家工作
- E 退休
- F 没有工作
- 9 您的乳腺癌檢查情況 (勾選所有適用選項)
- A 在過去接受過乳房 x 線照相檢查
- B 在近期接受過乳房 x 光檢查
- C 在過去接受過臨床乳房檢查
- D 在近期接受過臨床乳房檢查
- E 每個月都做自我乳房檢查

Debrief for older participants (English)

Thank you very much for taking part in the study. The aim of this study is to understand factors related to mammographic decisions among Chinese women in order to design and implement effective services to improve your participant rates.

In the UK, approximately 45,000 cases of breast cancer are diagnosed every year, usually in women who are over 50 years of age and who have reached menopause. Although Chinese women have lower breast cancer incidence and mortality than that white British population, breast cancer incidence among Chinese women significantly increases after they migrate to Western countries. For example, women who have been in United States for more than ten years have an 80% higher risk of developing breast cancer than those who newly arrived. In addition, breast cancer risk increase with successive generations. Therefore, more Chinese women are expected to be diagnosed with breast cancer in future years.

Mammography is the most reliable way of detecting breast cancer early and has the potential to reduce breast cancer mortality. It is a low dose x-ray. During the procedure of mammogram, each breast is placed in turn on the x-ray machine and gently but firmly compressed with a clear plate. Two views of each breast are taken at every screen. Compression is needed to keep the breast still and to get the clearest picture with the lowest amount of radiation possible. Most women find this uncomfortable and some feel short-lived pain. Research has shown that for most women it is less painful than having a blood test and compares with having blood pressure measured.

Compared with white British women, Chinese women are less likely to use mammography screening, which is routinely available to women over 50 through the NHS. Moreover, Chinese women are more likely than white women in Western countries to be diagnosed with late stage breast cancer, related to the low screening rates. Therefore, it is necessary to uptake of mammography in order to detect the early cancer.

In this study, you will not be identified at any time in the write up. Information given by you will not be disclosed to any third parties. No records will be kept which could identify any individual as being linked to any information disclosed in this study. The information you have provided will be only used to design and implement effective services to improve the prevention of breast cancer among Chinese women.

For more information about breast cancer and the prevention programme, please read the enclosed leaflet 'Breast screening the facts', or go to the websites of breast cancer campaign at

http://www.breastcancercampaign.org/, and the NHS Breast Screening Programme at http://www.cancerscreening.nhs.uk/breastscreen/index.html. A video of the procedure of mammogram is available at http://www.nhs.uk/Livewell/Screening/Pages/Breastscreening.aspx

If you have any queries or concerns regarding the study please contact the researcher, Ying Zhang, at <u>zhangv18@aston.ac.uk</u> or 0121 204 4205. If you feel that you have experienced any feelings of distress as a result of this study and want to discuss these feelings please contact your GP for counselling.

Debrief for older participants (Chinese)

匯報

非常感謝您參加这次研究。这次研究的目的在于了解华人妇女在乳腺癌方面的知识和观念,在预防中遇见的困难,以及哪些因素可以促进预防活动的开展,以便于我们更好地設計和實施有效的服務,以改善您的參與率。您所提供的信息将会被完全保密,不會向任何第三方透露。 在英國,每年大概有 4 万 5 千人被確診患乳腺癌,通常集中在 50 歲以上或者更年期妇女。雖 然华人婦女乳腺癌的發病率和死亡率比英國白人妇女低,但当华人妇女移居到西方国家后,她 们的发病率也随之提高。以华人为例,同居住在中国大陆、新加坡、香港的华人妇女相比,居 住在美国的华人妇女的乳腺癌年发病率要高两倍。此外,患乳腺癌的風險将会随着一代一代的 延续而增加。因此我们可以预测,华人妇女患乳腺癌的人数将会在未来几年里有所增加。 为了实现乳腺癌的早期发现,定期的进行 乳腺 X 线检查 是行之有效的方法。與英國白人婦女 相比,华人妇女在乳腺 X 线检查方面的参加率比较低,尽管这项检查对于 50 岁以上妇女是兔 费的。此外,华人婦女与白人婦女相比,更容易被確診為晚期乳腺癌,这跟不按时进行乳腺 X 线检查有关。因此,华人妇女有必要定期参加乳腺 X 光检查,以便發現早期乳腺癌。

欲了解更多有關乳腺癌的預防方法,可阅读我们附赠的乳腺癌检查资料。

或者訪乳腺癌運動網站(英文)

http://www.breastcancercampaign.org/

以及国民保健服务(NHS)网站(英

文) <u>http://www.cancerscreening.nhs.uk/breastscreen/index.html</u>

关于視頻乳房 X 光檢查的视频录像, 可访问网

站 http://www.nhs.uk/Livewell/Screening/Pages/Breastscreening.aspx

我們將嚴格保護實驗參加者的個人隱私,在任何情況下都不會洩露實驗參加者的名字。此外, 我們也不允許用可以得知個人信息的方法發表研究數據。本实验纯粹是以改进乳腺癌在华人妇 女中的预防作为学术研究为目的而进行的。

如果您有關於參加此研究的疑問,請致電張穎 0121 204 4205 或發送電子郵件至 zhangy18@aston.ac.uk 。如果您在參加此次活動後,出現例如壓力等不適感,請聯繫您的醫 生諮詢。

阿斯顿大学心理系





Illustration removed for copyright restrictions




Informed consent form for younger participants (English)

School of Life and Health Sciences, Aston University

<u>Why do this study?</u> We are the investigators at Aston University, and interested in developing an intervention to promote the breast cancer prevention among Chinese women living in the UK. Therefore, we need to collect some data to understand the Chinese women's knowledge and beliefs about breast cancer, barriers and motivators to breast cancer preventive behaviours.

<u>What will participation involve?</u> – At first, you will be asked to complete a questionnaire regarding some demographic information, such as your age. After that, you will be encouraged to discuss your views and experiences about breast cancer prevention with other women in your group. This conversation will be audio recorded for the purpose of data analyses. All information will be completely confidential and anonymous. You will be requested to respect and preserve the confidentiality of other participants. The audio record will be destroyed as soon as the data transcription has finished. You have the right to withdraw at any stage without having to give an explanation and without loss of payment of your expenses. You are free to ask any questions at any time.

<u>Is there any risks or discomfort?</u> – Usually, you will have no risks or discomfort in participation in this study. In rare cases, for some of you the questions could be distressing. You will be give details of counselling services that are available to help you.

How long will participation take? – This conversation will last approximately one to one and half hours.

Researcher's Signature:_____ Date: _____

As an informed participant of this experiment, I understand that:

- 1. My participation is voluntary and I may cease to take part in this study at any time.
- 2. I am aware of what my participation involves.
- 3. All my questions about the study have been satisfactorily answered.
- 4. I should respect and preserve the confidentiality of other participants.

I have read and understood the above, and give consent to participate:

Participant's Signature:_____ Date: _____

Informed consent form for younger participants (Chinese) 同意書

阿斯頓大學生命健康學院

<u>為什麼做這個研究?</u>-我們是阿斯頓大學的科研人員,並有興趣在華人婦女中開展一項乳腺癌 的預防活動。現在,我們需要收集一些信息,以了解您在乳腺癌方面的知識和觀念,在預防中 遇見的困難,以及您認為哪些因素可以促進預防活動的開展。

實驗過程 - 您將參加一個我們的討論小組。首先,您需要填寫一份簡單的問卷,比如年齡之類 的一些問題。之後,您將和其他几位女士一起討論一下你在乳腺癌防治方面的看法和經歷。這 個討論將會被錄音,以作為我們資料分析所用。討論結束時,我們將給您一些乳腺癌防治方面 的資料,以及一些我們本次研究的資料。

<u>參加此活動可能出現的不適</u> - 通常,您不會有任何不適。在罕見的情況下,您或許會有輕微的 壓力感。如果您出現這種情況,我們將為您提供詳細的諮詢服務,以消除您的不適感。 所需時間 – 此小組討論大概需要您一至一個半小時的時間。

研究者的簽名:_____日期:____

作為一名參與者,我理解:

- 1 我的參與是自願的,並且可以在任何時候退出。
- 2 我已經了解參加此項活動的過程。
- 3 我所有的關於參加此活動的問題,已得到令人滿意的回答。
- 4 我將尊重其他參與者,並不洩漏他們的資料。

我已經閱讀並了解上述情況,並同意參加:

參與者的簽名:_____日期:_____

Demographic data questionnaire for younger participants (English)

To complete this questionnaire, please state your answer on line, or tick the appropriate answer(s). Your responses are completely anonymous and will be treated in the strictest confidence.

- 1. Your age _____
- 2. Place of birth
 - A. Mainland China
 - B. Hong Kong
 - C. Tai Wan
 - D. UK
 - E. Other _____ (Please specify your place of birth)
- 3. How many years have you been in UK?
 - A. 1-5 years
 - B. 6-10 years
 - C. 11-15 years
 - D. 15 years or more

4. Marital Status

- A. Married / other live-in relationship
- B. Divorced /separated
- C. Widowed
- D. Single
- 5. Do you know any relatives who have breast cancer?
 - A. No
 - B. Yes

6. Education Level

- A. Never attended school
- B. Left school without qualification
- C. Left school with qualification
- D. Attended further education / college / technical school after high school
- E. Attended university

7. Employment status (Tick one answer which most closely describes your employment status)

- A. Full-time work
- B. Part-time work
- C. Unemployed
- D. Housewife
- E. Student
- 8. Have you ever consulted the doctor because you worried about getting breast cancer?
 - A. Yes
 - B. No
- 9. What is your breast cancer screening experience? (Tick all that apply)

- A. Had a mammography in the past
- B. Had a recent mammography
- C. Had a clinical breast examination in the past
- D. Had a recent clinical breast examination
- E. Had no experience of breast cancer screening
- 10. How often do you perform breast self examination?
 - A. Never
 - B. 3 or 4 times a year
 - C. Every month
 - D. More often than frequently

Demographic data questionnaire for younger participants (Chinese)

人口數據調查问卷

请您将答案写在横线上,或者標出適合你自己的答案。您的回答是完全匿名的,將被絕對保

密。

- 1 年齡_____
- 2 您在英國生活了多少年?
- A 1-5 年
- B 6-10 年
- C 11-15 年
- D 約15年或以上
- 3 出生地點
- A 内地
- B 香港
- C 邰灣
- D 英國
- E 其他國家,請寫出國家名稱_____
- 4 婚姻狀況
- A 已婚/同居
- B 離婚/分居
- C 喪偶
- D 單身
- 5 您是否有親人患乳腺癌?
- A 沒有
- B 有,請寫出與您的具體關係_____
- 6 您的英語能力
- A 一點都不會
- B 不好
- C 一般

D 非常好

- 7 教育水平(選中一個框其中最密切的描述您的教育水平)
- A 從未上過學
- B 中學未畢業
- C 中學畢業
- D 中學畢業後,參加過一步教育,如技校等
- E 大學
- 8 就業狀況(選中一個框其中最密切的描述您的就業狀況)
- A 全職
- B 兼職
- C 没有工作
- D 家庭主婦
- E 學生
- 9 您的乳腺癌檢查情況 (勾選所有適用選項)
- A 在過去3年接受過乳房 x 線照相檢查
- B 在過去1年接受過乳房 X 光檢查
- C 在過去3年接受過臨床乳房檢查
- D 在過去1年接受過臨床乳房檢查
- E 沒有接受過乳房檢查
- 10 您大概多久做一次乳房的自我檢查
- A 從沒
- B 每年 3-4 次
- C 每月1次
- D 每月多次

Debrief for younger participants (English)

Thank you very much for taking part in the study. The aim of this study is to understand factors related to breast cancer prevention among Chinese women in order to design and implement effective services to improve the breast health among Chinese women.

In the UK, approximately 45,000 cases of breast cancer are diagnosed every year, usually in women who are over 50 years of age and who have reached menopause. Although Chinese women have lower breast cancer incidence and mortality than that white British population, breast cancer incidence among Chinese women significantly increases after they migrate to Western countries. For example, women who have been in United States for more than ten years have an 80% higher risk of developing breast cancer than those who newly arrived. In addition, breast cancer risk increase with successive generations. Therefore, more Chinese women are expected to be diagnosed with breast cancer in future years.

In this study, you will not be identified at any time in the write up. Information given by you will not be disclosed to any third parties. No records will be kept which could identify any individual as being linked to any information disclosed in this study. The information you have provided will be only used to design and implement effective services to improve the prevention of breast cancer among Chinese women. The results of this study will be available at Aston University or local Chinese Society after the study have had completely finished.

For more information about breast cancer and the prevention programme, please go to the websites of breast cancer campaign at <u>http://www.breastcancercampaign.org/</u>, and the NHS Breast Screening Programme at <u>http://www.cancerscreening.nhs.uk/breastscreen/index.html</u>. Further information on breast self examination is given below.

If you have any queries or concerns regarding the study please contact the researcher, Ying Zhang, at <u>zhangy18@aston.ac.uk</u> or 0121 204 4205. If you feel that you have experienced any feelings of distress as a result of this study and want to discuss these feelings please contact your GP for counselling.

Most cases of breast cancer are found by women noticing unusual changes, taking the initiative and visiting their doctor. The earlier breast cancer is found, the better the chance of beating it – so you can see how important it is to make regular checks. Being breast aware simply means knowing what your breasts look and feel like normally, being on the lookout for any unusual changes and getting them checked out by your doctor. Lumps are vital to look out for – but there can be other important signs too. And even if you do find a lump, in nine out of ten cases they turn out not to be cancerous. So stay calm – remain in control.

TOUCH your breasts. Can you feel anything unusual?

LOOK for changes. Is there any change in shape and texture? **CHECK** anything unusual with your doctor.

No one knows your body better than you and everyone will have their own way of touching and looking for changes – there's no special technique and you don't need any training. It's good to get into the habit of doing this regularly – maybe when you're in the bath or shower,

or while getting dressed in the morning. You might prefer to do it while standing up or lying down. Either way, the important thing is to be familiar with how your breasts look and feel normally, so you notice anything unusual – and remember to check the whole breast area, including your upper chest and armpits. Please visit your doctor right away if you feel anything unusual.

Debrief for younger participants (Chinese)

匯報

非常感謝您對參與研究的一部分。本研究的目的是了解有關設計和實施有效的服務,以提高中 國婦女的乳房健康之間為了中國婦女預防乳腺癌的因素。

在英國,大約45,000 例乳腺癌患者被確診,每年通常在誰是50 歲以上的人已達到更年期的婦 女。雖然中國婦女有較低的乳腺癌發病率和死亡率比說白了英國的人口,中國婦女乳腺癌之間 的顯著增加後,他們遷移到西方國家的癌症發病率。例如,在美國已經十餘年的婦女比那些新 來港發展乳腺癌的風險高出80%。此外,乳腺癌,連續幾代人的風險增加。因此,越來越多 的中國婦女,預計在未來幾年被診斷出患有乳腺癌。

在這項研究中,您將不能在任何時間在寫鑑定。你所提供的信息將不會被透露給任何第三方。 您所提供的信息將只用於設計和實施有效的服務,以提高中國婦女預防乳腺癌。這項研究的結 果將在阿斯頓大學或當地的中國社會的研究後,已完全結束。

如需更多關於乳腺癌的預防方案的詳細信息,請訪問乳腺癌運動網站 http://www.breastcancercampaign.org/ NHS 的乳腺癌普查計劃在 http://www.cancerscreening.nhs.uk/breastscreen/index.html 下面給出對乳房自我檢查的進一步信息。

如果您有任何疑問或關切的研究,請聯繫研究員,英張,在 zhangy18@aston.ac.uk 或 0121 204 4205。如果你覺得你經歷過任何感情的困擾,作為本研究的結果,並希望討論這些感受,請聯繫您的醫生諮詢。

注意到不尋常的變化,採取主動行動,並參觀他們的醫生的婦女乳腺癌的大多數情況下被發現。被發現的早期乳腺癌,更好地戰勝它的機會-所以你可以看到做定期檢查,是多麼的重要。乳腺癌意識到,僅僅意味著知道你的胸部看起來像一般的感覺,瞭望任何不尋常的變化,並讓醫生檢查。腫塊是至關重要的看出來-但可以有其他重要標誌。即使你做一筆,發現了 10例在九他們變成不發生癌變。因此,保持冷靜-留在控制。

觸摸你的乳房 - 你能感覺到有什麼異常嗎? 尋找變化 - 沒有任何形狀和質地的變化呢? 檢查 -如果你覺得有什麼異常,請馬上去看醫生。

沒有人知道你的身體比你更好,每個人都會有他們的接觸和改變自己的方式-有沒有特殊的技術,你不需要任何培訓。這是很好的習慣,這樣做定期進入-也許當你在洗澡或淋浴,或在早晨起床穿著。你可能更喜歡站著或躺著,而做到這一點。無論哪種方式,重要的是要熟悉你的乳房的外觀和感覺一般,所以你注意到有什麼異常-記得要檢查整個乳房區域,包括你的上胸部和腋下。如果你覺得有什麼異常,請馬上去看醫生。

The culturally and linguistically tailored breast screening leaflet (English)



















The cultrally and linguistically tailored breast screening leaflet (Chinese)























Participant information sheet for potential participants (English)

School of Life and Health Sciences, Aston University

Why do this study? - We are the researchers at Aston University, and interested in developing an intervention to promote the breast cancer prevention among Chinese women living in the UK. Therefore, we would like to get some comments or feedbacks on the educational materials that will be used in the intervention.

Procedure – You will be allocated into one of the focus groups according to the place that you are originally come from such as mainland China or Hong Kong. Each group will include around 6 Chinese women. At first, you will be asked to complete a questionnaire regarding some demographic information such as your age. After that, you will be given a breast screening leaflet in Chinese to read. You will then be invited to watch two Chinese videos regarding breast screening. Finally, you will be encouraged to discuss the advantages and limitations of the leaflet and videos, and also to put forward some suggestions for further improvement on these educational materials with the other group members. This conversation will be audio recorded for the purpose of data analyses. A debrief will be provided once the conversation has finished. In this, you will get detailed information about this study.

How long will participation take? – This conversation will last approximately one to one and half hours.

Risk or discomfort – Usually, you will have no risks or discomfort in participation in this study. In rare cases, for some of you the questions could be distressing. You will be give details of counselling services that are available to help you.

Benefits of this study – By taking part in this study, your comments or feedbacks regarding the breast screening-related educational materials will be very helpful and useful for us to design and implement effective services to improve breast health and breast screening among Chinese women. In addition, you will be provided some useful information about breast cancer and the NHS Breast Cancer Screening Programme.

Compensation – You will be awarded 20 pounds for participation in this study.

Confidentiality - All information will be completely confidential and anonymous. The audio record will be destroyed as soon as the data transcription have finished. In addition, all participants are requested to respect and preserve the confidentiality of others.

Voluntary participation and withdrawal - You have the right to withdraw at any stage without having to give an explanation and without loss of payment. You are free to ask any questions at any time.

Place – This study will be carried out at Birmingham Chinese Society, 11 Allcock Street, Digbeth, Birmingham, B9 4DY.

Questions - If you have any questions about this research project or concerns about your rights as a research participant in this study, please call Ying Zhang at 07500807227 or email at <u>zhangy18@aston.ac.uk</u>.

Participant information sheet for potentional participants (Chinese)

阿斯頓大學心理系

為什麼做這個研究? - 我們是阿斯頓大學的科研人員,準備在華人婦女中開展一項改善善乳腺癌檢查的活動,以促進乳腺癌的早期發現並改善華人婦女的乳房健康狀況。我們設計了一些關於腺癌檢查方面的宣傳材料,想邀請您對我們的宣傳材料提出一些您個人的看法及寶貴的修改意見。

活動過程 - 您將被邀請參加一個小組討論。每個小組大約有 6 名女士參加。首先,您需 要填寫一份簡單的問卷,比如年齡之類的問題。之後,我們將給您一份關於乳腺癌檢 查方面的宣傳手冊去閱讀。當您閱讀完成後,我們會詢問一下您對這份宣傳手冊的看 法,比如優點和需要改進的方面。最後,我們將會給您播放兩個關於乳腺癌檢查的錄 像,並諮詢一下您對這兩個錄像的看法以及需要改進的方面。這個小組討論將會被錄 音,以作為我們以後資料分析所用。討論結束時,我們將給您一些關於我們這項研究 的詳細料。

所需時間-此小組討論大概需要您 1.5-2 小時的時間。

這項研究的好處-通過參加這次小組討論,您可以幫助我們了解我們的宣傳資料中有 哪些需要改進的地方。因此,我們可以設計和實施更有效的服務,以改善華人婦女的 乳房健康狀況。此外,您將獲得一些關於乳腺癌的起因,乳腺癌檢查,以及治療方面 的有用信息。

参加此活動可能出現的不適·通常,您不會有任何不適感。在罕見情況下,您或許會 有輕微的壓力感。如果您出現此情況,我們將為您提供詳細的諮詢服務,以消除您的 不適感。

酬金-您將獲得現金 20 鎊,以作為參與此項研究的感謝。

保密性-您所提供的所有資料將完全保密。錄音記錄將在我們完成資料分析後被銷毀。 此外,所有參加討論的女士都要求尊重和保護其他人的信息。

自願性-你有權在任何時候退出此研究,並且不必作出解釋。我們將依舊付給您 20 鎊 以示感謝。另外,您可以在任何時候,自由地詢問任何問題。

活動地點- 伯明翰華人統籌協會,Birmingham Chinese Society, 11 Allcock Street, Digbeth, Birmingham, B9 4DY。電話: 0121 773 0099。

問題-如果您有關於參加此研究的任何疑問,請致電阿斯頓大學的張穎 07500807227 或發送電子郵件至 zhangy18@aston.ac.uk 。

Informed consent form for potential participants (English)

School of Life and Health Sciences, Aston University

<u>Why do this study?</u> - We are the researchers at Aston University, and interested in developing an intervention to promote the breast cancer prevention among Chinese women living in the UK. Therefore, we would like to get some comments or feedbacks on the educational materials that will be used in the intervention, and then help us to design and implement effective services to improve breast health and breast screening among Chinese women.

What will participation involve? – At first, you will be asked to complete a questionnaire regarding some demographic information such as your age. After that, you will be given a breast screening leaflet in Chinese to read. You will then be invited to watch two Chinese videos regarding breast screening. Finally, you will be encouraged to discuss the advantages and limitations of the leaflet and videos, and also to put forward some suggestions for further improvement on these educational materials. This conversation will be audio recorded for the purpose of data analyses. All information will be completely confidential and anonymous. The audio record will be destroyed as soon as the data transcription have finished. You have the right to withdraw at any stage without having to give an explanation and without loss of payment of your expenses. You are free to ask any questions at any time.

<u>Is there any risks or discomfort?</u> – Usually, you will have no risks or discomfort in participation in this study. In rare cases, for some of you the questions could be distressing. You will be give details of counselling services that are available to help you.

How long will participation take? – This conversation will last approximately one to one and half hours.

Researcher's Signature:_____ Date:_____

As an informed participant of this experiment, I understand that:

- 1. My participation is voluntary and I may cease to take part in this study at any time.
- 2. I am aware of what my participation involves.
- 3. All my questions about the study have been satisfactorily answered.
- 4. I should respect and preserve the confidentiality of other participants.

I have read and understood the above, and give consent to participate:

Participant's Signature:_____ Date:_____

同意書

阿斯頓大學生命健康學院

為什麼做這個研究? - 我們是阿斯頓大學的科研人員,準備在華人婦女中開展一項改善乳腺癌檢查的活動,以促進乳腺癌的早期發現並改善華人婦女的乳房健康狀況。我們設計了一些關於腺癌檢查方面的宣傳材料,想邀請您對我們的宣傳材料提出一些您個人的看法及寶貴的修改意見。

活動過程 - 您將被邀請參加一個小組討論。每個小組大約有 6 名女士參加。首先,您 需要填寫一份簡單的問卷,比如年齡之類的問題。之後,我們將給您一份關於乳腺癌 檢查方面的宣傳手冊去閱讀。當您閱讀完成後,我們會詢問一下您對這份宣傳手冊的 看法,比如優點和需要改進的方面。最後,我們將會給您播放兩個關於乳腺癌檢查的 錄像,並諮詢一下您對這兩個錄像的看法以及需要改進的方面。這個小組討論將會被 錄音,以作為我們以後資料分析所用。討論結束時,我們將給您一些關於我們這項研 究的詳細料。

所需時間-此小組討論大概需要您 1.5-2 小時的時間。

参加此活動可能出現的不適 · 通常,您不會有任何不適感。在罕見情況下,您或許會 有輕微的壓力感。如果您出現此情況,我們將為您提供詳細的諮詢服務,以消除您的 不適感。

研究者的簽名:_____ 日期:_____

作為一名參與者,我理解:

- 1 我的參與是自願的,並且可以在任何時候退出。
- 2 我已經了解參加此項活動的過程。
- 3 我所有的關於參加此活動的問題,已得到令人滿意的回答。
- 4 我將尊重其他參與者,並不洩漏他們的資料。

我已經閱讀並了解上述情況,並同意參加: 參與者的簽名: 日期:

Demographic questionnaire for potential participants (English)

To complete this questionnaire, please state your answer on line, or tick the appropriate box(es). Your responses are completely anonymous and will be treated in the strictest confidence.

- 1. Your age
- 2. How many years have you been in UK?
 - A.1-5 years B. 6-10 years C.11-15 years D.15 years or more
- 3. Place of birth
 - A. Mainland China
 - B. Hong Kong
 - C. Tai Wan
 - D. Other countries _____ (Please state your answer on line)
- 4. Marital Status
 - A. Married / other live-in relationship
 - B. Divorced /separated
 - C. Widowed
 - D. Single
- 5. Do you know any relatives who have breast cancer?
 - A. No
 - B. Yes
- 6. Are you able to speak English?
 - A. Not at all
 - B. Somewhat
 - C. Moderately
 - D. Very or extremely well
- 7. Education Level
 - A. Never attended school
 - B. Attended primary school
 - C. Attended middle school
 - D. Attended high school
 - E. Attended further education / college / technical school after high school
 - F. Attended university
- 8. Employment status
 - A. Employed outside the home/full time
 - B. Employed outside the home/part time
 - C. Homemaker
 - D. Employed at home
 - E. Retired
 - F. Not working

- 9. What is your breast cancer screening experience? (Tick all that apply)
 - A. Had a mammography in the past
 - B. Had a recent mammography
 - C. Had a clinical breast examination in the past
 - D. Had a recent clinical breast examination
 - E. Do breast self examination every month
- 10. Did you attend the previous workshop?
 - A. Yes
 - B. No

Demographic questionnaire for potential participants (Chinese)

人口數據調查问卷

请您将答案写在横线上,或者標出適合你自己的答案。您的回答是完全匿名的,將被絕對保 密。

- 1 年齡____
- 2 您在英國生活了多少年?
- A 1-5 年
- B 6-10 年
- C 11-15 年
- D 約15年或以上____(请写出具体年数)
- 3 出生地點
- A 内地
- B 香港
- C 邰灣
- D 其他國家,請寫出國家名稱____

4 婚姻狀況

- A 已婚/同居
- B 離婚/分居
- C 喪偶
- D 單身
- 5 您是否有親人患乳腺癌?
- A 沒有
- B 有,請寫出與您的具體關係____
- 6 您的英語能力
- A 不會講英語
- B 不好
- C 一般
- D 非常好
- 7 教育水平(選中一個框其中最密切的描述您的教育水平)
- A 從未上過學
- B 小學畢業
- C 初中畢業
- D 高中畢業
- E 高中畢業後,參加過一步教育,如技校等
- F 大學
- 8 就業狀況(選中一個框其中最密切的描述您的就業狀況)
- A 全職
- B 兼職
- C 家庭主婦
- D 在家工作
- E 退休
- F 没有工作
- 9 您的乳腺癌檢查情況 (勾選所有適用選項)
- A 在过去三年中接受過乳房 X 光检查
- B 在近一年中接受過乳房 X 光檢查
- C 在過去接受過臨床乳房檢查
- D 在近期接受過臨床乳房檢查
- E 每個月都做自我乳房檢查
- 10 您以前是否參加過我們關於乳腺癌預防活動的小組討論
- A 是
- B 否

Debrief for potential participants (English)

Thank you very much for taking part in the study. The aim of this study is to design and implement effective services to improve breast health and the breast screening rates among women in Chinese community who have been found to be less likely use mammography screening, which is routinely available to women over 50 through the NHS.

In this study, you will not be identified at any time in the write up. Information given by you will not be disclosed to any third parties. No records will be kept which could identify any individual as being linked to any information disclosed in this study. The information you have provided will be only used to design and implement effective services to improve the prevention of breast cancer among Chinese women.

For more information about breast cancer and the prevention programme, please read the leaflet 'breast screening programme' which was distributed during the focus group, or go to the websites which are mentioned in the leaflet as well. If you would like to get more support on breast screening, please refer to the last section of the 'breast screening programme' leaflet.

If you have any queries or concerns regarding the study please contact the researcher, Ying Zhang, at <u>zhangy18@aston.ac.uk</u> or 07500807227. If you feel that you have experienced any feelings of distress as a result of this study and want to discuss these feelings please contact your GP for counselling.

School of Life and Health Sciences Aston University

Debrief for potential participants (Chinese)

促進華人婦女乳腺癌檢查活動匯報

非常感謝您參加這次研究。乳腺癌是華人婦女中最常見的癌症。為了實現 乳腺癌的早期發現,週期性進行乳腺癌檢查是行之有效的方法。與英國白 人婦女相比,華人婦女在乳腺癌檢查方面的參加率比較低,儘管這項檢查 對於 50 歲以上婦女是免費的。此外,華人婦女與白人婦女相比,更容易 被確診為晚期乳腺癌,這跟不按時進行乳腺癌檢查有關。因此,華人婦女 有必要定期參加乳腺癌檢查,以便發現早期乳腺癌。我們設計了一些關於 乳腺癌檢查方面的宣傳材料,希望能夠促進乳腺癌的早期發現並改善華人 婦女的乳房健康情況。

我們將嚴格保護實驗參加者的個人隱私,在任何情況下都不會洩露實驗參 加者的名字。此外,我們也不允許用可以得知個人資訊的方法發表研究數 據。本實驗純粹是以改進華人婦女參加乳腺癌檢查為學術研究為目的而進 行的。

欲瞭解更多有關乳腺癌檢查方面的資訊,可閱讀我們在小組討論中提供的 乳腺癌檢查手冊。或者您可以流覽手冊中提到的網站。如果您想得到更多 的支援,可以參考乳腺癌檢查手冊的最後一部分:更多資料與支援。

如果您有關於參加此研究的疑問,請致電阿斯頓大學張穎 07500807227 或 發送電子郵件至 zhangy18@aston.ac.uk。如果您在參加此次活動後,出現 例如壓力等不適感,請聯繫您的醫生進行諮詢。

阿斯頓大學心理系

Cover letter for service providers

I am a PhD student at Aston University and have designed two culturally and logistically tailored interventions to promote the breast screening among Chinese women living in the UK. I am writing to you as I would like to ask you giving some comments on the design of these two interventions or suggestions for further improvement.

The first intervention is a Breast Screening Service setting based intervention that using trained receptionist to contact non-attenders by sending an invitation and a culturally and linguistically tailored breast screening leaflet. The second intervention is a trained Chinese lay worker-led video educational workshop among non-attenders. These two interventions are novel in the UK as it is the first time that culturally and linguistically tailored information and services on breast screening have been designed for Chinese women. It is anticipated that these two interventions would improve the breast health and breast screening adherence among Chinese non-attenders.

Please find attached an information sheet on how the interventions were developed and the educational leaflet to be used for both interventions. If you could you answer the questions below and/or provide any other comments on the two interventions that would be extremely helpful. I do appreciate your time and comments. If you need any further information about these two interventions, please email me at zhangy18@aston.ac.uk.

Yours sincerely

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Information sheet for service providers

Using culturally and linguistically tailored educational interventions to increase the uptake of mammography screening among Chinese women in the UK

Background

Since the establishment of the NHS Breast Screening Programme, there has been a significant improvement in breast cancer related mortality and morbidity (Cancer Research UK, 2009), which were partly attributed to the increased screening rates. However, not everyone benefits equally from this screening programme. Previous studies have shown that women from the Chinese community are less likely to get access to breast screening though it is the most prevalent cancer among this population (Breast Cancer Care, 2005; Hoare, 1996; Liao & McIlwaine, 1995). It highlights the necessity to promote the NHS Breast Cancer Screening Programme among Chinese-British women in order to increase the breast screening rates, and thus reduce the breast cancer-related mobility and mortality among them.

Two culturally and linguistically tailored interventions, a Breast Screening Service setting based intervention and a Chinese lay health worker-led intervention, were designed for the purpose of improving breast health and breast screening among Chinese-British women who are non-adherent to the NHS Breast Screening Programme. These two interventions were developed on the synthesis of three studies: 1) focus groups among older Chinese-British women in order to understand the psycho-social factors related with the uptake of mammography screening among this population, 2) a literature review on psycho-social factors related to mammography screening among Chinese women in Western countries, and 3) a systematic review of interventions aimed at increasing breast health and mammography screening among Chinese women in Western countries.

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Intervention 1 - Breast Screening Service setting based intervention

Design

This intervention used trained Chinese receptionist to contact non-attenders through sending invitation and the culturally and linguistically tailored breast screening leaflet. As was assessed in the systematic review, using trained receptionists to contact non-attenders significantly improved the uptake of breast screening. The procedure of this intervention is listed in Figure 1.

Programme material

By viewing the NHS existing educational leaflets about breast screening in Chinese, it was found that these leaflets are developed for the general population and did not take the Chinese cultural and language issues into consideration. Therefore, a culturally and linguistically tailored breast screening leaflet (Appendix 1) was developed on the basis of the NHS Breast Screening leaflet (2010). This leaflet was presented in Chinese and was pretested within two groups of Chinese women and gained very good feedback from both groups. Participants stated that they were interested in the content, understood the educational message, gained comprehensive information and felt being involved in the intervention.

Evaluation

- As the systematic review indicated that there is a shortage of RCTs used to evaluate the
 effectiveness of breast cancer-related interventions among Chinese women living in
 Western countries, the effectiveness of this intervention would be assessed through an
 RCT.
- The effect of this intervention would be measured by the actual utilization of mammography. This measure would be completed by viewing the breast screening record at the breast screening services.



Fig.1 – Flowchart of the Breast Screening Service setting based intervention



Intervention 2 - Chinese lay health worker-led intervention Design

This intervention used trained Chinese lay worker to carry out a video educational workshop among Chinese women who have failed to attend the mammography screening. The effectiveness of this kind of intervention on increasing breast health and the uptake of mammography was supported in the systematic review. In addition, older Chinese women in focus groups also suggested that more workshops should be held in the local Chinese society in order to improve their health-related information. Receiving educational information through DVDs was also mentioned as a favourite format of receiving information regarding breast health by them.

Programme materials

There are two existing DVDs regarding breast cancer prevention developed by NHS available in Chinese: Remdedica Breast Screening DVD and the video 'Breast screening: your health, your choice' (NHS Cancer Screening Programmes, 2006). The former one was just translated versions of the English ones, and the later one was specially developed for Chinese and South Asian. The 'Breast screening: your health, your choice' was chosen as the educational DVD in this intervention because Chinese participants stated that this DVD was more culturally tailored to them compared with the Remdedica Breast Screening DVD during the pre-test. In addition, the modified breast screening leaflet (Appendix 1) was also used in this intervention. The procedure of this intervention is listed in Figure 2.

Evaluation

This intervention would be measured by using questionnaires, which would be allocated to
participants before and after the workshop. The questionnaires would assess the outcome
variables including knowledge, cultural views towards to breast cancer, health beliefs, selfefficacy, perceived susceptibility, perceived benefits and barriers to mammography, and
intentions to go for mammography. Chinese women will be contacted through phone call
to ask whether they have been to mammography screening about 6 months after the
workshop.



Fig.2 - Flowchart of the Chinese lay health worker-led intervention

Conclusion

It was anticipated that these two interventions would significantly improve Chinese women's breast cancer-related knowledge, cultural views on breast cancer and screening behaviour, reduce the perceived barriers to mammography screening, increase their intention to screening, and finally increase adherence to the NHS Breast Screening Programme.

The culturally and linguistically breast screening programme leaflet for service providers































Questions for service providers

Intervention 1 - Breast Screening Service setting based intervention

- 1. What do you think about the participant recruitment method that using Chinese surname to identify potential participants?
- 2. What do you think about the training program for Chinese receptionists?
- 3. What do you think about the activities used in this intervention, such as sending an invitation letter and culturally and linguistically tailored leaflet, and phone calls from Chinese receptionists?
- 4. What do you think about the culturally and linguistically tailored breast screening leaflet?
- 5. Do you think this intervention would work in practice?
- 6. Could you please provide any further comments or suggestions on this intervention?

Intervention 2 - Chinese lay health worker-led intervention

- 1. What do you think about the participant recruitment method of recruiting participants through local Chinese Society?
- 2. What do you think about the activities used in this intervention, such as watching the breast screening DVD, the lay-worker led discussion, and culturally and linguistically tailored breast screening leaflet?

3. Do you think this intervention would be work in practice?

4. Could you please provide any further comments or suggestions on this intervention?