

**Factors associated with Taiwanese lesbians' breast healthcare  
behaviour and intentions**

A thesis submitted to the University of Manchester for the degree of  
Doctor of Philosophy  
In the Faculty of Medical and Human Sciences

**2015**

**Ya-Ching Wang**

**School of Nursing, Midwifery and Social Work**

# Contents

List of Contents	Page
List of Tables.....	6
List of Figures.....	7
List of Appendices.....	8
List of Abbreviations.....	9
Abstract.....	10
Declaration.....	11
Copyright Statement.....	11
Acknowledgement.....	12
The Author Bio.....	13
<b>Chapter 1 Introduction</b>	
1.1 Overview and background .....	14
1.2 Purpose of the study.....	16
1.3 Overview of the methodology .....	16
1.4 Thesis organization.....	16
<b>Chapter 2 Background and literature review</b>	
2.1 Introduction.....	18
2.2 Definitions of the key terms.....	18
2.3 The hidden population: Taiwanese lesbians.....	20
2.3.1 Formation of the Taiwanese lesbian community.....	20
2.3.2 Gender identity and gender role expression among Taiwanese lesbians.....	24
2.3.3 Taiwanese lesbians' views on medical services.....	28
2.4 Breast cancer risk and risk factors among lesbians.....	30
2.5 Breast cancer screenings.....	35
2.5.1 Definitions of breast cancer screening.....	35
2.5.2 Utilization rates of breast cancer screenings among lesbians	36
2.6 Literature review.....	38
2.6.1 Aim of the review.....	38
2.6.2 Search strategy.....	39
2.6.3 Inclusion and exclusion criteria.....	40
2.6.4 Studies identified and included.....	41
2.6.5 Study quality assessment tools.....	43
2.6.6 Findings.....	46
2.6.7 Critical appraisal of the evidence.....	52
2.6.8 Summary.....	56
<b>Chapter 3 Methodology and research framework</b>	
3.1 Introduction .....	58
3.2 Sequential exploratory mixed-methods research design.....	58
3.3 Application of sequential exploratory mixed-methods to the current study.....	61
3.3.1 Phase one: semi-structured face-to-face interviews.....	61
3.3.2 Phase two: cross-sectional online survey.....	63
3.4 Summary .....	65

<b>Chapter 4</b>	<b>Phase one-Methods</b>	
4.1	Introduction .....	66
4.2	Aim .....	66
4.3	Gaining access for fieldwork.....	66
4.4	Sampling and recruiting lesbians.....	68
4.4.1	Inclusion and exclusion criteria.....	68
4.4.2	Sampling strategies and recruitment .....	69
4.4.3	Sample size.....	71
4.5	Data collection .....	72
4.5.1	The structured questionnaire and the topic guide.....	72
4.5.2	The setting for the interviews: issues of interruptions and management.....	73
4.5.3	Conducting the interview.....	75
4.5.4	Influence of the interviewer.....	76
4.6	Data analysis.....	78
4.6.1	Constant comparative analysis.....	79
4.6.2	Computer-assisted qualitative data analysis software: NVivo audio-coding.....	79
4.6.3	Data analysis procedure.....	82
4.7	Ethical considerations and the researcher's safety issues...	87
4.8	Rigour in qualitative research.....	90
4.9	Summary .....	93
<b>Chapter 5</b>	<b>Phase one-Findings</b>	
5.1	Introduction.....	94
5.2	Demographics and breast healthcare behaviour.....	94
5.3	Gender identity.....	95
5.3.1	Self-identification as a T.....	96
5.3.2	Self-identification as a Po.....	100
5.3.3	Self-identification as a Bufen.....	102
5.3.4	Self-identification as a Bufen pian T.....	105
5.4	Gender role expression.....	107
5.4.1	Masculine appearance.....	108
5.4.1.1	Masculine-identity lesbians' views about their own breasts .....	108
5.4.1.2	Constructions of masculine appearance: breast-binding.....	112
5.4.1.3	Masculine appearance as a barrier to having breast cancer screenings.....	113
5.4.2	Feminine appearance.....	116
5.4.2.1	Feminine-identity lesbians' views about their own breasts.....	116
5.5	Partners' support.....	118
5.5.1	Relationship status: single or partnered.....	119
5.5.2	Support from a partner.....	120
5.5.3	The impact of breast cancer in relation to lesbian couple relationships.....	125
5.6	Patient-provider interaction.....	126
5.6.1	HCP's gender.....	126
5.6.2	HCP's knowledge about multiple gender diversity and lesbian healthcare needs.....	129
5.6.3	HCP's acceptance of lesbians.....	131
5.7	Summary.....	134

<b>Chapter 6</b>	<b>Phase one-Discussion</b>	
6.1	Introduction.....	137
6.2	Gender identity.....	137
6.2.1	Self-identification as a T.....	137
6.2.2	Self-identification as a Po.....	139
6.2.3	Self-identification as a Bufen.....	140
6.2.4	Self-identification as a Bufen pian T.....	141
6.3	Gender role expression.....	143
6.3.1	Masculine appearance.....	143
6.3.1.1	Masculine-identity lesbians' views about their own breasts.....	143
6.3.1.2	Constructions of masculine appearance: breast-binding.....	145
6.3.1.3	Masculine appearance as a barrier to having breast cancer screenings.....	146
6.3.2	Feminine appearance.....	148
6.3.2.1	Feminine-identity lesbians' views about their own breasts.....	148
6.3.2.2	Criticism regarding feminine appearance.....	149
6.4	Partners' support.....	150
6.4.1	Relationship status: Being partnered as a facilitating factor.....	151
6.4.2	Support from a partner .....	151
6.4.3	The seriousness of breast cancer in relation to lesbian couple relationships.....	152
6.5	Patient-provider interaction.....	153
6.5.1	HCPs' gender.....	153
6.5.1.1	Female HCPs.....	153
6.5.1.2	Male HCPs.....	154
6.5.1.3	Having no preference as to the HCP's gender.....	155
6.5.2	HCPs' knowledge about multiple gender diversity and lesbian healthcare needs.....	155
6.5.3	HCP's acceptance of lesbians.....	157
6.6	Summary and development of a conceptual framework.....	159
<b>Chapter 7</b>	<b>Instrument development and pilot studies</b>	
7.1	Introduction .....	161
7.2	Identify the purpose of the questionnaire.....	162
7.3	Develop a conceptual framework for the questionnaire's design..	162
7.3.1	The health belief model.....	163
7.3.2	The theory of reasoned action.....	164
7.3.3	Conceptual framework of the questionnaire.....	166
7.4	Developing the questionnaire.....	169
7.4.1	Selecting the questionnaire items.....	169
7.4.2	Choosing the format of the questionnaire items.....	180
7.5	Translating the questionnaire from English to Chinese.....	182
7.6	Pilot of the questionnaire and its modification using the comments provided by the participants.....	182
7.7	Posting the questionnaire on an online survey website and piloting its performance.....	184
7.8	Summary.....	185

<b>Chapter 8 Phase two-Online survey</b>		
8.1	Introduction .....	186
8.2	Purposes of the study.....	186
8.3	Methods.....	186
8.3.1	Sampling.....	186
8.3.1.1	Inclusion and exclusion criteria.....	186
8.3.1.2	Sampling and recruitment.....	187
8.3.1.3	Sample size.....	190
8.3.2	Data collection methods.....	190
8.3.2.1	Online survey.....	190
8.3.2.2	Challenges in recruiting older lesbians and amendments.....	191
8.3.3	Data management and analysis.....	193
8.3.3.1	Preparation of the data for statistical analysis.....	193
8.3.3.2	Data analysis.....	195
8.3.4	Ethical considerations.....	198
8.4	Results .....	200
8.4.1	Study participation.....	200
8.4.2	BSE.....	202
8.4.3	Mammograms.....	211
8.4.4	Associations between gender identity and the psychological health variables.....	220
8.5	Summary .....	223
<b>Chapter 9 Synthesis and conclusion</b>		
9.1	Introduction .....	228
9.2	Synthesizing the PhD findings.....	228
9.2.1	Gender identity and gender role expression.....	230
9.2.2	Patient-provider interaction .....	232
9.2.3	Subjective norms (partners' support)-the TRA.....	234
9.2.4	Attitudes and beliefs about breast cancer and breast cancer screenings, self-efficacy and cues to action-the HBM.....	235
9.2.5	Summary.....	240
9.3	Recommendations and implications.....	240
9.4	Strengths and limitations.....	247
9.5	Directions for future research.....	252
9.6	Conclusion .....	253
<b>References</b>	.....	254
<b>Appendices</b>	.....	281

**Word account: approximately 87,000 words**

## List of Tables

<b>Chapter 2</b>		
Table 2.1	Formation of the Taiwanese lesbian community-historical events and politics.....	24
Table 2.2	Studies of the breast cancer risk and risk factors among lesbians.	31
Table 2.3	Study quality assessment tools.....	45
<b>Chapter 4</b>		
Table 4.1	Access for the study's fieldwork.....	68
<b>Chapter 7</b>		
Table 7.1	Item generation matrix.....	172
Table 7.2	Modifications from the CHBMS.....	176
<b>Chapter 8</b>		
Table 8.1	A summary of the access points.....	188
Table 8.2	Demographic characteristics and BSE.....	206
Table 8.3	Breast cancer risk factors and BSE.....	207
Table 8.4	Partners' support and BSE.....	208
Table 8.5	Psychological health variables and BSE.....	209
Table 8.6	Demographics characteristics and mammograms.....	215
Table 8.7	Breast cancer risk factors and mammograms.....	216
Table 8.8	Partners' support and mammograms.....	217
Table 8.9	Psychological health variables and mammograms.....	218
Table 8.10	Psychological health variables and gender identity.....	221
Table 8.11	A summary of the significant factors associated with the participants' behaviour and intentions regarding BSE.....	226
Table 8.12	A summary of the significant factors associated with the participants' behaviour and intentions regarding mammograms...	227
<b>Chapter</b>		
Table 9.1	The main findings from the two studies.....	229

## List of Figures

<b>Chapter 1</b>		
Figure 1.1	Highest breast cancer incidence and mortality rates in East Asia.....	14
<b>Chapter 2</b>		
Figure 2.1	The process of identifying the relevant literature.....	42
<b>Chapter 3</b>		
Figure 3.1	The research framework.....	60
<b>Chapter 4</b>		
Figure 4.1	Open coding.....	86
<b>Chapter 6</b>		
Figure 6.1	Factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions .....	160
<b>Chapter 7</b>		
Figure 7.1	Process of developing, piloting and posting the online questionnaire.....	161
Figure 7.2	Conceptual framework of the online questionnaire.....	168
Figure 7.3	Stages of the PAPM.....	178
<b>Chapter 8</b>		
Figure 8.1	Recruitment of participants.....	201
Figure 8.2	PAPM stages and comparable group descriptions in this study (BSE).....	204
Figure 8.3	PAPM stages and comparable group descriptions in this study (Mammograms).....	212
<b>Chapter</b>		
Figure 9.1	Recommendations for Taiwanese lesbians' breast healthcare behaviour (based on the social-ecological model).....	241

## List of Appendices

<b>Appendix 1</b>	A protocol of Hawker et al's (2002) score system.....	281
<b>Appendix 2</b>	Summary of the Taiwanese studies .....	283
<b>Appendix 3</b>	Summary of US and UK studies conducted with heterosexual women.....	285
<b>Appendix 4</b>	Summary of US and UK studies conducted with lesbians.....	288
<b>Appendix 5</b>	Qualitative interviews: Poster .....	291
<b>Appendix 6</b>	Qualitative interviews: Participant information sheet .....	292
<b>Appendix 7</b>	Qualitative interviews: consent form .....	295
<b>Appendix 8</b>	Structured questionnaire .....	296
<b>Appendix 9</b>	Topic guide .....	297
<b>Appendix 10</b>	Field note format .....	298
<b>Appendix 11</b>	Ethical approval for the qualitative interviews .....	299
<b>Appendix 12</b>	Participants' characteristics and breast healthcare behaviour....	300
<b>Appendix 13</b>	Comment sheet for the instrument .....	301
<b>Appendix 14</b>	Questionnaire .....	303
<b>Appendix 15</b>	Comment sheet for the online questionnaire performance.....	311
<b>Appendix 16</b>	Online Survey: Invitation.....	313
<b>Appendix 17</b>	Online Survey: Participant information sheet .....	314
<b>Appendix 18</b>	Online Survey: Welcome page and consent .....	317
<b>Appendix 19</b>	Online survey: Business card with a QR code .....	318
<b>Appendix 20</b>	Missing data.....	319
<b>Appendix 21</b>	Ethical approval for the online survey.....	321
<b>Appendix 22</b>	Ethical approval for amendments of the online survey	322



## List of Abbreviations

<b>ATHQ</b>	Attitudes Towards Homosexuality Questionnaire
<b>BSE</b>	Breast Self-Examination
<b>CAQDAS</b>	Computer-Assisted Qualitative Data Analysis Software
<b>CBE</b>	Clinical Breast Examination
<b>CHBMS</b>	Champion's Health Belief Model Scale
<b>DVs</b>	Dependent Variables
<b>GLMA</b>	Gay and Lesbian Medical Association
<b>HBM</b>	Health Belief Model
<b>HCP</b>	Health Care Provider
<b>IARC</b>	International Agency for Research on Cancer
<b>IOM</b>	Institute of Medicine
<b>IVs</b>	Independent Variables
<b>LGBT</b>	Lesbian, Gay, Bisexual and Transgender
<b>NHSBSP</b>	NHS Breast Screening Programme
<b>PAPM</b>	Precaution Adoption Process Model
<b>Po</b>	Laopo (wife in English; Feminine lesbian)
<b>QR code</b>	Quick Response code
<b>ROC</b>	Republic of Chia
<b>T</b>	Tomboy (Masculine lesbian)
<b>TAPWR</b>	Taipei Association for the Promotion of Women's Rights
<b>TBCA</b>	Taiwan Breast Cancer Alliance
<b>TRA</b>	Theory of Reasoned Action
<b>USPSTF</b>	US Preventive Services Task Force
<b>WHO</b>	World Health Organization

**The University of Manchester  
Ya-Ching Wang  
Doctor of Philosophy**

**Factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions  
April 2015**

### **Abstract**

Taiwanese lesbians have been found to utilize screening tests for breast cancer at lower rates when compared to women in general in Taiwan. However, there is a lack of evidence regarding the factors which influence Taiwanese lesbians' breast healthcare behaviour and intentions.

A two-phase sequential exploratory mixed-methods study was employed to explore the factors influencing Taiwanese lesbians' breast healthcare behaviour and intentions, including semi-structured interviews and an online survey. Taiwanese women aged 20 years or above and who self-identified themselves as lesbians or as partnered with the same gender were targeted and recruited, using purposive and snowball sampling. Thirty-seven semi-structured interviews were conducted initially. According to the interview findings and two existing health psychology models (the health belief model and the theory of reasoned action), a questionnaire was developed and an online questionnaire survey was undertaken with a larger population. A total of 284 women completed the online survey.

The findings showed that the lesbians' breast healthcare behaviour and intentions were directly or indirectly affected by their gender identity, gender role expression, patient-provider interaction and partners' support. In addition, it was also found that the lesbians may share similar views about breast cancer and breast cancer screenings, self-efficacy and cues to action with women in general in Taiwan. Some of these factors had an important effect on the lesbians' breast healthcare behaviour and/or intentions, in particular the perceived barriers to performing and/or having breast cancer screenings, the perceived susceptibility to breast cancer, self-efficacy and cues to action.

Based on the PhD findings and social-ecological model, four levels of recommendations were proposed in order to encourage Taiwanese lesbians' utilization of breast cancer screenings and to promote their breast health.

## Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning

## Copyright Statement

**i.** The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the “Copyright”) and s/he has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.

**ii.** Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made **only** in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.

**iii.** The ownership of certain Copyright, patents, designs, trade marks and other intellectual property (the “Intellectual Property”) and any reproductions of copyright works in the thesis, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.

**iv.** Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see <http://www.campus.manchester.ac.uk/medialibrary/policies/intellectual-property.pdf>), in any relevant Thesis restriction declarations deposited in the University Library, The University Library’s regulations (see <http://www.manchester.ac.uk/library/aboutus/regulations>) and in The University’s policy on presentation of Theses.

## Acknowledgements

I would like to acknowledge Dr Jane Griffiths and Professor Gunn Grande, my supervisors, for their constant encouragement and guidance during these years. Without their consistent and illuminating instruction, this thesis would not have reached its present form.

Secondly, I would like to thank all of the participants who took part in the study and the staff in the LGBT organisations and communities who assisted in advertising the study. Without their support, this study could not have been completed.

Other thanks would go to my consultant group: C (小 C), Chun-Yi (春怡), Han-Yu, Lin (寒玉姊) and Will Liu. As an outsider in the circle (Taiwanese lesbian community), I was sometimes uncertain about what actions and languages were inappropriate or appropriate when interacting with the subgroup. With their suggestions and support, the process of data collection for both phases of the study went well and smoothly. In addition, I would also like to give a special thanks to my best friend, Chun-Yi (春怡), who dedicated her time to practise interviewing several times with me.

Lastly, my thanks go to my beloved parents, Wang Ming De and Wang Huang Shu, for their loving considerations and great confidence in me all through these years.

## **The Author's Bio**

Ya-Ching Wang is currently a full-time Nursing PhD student at the University of Manchester, UK. She completed her BS in Nursing at the National Taipei College of Nursing in Taiwan in 2004 and her MSc in Advanced Nursing Studies at the University of Manchester in 2008. She was an oncology nurse at the National Taiwan University Hospital from 2004 to 2006. After she completed her masters in 2008, she was a nurse lecturer at Tzu-Chi University for two years. In 2012, she was invited as a speaker for introducing lesbians' breast healthcare issues by the Taiwan Tongzhi (*LGBTQI people in Chinese*) Hotline Association. This thesis is her first study and the first study related to Taiwanese lesbians' breast health in Taiwan.

## Chapter 1: Introduction

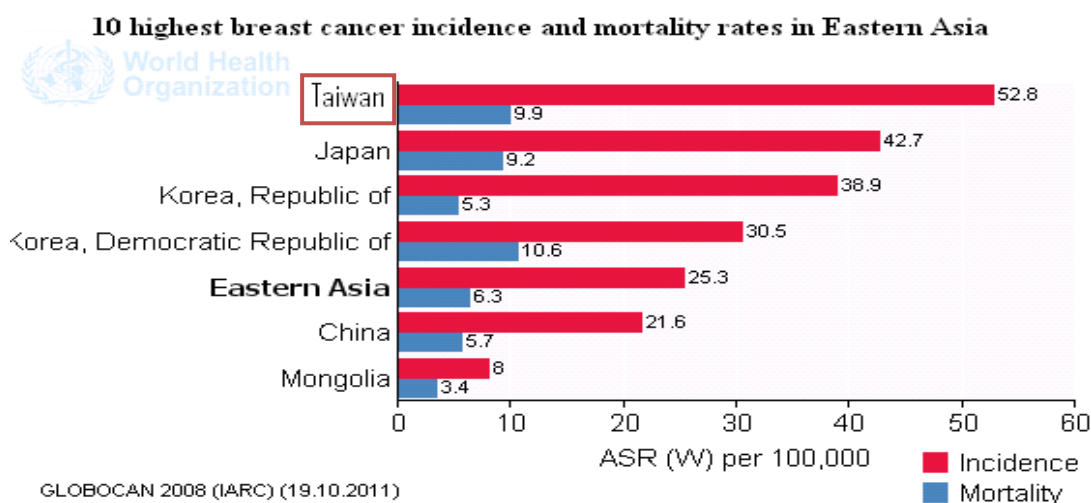
This chapter aims to give a brief background of the study, the purpose of the study, an overview of the methodology and the structure of this thesis.

### 1.1 Overview and background

Breast cancer is the most commonly diagnosed cancer and the leading cause of cancer death among women worldwide (World Health Organization, WHO, 2014). Europe had the highest incidence and mortality rates in 2012, at 96 and 16.2 per 100,000 women, respectively. America had the second highest incidence and mortality rates at 91.6 and 14.8 per 100,000 women, respectively. In terms of the rates in Asia, the incidence rate was 27 per 100,000 women and the mortality rate was 6.1 per 100,000 women in 2012 (Ferlay et al., 2013). Although the rates in Asia are much lower when compared to the rates in Europe and America, the incidence rates in Asia have been found to be increasing gradually in recent years and are expected to continue to rise over the next 10 years (Shin et al., 2010<sub>b</sub>).

While the incidence of breast cancer has been lower in Asian countries, Taiwan had the highest incidence rate and the second highest mortality rate in **2008**<sup>1</sup> when compared to the rates for Japan, the Republic of Korea, the Democratic Republic of Korea, China and Mongolia (see Figure 1.1; Ferlay et al., 2010).

**Figure 1.1: Highest breast cancer incidence and mortality rates in East Asia**



<sup>1</sup> Taiwan has been omitted from the GLOBOCAN 2012 database, hence, the comparison data presented in this thesis was from the GLOBALCAN 2008 database.

Over the last decade, breast cancer has replaced cervical cancer as the most diagnosed cancer site for Taiwanese women (Chen et al., 2002). Based on the latest Taiwanese cancer registry report, 10,056 women were diagnosed with breast cancer, and 1,852 died of this disease, in 2011 (Health Promotion Administration-Ministry of Health and Welfare, 2014). Despite the relatively lower incidence rate of 59 per 100,000, when compared to the rates in Europe and America, the number of newly diagnosed breast cancer cases has increased every year (Taiwan Cancer Registry, 2014). The mean age of breast cancer incidence is around 40 to 64 years in Taiwan, which is less than the mean age for the rest of the world (which is between 50 and 69 years). In addition, among Taiwanese women, breast cancer was the fourth leading cause of death from cancer in 2011 (Health Promotion Administration-Ministry of Health and Welfare, 2014). According to the statistics, breast cancer is not only the most commonly diagnosed cancer but also a life-threatening disease to Taiwanese women.

Numerous studies conducted in the US have increased concerns about the higher breast cancer risk among lesbians because of nulliparity (Case et al., 2004; Kavanaugh-Lynch et al., 2002) and behavioural risk factors (Roberts et al., 2004; Roberts & Sorensen, 1999; Roberts et al., 1998; Zaritsky & Dibble, 2010). Roberts et al. (2004) indicated that although lesbians in the US have increased their utilization of breast healthcare services recently (about 51-66% of lesbians aged over 40 years), their use of such services still lags behind women in general (approximately 67-70% of heterosexual women aged over 40 years). Barriers when accessing healthcare among homosexual people have been investigated during recent decades. The subgroup has been found to meet many inhibitors when attempting to access healthcare (Institution of Medicine, IOM, 2011), such as homophobia and heterosexism from healthcare providers and unfriendly medical environments. These barriers are recognized as causes of the low utilization of preventive health services (Clark et al., 2003; DeHart, 2008; Pennant et al., 2009).

In Taiwan, there is a lack of evidence regarding the breast cancer risk among Taiwanese lesbians. However, an unpublished online survey conducted by the Taipei Association for the Promotion of Women's Rights (TAPWR) in 2008 shows lower breast screening rates in this subgroup; only 4.5% of the lesbians (68 out of 1,523; age not specified) had had a screening previously when compared with Taiwanese heterosexual women (32.5% of women aged 45-69 years had had a screening within the past two years in 2012; Health Promotion

Administration, Ministry of Health and Welfare, 2013<sub>a</sub>). Only 2% (31 out of 1,523; age not specified) of lesbians have regular cancer screenings. Although low utilization rates of breast cancer screening were found, there is a lack of evidence to help understand the factors that affect breast healthcare behaviours among Taiwanese lesbians.

## **1.2 Purpose of the study**

The purpose of this PhD study is to explore the factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions.

## **1.3 Overview of the methodology**

In order to understand Taiwanese lesbians' breast healthcare behaviour and intentions and their influencing factors, a sequential exploratory mixed-methods study design was used which included qualitative interviews, instrument development and an online survey.

## **1.4 Thesis organization**

The overall structure of this thesis takes the form of nine chapters, including this introductory chapter.

Chapter 2 provides background information about Taiwanese lesbians, the breast cancer risk and the risk factors among lesbians, and the utilization rates of breast cancer screenings among the subgroup. The current evidence on the factors associated with women's breast healthcare behaviour is also reviewed in this chapter.

Chapter 3 gives the overall study design and the research framework.

Chapter 4 presents the methods used in the qualitative interviews.

Chapter 5 provides the interview findings, which are mainly focused on the factors associated with the participants' sexual orientation.

Chapter 6 discusses the interview findings with the existing evidence and describes various rationales for the influencing factors chosen for the questionnaire design.



Chapter 7 presents the process of the online questionnaire's development which was used in the online survey.

Chapter 8 provides the online survey methods and results.

Chapter 9 gives a synthesis of the main findings from the two studies as well as recommendations and implications. The strengths and limitations of the PhD study, the challenges met during the data collection periods and possible solutions are also discussed. Directions for future studies are suggested for researchers.

## Chapter 2: Background and literature review

### 2.1 Introduction

This chapter is divided into five sections. First, the definitions of the key terms are provided. Second, the hidden population of Taiwanese lesbians is introduced regarding their social construction in terms of history, politics and culture. Gender identity and gender expression are also discussed in this section to understand the formation of Taiwanese lesbians' body image, appearance, role and behaviour. This is followed by a look at the current evidence associated with lesbian's breast cancer risk and the risk factors and utilization rates of breast cancer screenings among the subgroup. Finally, the literature that is related to the study question is reviewed.

### 2.2 Definitions of the key terms

Before introducing the target population of Taiwanese lesbians, some key terms are provided in this section in order for the researcher and readers to have the same concepts when discussing the subgroup.

The term *sex* is a biological construct, referring to the genetic, hormonal, anatomical and physiological features that define a male or a female (IOM, 2011; WHO, 2013). *Gender* refers to the cultural meanings of the patterns of roles, behaviour, activities and personality that guide society to consider a person male or female (IOM, 2011; WHO, 2013).

*Sexual orientation* has been defined as “*an enduring pattern of or disposition to experience sexual or romantic desires for, and relationships with, people of one's same sex, the other sex, or both sexes*” (IOM, 2011, p. 27). In this thesis, sexual orientation within the target population refers to a woman's sexual or romantic desire for and relationship with a person of the same biological sex.

The term *lesbian* is originally from the name of the Greek island of Lesbos. The prominent Greek poetess Sappho lived there and expressed affection for women in her poetry in the seventh century BC (Stonewall, 2013; Oxford Dictionaries, 2013). Since the nineteenth century, lesbian has been used to refer to a woman who is sexually attracted to other women (Oxford Dictionaries, 2013). A Taiwanese lesbian, in this thesis, indicates a Taiwanese woman who is sexually or romantically attracted to other women.

In terms of the definitions of *gender identity* and *gender expression*, according to IOM (2011, p. 26), “*gender identity refers to a person’s basic sense of being a man or boy, a woman or girl, or another gender (for example, transgender, bisexual or gender queer – a rejection of the traditional binary classification of gender). Gender identity can be congruent or incongruent with one’s sex assigned at birth based on appearance of the external genitalia. Gender expression denotes the manifestation of characteristics in one’s personality, appearance and behaviour that are culturally defined as masculine or feminine.*” In this thesis, gender identity refers to a woman who self-identifies according to one of the following terms commonly used in Taiwan: T (masculine lesbian), Po (feminine lesbian), Bufen (undifferentiated lesbian), Bufen pain T (a slightly T-tinged Bufen) and Bufen pian Po (a slightly Po-tinged Bufen). Gender expression denotes the attributes in a woman’s appearance, behaviour and erotic role and responsibility which are associated with her gender identity.

T and Po identities are widely used among Taiwanese lesbians. *T* originally derived from the English word ‘tomboy’. Abate (2011, p. 407) defined the term ‘tomboyism’ as: “*a girl who prefers the activities, toys, and usually attire of a boy, few are aware of its long, complex, and largely overlooked history. Over the centuries, this code of female conduct has assumed both masculine and feminine forms, been found in both urban and rural locales, been associated with both heterosexual and homosexual sexualities, been attributed to both dispositional and circumstantial origins, been viewed as a temporary development phase as well as a lifelong identity, and been present in both Western and non-Western cultures.*” In Taiwan, T only refers to a masculine lesbian due to the T-bar culture and significant media influence (Chao, 2001). The formation of the T-bar culture and related historical events are introduced in the following sections. The counterpart to T is Po. The term *Po* in Mandarin Chinese serves as a suffix in communication. *Laopo* in Chinese means wife, and in this case means the T’s ‘wife’ (a feminine lesbian) (Chao, 2000; 2002). The sharing of roles and responsibility between a T/Po couple is considered similar to traditional dichotomous heterosexual roles (man and woman) (Cheng, 1997; Zhang, 2011), although same-sex marriage is currently still not legal in Taiwan.

The term *Bufen* became popular in the 1990s in Taiwan, when its use was encouraged among Taiwanese lesbians by academic feminists (Chao, 2000). Bufen refers to an undifferentiated lesbian, meaning a lesbian who does not play either masculine or feminine gender roles

(Kuang et al., 2004). Unlike the strict differentiations of role and responsibility between T and Po, *Bufen* couples share equal roles and responsibility generally (Cheng, 1997). The terms *Bufen pain T* and *Bufen pain Po* emerged in recent years (Chiang & You, 2011). The term *Bufen pain T* refers to a lesbian who identifies herself as lying between T and *Bufen*. On the other hand, the term *Bufen pain Po* refers to a lesbian who identifies herself as lying between *Bufen* and Po.

### **2.3 The hidden population: Taiwanese lesbians**

In this section, the social construction of Taiwanese lesbians is introduced in the context of history, politics and culture. The association between gender identity, body image, gender expression and erotic role and responsibility are discussed in order to understand women's behaviour and their way of thinking and decision-making in relation to breast healthcare. The final part reviews the current literature which explores Taiwanese lesbians' views on medical services in Taiwan and their medical experiences.

#### **2.3.1 Formation of the Taiwanese lesbian community**

Fishel (1994) suggests that the confusing complexity of Taiwanese history, culture and global trends should be considered carefully when studying local homosexuality because these may have shaped the changing constructs of sexuality.

Taiwan became a Chinese colony during the seventeenth century. In 1895, Taiwan was ceded to Japan until 1945 (The archives of the Institute of Taiwan History, Academia Sinica, 2010). The Republic of China (ROC, today's *Taiwan*) was formed in China in 1912. At the end of World War II, in 1945, Japan surrendered Taiwan to ROC military forces. Following the Chinese Civil War (1946-1949), the Communist Party of China took control of mainland China and established the People's Republic of China (PRC) in 1949. As a result, the ROC relocated its government to Taiwan. Towards the end of the Chinese Civil War, many single or widowed army men emigrated from China to Taiwan to set up the ROC government. Chao (2000) suggests that those army members probably helped to form the first gay community in Taiwan.

In Taiwan, the *White Terror* took place between 1949 and 1987, which resulted in approximately 140,000 Taiwanese people being imprisoned, of which about 3,000 to 4,000 were executed for their real or perceived opposition to the ROC government. This was a time

witnessing the suppression of political dissidents during a period of martial law (Chen, 2008; Hou, 2007). Most of those prosecuted were labelled as communist spies in the 1950s. Cross-dressing and transgender people, during this time, were suspected of spying and were either imprisoned or killed (Chao, 2000). Although the concept of T/Po-identity was not popular in the 1950s, lesbians who self-identified as masculine and dressed in masculine clothes were much more oppressed than feminine lesbians. This event is considered to be one of the factors resulting in the majority power and rights among Taiwanese lesbians being controlled by Ts after the T/Po community was formed, and Pos – even today – are viewed as outsiders by some traditional Ts.

The White Terror was supported by the government of the United States both militarily and financially for 20 years following the onset of the Korean War. Taiwan was incorporated into the Cold War structure as a US military base in the Asia-Pacific. American culture began to spread in Taiwan, together with American military men who used the country as a base during the Vietnam War. Gay bars, during that period, were formed under the safeguard of American GI culture in Taipei, Taichung and Kaohsiung (in North, Middle and South Taiwan, respectively). Upper-class lesbians, who were born into wealthy families and who had an American educational background, would hang out with American GIs in gay bars (Chao, 2000).

In the 1960s, the first waves of modernization and industrialization were initiated by the governments of the US and Japan through financial investment. The traditional economy and lifestyle collapsed, resulting in large-scale rural migration to urban and industrial areas. These changes were also reflected in the historical transformation of gender roles. Previously, Taiwanese women had to stay at home, confined to a household. Urbanization and industrialization in Taiwan changed women's lifestyles and ways of working. Many young women came to the big cities to work in clubs or factories (Chao, 2000). A well-known red-light district emerged towards the end of the Japanese colonial period and developed further during the early 1960s under American GI culture. Lesbian sex workers usually gathered together at bars to socialize and to pick up sex partners. A lesbian community began to form with the gender identities of T and Po (Chao, 2000; 2001).

Although the identity T/Po was created in the 1960s, it did not emerge widely until the first T-bar (Tomboy bar) opened. In 1985, Wang You Gu ("Forget-Sadness Valley" in English),

the first T-bar, was opened by a T/Po couple in a red-light district of Taipei (Chao, 2000). Low-class T and Po sex workers in the same neighbourhood gathered together in the T-bar. The T-bar culture strengthened the lesbian community and the gender identities T and Po became the norm (Chao, 2000). After the first T-bar, more T-bars were opened in the three newest and most Westernized cities, Taipei, Taichung and Kaohsiung. In the T-bars, lesbians usually introduced themselves with an invented name instead of a real name (Chao, 2000; 2001). During this period, use of an invented name was a way to protect their identity during the White Terror. However, the new generation of Taiwanese lesbians continue to use a fake name.

After 1987, the ROC Government gradually replaced the name *The Republic of China* with *Taiwan* in both the domestic and the diplomatic arena. Increasing emphasis was also placed on Taiwan's cultural specificity as being distinct from that of the People's Republic of China. During this period, the Taiwanese government still relied on the US military to defend the country from China. Martial law and the consequent democratization of Taiwan's political structure resulted in the propagation of liberal ideas. Gay rights were some of the ideas raised during this time (Chao, 2000; 2001).

In February 1990, the first lesbian organization 'Between Us' (我們之間) was formed in Taiwan and the members made efforts to develop international contacts and sent a delegation to the Asian lesbian conference held in Bangkok in the same year (Fishel, 1994). Initially, the members of the organization included both college students oriented towards feminist study groups and Ts/Po from the communities. However, conflicts arose between the young (feminists) and the old cohort (traditional T/Po-identity) lesbians in the organization. In the first year, many of the Ts and Pos involved during the initial months withdrew their participation because of tensions in the meetings, different opinions regarding role-identification and priority, and frustration over the meetings being inefficient and disorganized. The original feminist members aimed to alleviate the isolation of many Ts and Pos and create an alternative space for socializing outside of bars and away from alcohol. They were not willing to politicize these efforts or have the roles T and Po called into question. Due to these conflicts, the organization changed the initial membership recruitment methods; in addition to older and younger generation lesbians, young cohort lesbians (who were mainly feminists) were invited and recruited into the organization (Chao, 2000; 2001).

The concept Bufen (undifferentiated lesbian) emerged in the 1990s with the rise of feminism. Cheng (1997), a contemporary feminist, indicates that the role played by T/Po and the behaviour norms practiced in the circle differ greatly from those in wider society. During this period, the lesbian identity was not the only dichotomous option in Taiwan. Although T and Po identities were still used as gender-role labels, other categories were proposed to be used by the subgroup, including Bufen (Cheng, 1997), Bufen pian T and Bufen pian Po (Chiang & You, 2011).

Recently, a number of lesbian, gay, bisexual and transgender (LGBT) supportive organizations and communities have been formed in Taiwan. The Gender Equity Education Act and the Act of Gender Equality in Employment were passed and announced in Taiwan in 2003 and 2007, respectively (Laws & Regulations Database of the Republic of China, 2013). In addition, issues of equal rights regarding marriage and having children have also been raised within LGBT people since 2003. The executive branch in the Taiwanese government proposed the legalization of same-sex marriage in 2003, although the bill met with opposition and was not voted on. However, the same-sex marriage bill was re-sent to the executive branch in 2013 and the first reading was passed in the same year (Taiwan Alliance to Promote Civil Partnership Rights, 2013). Today, LGBT members in Taiwan still fight for equality in terms of same-sex marriage and having/adopting children. A summary of the historical events in Taiwan and the formation of the lesbian community can be seen in Table 2.1.

**Table 2.1: Formation of the Taiwanese lesbian community – historical events and politics**

Years	Historical events and politics	Formation of the Taiwanese lesbian community and important LGBT events
Seventeenth century	Taiwan became a Chinese colony.	
1895-1945	Japanese colonization.	
1946-1949	The ROC relocated its government to Taiwan.	Formation of the first gay community in Taiwan by single and widowed army men.
1949-1987	The White Terror.	Lesbians who dressed like men were seen as spies and either imprisoned or executed.
1960s	The first waves of modernization and industrialization initiated by the governments of the US and Japan with financial investment.	Gender-role transformation.
1960s-1980s	A US military base in the Asia-Pacific.	1) Gay bars were formed under the safeguard of American GI culture in Taipei, Taichung and Kaohsiung. 2) Lesbians frequented gay bars. 3) Formation of the T/Po-identity and T/Po community.
1980s-1989	The ROC government emphasized Taiwanese culture as being distinct from that of the People’s Republic of China.	1) The first T-bar is opened. 2) T/Po-identity became a norm. 3) Rising visibility of gay rights.
1990	Beginnings of feminism.	1) The first lesbian organization is formed. 2) International contact development. 3) The new Bufen-identity is proposed.
2003	1) For the first time, legalization for same-sex marriage is proposed, it but fails. 2) Gender Equity Education Act passed.	Taiwan LGBT Pride, the annual LGBT pride parade, was first held in Taipei in 2003.
2007	Act of Gender Equality in Employment passed.	
2013	The first reading of the legalization for same-sex marriage is passed.	

### 2.3.2 Gender identity and gender role expression among Taiwanese lesbians

This section focuses on the association between gender identity and gender role expression as well as the relationship between gender identity and Taiwanese lesbians’ views of their own female characteristics – their breasts – and erotic roles. In addition, the new identities of Bufen, Bufen pain T and Bufen pian Po are discussed in order to understand the differences between the traditional T/Po labels and the newly emerged labels.



The identity of T/Po is mainly employed among Taiwanese lesbians and it helps the women to structure expectations regarding personal identity, social interactions and romantic exchange within lesbian culture (Halberstam, 1998; Levitt et al., 2003; Levitt & Hiestand, 2004). The construction of T and Po identities requires a process of body transformation. Transforming a T's body involves a whole series of *de-feminizations* (Chao, 2000). Ts usually wear trousers and breast bindings, and have short hair to form a masculine appearance. Non-feminine acts are also important to present the women's identity, for example, smoking, drinking, gesturing and speaking in a mannish manner in both public and private spaces (Chao, 2000; 2001).

Wearing breast bindings is a significant act in de-feminizing a T's body by making socially defined feminine sexual characteristics – the breasts – invisible. In Kuang et al.'s (2004) online survey, over 70% of the 38 self-identified Ts had tried to hide their breasts. Ethnographic fieldwork by Chao (1997; 2000; 2001; 2002) was conducted between 1993 and 1994 involving 76 lesbians in bars in Taipei and Taichung and 30 feminists who were members of Taiwan's Queer Rights Movement. The researcher found that, in being a T, the woman's breasts cannot be seen because they are strongly related to provoking men's amorous desire and attention and presenting sexual availability, as associated with heterosexual women. Moreover, the breasts are not only bound to distance Ts from the heterosexual role – they are also important and visible signals to distinguish between Ts and Pos. Binding breasts is an important act to present a T's identity (Chao, 1997). Chao (1997) indicates that the division T/Po in Taiwan is significantly based on Ts' breasts, which are seen as non-corporeal and non-existent by both Ts and Pos. Due to the body boundaries between Taiwanese Ts and Pos, Ts' breasts cannot be seen or touched by Pos and the Po is asked not to bind her breasts.

Similar findings can also be seen in more recent studies. Hong (2013) interviewed seven lesbians who had experience of wearing breast bindings in 2010. She found four reasons why the women wore breast bindings: 1) to identify their sexual orientation; 2) to avoid a crisis of self-identification induced by an incorrect choice of erotic partner; 3) to strengthen their gender identity, and 4) to promote the identification of sexual orientation and sexual attraction. Hong indicates that the lesbians' use of breast bindings is strongly associated with mainstream lesbian culture, traditional heterosexual identification and social expectations. In addition, Su (2005) believes that wearing breast bindings is an action to control one's own

body and to develop self-identification. However, Cheng (1997), a contemporary feminist, argues that the action strongly relates to heterosexual identification and also to mimicking men.

In the last decade, Ts' views on their own bodies and women's use of breast bindings have been found to be fluid and influenced by their social surroundings (Chan, 2000; Peng, 2008). Peng (2008) points out that Ts' breasts are initially seen as troublesome matters, which make it difficult to coincide a masculine identity with a female body. No matter how hard Ts dressed themselves to look like a man, their breasts revealed their true sex, resulting in a physical and psychological imbalance. Ts' partners' and friends' attitudes towards breasts, and the Ts' own body experiences and self-identification were found to change their views on breasts and to assist them in living with their female bodies in peace. The researcher indicates that Ts' views on their own breasts are transferable. Their gender identity, gender expression and body image interact with the social environment. Similar findings can also be seen in Chan's (2000) study. Chan interviewed two Ts and five BuFens whose ages ranged from 21 to 33 years. The lesbians' gender identity and gender expression were found to be influenced by social interaction, mainly their friends.

Body construction among Taiwanese lesbians should be considered with not only the women's gender identity and social surroundings but also historical events (political environment). For lesbians who self-identified before the 1990s (before the start of the feminist movement), strict regulation of body expression is pursued by conventional Ts within the T/Po community. These women bind their breasts so that they are as flat as possible; their aim is to create a male-like appearance and to attempt to transform their body from a woman into a man. Those who belong to the new cohort Ts (mainly born after the 1990s) tend to show their masculine identity to Pos in social contexts by binding their breasts in order to increase their chances of finding the right sexual/romantic partner. These women's views about their own female characteristics are much more flexible than older Ts.

In terms of erotic roles and responsibilities among T/Po-identity lesbians, the relationships between Taiwanese lesbian couples have been studied in the last decade. Taiwanese lesbian gender role presentation was indicated to reflect the rigid gender differences in mainstream Taiwanese society (Kuang et al., 2004). Although some researchers have argued that there was no difference between the responsibilities and decision-making rights according to the

gender role division in a lesbian relationship (Tsai, 2006; Tseng et al., 2008), homosexual love was indicated as being as attractive and romantic as “heterosexual love” and both types of relationships shared rather similar features (Chiang, 2008; Shieh, 2010). Traditionally, when a heterosexual couple has a family, the masculine partner is usually expected to be the breadwinner and protector, and the feminine partner is the homemaker and mother figure (Li & Zhong, 1996).

Zhang (2011) proposes different roles and responsibilities between T/Po lesbians. The researcher indicates that the traditional T-bar culture affects T/Po-identity enormously because the T-bar is the original place where the T/Po community began. Among the T/Po community, strict codes are followed by Ts and Pos. To be a T, a woman has to play a masculine role, take care of her partner, pay the bills and be altruistic. Traditional Ts (who are older) are more likely to follow these codes. In addition, Zhang (2011) also found that there are more Ts than Pos in Taiwan. A T would try to maintain a relationship by devoting as much time as she could to satisfy her partner (Po). Chiang and You (2011) interviewed three Ts, two Pos and one Bufen to explore Taiwanese lesbians’ gender role identifications and relationships with their partners. The researchers found that the Ts usually partnered with women who were heterosexual, at least initially. Therefore, the Ts tried hard to present themselves as gentlemen in order to fit in with their partners’ (i.e., Pos’) imagination of a heterosexual couple’s interaction. Similar findings can also be seen in Su’s (2005) article. She argues that gender identity is strongly associated with lesbians’ erotic roles and responsibilities. For instance, Ts try to take care of Pos in their daily life in order to present a masculine character.

Since the start of the feminist movement in Taiwan in the 1990s, different opinions of gender identity and gender expression among Taiwanese lesbians have been discussed. Feminists argue that Taiwanese lesbians should develop new forms of identification outside the traditional T/Po-identity (Cheng, 1997). Cheng indicates that traditional T/Po identities followed heterosexual identification, which should be abandoned because the dichotomous identity can only be known by lesbians who usually hang out in T-bars or clubs, and because it is not suitable for the larger lesbian population. In particular, for those who have never been to a T-bar, the T/Po-identity is unknown. As contemporary lesbians, the women have to break the stereotype of the traditional heterosexual identity. The new identity, Bufen (undifferentiated lesbian), was therefore proposed. The erotic roles and responsibilities within

the relationship were also suggested to be equal among Bufens (Cheng, 1997). Cheng, however, notes that lesbian gender expression is seen as an important factor in increasing identification as an insider and looking for a partner.

Recently, Chiang and You (2011) found that the new identities of ‘Bufen pian T’ and ‘Bufen pian Po’ were also employed among Taiwanese lesbians. ‘Bufen pian T’, for example, refers to lesbians who identify themselves as lying between T and Bufen. In other words, the individuals identified themselves as Bufen, but they shared some T-like characteristics, such as, a masculine appearance (making their own breasts invisible/wearing breast bindings). ‘Bufen pian Po’, on the other hand, refers to women who identify themselves as lying between Po and Bufen. They usually have a feminine appearance, such as wearing a bra and makeup and having long hair.

The T/Po identities have been widely used among Taiwanese lesbians since the 1980s, with strict body codes for being a T or a Po. Although the new identities of Bufen, Bufen pian T and Bufen pian Po have been proposed in recent decades, the T/Po identities are still used among the majority of Taiwanese lesbians. In addition, masculine and feminine role expressions are acknowledged to be useful in identifying a ‘right’ partner and recognizing insiders in the circle by both new and old generations of Taiwanese lesbians and feminists.

### **2.3.3 Taiwanese lesbians’ views on medical services**

Before 2007, there were no studies on lesbians’ views on medical services in Taiwan. The Taipei Association for the Promotion of Women’s Rights (TAPWR, 2007) organized a lesbian study group to discuss the research associated with lesbian health in Western countries, mainly the US. The content of the discussion was published as a handbook in 2007. Physicians’ homophobia and their lack of knowledge about multiple gender diversity issues and inappropriate medical forms are proposed by the members as major barriers to lesbians using medical services and even seeing them delaying going to a clinic. TAPWR indicates that the lack of research exploring Taiwanese lesbians’ medical needs is strongly related to the current barriers in physicians’ training. Physicians do not know how to care for lesbians or how to provide appropriate care and treatment.

In 2008, TAPWR conducted a survey to explore lesbians’ medical experiences, sexual behaviour, willingness to give birth, social support and retirement planning (TAPWR, 2008).

A total of 1,523 Taiwanese lesbians participated in the survey: 24.1% were satisfied with their experience of having cervical or breast cancer screenings; 13.9% found it difficult to talk with or to see a physician because of their gender role expression; 23.3% of the Ts indicated difficulty in using medical services due to their gender expression; and 40-55% of the 1,523 participants answered the questions in the medical experience section with 'no idea (neither agree nor disagree)'. The survey was the first lesbian health study conducted in Taiwan. The information provides a general idea about Taiwanese lesbians' views on medical services and their experiences of having cancer screenings. However, it was not published and only announced on the TAPWR website. The demographics of the participants and the methods of the study are unknown.

In 2013, Wang explored the medical experiences of 14 Taiwanese lesbians, five lesbians who were also healthcare providers, and four heterosexual healthcare providers (including both males and females). The participants' ages ranged from 20 to 40 years, and only one lesbian was over 50 years old. Semi-structured interviews and one focus group were used as methods to collect data. The participants were recruited using snowball sampling (from the researcher's friends) and purposive sampling (from one lesbian chart board and bulletin board system, which is a terminal-based bulletin board system based in Taiwan). Wang (2013) found that the negative medical experiences of the lesbians was strongly associated with the unfriendly medical environment (non-private space, open space), physicians' negative attitudes (heterosexual assumptions, heterosexism or homophobia) and the women's gender expression (body image and being judged by other patients). In order to adopt in the current heterosexual medical environment, several strategies were proposed by the participants in Wang's study: 1) keep silent and accept the heterosexual assumptions of the healthcare provider; 2) avoid, refuse or delay seeing a doctor if there are symptoms; 3) choose a female physician; 4) choose a physician based on her/his reputation; and 5) try to find a lesbian physician. In addition to the barriers, the lesbians' partners were found to have an important role acting between the physician and the patient, especially when the issues are related to psychology or gynaecology.

It could therefore be that the medical experiences of Taiwanese lesbians are associated with the women's gender identity, gender role expression, medical environment and the physician's attitude towards and knowledge of multiple gender diversity. However, the methods used to conduct the research in Taiwan should be considered. Details of the methods

of the lesbian health survey conducted by TAPWR in 2008 were not provided. The rigour of the methodology cannot be assessed, although the study had a large sample size, with 1,523 lesbians. In Wang's (2013) study, the participants were mainly recruited from the researcher's friends, and the information provided was limited to the local lesbian population which shared similar characteristics. Hence, the findings in Wang's study might not be generalizable to lesbians outside the circle. In addition, Wang only explored lesbians' views about medical services in Taiwan and the women's medical experiences. The association between the Taiwanese lesbians' gender identity, gender role expression and their views on medical services or medical experience, and how and why these issues relate to each other, were not discussed, although the researchers indicated their importance. A further study is needed to understand whether lesbians' gender identity and gender role expression are associated with the women's views on medical services and their medical experiences and how these issues relate to each other.

The previous evidence offers some ideas of how Taiwanese lesbians might view medical services and their experiences of using them. Although the evidence is not directly related to the subgroup's breast healthcare services in Taiwan and it is considered to have certain limitations, it provides ideas of how Taiwanese lesbians might think about breast healthcare services and what issues might influence their utilization of those services.

#### **2.4 Breast cancer risk and risk factors among lesbians**

Although there was no evidence to explore Taiwanese lesbians' breast cancer risk or the risk factors, current international evidence suggests that lesbians might have a higher risk of getting breast cancer than heterosexual women. Table 2.2 provides details of 11 studies that investigated the breast cancer risk and risk factors among lesbians.

**Table 2.2: Studies of the breast cancer risk and risk factors among lesbians**

Authors (country)	Sample size, age	Study design/data collection	Model used	Factors assessed
Brandenburg et al., 2007 (US)	550 lesbians 279 heterosexuals Mean age: 43	Cross-sectional survey	Gail	Age, age at menarche, age at first live birth, nulliparity, previous breast biopsy, biopsy with a typical hyperplasia, first-degree relative with breast cancer
Dibble et al., 2004 (US)	324 lesbians (mean age: 49.7) 324 heterosexual sisters (mean age: 48.9)	Cross-sectional survey	Modified Gail model	Menarche age, menopause age, contraceptive pill use, parity, HRT, breastfeeding, hysterectomy, BMI, waist/hip ratio, exercise, smoking, alcohol use, low-fat diet, radiotherapy treatment
Austin et al., 2012 (US)	665 lesbians 309 bisexuals 86,418 heterosexuals Age range: 25-42	Prospective population cohort study	Rosner-Colditz	Age, age at menarche, duration of pre-menopause, age at first birth, number of births, mean BMI during pre-menopause, height at baseline, mean alcohol intake during pre-menopause, history of benign breast disease, family history of breast cancer
McTiernan et al., 2001 (US)	65 lesbians (mean age: 40.8) 317 general sample (mean age: 42.2)	From RCTs of breast cancer risk counselling methods	Gail and Claus	Gail – age, age at menarche, age at first live birth, nulliparity, number of previous breast biopsies, biopsy with atypical hyperplasia, first degree relative with breast cancer Claus – age, relative with breast cancer and their age of onset
Case et al., 2004 (US)	694 lesbians 90,129 heterosexuals Ages: 32-51	Nurses' Health Study II	x	Nulliparity, alcohol use
Cochran et al., 2001 (US)	11,876 lesbians/bisexuals ? women in general Ages: 18-75	Two national and five regional lesbian surveys, NHANES III, NHIS	x	Obesity, alcohol use, smoking, parity, contraceptive use, health insurance, mammography
Grindel et al., 2006 (US)	1,139 lesbians Mean age: 38.63	Self-administered questionnaire compared with various US national surveys	x	Family history of cancer, smoking, nutrition, exercise, body weight, alcohol use, HRT, sunscreen use, mammography
Rankow & Tessaro, 1998 (US)	570 lesbian and bisexual women over the age of 40 years	Regional lesbian survey, BRFSS, NHANES III, NHIS	x	Family history, nulliparity, overweight (BMI > 27.3), alcohol use, menarche < 12 years, mean age at menarche
Roberts et al., 1998 (US)	433 lesbians 586 heterosexuals Mean age: 42.9	Retrospective medical record audit	x	Alcohol use, smoking, parity, contraceptive pill use, HRT, family history, BMI, menarche age, menopause age, mammogram age

Modified from Meads & Moore (2013, pp. 7-8; <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3890640/pdf/1471-2458-13-1127.pdf>)

**Table 2.2: Studies of breast cancer risk and the risk factors among lesbians (con.)**

Valanis et al., 2000 (US)	573 lesbians 740 bisexuals 90,578 heterosexuals 1,420 asexuals Mean ages: 56.7-64.8	Women's Health Initiative survey	x	Mammogram, diet, smoking, alcohol use, overweight, exercise, psychosocial characteristics, contraceptive pill, HRT, pregnancy, hysterectomy
Zaritsky & Dibble, 2010 (US)	42 lesbians (mean age: 63.9) 42 heterosexual sisters (mean age: 64.2) *derived from Dibble et al.'s (2004) study.	Cross-sectional survey	x	Age at menarche, number of years used BCP, number of live births, number of miscarriages, total months pregnant, total months nursing, age at menopause, number of years used HRT, ever pregnant, abortion, miscarriage, breastfed child, ever used BCP, hysterectomy, ever used HRT, taking HRT now, number of children

Modified from Meads & Moore (2013, pp. 7-8; <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3890640/pdf/1471-2458-13-1127.pdf>)



Of the 11 studies, four used a risk model to compare the breast cancer risk and risk factors between lesbians and heterosexual women. Austin (2012) employed the Rosner-Colditz model and the other three studies used the Gail model (Brandenburg et al., 2007; Dibble et al., 2004; McTiernan et al., 2001). McTiernan's study also used the Claus model. Of these four studies, three of the studies suggest that lesbians might have higher risk estimates of breast cancer while the other study contradicts this.

Brandenburg et al. (2007) compared the breast cancer risk between 550 lesbians and 279 heterosexual women. The estimates of five-year and lifetime breast cancer risks were higher for lesbians than for heterosexual women.

Dibble et al.'s (2004) study explored the similarities and differences among 324 sister pairs (324 lesbians and their 324 sisters) to establish the risks associated with developing breast cancer. The results showed that the lesbians had significantly higher scores in the five-year risk estimations than their sisters. In exploring the lifetime risk estimations between the two sample groups, the lesbians also had significantly higher lifetime risk estimations of developing breast cancer than their sisters.

A prospective cohort study was conducted to estimate the breast cancer risk in a US cohort of pre-menopausal women (Austin et al., 2012). A total of 665 lesbian, 309 bisexual and 86,418 heterosexual women were recruited in the study. The findings suggest that both lesbian and bisexual women have a slightly increased predicted breast cancer incidence compared with heterosexual women.

Lower risk estimates of getting breast cancer among lesbians are proposed by McTiernan et al. (2001). The study used two different models – Gail and Claus – to compare the risk estimates of breast cancer among women with a family history of breast cancer. Sixty-five lesbians and 317 heterosexual women from risk counselling clinical trials in Seattle, Washington, were recruited in the analysis from 1996 to 1997. The researchers found that, in both models, lesbians had lower risk estimates of getting breast cancer compared to heterosexual individuals.

The varied estimates of breast cancer risk among lesbians might be influenced by the applied methodologies, equipment and recruitment criteria in the studies. In particular, all the

participants in McTiernan et al.'s (2001) study had a high risk of getting breast cancer because of their family history of breast cancer. Although the breast cancer risk among lesbians remains uncertain based on the current evidence, the balance of the evidence seems to suggest a higher incidence rate of breast cancer among lesbians.

In terms of the factors that contributed to the higher risk of breast cancer among lesbians, reproductive factors were highlighted as significant causes in increasing lesbians' breast cancer risk when compared to women in general. Several reproductive variables have been found to be positively related to lesbians' breast cancer risk, including nulliparity (Case et al., 2004; Cochran, 2001; Rankow & Tessaro, 1998), early age of menarche (< 12 years) (Rankow & Tessaro, 1998), fewer pregnancies (Dibble et al., 2004; Zaritsky & Dibble, 2010), lower total number of months of pregnancy (Zaritsky & Dibble, 2010), fewer children (Dibble et al., 2004; Zaritsky & Dibble, 2010) and lower total number of months of breastfeeding (Zaritsky & Dibble, 2010).

In addition to reproductive factors, behavioural factors have also been suggested as a significant reason for the increase in the risk of getting breast cancer among lesbians, such as drinking (Brandenburg et al., 2007; Case et al., 2004; Cochran, 2001; Dibble et al., 2004; Rankow & Tessaro, 1998; Valanis et al., 2000) and smoking (Cochran, 2001; Dibble et al., 2004; Valanis et al., 2000). In Brandenburg et al.'s (2007) paper, lesbians were found to be more likely to have higher daily alcohol consumption levels ( $\geq 2$  drinks/day) than heterosexual women. Dibble et al. (2004) also found that significantly more lesbians reported having a drinking problem when compared to their heterosexual counterparts.

Although the previous evidence suggested that behavioural factors were significantly associated with lesbians' higher risk of getting breast cancer, some researchers found that there were no differences in smoking and drinking between lesbians and heterosexual women. Zaritsky and Dibble (2010) compared the breast cancer risks among 42 pairs of lesbians and their heterosexual counterparts. The findings support the view that there is no significant difference in smoking and drinking between the two groups. Similar findings can also be seen in Roberts et al. (1998). There was no difference between lesbians' and heterosexual women's alcohol use in Roberts' study. Moreover, Grindel et al.'s (2006) national survey with 1,139 self-identified lesbians from 44 states in the US also found that the majority of the participants in the study did not smoke and that they consumed alcohol at a

moderate rate (4.14 drinks per week). In addition to the reproductive factors, the differences in the risk factors of breast cancer between lesbians and heterosexual women remain uncertain. Although drinking and smoking have been suggested as important reasons that are positively associated with lesbians' breast cancer risk, a large-scale survey or cohort study is needed to support the results.

All of the 11 studies were conducted in the US. In terms of different racial characteristics, lifestyles and living environments regarding Taiwanese lesbians, the risk estimates of breast cancer might be different from those for lesbians in the US. However, reproductive factors – in particular, nulliparity – are common risk factors among lesbians, whether in Taiwan or in the US. In addition, the Westernized lifestyle changes in Taiwan during recent decades may lead to similar risk estimates of breast cancer among lesbians in the US. Hence, higher risk estimates of breast cancer among Taiwanese lesbians are considered.

## **2.5 Breast cancer screenings**

Prevention and early detection are seen as key elements in controlling breast cancer. Early detection is significant in decreasing the number of cancer deaths and improving the survival rate of breast cancer treatments (International Agency for Research on Cancer, IARC, 2002). Generally, the early detection of breast cancer comprises three main methods: breast self-examination (BSE), clinical breast examination (CBE) and mammography (Kearney & Murray, 2009). The following provides definitions of breast cancer screening and the utilization of breast cancer screenings among lesbians.

### **2.5.1 Definitions of breast cancer screenings**

BSE is defined as “*a monthly self-examination of a woman's breasts to check for lumps or other changes*” (NCI Dictionary of Cancer Terms). The purpose of a BSE is for the woman to learn the topography of her breasts, to know how her breasts feel, and also to be able to recognize any changes in them. The examination involves two basic steps: visual examination and tactile examination of the breasts. The visual examination identifies any changes in the shape, form, colouring or structure of the breasts. The tactile examination is used to feel for changes in the texture and feel of the breasts (Khatib & Modjtabai, 2006).

CBE is defined as “*a physical examination of the breast performed by a health care provider to check for lumps or other changes*” (NCI Dictionary of Cancer Terms). This examination

comprises two steps: inspection of the breasts (looking) and palpation (feeling). The areas examined comprise the entire breast area, including the lymph nodes, above and below the collarbone, and under each arm (Khatib & Modjtabai, 2006). The process is similar to a BSE but it is performed by a healthcare provider.

Mammography is defined as “*a specific type of imaging that employs a low-dose X-ray system to examine breasts*” (Radiological Society of North America, 2011).

In this thesis, women’s actions and intentions in relation to performing BSEs or obtaining CBEs or mammography screenings are together categorized as *breast healthcare behaviours and intentions*.

### **2.5.2 Utilization rates of breast cancer screenings among lesbians**

Lesbians might have lower utilization rates of breast cancer screenings than women in general in Taiwan. Among Taiwanese women, a free biennial mammogram is provided under the Taiwanese breast cancer, oral cancer and colorectal cancer screening programmes. Eligible women include those aged 45-69 years and those aged 40-44 years who have first- and second-degree relatives (grandmother, mother, daughter or sister) with breast cancer. In 2012, the utilization rate of mammograms among women aged 45-69 years was 32.5% (Health Promotion Administration, Ministry of Health and Welfare, 2013). Before 2012, an annual CBE was also offered under the cancer screening programme; however, it was removed from the programme in 2012. Both monthly BSEs and annual CBEs are recommended for women in Taiwan, starting in their 20s, by the Taiwan Breast Cancer Foundation. In addition, the Taiwan Clinical Oncology Research Foundation and the Taiwan Breast Cancer Alliance also recommend that women perform BSEs monthly from age 20 onwards, although the benefits and potential harm of BSEs have been argued over in the last decade (Al-Foheidi et al., 2013; Kösters & Gøtzsche, 2003). The utilization rates for performing BSEs and having CBEs regularly among Taiwanese women were around 30-40% and 10-20%, respectively (Chiang et al., 2011; Lin, 2008; Luo et al., 2001). A survey conducted by Chang et al. in 2000 found that 723 (50.6%) of the 1,450 participants had never performed BSEs and that 594 (41.6%) performed them only irregularly.

There were no statistics about the utilization rates of BSE and CBE among Taiwanese lesbians.

In Taiwan, in 2008, an unpublished online survey conducted by the TAPWR showed lower utilization rates of having mammograms among Taiwanese lesbians. Of 1,523 Taiwanese lesbians recruited in the study, only 4.5% (n = 68; age not specified) had had a mammogram and 2% (n = 31; age not specified) had a mammogram every two years. Based on the information provided, there was no heterosexual comparison group in the study; hence, the differences in mammogram use between lesbians and women in general in Taiwan are unknown. However, when comparing the rates with the national utilization rate of women aged 45-69 years who had a biennial mammogram in 2012 (32.5%), it seems that the lesbians have a much lower utilization rate of mammograms when compared to women in general. With only one survey which did not provide detailed information about methods, a further study is needed to understand the utilization rates of BSE, CBE and mammograms among Taiwanese lesbians, particularly the utilization rates of mammograms among lesbians aged 45-69 years.

In addition to Taiwanese lesbians, lesbians in the US were also found to potentially have lower utilization rates of mammograms. Buchmueller and Carpenter (2010) compared health insurance coverage, access to care and women's cancer screenings among 5,265 women in same-sex relationships and 802,659 women in different-sex relationships. The individuals in same-sex relationships were significantly less likely to have had a recent mammogram than the women in different-sex relationships. A further population survey found that women who had sex with women were less likely to have had a mammogram than other women, at 53% and 73%, respectively (Kerker et al., 2006). Moreover, Roberts et al. (2004) found that 66% of lesbians aged 50 years or over had undergone a mammography screening and 78% had had one within the previous two years. A total of 51% of homosexual women aged 40-49 years in the study had had a mammogram during the previous year and 68% had had one within the last two years. The researchers concluded that the utilization of breast cancer screenings by lesbians had increased, but that the rates were still lower than those for women in general. However, the lack of a comparison group (heterosexual women) in this study should be considered along with the conclusion.

Recent evidence, on the other hand, shows that there is no difference in the utilization rates of mammograms between lesbians and heterosexual women in the US (Austin et al., 2013; Bowen et al., 2004; Conron et al., 2010). Austin et al. (2013) investigated breast and colorectal cancer screening adherence among different sexual orientation groups in 85,759

US women (1989-2005). Mammogram use over the previous two years saw no differences among the groups (84% of heterosexual women, 79% of bisexual women and 82% of lesbians). In the 2001-2008 Massachusetts behavioural risk factor surveillance surveys (n = 67,359), there were no differences in the lifetime mammography use between heterosexual women and sexual minority women (Conron et al., 2010). In addition, another US study with a relatively small sample size (170 heterosexual women and 35 sexual minority women) found that intentions to follow mammography recommendations were similar between the two groups (Bowen et al., 2004).

Taiwanese lesbians may exhibit lower utilization rates of breast cancer screenings when compared to the rates for women in general in Taiwan and the rates for lesbians in the US and the UK. In the following section, the current evidence on possible factors associated with Taiwanese lesbians' breast healthcare behaviour is reviewed and presented.

## **2.6 Literature review**

In the following sections, the methods of the literature review are provided, followed by a synthesis of the findings and a critical appraisal of the evidence. At the end, a summary is given.

### **2.6.1 Aim of the review**

Because of the lack of research exploring Taiwanese lesbians' breast healthcare behaviour and its influencing factors, the aim of this review is to identify the factors influencing breast healthcare behaviour among women who might share similar characteristics with Taiwanese lesbians.

Three groups of women were considered who might share similar characteristics with the target population: 1) Taiwanese heterosexual women, 2) heterosexual women in the US and the UK, and 3) lesbians in the US and the UK. The reasons for including these three groups of women are provided as follows.

#### **1) Taiwanese heterosexual women**

Taiwanese heterosexual women and Taiwanese lesbians share the same cultural background, religion and lifestyles. Whether Taiwanese women's sexual orientation is heterosexual or homosexual, all have public health insurance and are eligible for free mammograms every

two years if they were aged 45 years or over. The recommendations and procedures for breast cancer screenings are also the same between the Taiwanese heterosexual women and Taiwanese lesbians.

## **2) Heterosexual women in the US and the UK**

The increase in breast cancer risk among Taiwanese women was suggested as being associated with Westernized lifestyle changes (Leong et al., 2010). Such lifestyle changes among Taiwanese women have been mostly adopted from the US and the UK. The similar lifestyles of Taiwanese lesbians and women living in the US and the UK were considered. Moreover, due to political and historical events, Taiwanese lesbians' attitudes, beliefs and behaviour were also thought to be influenced by US culture, in particular modernization and industrialization in 1960s, which were initiated by the US government. Due to the influences of Westernized lifestyle changes, modernization and industrialization during recent decades in Taiwan, heterosexual women in the US and the UK were considered to share similar characteristics and views on breasts, breast cancer and breast cancer screenings with Taiwanese lesbians. Hence, heterosexual women in the US and the UK were included.

## **3) Lesbians in the US and the UK**

The Taiwanese lesbian community developed based on the US gay culture of the 1960s. During that period, Taiwan was a US military base in the Asia-Pacific. The similar social behaviour of lesbians in Taiwan and those in the US was also considered (for example, smoking, drinking and bar culture). Hence, lesbians in the US were included. In addition, and as with heterosexual women in the UK, similar lifestyles were considered to exist between lesbians in the UK and those in Taiwan (Leong et al., 2010). Therefore, lesbians in the UK were also included.

### **2.6.2 Search strategy**

Two languages (Chinese and English) were used to search for relevant studies. Searches were conducted using two Chinese databases (the Airiti Library and the National Central Library), the Taiwan Digital Meta-Library, and seven English databases (CINAHL, Medline, PsycINFO, the Cochrane Library, the Campbell Library, the British Nursing Index (BNI) and the Centre for Reviews and Dissemination (CRD)).

The search terms were: ‘breast awareness’, ‘breast palpation’, ‘mammography’, ‘mammogram’, ‘self-examination’ and ‘mass screening’ (which were independently combined with ‘breast’), ‘female’, ‘breast neoplasms’, ‘health promotion’, ‘health behaviour’, ‘primary healthcare’, ‘attitudes to health’ and ‘guideline adherence’.

The studies were limited to the geographic subsets ‘USA’, ‘UK & Ireland’ and ‘Taiwan’. The search results showed the relevant literature regarding both heterosexual women and lesbians in the UK and in the US. No relevant studies were identified which took lesbians in Taiwan as their subjects.

The date range of these published papers was limited to between the years 2000 and 2014, reflecting the inception of breast cancer screening programmes in the UK (2010-2016), the US (the National Breast and Cervical Cancer Early Detection Programme, 2000-present) and Taiwan (2004-present). However, related studies conducted among lesbians in the US and the UK were few, and four out of the 10 lesbian studies published between 2000 and 2014 used the same data resource (the Lesbians and Health Care Survey, UK, 1997-1998). Therefore, the key papers written before 2000 are included in this review to help in understanding lesbians’ breast healthcare behaviour and its various influencing factors. No relevant studies regarding lesbians in the US and the UK before 1998 were identified.

In addition to searching electronic databases, some of the articles that were included were identified by reviewing the reference lists of the identified studies. An Internet search was conducted using Google Scholar together with additional targeted searches of selected relevant websites, such as the National Coalition for LGBT Health, GLMA (Gay and Lesbian Medical Association), the National LGBT Cancer Network and Health with Pride, and the NHS.

### **2.6.3 Inclusion and exclusion criteria**

#### ***Inclusion criteria***

A study was included in the review if the study met all of the following inclusion criteria:

- 1) It explored the factors associated with heterosexual or homosexual women’s breast healthcare behaviour;
- 2) It was conducted in the US, the UK or Taiwan;



- 3) It was published after 2000 (heterosexual women) or else published after 1998 (lesbians);
- 4) It was either a qualitative or a quantitative study.

### ***Exclusion criteria***

As previously described, the aim of this review is to identify the factors influencing breast healthcare behaviour among women who might share similar characteristics with Taiwanese lesbians. Therefore, studies recruiting women who did not share similar characteristics with Taiwanese lesbians were excluded:

- 1) Studies conducted with women who had physical or intellectual disabilities;
- 2) Studies which only recruited race-based female minority groups.

The review excluded studies that mainly recruited women with physical or intellectual disabilities in the US, the UK and Taiwan because their utilization of breast cancer screenings was found to be lower than that of the general female population (Davies & Duff, 2001). Their breast healthcare behaviour was associated mainly with the need for a direct invitation or referral, difficulty in understanding the breast cancer screening procedure, and the possibility that, due to physical disability, the process of undergoing a mammogram would not be possible (Schoutman & Jeffe, 2003; Sullivan et al., 2004).

The review further excluded studies exploring factors exclusively relating to the breast healthcare behaviour of racial minority women in the US, the UK and in Taiwan. The breast healthcare behaviour of racial minority women was found to be influenced by their specific beliefs regarding cancer and their cultural backgrounds (Fernandez et al., 2005).

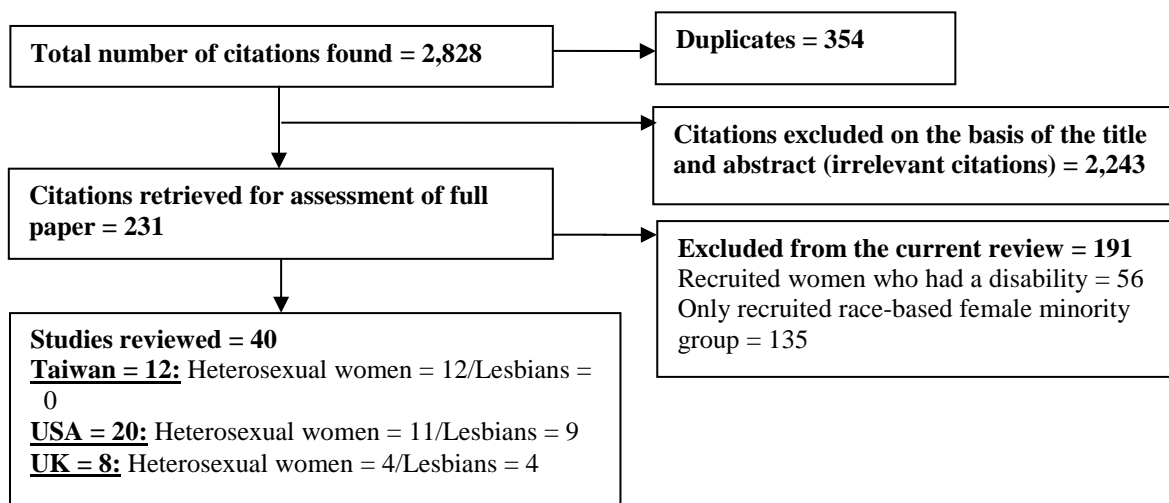
### **2.6.4 Studies identified and included**

Figure 2.1 shows the process of identifying the relevant literature. A total of 2,828 studies were found with 354 duplicates. The title and abstract of each study uncovered were reviewed, and 2,243 studies were excluded because they were not relevant to this review. There were 231 studies that were reviewed and assessed for relevance. Of these studies, 56 recruited women who had a disability and 135 were concerned only with race-based female minority groups, all of which were excluded from the review.

A total of 40 studies were included in this review, comprising 12 studies conducted in Taiwan, 20 in the US and eight in the UK. All of the Taiwanese studies were conducted with heterosexual women. No relevant studies conducted with lesbians in Taiwan were identified. Of the 20 US studies, 11 were conducted with heterosexual women and nine with lesbians. Among the eight UK studies, four were conducted with heterosexual women and four with lesbians. Each of the four UK studies conducted with lesbians used the same data resource, collecting data from the Lesbians and Health Care Survey, UK, 1997-1998 programme, with 1,066 British lesbians. All of these studies were included in this review because of the different findings relating to lesbians' breast healthcare behaviour.

In this review, studies conducted with women sampled from the general population (i.e., which did not specify the women's sexual orientation) were categorized as *heterosexual women* in order to distinguish them from studies conducted with lesbians. The term *general population* is not used in this review because it refers to the generalizability of the study's findings, and some of the studies conducted using the term *general population* might have limited generalizability. Therefore, the term *heterosexual women* was employed to help readers distinguish between studies conducted with participants sampled from the general population and those conducted with participants sampled from lesbians.

**Figure 2.1: The process of identifying the relevant literature**



### 2.6.5 Study quality assessment tools

Four assessment tools were employed for the critical appraisal of the included studies:

- 1) A qualitative research checklist developed by the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, CASP, 2013);
- 2) A cohort study checklist developed by the Critical Appraisal Skills Programme (CASP, 2013);
- 3) A descriptive/cross-sectional research checklist adopted from Guyatt et al.'s (1993; 1994) user guides to medical literature; and
- 4) A checklist developed by Hawker et al. (2002), used to provide a summed quality score, which gives an overall judgment of the methodological rigour of each study.

Details of the checklists can be seen in Table 2.3. The assessment tool for qualitative studies developed by CASP was used to assess the quality of the studies included. The studies were appraised through 10 questions about study design, study aims, sampling, data collection, reflexivity in the process of the research, ethical issues, data analysis, study findings and value of the study. The assessment tips under each question provided by the CASP were considered and appraised. For example, the quality of the sampling in a study was assessed through three suggestions: “1) *if the researcher has explained how the participants were selected; 2) if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study; and 3) if there are any discussions around recruitment, such as why some people chose not to take part.*”

A cohort study checklist developed by the CASP (2013) was used to assess the included longitudinal studies. The studies were appraised through 12 questions about study design, study aims, recruitment, bias-minimization, confounding factors, follow-up, findings, generalization, and implications. Each question was assessed through tips provided under each question in the tool. For example, follow-up was assessed through three sub-aspects: “1) *the good or bad effects should have had long enough to reveal themselves; 2) the persons that are lost to follow-up may have different outcomes than those available for assessment; and 3) in an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort?*”

As no tool was developed by the CASP for appraising cross-sectional studies, the descriptive/cross-sectional studies and secondary data analysis of the cross-sectional survey included in the review were assessed by using a checklist adopted from Guyatt et al.'s (1993; 1994) work. The framework of Guyatt's checklist was similar to the appraisal tools developed by the CASP and tips under each question were also provided to help reviewers to appraise cross-sectional studies. There were a total of 11 questions included in the tool for assessing the quality of the research, comprising two screening questions and nine detailed questions. The screening questions mainly focus on the study aims and design. The detailed questions aim to appraise the sampling, sample size, measurement tool, data collection procedure, results, rigour, credibility of the findings and generalization of the study. The tips for assessing the quality of each study provided in the tool under each question were considered and appraised. For instance, four hints were assessed in terms of the quality of the data collection in a cross-sectional study: "1) *if the setting for data collection was justified*; 2) *if it is clear how data were collected*; 3) *if the researcher has justified the methods chosen*; 4) *if the researcher has made the methods explicit*."

A summed quality score system was used to judge the methodological rigour of each study included in this review. The quality score criteria were established by Hawker et al. (2002), comparing nine aspects: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalizability, and implications and usefulness. Each aspect can be scored as '1' (very poor), '2' (poor), 3 (fair) or '4' (good), and the summed score for a study can range between '9' (very poor) and '36' (good) points. In this review, a summed quality score of '9' is defined as *very poor* quality, a score between '10' and '18' as *poor* quality, and '19' and '27' and '28' and '36' as *fair* and *good* quality, respectively. A protocol of Hawker's score system is provided in Appendix 1 (see p.281). The score system was used in this review because:

- 1) The tool can be employed in a variety of study designs;
- 2) The included domains are similar to the chosen tools, CASP and the tool adopted from Guyatt et al. (1993); and
- 3) The scores provide a general idea about the strength of the included evidence for readers.

**Table 2.3: Study quality assessment tools**

	<b>Qualitative research checklist (CASP, 2013)</b>	<b>Cohort study checklist (longitudinal study) (CASP, 2013)</b>	<b>Descriptive/cross-sectional study checklists (Guyatt et al., 1993; 1994)</b>	<b>The quality score system (Hawker et al., 2002)</b>
	<b><u>Yes/No/Cannot tell</u></b>	<b><u>Yes/No/Cannot tell</u></b>	<b><u>Yes/No/Cannot tell</u></b>	<b>1 (very poor)/2 (poor)/ 3 (fair)/4 (good)</b>
<b>1</b>	Was there a clear statement of the aims of the study?	Did the study address a clearly focused issue?	Did the study address a clearly focused issue?	Abstract and title
<b>2</b>	Is a qualitative methodology appropriate?	Was the cohort recruited in an acceptable way?	Did the authors use an appropriate method to answer their question?	Introduction and aims
<b>3</b>	Was the research design appropriate to address the aims of the research?	Was the exposure accurately measured to minimize bias?	Were the subjects recruited in an acceptable way?	Method and data
<b>4</b>	Was the recruitment strategy appropriate to the aims of the research?	Was the outcome accurately measured to minimize bias?	Were the measures accurately measured to reduce bias?	Sampling
<b>5</b>	Was the data collected in a way that addressed the research issue?	A. Have the authors identified all important confounding factors? B. Have they taken account of the confounding factors in the design and/or analysis?	Were the data collected in a way that addressed the research issue?	Data analysis
<b>6</b>	Has the relationship between researcher and participants been adequately considered?	A. Was the follow-up of the subjects complete enough? B. Was the follow-up of the subjects long enough?	Did the study have enough participants to minimize the role of chance?	Ethics and bias
<b>7</b>	Have ethical issues been taken into consideration?	What are the results of this study?	How are the results presented and what is the main result?	Findings/Results
<b>8</b>	Was the data analysis sufficiently rigorous?	How precise are the results?	Was the data analysis sufficiently rigorous?	Transferability/Generalizability
<b>9</b>	Is there a clear statement of findings?	Do you believe the results?	Is there a clear statement of findings?	Implications and usefulness
<b>10</b>	How valuable is the research?	Can the results be applied to the local population?	Can the results be applied to the local population?	
<b>11</b>		Do the results of this study fit with other available evidence?	How valuable is the research?	
<b>12</b>		What are the implications of this study for practice?		

### **2.6.6 Findings**

A number of influencing factors associated with women's breast healthcare behaviour were identified. The factors were synthesized into six categories: 1) demographics; 2) attitudes and beliefs regarding breast cancer and breast cancer screenings; 3) knowledge and information about breast cancer and breast cancer screenings; 4) social support; 5) physician-patient communication; and 6) accessibility and cost. These factors represent important similarities and differences in breast healthcare behaviour among the three groups of women: Taiwanese heterosexual women, heterosexual women in the US and the UK, and American and British lesbians. Other factors which were also found to be associated with the women's breast health behaviour were grouped into one of the six categories in order to maintain the clarity of the review context and to avoid repeating the content. For example, emotional factors (feeling embarrassed or anxious regarding breast screenings) were included in the category of 'attitudes and beliefs regarding breast cancer and breast cancer screenings'.

A synthesis of the findings regarding the six factors is provided in the following sections.

#### **1) Demographics**

Age, level of education and income were identified as being associated with the women's breast healthcare behaviour. The findings were found to be similar whether the women were heterosexual or lesbian, and whether they lived in the US, the UK or Taiwan. In addition, sexual orientation among the lesbians in the US and the UK was indicated as a barrier in the women's breast healthcare behaviour.

Twelve out of the 40 reviewed studies investigated the association between age and breast healthcare behaviour. Women aged between 50 and 64 years were found to be most likely to have a CBE (Lin, 2008) or a mammogram (Coughlin et al., 2004; Diamant et al., 2000; Lin 2008). Younger and older women were indicated as being less likely to have a mammogram, especially those individuals aged younger than 50 years (Kratzke et al., 2010; Lopez et al., 2009) or older than 65 years (Huang et al., 2012). "Too old" or "too young" were reported as being barriers to BSE. Women aged younger than 17 years (Fish & Wilkinson, 2003<sub>b</sub>) or older than 50 years (Chang et al., 2003; Fish & Wilkinson, 2003<sub>b</sub>) were found to be less likely to perform a BSE than women in between 20 and 49. One study found no association between age and women's utilization of mammography (Miller et al., 2011). The finding,

however, was considered to have limited generalizability because only women aged 54 years or over were recruited in Miller's study.

Women with a higher level of education were found to be more likely to perform BSE (Chang et al., 2003), to have a CBE (Chang et al., 2003; Lin, 2008) or to have a mammogram, especially those with a high-school level of education or above (Coughlin et al., 2004; Diamant et al., 2000; Lai et al., 2012; Lin, 2008; Lopez et al., 2009; Miller et al., 2011). However, two studies pointed out that education was not associated with the use of mammograms (Gierisch et al., 2009; Kratzke et al., 2010). In both studies, recruitment was indicated as affecting the result. In Gierisch's (2009) study, all of the participants were insured with the State Health Plan and had had mammograms recently – prior to study enrolment – leading to a sample that might be more homogeneous than previous studies. In Kratzke et al.'s (2010) study, all of the participants were community health workers. These women tended to have a positive attitude towards breast cancer screenings and their healthcare providers. The samples in both studies might not be representative of the general population.

Income was found to be positively associated with the women's utilization of mammography (Burnett et al., 1999; Coughlin et al., 2004; Diamant et al., 2000; Lai et al., 2012; Lin, 2008; Miller et al., 2011; Rankow & Tessaro, 1998). Women with higher incomes were more likely to use mammograms than those with lower incomes. However, no association between income and use of mammograms was indicated by Gierisch et al. (2009) or Kratzke et al. (2010). Gierisch (2009) suggested that income was not associated with mammogram screening attendance among women in their 40s. In Kratzke et al.'s study (2010), income was not found to be a significant factor in relation to the use of mammograms among community health workers. As above, there was limited generalizability in both studies.

Sexual orientation was suggested as a factor influencing lesbians' breast healthcare behaviour (DeHart, 2008; Kerker et al., 2000) and the intention (Hart & Bowen, 2009) or decision (Clark et al., 2003) to use breast cancer screenings. Lesbians were found to be less likely to have a mammogram (Kerker et al., 2006) and more likely to have a negative view regarding breast cancer screenings than heterosexual women (Hart & Bowen, 2009). Disclosing sexual orientation to physicians was identified as one of the reasons inhibiting lesbians' use of breast healthcare services (DeHart, 2008). In addition, lesbians' negative feelings about their own

bodies or breasts – such as nausea or discomfort – were found to be barriers to the individuals performing BSEs (Fish & Wilkinson, 2003<sub>b</sub>).

## **2) Attitudes and beliefs regarding breast cancer and breast cancer screenings**

Various studies found that women's attitudes and beliefs regarding breast cancer and breast cancer screenings affected their breast healthcare behaviour. Women's attitudes towards breast cancer, such as 'not much can be done to avoid cancer' (Ahmed et al., 2009) and 'cancer treatment is not worth going through' (Ahmed et al., 2009; Lopez et al., 2009), were found to be negatively associated with the individuals' breast healthcare behaviour in the US. In addition to women in the US, a similar finding can also be seen for Taiwanese women. The women were found to believe that there was nothing that could be done if they had breast cancer. This belief discouraged the individuals from performing BSEs (Ku, 2004).

Eleven studies investigated the association between women's perceived risk of having breast cancer and their utilization of breast cancer screenings. Perceiving a lower risk of having breast cancer was identified as inhibiting the practice of BSE (Fish & Wilkinson, 2003<sub>b</sub>), having CBEs (Hart & Bowen, 2009) or using mammograms (Fish, 2006; Rankow & Tessaro, 1998). Lesbians in particular were found to perceive a lower risk of having breast cancer compared to heterosexual women (Hart & Bowen, 2009). 'I do not think I am at much risk' (Fish, 2006; Rankow & Tessaro, 1998) and 'having no symptoms' (Fish & Wilkinson, 2003<sub>b</sub>) were reported as being related to lesbians' lack of use of breast cancer screenings. On the other hand, perceiving a higher risk of getting breast cancer was suggested as being positively associated with breast healthcare behaviour for both heterosexual women and lesbians. Women who had a history of breast disease (Chang et al., 2003; Chiang et al., 2011; Diamant et al., 2000; Fish & Wilkinson, 2003<sub>a</sub>; Huang et al., 2012; Lai et al., 2011) or a family history of breast cancer (Chiang et al., 2011; Fish & Wilkinson, 2003<sub>a</sub>; Gierisch et al., 2009; Lai et al., 2011; Miller et al., 2011) were found to be more likely to use or perform breast screenings than those who had not.

Six studies found that perceiving the benefits related to breast cancer screenings was positively associated with women's breast healthcare behaviour (Barter-Godfrey & Taket, 2007; Chiang et al., 2011; DeHart, 2008; Gierisch et al., 2009; Nekhlyudo et al., 2003; Yang et al., 2010). The findings were found to be similar whether the women were heterosexual or lesbian, and whether they lived in the US, the UK or Taiwan. In Nekhlyudo et al.'s (2003)



US study, mammography was reported as a valuable tool for the early detection of breast cancer by the participants. In Taiwan, Yang et al. (2010) found that BSE was seen as an additional method for women's continuous monitoring of their own breasts, although screening had been criticized regarding its efficacy. Some individuals in Yang's study believed that a single method for the early detection of breast cancer could not achieve its purpose. DeHart (2008) found that US lesbians' performance of BSE was positively associated with one "benefit variable" (a lot to gain by doing self-examinations).

However, if the women were unsatisfied with their examination results, held negative views about breast screenings or felt that having a breast screening was not a high priority for them, they would tend not to make use of breast cancer screenings. Incomplete assessment and a need for additional evaluation were identified as barriers to undergoing mammograms (Tsai et al., 2011). Negative feelings or views about breast cancer screenings, such as feeling embarrassed or anxious about having a mammogram, were found to be inhibitors in women's breast healthcare behaviour (Barter-Godfrey & Taket, 2007; Chiang et al., 2011; Fish & Anthony, 2005; Kratzke et al., 2010; Tsai et al., 2011). In addition, the women's specific concerns about mammograms – particularly pain and unnecessary radiation exposure – inhibited their use of screenings (Barter-Godfrey & Taket, 2007; Clark et al., 2003; Fish & Anthony, 2005; Kratzke et al., 2010; Tsai et al., 2011). Other barriers to women performing or having breast screenings included the low priority of undergoing a breast cancer screening (Fish & Wilkinson, 2003<sub>b</sub>; Kratzke, 2010; Lopez, 2009), being too busy (Gierisch, 2009) and having no time (Chiang et al., 2011; Wu et al., 2012).

In addition to women's views or beliefs about breast cancer screenings, self-efficacy beliefs were found to be related to women's performance of BSE or women's breast awareness (Chang et al., 2003; Chiang et al., 2011; Fish & Wilkinson, 2003<sub>b</sub>; Forbes et al., 2011; Linsell et al., 2008; Luo et al., 2001; Norman & Cooper, 2011; Yang et al., 2010). In the UK, a lack of self-efficacy in detecting a breast change was identified as a barrier among heterosexual women (Forbes et al., 2011; Linsell et al., 2008). Lesbians in Fish and Wilkinson's (2003<sub>b</sub>) UK national survey also reported that being 'uncertain what to look for' was an inhibitor of BSE. In Taiwan, Chiang et al. (2011) found that a lack of self-efficacy was associated with the irregular performance of BSE among the women. On the other hand, self-efficacy in performing BSEs was found to be a factor to encourage Taiwanese women (Chang et al.,

2003; Luo et al., 2001; Yang et al., 2010) and heterosexual women in the UK to perform the examinations (Norman & Cooper, 2011).

Attitudes and beliefs regarding regular physical examinations were identified as influencing factors for women in performing BSEs (DeHart, 2008), having CBEs (DeHart, 2008) or making use of mammograms (Diamant et al., 2000; Fish & Anthony, 2005; Fish & Wilkinson, 2003<sub>a</sub>; Grindel et al., 2006; Lin, 2008; Tang et al., 2009). Both heterosexual women and lesbians who hold positive attitudes towards and beliefs about regular physical examinations were found to be more likely to perform or to have breast screenings than those who did not. In addition, regularly visiting healthcare providers was identified as a factor that facilitated having mammograms among US lesbians (Diamant et al., 2000). In Fish and Wilkinson's (2003<sub>a</sub>) UK study, establishing routine (performing BSEs regularly as a habit) was reported as facilitating the lesbians' practices of BSE.

### **3) Knowledge and information about breast cancer and breast cancer screenings**

Thirteen studies explored the association between knowledge and information about breast cancer and breast cancer screenings and women's behaviour in using breast screenings. Three out of the 13 studies found that knowledge about breast cancer was positively related to women's breast healthcare behaviour (Ahmed et al., 2009; Forbes et al., 2011; Luo et al., 2001). Information relating to breast screenings was reported as being an influencing factor for both heterosexual women and lesbians. 'Knowing how' was identified as facilitating performing BSEs (Fish & Wilkinson, 2003<sub>a</sub>) and undergoing mammograms (Ahmed et al., 2009). On the other hand, a lack of information about breast screenings inhibited women in performing BSEs (Chang et al., 2003; Chang et al., 2000; Fish & Wilkinson, 2003<sub>b</sub>; Luo et al., 2001) and attending (Fish, 2006; Kratzke et al., 2010) or re-attending for mammograms (Gierisch et al., 2009).

### **4) Social support**

Support from others (for example, family members and friends) was suggested as a factor that facilitates women's breast healthcare behaviour (Chang et al., 2000; Lopez et al., 2009; Norman & Cooper, 2011). The findings were found to be similar whether the study was conducted in the US, the UK or Taiwan. In Fish's UK national lesbian study, however, the lesbians' partners inhibited the lesbians' in performing BSEs because the partners did the examinations for them as a part of their sexual activity (Fish & Wilkinson, 2003<sub>b</sub>). Based on

the findings in Fish's study, it is not clear whether a partner's support facilitates or is a barrier to BSE. This is because the utilization rates of BSE among the lesbians who performed it by themselves and those whose partners did it for them were not compared. In addition, the efficacy of BSEs performed by the lesbian's partner is uncertain. For example, whether the partner would notice any changes in the lesbian's breasts by performing BSEs during sexual activity. Further evidence is needed to understand the association between the lesbians' partners' support and the women's breast healthcare behaviour.

### **5) Physician-patient communication**

For both heterosexual women and lesbians, physicians' recommendations and their attitudes towards patients were found to affect individuals' breast healthcare behaviour. Physicians' recommendations were suggested as being positively associated with women's behaviour as regards having mammograms (Barter-Godfrey & Taket, 2007; Fox et al., 2009; Kratzke et al., 2010; Lauver et al., 1999; McAlearney et al., 2005). Having no physician-advice was found to inhibit the women in performing BSEs (Fish & Wilkinson, 2003<sub>b</sub>) or making use of CBEs (Chiang et al., 2011).

Considerations as to the physician's attitudes were found to be different between heterosexual women and lesbians. Among the heterosexual women, the individuals reported that health workers' attitudes greatly affected their behaviour in having mammograms, in particular the perceived rudeness of health workers (Kratzke et al., 2010). However, lesbians' considerations regarding physicians' attitudes were found to be mainly related to their sexual orientation. Homophobic, heterosexist and heterosexual assumptions by healthcare providers were indicated as barriers to the lesbians' use of breast healthcare services (DeHart, 2008). In addition, fear of discrimination from a healthcare provider and low levels of trust were also related to the women not making use of CBEs or mammograms (Clark et al., 2003; Hart & Bowen, 2009).

### **6) Accessibility and cost**

Access to mammograms and regular resources of care were suggested as being associated with women's use of mammography in the US and the UK (Ahmed et al., 2009; Kratzke et al., 2010; Lopez et al., 2009). The difficulty (Forbes et al., 2011) or inconvenience of making an appointment (Barter-Godfrey & Taket, 2007) was found to be a common factor that inhibited women in having a mammogram. Forgetting to make or keep a mammogram

appointment was also identified as a barrier associated with having screenings (Gierisch et al., 2009).

In the US, the cost of mammography is paid for by insurance companies or else by the women themselves if they are uninsured. Cost was found to be an important barrier to having a mammogram among US heterosexual women and lesbians (Makuc et al., 2007; McAlearney et al., 2005; Rankow & Tessaro, 1998). Three papers also described insurance coverage as a major barrier to undergoing mammogram screenings (Ahmed et al., 2009; Coughlin et al., 2004; Gierisch et al., 2009). Women were found to be more likely to be screened if they had health insurance coverage (Coughlin et al., 2004; Rankow & Tessaro, 1998). One study, however, suggested that health insurance was not a significant factor influencing women's use of mammography (Kratzke et al., 2010). In Kratzke et al.'s study, the participants were recruited from two urban, volunteer community-health worker programmes. The researchers explained that the sampling procedure and criteria used for the study might have influenced the individuals' responses associated with their breast healthcare behaviours. Hence, limited generalizability was attributed to the study.

### **2.6.7 Critical appraisal of the evidence**

In this section, an overall appraisal of the reviewed studies is provided, followed by an examination of the limitations of the studies as regards the study settings and the participants' sexual orientation. Details of the reviewed studies can be seen in Appendix 2 (see p.283, studies conducted with heterosexual women in Taiwan), Appendix 3 (see p.285, studies conducted with heterosexual women in the US and the UK) and Appendix 4 (see p.288, studies conducted with lesbians in the US and the UK).

Of the 40 review studies, four were qualitative studies, three were qualitative interview studies and one was a focus group study. Thirty-six were quantitative studies, comprising four longitudinal studies, eight secondary data analyses of national or population-based health surveys, and 24 cross-sectional surveys.

Based on Hawker et al.'s (2002) quality score system, the quality of two of the qualitative studies was assessed as 'good' and 'fair'. All of the studies provided a clear statement of their research aims, and their research designs were appropriate for addressing those aims. The participants selected were appropriate for answering the research questions. The two 'good'

quality studies provided details on how the researchers ensured their study's rigour (Ku, 2004; Nekhlyudov, 2003). The other two studies did not specify what had been done in order to enhance the study's rigour (Clark et al., 2003; Yang et al., 2010) and so the confirmability of the works could not be assessed.

Among the four longitudinal studies, the quality varied, with two of fair quality and the others of good quality. The 'fair' quality studies did not provide their sampling strategies, details of how the researcher followed up the participants or else the follow-up rates (Norman & Cooper, 2011; Tang et al., 2009). Without descriptions of sampling strategies, follow-up methods and follow-up rates in these two studies, the selection bias and differences between the initial recruited samples and the lost follow-up samples could not be assessed. The breast healthcare behaviour and the influencing factors among the lost follow-up cases might be different from those who participated in the follow-up assessment.

Of the 36 quantitative studies, 32 were based on a single cross-sectional study design. Although cross-sectional studies have been suggested to have the advantages of being quick, cheap and useful at identifying associations, several limitations of the study design are proposed (Mann, 2003). Mann (2003) indicated that the most important problem with this type of study was differentiating cause and effect from simple association. For example, an association between established routine (performing BSEs regularly as a habit) and women's behaviour in performing BSEs was identified in Fish and Wilkinson's (2003<sub>a</sub>) study. However, it was not clear whether established routine facilitates the women's behaviour or whether the women's behaviour establishes a habit to perform BSEs regularly. In addition to the difficulty of differentiating cause and effect, another potential problem is that the participants might give the answers that they believe the researcher wants to hear rather than expressing their genuine views. For instance, Grindel et al. (2006) indicated that response bias might limit the study, as the participants might have given socially desirable responses regarding their breast health in the survey. Moreover, in addition to the four longitudinal studies, the majority of the cross-sectional studies reviewed collected data at one point in time. Hence, it has been suggested that this study design does not measure changes over time (McKenna et al., 2007). For example, as women age, changes in their breast healthcare behaviour or intentions cannot be measured.

Among these 32 cross-sectional studies, 21 were of good quality while the others were appraised as being of fair quality. Most of these studies provided detailed information in terms of study design, data collection and data analysis. The studies using random or stratified random sampling may produce generalizable research findings, although the small sample sizes were a concern and might result in limited generalizability. Some samples were too homogenous to identify particular associations, such as the participants in Gierisch et al.'s (2009) and Kratzke et al.'s (2010) studies. Gierisch recruited the participants from one setting and all of the individuals had had a mammogram just before participating in the study, while all of the participants in Kratzke's study were community health workers. The findings from these studies were considered to have limited generalizability.

Most of the studies explained how their questionnaires were designed or else referred to previously published studies for details on the measurement design, but many of the studies did not provide information about the validity or reliability of the measurement (Barter-Godfrey & Taket, 2007; Fox et al., 2009; McAlearney et al., 2005; Tsai et al., 2011). Hence, the quality of those questionnaires was difficult to assess. In addition, a lack of a theoretical orientation was a common deficiency among these cross-sectional studies, which might have resulted in weaknesses in the systematic investigation of the factors influencing women's breast healthcare behaviour.

Comparing the quality of the reviewed studies conducted in Taiwan, the UK and the US, the range of the quality scores for the UK and US studies was higher than that for the Taiwanese studies because of random sampling, representative participants, consistent data collection procedures and validation of the measurements. Some studies conducted with Taiwanese heterosexual women were considered to have limited generalizability. Of the 12 Taiwanese studies included, approximately half recruited participants in specific circumstances, meaning that the women were more likely to take part in the study (for example, recruiting the participants directly from breast cancer screening programmes or a BSE training programme). These participants may have already exhibited positive attitudes, motivations and knowledge about breast cancer screenings – such women might be more likely to perform BSEs or undergo breast screenings. For example, the utilization rate of mammography among the participants in Tsai et al.'s (2011) study was 73.5%. Compared to the national utilization rate of mammography (32.5% in 2012), this was much higher.

Furthermore, the factors influencing their breast healthcare behaviour might differ for those who did not attend the programmes.

However, more Taiwanese studies were designed with a theoretical underpinning when compared to the studies conducted in the US and the UK. Seven out of the 40 reviewed studies used theoretical approaches to investigate factors associated with women's breast healthcare behaviour. The healthcare models included the health belief model (HBM), the theory of planned behaviour (TPB) and the PRECEDE-PROCEED planning model. The HBM was used in four Taiwanese studies (Chiang et al., 2011; Chang & Nien, 2003; Ku, 2004; Luo et al., 2001) and one US cross-sectional survey (DeHart, 2008), while the TPB was employed in one US longitudinal study (Norman & Copper, 2011) and the PRECEDE-PROCEED planning model was used in one US cross-sectional survey (Kratzke et al., 2010). In contrast to the studies that did not have a theoretical framework, these seven studies were considered to have more comprehensive findings and generalization in the studies.

Varying breast screening recommendations and services and the high utilization rates of breast screenings among women in general in the UK and the US affected the study methods and objectives. The studies associated with the women's BSE practices and their influencing factors were limited or replaced by the notion of 'breast cancer awareness'. The efficacy of BSE has been challenged by researchers in recent decades (Thornton & Pillarisetti, 2008). Studies have suggested that BSE might do more harm than good (Kösters & Götzsche, 2003) and that it cannot reduce mortality from breast cancer sufficiently (IARC, 2002). In the US, the US Preventive Services Task Force (USPSTF) has recommended that BSE should not be taught. On the other hand, some researchers still believe that regularly checking their breasts encourages women to know how their own breasts look and feel normally; hence, they gain confidence about noticing any changes which might help detect breast cancer early (Thornton & Pillarisetti, 2008). Therefore, *breast awareness* has become acceptable instead of performing BSEs step by step. For example, it has been supported by the NHS Breast Screening Programme (NHSBSP) in the UK, and a leaflet is available in 19 languages that shows how and why women should be breast-aware.

The utilization rates of mammography in the US and the UK ranged from 50-70%, which was considered to be high among women in general when compared to the low utilization rates among specific groups of women in these two countries (for example, the utilization rate of

mammography among uninsured women in the US was 14% in 2013). The studies exploring the factors influencing women's breast healthcare behaviour changed focus, moving from the general population to consideration of the low utilization rates of mammography in specific areas or else among women subject to specific conditions (such as women with low incomes or those without insurance coverage in the US). Hence, these studies were considered as having limited generalizability.

The strength of the studies conducted among lesbians in the US and the UK was considered to be limited. The challenges involved in sampling sexual minority people have been discussed by previous researchers (Herek et al., 2010; IOM, 2011). Non-probability sampling is the most commonly used method for sampling a hidden target population, although sampling errors and limitations in terms of the representativeness of the population have been indicated (IOM, 2011). The majority of the lesbian studies employed convenience sampling or convenience sampling combined with snowball sampling. In addition, the response rates in some of these studies were specified as '*unknown*' because the researchers were uncertain how many lesbians had been approached and how many of them had agreed or disagreed to participate in these studies. Of the 13 lesbian studies, 11 recruited the participants using the criterion '*self-identify as a lesbian*', and two recruited women who met the criterion '*never married and previously married women who partnered with women (WPW)*' or '*women who had sex with women*'. Self-selection bias could result from the criteria of these 11 studies. Women who partner with women might not identify themselves as '*lesbians*'. Potential participants could have been missed or else might not have responded to the studies because they did not think that they satisfied the criteria. Based on the limitations of the lesbian studies, it was considered that the findings might be biased or else limited.

### **2.6.8 Summary**

Based on the studies reviewed, the demographic variables and variables regarding attitudes towards and beliefs about breast cancer and breast cancer screenings, knowledge and information regarding breast cancer and breast cancer screenings, social support, physician-patient communication, accessibility and cost were identified associated with the women's breast healthcare behaviour. Comparing the various factors among the three groups of women – Taiwanese women, heterosexual women in the US and the UK and American and British lesbians – the majority of the influencing factors were similar in addition to accessibility, cost and the women's sexual orientation. The lesbians' views about their own bodies and



physician-patient communication regarding sexual orientation were also found to be factors differentiating the lesbians from heterosexual women. Although the limitations of the included studies have been assessed, the findings provide an overview view of potential influencing factors relating to breast healthcare behaviour among women in the US, UK and Taiwan who might share similar influencing factors with Taiwanese lesbians.

## **Chapter 3: Methodology and research framework**

### **3.1 Introduction**

This chapter describes the research design and the methodology that was implemented. The overall purpose of this sequential exploratory mixed methods study was to explore the factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions. The study included two phases: 1) qualitative interviews and 2) an online survey.

### **3.2 Sequential exploratory mixed-methods research design**

An advantage of using the mixed methods approach is the flexibility afforded the researcher to carry out whatever data collection and analysis best suits the research question. This is characteristic of the pragmatism paradigm which accommodates singular or multiple realities, is extremely practical in the choice of data collection technique, and which allows and uses both qualitative and quantitative data (Creswell & Clark, 2007).

The underlying focus of the pragmatism paradigm is the outcome of the research, not the adherence of the method to a particular worldview (Patton, 1990). Instead of focusing on methods, researchers emphasize the research problem and use all the approaches available to understand the problem. As a philosophical understanding for mixed methods studies, Tashakkori and Teddlie (1998), Morgan (2007) and Patton (1990) state its importance for focusing attention on the research problem in social science research and then using pluralistic approaches to derive knowledge about the problem. In addition, Creswell (2009) argues that for mixed-methods researchers both quantitative and qualitative methods should be used to complement each other, as they have the potential to provide the best understanding of the problem under investigation.

Cherryholmes (1992), Morgan (2007) and Creswell (2009) indicate that pragmatism is not committing to any one system of philosophy or reality. It is different from positivism (quantitative) and constructionism (qualitative). Pragmatists have a freedom of choice. In this way, researchers are free to choose the methods, techniques and procedures of research that best meet their needs and purposes. The flexibility of the pragmatic paradigm facilitates the adoption of the elements of other paradigms. Morrow (2007) argues that to expect a research topic to fit within the boundaries of a single paradigm would be to oversimplify the beliefs,

and that paradigms can be ‘crossed’ (Morrow, 2007, p. 214) if determined by the research question and emerging data.

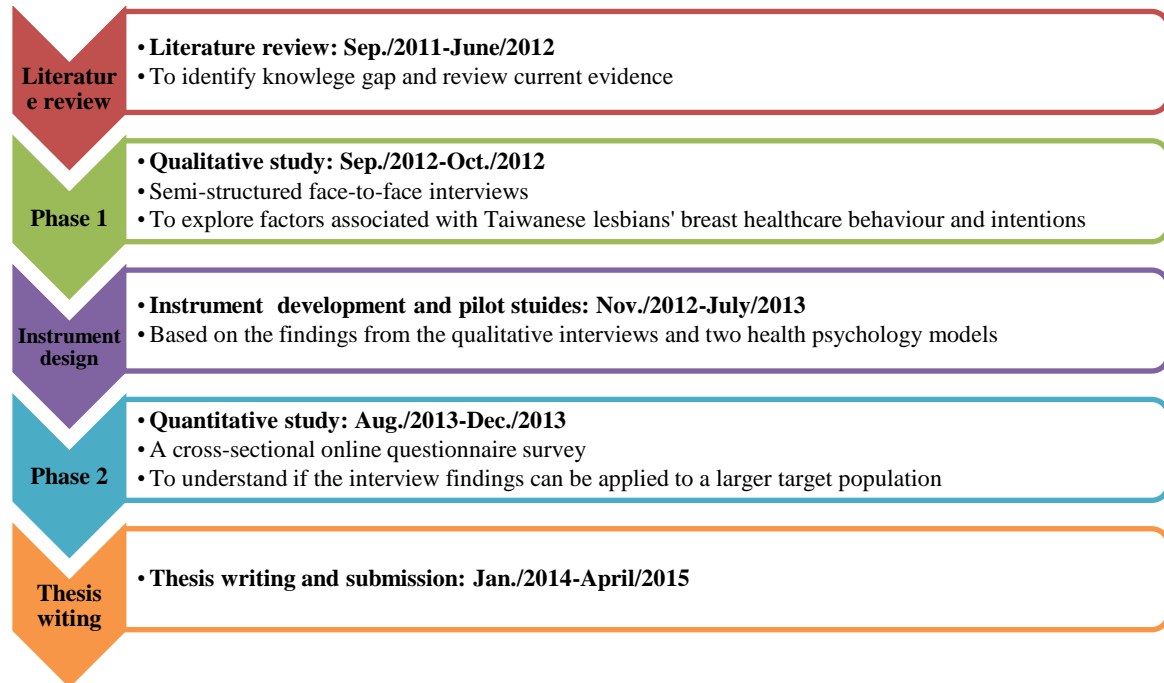
Pragmatism provides a philosophy that embraces mixed-methods designs. It guides the research clear from the metaphysical concepts of truth and reality that cause endless and unresolved debates, and presents highly practical solutions to the research problem (Tashakkori & Teddlie, 1998). It has been suggested that it can provide rigour to the research process as well as provide valid and reliable results, that it can provide stronger evidence for a conclusion through convergence and corroboration of the findings, that it can add insight and understanding which might be missed if only a single method is employed, and that it can be used to increase the generalizability of the results (Johnson & Onwuegbuzie, 2004).

Moreover, a mixed-methods approach allows both an inductive and a deductive investigation to take place in the same project. This design incorporates both sequential and concurrent data collection. A theme and an advantage of using concurrent designs is the ability to see the context from a variety of perspectives; for example, triangulation. Sequential designs, on the other hand, use the analysis of one form of data to inform the collection of the second form of data. In any mixed-methods design, the data may be combined by embedding, merging or connecting (Creswell, 2009). In sequential exploratory mixed methods, the emphasis is on the qualitative first phase, the findings of which are tested in the second-phase quantitative study (Hesse-Biber, 2010). This design is seen to be useful to the researcher who wants to explore a phenomenon but who also wants to expand upon the qualitative findings (Creswell & Clark, 2007; Morgan, 1998). It is also recommended as the procedure of choice when the researcher needs to develop an instrument because the existing instruments are inadequate or else not available (Creswell & Clark, 2007; Morgan, 1998). Hanson et al. (2005) suggest that such a design is ideal when the variables to be investigated are not known and where elaboration of the findings is required. In addition, Creswell and Clark (2007) state that this strategy is straightforward to design, implement and report, and that the inclusion of a quantitative element makes the qualitative inclusion more acceptable to quantitative-biased audiences.

A two-phase sequential exploratory mixed-methods study design was applied in the present study (see Figure 3.1). In addition to exploring the factors associated with Taiwanese lesbians’ breast healthcare behaviour and intentions, a questionnaire was developed based on

the first-phase interview findings. The questionnaire was then used to understand if the interview findings could be applied to a larger target population.

**Figure 3.1 The research framework**



A sequential exploratory mixed-methods study design, however, has been suggested as having some weaknesses (Johnson & Onwuegbuzie, 2004). For example, it might be more time consuming, more expensive, and researchers might need to learn about multiple methods and approaches and understand how to mix them appropriately. Another weakness suggested by Johnson and Onwuegbuzie (2004) and Bryman (2012) is that methodological purists argue that a researcher always should work within either a qualitative (constructivist) or a quantitative (positivist) paradigm and not mix the two. Bryman (2012) points out that there are two main arguments against mixed methods: 1) research methods carry epistemological commitments (every instance of research is rooted in a specific way of perceiving the world; Hughes, 1997); and 2) the two approaches represent separate paradigms (qualitative and quantitative research methods are incompatible; Morgan; 1998).

In the present study, time was the biggest challenge to the researcher. She needed to learn both qualitative and quantitative approaches, to collect and analyse both sets of data, and to design and test a questionnaire. Hence, a six-month PhD study extension was applied to ensure the rigour of both studies and the quality of the thesis. In terms of the arguments that qualitative and quantitative studies cannot be mixed, they were considered by the researcher

according to the previous evidence proposed by pragmatists (Cherryholmes, 1992; Creswell, 2009; Morgan, 2007; Morrows, 2007; Patton, 1990; Tashakkori & Teddlie, 1998), the goals of the present study and a lack of instruments to explore Taiwanese lesbians' breast healthcare behaviour and intentions and the influencing factors. A mixed-methods research design was thought as the most appropriate design to meet the study objectives: 1) to explore the factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions; 2) to develop a suitable instrument for the target population; and 3) to understand a larger target population's breast healthcare behaviour and intentions and their influencing factors by using the instrument developed specifically for the subgroup. In addition, this design was also considered as providing rigour to the research process, providing more reliable results, and also increasing the generalizability of the results (Johnson & Onwuegbuzie, 2004).

### **3.3 Application of sequential exploratory mixed-methods to the current study**

As can be seen in Figure 3.1, this study included two phases: qualitative interviews and an online survey. In this section, the rationales of the chosen study design are described. The detailed methods employed in each phase are provided in Chapter 4: Phase one methods, and Chapter 8: Phase two online survey.

#### **3.3.1 Phase one: semi-structured face-to-face interviews**

A literature review conducted by the researcher revealed that there was a lack of evidence for understanding Taiwanese lesbians' breast healthcare behaviour and intentions and their influencing factors, and that there was no instrument that could be used to investigate and compare the behaviour and intentions towards having breast cancer screenings between Taiwanese lesbians and women in general in Taiwan (details can be seen in Section 2.6). Qualitative interviews were therefore initially used in the first phase of this study in order to obtain rich data about the factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions, as well as to develop themes for a detailed rendering of the complexity of this phenomenon.

Focus groups and face-to-face (individual) interviews are two of the most commonly used forms of qualitative research methods. They are useful for exploring participants' attitudes and opinions in ways which may not be possible through participant observation (Mason, 1996). Focus groups were not employed in this study due to characteristics of the target population. Taiwanese lesbians were a hidden subgroup within their society. In order to

promote confidentiality and anonymity and avoid potential harm from others, face-to-face interviews were conducted because they involve only the researcher and the participant. With only the researcher and the participant present, the lesbian could express her ideas freely, without interruption or fear of discrimination from others, although the researcher (interviewer) nonetheless needed to consider her influence on the participant.

Interviewing is a method in which researchers attempt to understand what people think and feel about their words through an interaction between themselves and interviewees. Interviewees are encouraged to express their feelings, understandings, stories and narratives about their lives. From this information provided by interviewees, researchers acquire a deep understanding about research phenomena (Kvale, 2008). There are two types of qualitative interviews: unstructured and semi-structured interviews. Unstructured interviews are the most in-depth and least directed. They are used to explore in great detail a general area of interest. A few themes may be used to guide the interview, but it is mainly led by the participant's perspective and viewpoint. This type of interview is informal and can appear more like a conversation than an interview (Tod, 2007). Semi-structured interviews work well for obtaining in-depth information and they are flexible. The interviewer uses a topic guide and asks questions to encourage the interviewee to express details associated with the research purpose/aim and to ensure that all topics are covered during the interview (Backman & Kyngäs, 1999; Robson, 2011; Starks & Trinidad, 2007). The wording and order in semi-structured interviews are usually substantially modified based on the flow of the interview process, with the ability to ask extra unplanned questions to follow up on what the interviewee has said to obtain more in-depth information (Robson, 2011).

Semi-structured face-to face interviews were used in the first phase. The justification for choosing this method was twofold. Firstly, the target population was considered to be a vulnerable group. Vulnerable groups are "certain population groups that often face discriminatory treatment or need special attention to avoid potential exploitation" (Reichert, 2006, P. 78). As Taiwanese women's roles are being regulated and conceptualised within conventional Chinese culture. Being a lesbian in Taiwan is to go against conventional Confucian ideology because the woman cannot satisfy patrilineal obligations and maternal productivity as heterosexual women. Taiwanese lesbians, particularly lesbians with a masculine appearance, usually face sexist insults and homophobic comments in their social surroundings (Chao, 2000; 2001). Hence, in this study, the researcher considered Taiwanese

lesbians as a vulnerable group and needed to pay special attention when conducting research with this subgroup. Face-to-face individual interviews could prevent possible harm from others and to promote confidentiality and anonymity. Secondly, this method provides certain flexibility for the participants such that the women could express the issues that they also thought important to their breast healthcare behaviour and intentions, though also some key information was obtained from the women according to the topic guide.

### **3.3.2 Phase two: cross-sectional online survey**

In order to understand whether the interview findings can be applied to a larger target population, the findings from the qualitative interviews were used to develop a questionnaire to collect quantitative data. An online questionnaire survey was conducted to examine Taiwanese women's breast healthcare behaviour and intentions and the influencing factors in the larger population.

A survey is a method of inquiry which involves the systematic collection of information across a sample of cases, a statistical analysis of the results, and a subsequent interpretation of the distribution of the wide range of the participants' characteristics, opinions and attributes (Robson, 1993; Marsh, 1982). It allows the researcher to collect data in real and potentially complicated circumstances and enables him/her to capture the attributes of the variables and their associations with others.

There are two commonly used formats for collecting survey data: interviews (face-to-face interviews and telephone interviews) and questionnaires (paper-pencil surveys and web-based surveys). Collecting survey data via interviews is suggested as having greater flexibility in allowing for the opportunity to re-interpret a question that a participant does not understand (Tod, 2007). A questionnaire survey is a strategy that asks respondents to complete and return a form containing sets of questions, aiming to understand the respondents' perceptions, attitudes and behaviours (Aldridge & Levine, 2001). It is often used because it is cost-effective. This is especially true for studies which include a larger sample size and wide geographic access. In contrast to interviews, self-administered questionnaires have limitations in that the researcher has no opportunity to find out whether the respondents understand the instructions and questions. Questionnaire respondents have to read, interpret and answer the questionnaire by him-/herself (Trochim, 2006).

In this study, questionnaires were employed because: 1) it was considered to give the participants a more confidential and convenient way to take part in the study; 2) the purpose of this study was to survey a larger target population, and face-to-face interviews were considered to be time-consuming should the researcher want to obtain a larger sample size; and 3) telephone interviews were thought to be inappropriate because there was no phone list available.

Traditionally, questionnaires are distributed by post or by hand (McKenna et al., 2007). In contrast to postal questionnaires, a questionnaire handed out personally has the advantage that the respondents connect it with an individual or an organization, and this may improve the response rate (Edwards et al., 2002). Recently, researchers have been distributing questionnaires by email using a distribution list or by simply asking respondents to complete an online questionnaire (Morris et al., 2004). This method is found to elicit less social desirability bias for studies investigating highly sensitive issues (Booth-Kewley et al., 2007; Greene et al., 2008; Huang, 2006; Kays, 2012).

In this study, an online questionnaire was used to collect data because of the characteristics of the target population and the sensitivity of the study topic. Sexual minority populations are not very visible in Taiwanese society due to stigma and social oppression (Kuang et al., 2004). Mathy (2002) pointed out that, on the Internet, lesbian and bisexual females are more likely to reveal themselves on certain websites, homepages or chat rooms. Therefore, in order to recruit a larger and more varied Taiwanese lesbian sample and encourage this subgroup taking part in the study, an online questionnaire survey was used as a method in this study due to its characteristics of being easy for unique populations to access (Wright, 2005), anonymous (Mustanski, 2001; Pealer et al., 2001) and convenient for the respondents (Madge & O'Connor, 2002). This online survey design aimed to make use of the confidential and anonymous nature of the Internet to facilitate the women's participation and their responses to sensitive questions regarding their sexual orientation, gender identity, gender role expression and breast healthcare intentions and behaviours.

In this study, both the qualitative and quantitative methods had their own rules on data collection, data analysis and evaluations of the quality of the findings. The results of the two methods are first presented separately and then synthesized at the end of the thesis in Chapter 9. Convergent results may indicate the trustworthiness of the findings initially obtained from



the qualitative interviews. Divergent results may be an indicator that biases are attached to any one of the research methods. However, these divergent results may also indicate different viewpoints or perspectives that were identified by the different research methods, and so they are considered to facilitate the understanding of the research topic (Erzberger & Kelle, 2003).

### **3.4 Summary**

A two-phase sequential exploratory mixed methods study design was employed to explore the factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions. Semi-structured face-to-face interviews and an online survey were chosen and used due to the study purposes, the characteristics of the target populations and the sensitivity of the study topic. The next chapter will present and discuss in detail the methods used in the first-phase qualitative interviews.

## **Chapter 4: Phase one – methods**

### **4.1 Introduction**

This chapter aims to look at the methods employed for conducting the first phase of the mixed-methods sequential exploratory study – the qualitative interviews. The first part deals with the aims of the study, followed by a discussion on gaining access for the fieldwork, the sampling and recruitment, the procedures of data collection and data analysis, as well as the ethical considerations of the study. The strategies used for ensuring the rigour of the qualitative interviews are presented at the end of this chapter.

### **4.2 Aim**

The purpose of this study is to explore the factors that influence Taiwanese lesbians' breast health behaviour and intentions. Based on the findings from the qualitative interviews, the intention was to design a questionnaire in order to assess whether the findings of this study could be applied to a larger population.

### **4.3 Gaining access for fieldwork**

Gaining access to the subjects in the field is considered important in ensuring success when conducting research (Gummesson, 2000; Johl & Renganathan, 2009; Laurilla, 1997; Wasserman & Jeffrey, 2007). However, one of the most common challenges when conducting a study on homosexual people is that it can be hard to approach the population (Fish, 2000; IOM, 2011). Fear of discrimination and social isolation within the homosexual community have been found to prevent researchers from reaching individuals (Sullivan & Losberg, 2003).

As Taiwanese lesbians were a hidden group in Taiwanese society and there was no previous indication of how to access the target population, possibilities for approaching Taiwanese lesbians were investigated before the study was designed. The Google search engine and a list of LGBT organizations and communities (which were listed by the Taiwan Tongzhi Hotline Association) were used to find accessible Taiwanese lesbian organizations and communities.

An investigation was carried out using emails and telephone calls to contact Taiwanese lesbian communities between 26 September 2011 and 9 October 2011 in order to confirm the

method to be used to approach the subgroup and to acquire a general idea about the potential number of eligible participants. A total of eight lesbian organizations, two gay/lesbian bookstores and one lesbian student association were contacted. Of these, four organizations, one bookstore and the student association agreed for the proposed study to be advertised and/or conducted in the areas where these organizations were located.

The qualitative interviews were carried out from August 2012 to October 2012. The lesbian organizations and the bookstore which agreed to advertise the study were contacted again before the study started. The lesbian student association was not considered because the study was conducted during the summer holidays. An appointment was made with all of the organizations' managers and the bookstore's owner so as to explain the aim of the study and the procedures for data collection and data protection. In addition, the study's posters (Appendix 5, p.291), flyers (the content being the same as the poster design), participant information sheets (Appendix 6, p.292) and consent forms (Appendix 7, p.295) were given to the managers and the bookstore owner at the end of the meeting to advertise the study.

In order to recruit eligible individuals with varied demographic characteristics, the researcher attempted to recruit the participants from four main areas of Taiwan, namely North, South, East and West Taiwan. There was no means to approach the lesbians in East Taiwan within the organizations and communities. The researcher, therefore, asked one organization's manager if she could introduce any potential contacts in East Taiwan. Two organizations were introduced by the manager. One organization was located in East Taiwan and the other was located in North Taiwan. Both organizations were contacted in order to ensure that as many lesbians as possible knew about the study. The organization located in East Taiwan agreed to advertise the study but the one which was located in North Taiwan did not agree because the study's aims were not related to the organization's future targets. Overall, therefore, a total of five lesbian organizations and one bookstore agreed to help by advertising the study. One of the organizations and the bookstore were located in North Taiwan, two of the organizations were in West Taiwan and one was in East Taiwan. One of the organizations had two locations, one in North Taiwan and the other in South Taiwan. Table 4.1 summarizes the names of the organizations and communities and their locations. The methods used to advertise the study in these locations are also presented in the table.

**Table 4.1: Access for the study's fieldwork**

<b>Names of organization (locations in Taiwan)</b>	<b>Methods of advertising</b>
Taiwan LesHand Association (North Taiwan)	■ Posted information about the study on the website.
Fembooks publishing house and bookstore (North Taiwan)	■ Put flyers on the bookstore's information desk.
Taiwan Tongzhi Hotline Association (North and South Taiwan)	■ Announced the study at the beginning of their regular meetings.
Libro Central (West Taiwan)	■ Advertised the study in the monthly e-handbook. ■ Announced the study at the beginning of their regular meetings.
GisneyLand (West Taiwan)	■ Posted the study's poster on the organization's board. ■ Posted information about the study on a lesbians' chatroom (BBS: Bulletin Board System).
Must Muster Publisher (East Taiwan)	■ Posted information about the study on a 30s lesbian discussion board (lesbians who joined in were aged 30 years and above). ■ Posted information about the study on the bookstore owner's Facebook homepage.

#### **4.4 Sampling and recruiting lesbians**

This section mainly presents and discusses the inclusion and exclusion criteria, the sampling strategies, recruitment and the sample size.

##### **4.4.1 Inclusion and exclusion criteria**

Clear criteria for the inclusion and exclusion of lesbians were established in order to meet the study's purpose and to reflect the definitional issues of 'lesbian' within the previous evidence (see Section 2.6.7 critical appraisal of the evidence) and the legal definition of 'adult' in Taiwan. The criteria for the selection included Taiwanese women who:

- (1) were 20 years of age or over;
- (2) *self-defined* as a lesbian or partnered with someone of the same gender;
- (3) had fluency and the ability to communicate with the interviewer in either Mandarin or Taiwanese Hokkien.

The age was set in order to recruit lesbians who were legally defined as 'adults' in Taiwan. The target population in this study was Taiwanese lesbians. However, the definition of 'lesbian' could vary within the target population. This might have the effect of some lesbians not taking part in the study because they may think they would be excluded. Roberts et al. (2004) point out that the variation in the definition of lesbian is a challenge when conducting

lesbian research. In recent lesbian-focused breast healthcare articles, self-identification – or self-defining – as a lesbian was still employed as an inclusion criterion to recruit participants in lesbian studies (Fish, 2006; Fish & Anthony, 2005; Fish & Wilkinson, 2003<sub>a</sub>; Fish & Wilkinson, 2003<sub>b</sub>; Grindel et al., 2006; Hart & Bowen, 2009). Evidence shows that some lesbians do not think that they are a ‘lesbian’, and just ‘partner with a person who is of the same gender’ (IOM, 2011). Therefore, the inclusion criteria in the present study included not only ‘self-identified as a lesbian’ but also ‘women who partnered with the same gender’. The language was set due to the researcher’s own language limitations. In Taiwan, apart from Mandarin and Taiwanese Hokkien, several other languages are used by Taiwanese people, including Hakka and aboriginal languages (there are approximately 26 Taiwanese aboriginal languages) (Zeitoun & Yu, 2005).

On the other hand, the exclusion criteria for this study included participants who:

- (1) were not Taiwanese lesbians;
- (2) could not understand or speak Mandarin or Taiwanese;
- (3) had been diagnosed with breast cancer.

Regarding the exclusion criterion of lesbians who had been diagnosed with breast cancer, research indicates that the breast healthcare behaviours, beliefs and expectations of women who have been diagnosed with breast cancer differ from those who have no personal history of breast cancer (Clark et al., 2003; Lopez et al., 2009; Luo et al., 2001; Nekhlyudov et al., 2003). Therefore, in the present study, lesbians who had been diagnosed with breast cancer were excluded.

#### **4.4.2 Sampling strategies and recruitment**

Purposive sampling and snowball sampling were employed to recruit the participants in this study. The rationale and methods of recruiting the participants by using these two sampling strategies are provided in the following subsections.

##### **1) Purposive sampling**

Purposive sampling is a method of recruiting specific sample elements because the researcher believes that the sample is likely to supply the most useful information associated with the

research questions (Binson et al., 2007). It is suggested to be the most common qualitative sampling strategy (Marshall, 1996).

In the present study, the initial sampling was purposeful, driven by the aim of incorporating variation in the sample in order to acquire rich and useful information about the topic to be researched. The participants were recruited from the LGBT organizations and communities which were located in different areas of Taiwan. The staff in the organizations and the bookstore who met the inclusion criteria were invited to take part in the study. Posters and flyers were used to advertise the study in order to recruit other participants. With the manager's consent, the study was advertised on the organizations' websites and the bookstore owner's Facebook homepage and lesbian discussion board so as to ensure that as many lesbians as possible would learn about and understand the study and to facilitate them to take part in the study. In addition, the study was presented at the beginning of the organizations' regular meetings with the manager's consent. The study's purpose, methods and potential harm and benefits were explained. When a potential participant contacted the researcher and expressed her willingness to participate in the study, a flyer, a participant information sheet and a consent form were given via email. By the end of the study, each LGBT organization and community recruited around five to seven participants.

## **2) Snowball sampling**

Snowball sampling was employed as the second method to recruit participants with specific characteristics; in particular, lesbians of older age (aged 40 years and above).

Snowball sampling is a method that relies on the initial participants to recruit others into the study using their social networks, being described as a 'chain-referral method' (Binson et al., 2007; Meyer & Wilson, 2009). The sample development starts when individuals of the target population are identified and recruited as seeds who will identify others who meet the study's inclusion criteria. Snowball sampling is suggested for use in early studies of sexual and gender minorities and continues to be employed when previously unstudied population groups are engaged in research (IOM, 2011).

In the present study, snowball sampling was employed due to the difficulty in recruiting older lesbians. The initial participants recruited from the organizations and communities were asked if they knew of other potential participants aged 40 years or over. When the

participants agreed to introduce the study to the potential participants, flyers and information packages (including information sheets, consent forms and the researcher's contact information) were given to them to pass on to the eligible women.

All of the participants were given a minimum of 24 hours and up to as much time as they wished to take during the data collection period to consider participating. The researcher's contact information, including email address and mobile phone number, was provided on the flyer and participant information sheet. When a participant contacted the researcher and expressed agreement to participate in the study, the time, date and place of the interview was arranged.

### **3) Lost contact**

During the data collection period, the researcher lost contact with two individuals for unknown reasons. Initially, they contacted the researcher by email and agreed to take part in the study, but they did not reply to emails about arranging an interview. A second email was sent a week after the first email in order to ensure that the individuals received the emails and to eliminate email system errors. However, there was still no response from the women by the time the data collection had finished.

#### **4.4.3 Sample size**

Sample sizes in qualitative studies tend to be much smaller than in quantitative studies (Mason, 2010). Ritchie et al. (2003) point out that collecting more data in qualitative studies does not lead to more information. However, Corbin and Strauss (1990) suggest that the sample size in qualitative studies should be large enough to ensure that most or all of the perspectives are obtained, even though this approach can be time consuming and/or costly. The principle used to determine the sample size is data saturation, meaning that the data are collected and analysed until no new themes or perspectives can be identified; it is assumed that all the component parts of the phenomenon of interest have been obtained (Corbin & Strauss, 1990; Procter & Allan, 2006). Guest et al. (2006), however, suggest that although the idea of saturation is helpful at the conceptual level, it gives little practical guidance for estimating sample sizes for study prior to the data collection. Researchers propose that suitable sample sizes for conducting qualitative studies should range from 20 to 50 participants (Green & Thorogood, 2009; Ritchie et al., 2003). Mason (2010) investigated 560 PhD studies to collect data using qualitative interviews, finding that the mean sample size of

the PhD studies was 31. In addition, the sample sizes in recent qualitative interview studies investigating US, UK or Taiwanese women's and lesbians' breast healthcare behaviours are around 27 (Clark et al., 2003; Nekhlyudo et al., 2003; Ku, 2004).

In the present study, the researcher noticed that when the last five to seven participants (ID 30-37) were interviewed, no new themes or perspectives were identified from the lesbians. Based on the previous studies discussing the sample size of qualitative research and given that there was no new data from the new cases in relation to the study topics in the present study, the number of participants was considered to be reasonable to answer the research question.

#### **4.5 Data collection**

Semi-structured face-to-face interviews were used to collect data from the participants in the phase-one qualitative study. Details of the methods, in terms of the structured questionnaire and the topic guide, the settings and the data collection procedure, are presented in the following subsections. The influence of the interviewer during the data collection period is discussed towards the end of this section.

##### **4.5.1 The structured questionnaire and the topic guide**

With semi-structured interviews, an appropriate schedule is necessary to achieve the right balance of direction and flexibility. This means that the central research question is then addressed as well as allowing new and interesting responses to be discussed further (Tod, 2007).

In this study, a structured questionnaire (Appendix 8, p.296) and a topic guide (Appendix 9, p.297) were developed and used during the first-phase data collection period. The structured questionnaire was mainly used to collect the participants' demographic information and the topic guide was designed based on the study's initial purpose: to explore the factors associated with the subgroup's breast healthcare behaviour.

The sample's background information has been suggested as being useful for contextualizing the individuals' answers (Bryman, 2012). The questions were designed based on the literature concerning the factors that influenced women's breast healthcare behaviour, namely age,



family history of breast cancer, occupation, level of education, employment status, relationship status and religion.

Details of the existing evidence regarding age, family history of breast cancer, income and level of education as influencing factors in women's breast healthcare behaviour, intentions and decision-making can be seen in Section 2.6 of the literature review. Although income was identified as an influencing factor, questions related to the participants' income could raise sensitive issues (Colosi, 2006). Therefore, questions about the lesbians' occupation and employment status were asked instead of asking about the lesbians' income directly. In addition, being married was also found to be an influencing factor among US heterosexual women by Coughlin (2004). Hence, a question in relation to relationship status was asked in order to understand the lesbians' breast healthcare behaviour and intentions within varied relationship status groups. Lastly, a question about religion was also asked because it was found to be a factor affecting Taiwanese women specifically (Ku, 2004), and so had been included as one of the important demographic variables in this study.

There were eight questions in relation to breast cancer screenings, breast healthcare services and breast cancer included in the topic guide. It was developed based on the existing evidence (see Section 2.6). The questions in the topic guide were ordered according to their level of sensitivity because it has been suggested that the inappropriate timing of questions might sabotage the interview (Tod, 2007). Tod states that less sensitive questions should be asked at the beginning of the interview, and if rapport and trust are established during the interview period, it becomes possible to ask questions of an extremely sensitive nature. The questions about breast cancer screenings in the topic guide helped the researcher to understand the participants' experiences of performing and having breast cancer screenings. If the participant had no experience in relation to the screenings, questions about her intentions regarding breast cancer screenings and the influencing factors were then asked.

#### **4.5.2 The setting for the interviews: issues of interruptions and management**

Of the 37 interviews, 13 were conducted in the participant's house, four in a consulting room of the Taiwan Tongzhi Hotline Association, and 20 in cafes, tea rooms or restaurants.

Private and quiet places are suggested as ideal settings for obtaining rich information from participants, maintaining confidentiality and recording the interviews (Britten, 1995; Carey, 2012). In this study, when the interview was held at the interviewee's home or in a consulting

room in an organization, the setting was quiet, with only the researcher and the participant present. The participant usually paid full attention when answering the questions or expressing her views in relation to the study topics. There were no sudden stops during the interview period because of others' interruptions. The information provided was considered to be less affected by these settings, due to their privacy, when compared to public places.

Over half of the participants decided to have their interview in a public place in this study. Fourteen out of the 20 participants chose to have the interview in a coffee shop, particularly Starbucks, four in tea rooms, one in McDonald's and one in a restaurant. Apart from the restaurant, the majority of these places are usually frequented by students and white-collar workers in Taiwan, and they are commonly places for meeting people for the first time. For example, it is very common for students to have a private English conversation lesson in Starbucks, particularly when it is their first meeting with the tutor. In addition, these places are also the top choice when needing a quieter place to meet people, although they can be very busy during the weekend and interruptions may occur.

Three interviews were conducted in coffee shops during the weekend. Interruptions were more likely to occur if the interviews were conducted on Saturday or Sunday than if they were conducted on a weekday. During the weekend, the coffee shops were much busier and more crowded. The researcher observed that sometimes the interviewees stopped talking for several seconds and then continued what they had been talking about when the interrupter had walked away. Thus, it should be considered that the depth of information provided by these three participants might have been affected by the interview settings. Even though the women expressed that they did not mind talking about the issues in these places, their reactions actually evinced their concerns regarding the environment and interactions with other clients.

In terms of the methods that the researcher employed to limit possible interruptions, to ensure the participant's confidentiality and to make sure that they felt comfortable to talk, she went to the cafe, tea room or restaurant 30 minutes earlier and chose a table which would lead to fewer interruptions, provide more privacy and where there were no other customers sitting nearby. Before the interview started, the researcher introduced herself and asked the participant whether the place was appropriate to discuss issues related to their views on breast cancer, breast healthcare services and their own breasts. Of the 20 individuals, all of them

expressed that they felt comfortable talking about these topics in the place chosen. Some of the individuals mentioned that there was no one around who knew what the conversation was about, and so they did not feel uncomfortable about the interview location.

In addition, another issue that should also be considered is the quality of the recordings. The interview settings might have influenced the quality of the recordings, especially those interviews that were conducted in public areas during the weekend. Noise from other clients and background music might have resulted in poorer quality recordings. Details on improving the quality of the recordings can be seen in Section 4.6.3.

### **4.5.3 Conducting the interview**

In the present study, the process of data collection was divided into several stages, including the introduction, a warm-up, the main body of the interview, a cool-off and closure (Tod, 2007). The length of the interviews was dependent on how much time the participants had available and how much they wished to say. The length of the interviews varied from 42 minutes to one and a half hours, and overall they were about 60 minutes long.

#### **1) Introduction**

Before the interview was started, the purpose, method and process of the study were explained to the participant again in order to ensure that they fully understood the study. The researcher also informed the participant that they had the right to withdraw from the study at any time. Informed consent and permission to use a recorder were also obtained before the interview began.

#### **2) Warm-up**

During the warm-up stage, questions associated with the participant's demographic information were asked using a structured questionnaire. These questions were considered to be less sensitive than those related to the lesbians' views about breast cancer, breast cancer screenings and their breast healthcare behaviour and intentions.

#### **3) Main body of the interview**

During the main body of the interview, a topic guide was used to check that all the issues related to the study's purpose had been covered. A less sensitive question was asked at the beginning of the main body of the interview; for example, asking about the participant's

experience of breast healthcare behaviours instead of asking about their perspective on their own breasts or breast cancer. Moreover, the interview process remained flexible in order to obtain deeper and richer information. The researcher encouraged the participants to explain further when the women thought that some factors influencing their breast healthcare behaviour and intentions were important, such as their gender identity and appearance. The researcher asked the lesbians why and how these factors were associated with their breast healthcare behaviour and intentions, as well as their views in relation to their own breasts, breast cancer and breast cancer screenings.

#### **4) Cool-off**

The main aim of this stage was to allow the interviewee to understand that the interview was nearly finished. No new topics were raised by the researcher. Clarifying the information provided by the participants and checking whether there was anything that they would like to add were the key objectives during this stage.

#### **5) Closure**

At the end of the interview, the researcher thanked the participant. A brief summary of the interview was given by the researcher to check whether the researcher had misunderstood anything the participant had said. After the interview, field notes were made to record the body language of the researcher and the interviewee, the setting of the interview, the events that occurred during the interview, a summary of the key themes that emerged from the interview and observational notes in order to assist the data analysis and to assess the interviewer's influence during the data collection period.

#### **4.5.4 Influence of the interviewer**

Qualitative research sees the researcher as not being separated from the phenomenon under study but being part of the research setting and context that is being studied (Altheide & Johnson, 1994). Horsburgh (2003) points out that reflexivity requires a researcher to acknowledge that he or she is intimately included in both the process and the product of the research. Consequently, it is suggested that the researcher should engage in a continuous self-critique and self-appraisal, and explain how his or her own experience have or have not affected the stages of the study process in order to make explicit their own subjectivity and influence in the study (Koch & Harrington, 1998).

The main aim of reflexivity is to improve the quality of the research. Barry et al. (1999) suggest that when employing a reflexive method in research, the researcher needs to be aware of this as much as possible. Methods for attaining a reflexive stance in research are recommended and involve maintaining reflective diaries, writing field notes, recording analytical and methodological decisions in memos, and being reflective about every decision that the researcher makes (Mason, 1996). As reflective diaries are mainly based on a researcher's own experiences, it seems to be appropriate to use the first person ("I") for descriptions. However, in academic writing, it has been suggested that one should always use the third person for writing and avoid emotive or subjective terms (Skills Website, Faculty of Humanities Study, University of Manchester, 2015). Hence, the third person (the researcher; she) was used instead of the first person ("I") in this section.

In the present study, the researcher did not attempt to eliminate her influence during the data collection process. She attempted to understand herself, including her values, preconceptions, feelings and social cultural background, which helped in acknowledging her influence. The researcher shared the same physical gender, race and social-cultural background, and was within a similar age range as the majority of the participants, all of which were considered to influence the development of the relationship between the researcher and the lesbians. She also found it was easier to understand the words that the lesbians used in the interviews due being of the same generation.

The researcher's sexual orientation (heterosexual, as an outsider), however, was considered to be a potential influence on the data collection process. Prior to the interview, the researcher and the participants would often engage in 15 to 30 minutes of informal conversation, and it was at this point that the individuals would often enquire whether the researcher was a lesbian, too. When the researcher was acknowledged as a heterosexual, more questions were asked by the participants in terms of the motivation for conducting the study and the researcher's views on homosexuality. The researcher was identified as an outsider of the subgroup by the participants, and this was considered to develop barriers between the interviewer and the interviewees at the beginning of the interviews. For example, some participants expressed: 'I do not think you will understand why *we* think ...' The participants usually used the word '*we*' to refer to Taiwanese lesbian women and to make a distinction between the researcher (heterosexual) and this group of lesbians. When the researcher met with this situation, she asked the participants to explain further their own views, feelings and

past experiences of not being understood regarding the above-mentioned issues, by asking questions such as ‘Can you explain what you mean....?’ or ‘What do you mean...?’ These questions assisted the researcher in clarifying the ideas that the participants reported and to identify the factors that influenced the lesbians’ behaviour and intentions regarding breast cancer screenings.

In addition, the researcher’s gender identity (feminine) was also considered to influence the data collection when conducting the interviews with those participants who self-identified as masculine lesbians. Three individuals mentioned that one of the reasons for taking part in the study was their responsibility as masculine-identifying people to help ‘a woman/feminine (the researcher)’. The researcher thanked them for their help and also indicated their right to withdraw from the study at any time that they wished should the study topics make them feel uncomfortable. In addition to the lesbians’ participation, the information provided by these lesbians was also considered to be affected. They might have withheld relevant information if they thought it might have caused them emotional discomfort or if they thought revealing it might have gone against the strict codes of being a T within lesbian communities, such as that Ts should conceal their female characteristics from Pos.

The researcher attempted to keep an open mind during the data collection period. Any preconceptions or assumptions that were made were put aside. Asking ‘why’ was considered to be valuable, which increased understanding of the phenomenon under investigation from the participants’ points of view. In addition, discussions about the interview data with the researcher’s supervisors were also useful. The researcher might not have been aware of some key factors because she was immersed in the data or else too close to the information; however, discussing the data with supervisors helped the researcher to clarify the key issues and to notice her influence during the data collection and data analysis periods.

#### **4.6 Data analysis**

The data collection and data analysis occurred simultaneously in order to preliminarily identify the factors influencing Taiwanese lesbians’ breast healthcare behaviour and intentions and to assess whether the data had approached saturation. The data saturation in this study occurred when no new theme (influencing factor) associated with Taiwanese lesbians’ breast healthcare behaviour and intentions was identified.

#### **4.6.1 Constant comparative analysis**

Constant comparative analysis was used to analyse the data collected from the qualitative interviews. It is a process that involves taking one piece of data and comparing it with other data that may be similar or different in order to develop conceptualizations of the possible relationships between various pieces of data (Glaser & Strauss, 1968). Glaser and Strauss also explain that the data can be compared with not only qualitative data from interviews, documents and observations, but also related information found in existing evidence. The differences and similarities in the data are explored. Ideas that are established within a category are compared with those that previously emerged in the same category. Through comparison, the properties and dimensions of the categories are produced and patterns are developed which enhance the explanatory power of these categories (Holloway & Todres, 2007). It has been suggested to be useful for generating knowledge about common patterns and themes within human experience (Thorne, 2000). According to the nature of the method, constant comparative analysis was employed to identify the factors that influenced Taiwanese lesbians' breast healthcare behaviour and intentions in the present study. The researcher attempted to compare the findings from the participants as well as with the existing evidence, to find participants who held different views from the majority of the participants (negative cases) and to understand how and why the differences occurred in order to identify the important influencing factors (especially the factors associated with the women's sexual orientation) so as to develop a suitable questionnaire for the target population.

#### **4.6.2 Computer-assisted qualitative data analysis software: NVivo audio-coding**

Computer-Assisted Qualitative Data Analysis Software (CAQDAS) has been indicated to have several advantages that assist researchers to manage data. It can be used to structure the work, instantly access data, explore data, manage large volumes of data, search and interrogate the database, and memo the ideas by using writing tools (Padgett, 2008; Robson, 2011). The computer software NVivo 10 was used in the present study to manage large volumes of data, to assist the constant comparative analysis, and to do audio-coding directly in NVivo 10 along with field notes and transcriptions, which only contained key information about the influencing factors and the women's breast healthcare behaviour and intentions.

Full transcriptions were not employed in this study. Traditionally, qualitative researchers produce immense quantities of text from interviews because pure qualitative research emphasizes deep exploration of the values, meaning, beliefs, thoughts, experiences and

feelings characteristic of the phenomenon under investigation (Halcomb & Andrew, 2005). A verbatim record is recommended as an accurate way of representing an interview, enhancing the quality of the data analysis, and allowing the researcher to become more familiar with the data (Evers, 2011; Matheson, 2007; Tilley, 2003).

Different views about transcribing interviews in mixed-methods research have been proposed in the previous research. Halcomb and Davidson (2006) examined the issues that arise after conducting interviews in mixed-methods research, with particular emphasis on the transcription and data analysis phases of the data management, and they discussed the necessity of transcribing all audio-recorded interview data verbatim, in particular in mixed-methods investigations. Mixed-methods research uses a combination of data collection and analysis procedures in either parallel or sequential phases (Teddlie & Tashakkori, 2009). It has purposes that are disparate from those of pure qualitative or quantitative studies. Mixed-methods research often uses qualitative data in conjunction with quantitative data to provide a sense of confirmation of the data through the enhancement of the validity and confidence in the findings, and a sense of completeness of the understanding of the concepts under investigation (Halcomb & Andrew, 2005; Teddlie & Tashakkori, 2009). The research questions within mixed-methods research often have a clearly different level of exploration from those in pure qualitative studies. The use of analysis techniques seeks to identify common ideas from the data and, consequently, does not necessarily require verbatim transcripts (Halcomb & Davidson, 2006). Halcomb and Davidson (2006) suggest that audio-coding with field notes can increase the representation and the cost-effectiveness of the data management, in particular in health services research and evaluation.

Similar views can also be seen in Wainwright and Russell's (2010) research. The researchers tested whether the analytical process of thematic coding, previously employed in the analysis of text-based data, can be replicated by working exclusively with audio-recordings using the applications available in NVivo. This ability has been suggested to increase an interview's confidentiality when it is considered inappropriate to outsource the transcription to a third party, to allow researchers to focus on analysing and understanding the data instead of making descriptive transcriptions, to keep close to the original data, and to save time and money. The software has also been found to facilitate working with audio based on the same process that the researchers are accustomed to with transcripts – systematic and rigorous



analysis – allowing researchers to work through an entire interview without neglecting sections, annotating and writing memos along the way (Wainwright & Russell, 2010).

In the present study, full descriptions were ‘*not*’ used for the following reasons. Firstly, it was considered to be inappropriate to outsource the transcription to a third party due to the participants’ sexual orientation. The voice of one of the lesbians might be identified by the individual transcribing the recording if they happened to know the lesbian. Unpredictable situations and harm might arise for the lesbian. Hence, the researcher did not choose to outsource the transcription to a third party. Secondly, it was thought that transcribing the recordings by the researcher herself would be time consuming and it might have required the researcher to spend a lot of time transcribing the recordings instead of focusing on the data analysis. As mentioned in Chapter 3, one of the drawbacks of the mixed-methods sequential exploratory design is that it requires a substantial length of time to complete both the data collection phases. Thus, in order to ensure that the researcher focused on the data analysis, stayed close to the original data and worked within the time constraints, NVivo audio-coding was used to analyse the interview data along with the field notes and transcriptions, which contained key information. It has been suggested that this method can be used to narrow the gap during the analytical process, as the researcher is sensorially closer to the data (Wainwright & Russell, 2010).

However, some practical challenges of NVivo audio-coding have been proposed by previous researchers (Wainwright & Russell, 2010). Wainwright and Russell have raised the criticism that the audio data is hard to review and locate. It is more difficult to stop and rewind an interview than it is for the researcher’s eyes to move back and forth across a printed page. In addition, researchers have to listen to the recordings several times in order to make sure that they do not misunderstand the data and categorize it into the wrong category, and that they select the most appropriate quotation that they would like to transcribe fully and use in publications.

In the present study, the above drawbacks were dealt with by re-listening to the recordings at least seven times in order to ensure that the data were understood and categorized correctly by the researcher and to locate the data accurately (i.e., when the reported issue started and when it ended). In mixed-methods studies, although the need for transcriptions when analysing the interview data by using NVivo audio-coding has been a matter of argument, the

transcriptions contained ‘key information’ and were imported into NVivo in this study. Therefore, the researcher could listen to the recordings and read the written words concurrently in order to narrow the gap between the data and the researcher. Details of how the researcher decided what ‘*key information*’ was transcribed, how she made the transcriptions and the advantages and disadvantages of this method of transcribing the data are provided and discussed in the following section.

#### **4.6.3 Data analysis procedure**

There were five steps in the data analysis process, which were developed based on Halcomb and Davidson’s (2006, p. 41) data management steps in order to manage the interview data through a reflexive, cost-effective and constructive process. These steps are described in the subsequent subsections.

##### **Step 1: Making field notes and reflective journalizing immediately after an interview**

After each interview, the researcher made field notes to record the interview setting, the interactions between the interviewer and the interviewee, observations on the interviewee’s reactions during the interview process and a reflection of the interviewer’s influence. A form was used to help the researcher to record and to reflect upon the interview (Appendix 10, p.298). Any major concepts, ideas or issues raised by the participants were documented. For example, when a participant expressed that their main concerns about having a breast cancer screening were strongly related to their gender identity and gender role, the researcher recorded the influencing factors and paid attention to whether they were also reported by other participants. Initially, the researcher did not have any related knowledge regarding lesbians’ gender identities, and did not realize that these were important influencing factors. After the first few interviews, she found that the lesbians’ gender identities and gender roles were mainly associated with the lesbians’ views, beliefs, behaviour and decision-making in their daily lives. The researcher reflected that her social background might have led to misunderstandings or incorrect assumptions in relation to the information provided by the participants. Hence, during the subsequent interviews, when the participants reported their breast healthcare concerns or past experiences in relation to their sexual orientation and gender identity, the researcher encouraged the women to explain further by using the questions: ‘What do you mean by...?’ or ‘How does it relate to your actions, intentions or views regarding...?’

## **Step 2: Listening to the audio recording and amending/revising the field notes**

After the researcher completed the field notes and the reflective journal, the researcher listened to the recording, consulting the notes in order to ensure that the notes provided an accurate reflection of the interaction. The recording was compared with the notes and the notes were revised where necessary by the researcher.

## **Step 3: Listening to the audio recording and making transcriptions concurrently**

After the field notes and reflective journal were completed, the audio recording was listened to at 0.5 speed using the Sony Sound Organizer. Due to the majority of the interview settings being public places, this software was used to improve the sound quality of the interviews and to minimize background music and noise such as chatter by employing the N- (Noise) cut function.

During this stage, each recording was listened to carefully by the researcher and a selective transcription was made concurrently. Although the necessity of transcription in mixed-methods research has been debated (Halcomb & Davidson, 2006; Wainwright & Russell, 2010), selective transcriptions were made in the present study in order to help the researcher to identify and summarize the influencing factors, to assist the questionnaire's development and to provide illustrative data for the findings chapter when writing the thesis.

Unlike traditional word-by-word transcription, the data for when the participants reported the influencing factors were selectively transcribed; for example, their concerns and/or past experience of performing a BSE or having a mammogram. The researcher identified the influencing factors while listening to the recordings and only transcribed key phrases. An example of the transcriptions used in the present study can be seen below.

### *Physicians and intentions towards having a mammogram and CBE*

*“Some lesbians feel uncomfortable about seeing a physician*

*Some physicians are friendly*

*Some are not because they do not know how to be friendly”*

*(ID 13, Po, 30 yrs)*

This method of transcribing the data was used to help the researcher to understand, interpret and categorize the data because she could read what factors were related to the participants' breast healthcare behaviour and intentions, and how frequently the women reported the influencing factors. The researcher could get an overall idea of what factors were 'important' and specific to the participants, and she therefore chose these factors to design the questionnaire for the second phase of the study.

However, this strategy might cause the researcher to miss some of the key words and/or terms, and therefore might lead to incorrect interpretations of the data, the wrong categorization of the data and/or inappropriate choice of factors for the questionnaire's design. In order to avoid missing key words or terms when listening to and transcribing the recordings concurrently, the researcher repeated this process at least three times before doing a more detailed data analysis. In addition, during the coding process, the researcher did the coding of both the audio recordings and the transcriptions so as to ensure the rigour of the study.

During this period, the preliminary data analysis was begun. The researcher attempted to obtain an overall understanding about the influencing factors in relation to the participants' behaviour and intentions regarding having breast cancer screenings, and to confirm what factors have already been proposed in previous research and what was specifically identified from the interviews. In the first five interviews, some factors were found to be strongly and specifically related to the participants' behaviour and intentions regarding having breast cancer screenings, in particular gender identity. In the following interviews, questions about the lesbians' gender identity and how it was related to their breast health were asked by the researcher in order to obtain a deeper understanding about the relationship between this factor and the lesbians' behaviour and intentions. In addition to gender identity, as more interviews were conducted with the lesbians, more important factors emerged. The researcher constantly compared the interview data for the lesbians with the existing evidence and added questions about the influencing factors which were found to be mainly and specifically associated with the women's breast healthcare behaviour and intentions, such as the lesbians' partners' support and the lesbians' views about their own breasts. These questions were asked in the following interviews.

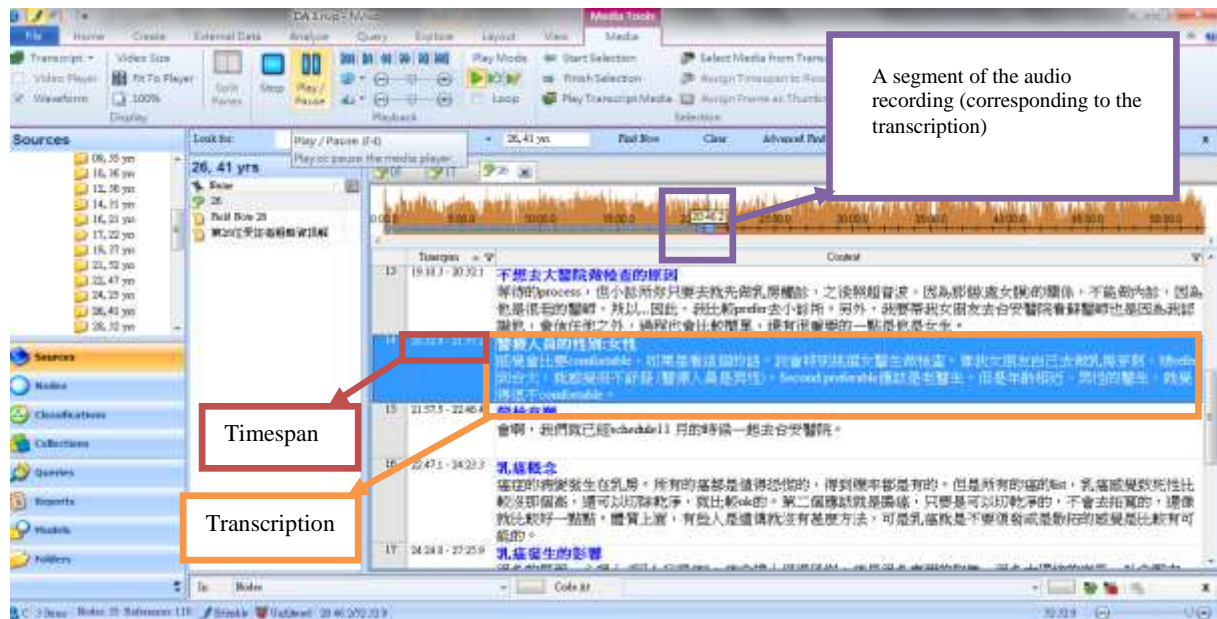
#### **Step 4: Audio-coding: open coding and axial coding**

Corbin and Strauss's (2008) approach (grounded theory) was used as the method for analysing the interview data in the present study because of the purpose of the qualitative interviews, the researcher's lack of experience in analysing qualitative data, and the detailed data analysis process proposed by Corbin and Strauss (2008). Usually, this approach is most useful when little is known about the topic or a phenomenon, and it is used to generate a theory via the strategies of open coding, axial coding and selective coding (Holloway & Todres, 2007). It should be noted that the purpose of the present study was to explore the factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions, not to build a theory. However, Corbin and Strauss (1990) indicate that if researchers are simply concerned with exploring or describing phenomena, open coding and axial coding would complete the analysis. The aim of open coding is to break down and conceptualize the data, and should start as soon as the researcher has collected the data. Types of coding include descriptive coding (for example, 'accepting advice') and *in vivo* coding (a direct quotation from the data). Robson (2011) suggests that open coding is essentially *interpreting* rather than summarizing. Axial coding involves linking together the categories developed through the open coding process (Robson, 2011). Corbin and Strauss (2008) indicate that axial coding leads to an understanding about the central phenomenon associated with an idea in terms of the context, the conditions that gave rise to it, the action and interaction strategies by which it is dealt with and their consequences.

During this stage, the audio recordings, field notes, reflective journals and transcriptions were imported into NVivo 10. Each interview was listened to again in consultation with the transcription. The data were examined for each concept that the participant proposed. Open coding was made directly in the audio recording using NVivo 10. Segments of the recording were attached with the transcriptions (an example can be seen in Figure 4.1). Thus, the researcher could retrieve the data (from the transcriptions or the recordings) easily when she examined the diagram of the influencing factors.

During the open coding, the researcher considered a set of questions; for instance, 'What is gender identity?', 'What is meant by being a T, Bufo or Po?', 'Why is it so important to maintain gender identity?', etc. The codes were then examined for similarities and differences, and compared and clustered together to create categories. These categories were systematically compared and contrasted to establish more inclusive categories.

**Figure 4.1: Open coding**



Variations within the categories were investigated through constant comparison and by investigating negative cases. The search for negative cases, which seemed to contradict the emergent themes or categories, was an analytical strategy that aimed to improve the quality of the research accounts and acknowledge the importance of multiple perspectives (Seale, 1999). In this study, the researcher compared the audio-coding, subcategories and categories with/within the participants. When a view was reported which was different from that of the majority of the participants, the reasons for contributing the view would be considered and the women's social and demographic background and their past experiences in relation to the topic would be compared to their counterparts. For example, the majority of the lesbians preferred a female healthcare physician to provide breast healthcare services to them; however, two out of the 37 participants expressed their preference for a male healthcare provider. In this case, the researcher considered the variation by comparing the two lesbians' gender identities, gender role expression, age ranges and views about their own breasts, breast cancer and breast cancer screenings with those of the lesbians who preferred a female physician. The audio recordings were listened to at least five to seven times in order to ensure the accuracy of the coding, to avoid misunderstanding what the participants really meant, and to distinguish the differences and similarities among the participants.

Codes and categories were developed quickly during the early stage of the research. A number of influencing factors associated with Taiwanese lesbians' breast healthcare

behaviour and intentions were identified. By the end of the data collection, no new themes emerged, the categories became saturated and their relationships were established. Memos and diagrams were used throughout the data analysis process to document the analytical process and record ideas about the emerging codes and categories and their relationships.

### **Step 5: Data presentation**

Writing up qualitative findings includes presenting quotations to enable the reader to assess how the findings have been derived from the data. Quotations give the reader an insight into the participants' experiences, exemplifying, illustrating and illuminating the findings (Holliday, 2002). As mentioned previously, the challenges involved in using NVivo audio-coding are the difficulty in reviewing and locating particular utterances and it being hard to decide where and when to present an audio quote (Wainwright & Russell, 2010). These challenges also existed during the data analysis process in this study. Therefore, the researcher attempted to overcome these challenges by listening to the recordings five to seven times to ensure when the participant started and finished talking about a particular issue, to check that all of the key words, terms and phrases had been transcribed, and that the audio quote was related to the issue discussed. The selective transcriptions were modified, if needed. They helped the researcher to review and locate utterances and to select the most appropriate quotations to use in the thesis.

In addition, how the researcher selected the quotations presented in the thesis was related to a variety of purposes, including: 1) showing variation in the lesbians' experiences (including negative cases) or their concerns; 2) providing vivid descriptions that encapsulated the lesbians' concerns or experiences, extracts that involved multiple features of a theme or which best exemplified a particular category or theme. The researcher attempted to ensure that particular participants' views did not dominate the findings and that they reflected how the researcher was making these decisions while selecting the quotes, which as has been suggested are subjective decisions (Richardson, 1990).

### **4.7 Ethical considerations and the researcher's safety issues**

Ethical approval for conducting the qualitative interviews was obtained from the Research Ethics Committee 3 at the University of Manchester (Appendix 11, p.299). According to the study's aim, methods and target population, four ethical issues were identified within the study, including informed consent, confidentiality, autonomy and potential harm.

## **1) Informed consent**

Consent should be obtained before an interview is conducted. Detailed information related to the nature of the research needs to be provided before obtaining consent from the participants (Allmark et al., 2009). In addition, potential participants should be provided with adequate time to reflect upon the implications of participating and so as to not feel pressurized into taking part (Tod, 2007).

In the present study, each of the participants was given a written information sheet that contained information associated with the research's purpose, method and process, the rights of the participants, and the benefits and potential harm of participating in the study. A minimum of 24 hours and up to as long as they wished to take during the research's data collection period (August 2012-October 2012) was given for all the participants to read the information sheet and decided whether or not they wished to participate. In addition, the researcher went through the information sheet and the consent form with the participants to ensure that they fully understood the study before the data collection commenced.

## **2) Confidentiality**

Platzer and James (1997) point out that lesbians and gay men have concerns about their confidentiality when taking part in studies. The names and identities of the interviewees should not be revealed in the process of data collection, analysis and reporting of the study so as to protect their anonymity and confidentiality (Tod, 2007). Studies conducted with homosexual people in the US have used pseudonyms as a method to obtain informed consent, to encourage homosexual individuals to participate in studies (Kitts, 2010; Zaritsky & Dibble, 2010) and to protect their confidentiality and anonymity (Chur-Hansen, 2004; Lark & Croteau, 1998).

Homosexual people are a hidden subgroup in Taiwanese society. Wang (2010) reports that Taiwanese lesbians usually use pseudonyms instead of their real names when talking about themselves with their friends and even family members. Therefore, Taiwanese researchers usually use pseudonyms as a method to obtain consent from the participants and the interviews are also conducted using pseudonyms (Chen, 2008; Hong, 2013; Yeh, 2012).



In the present study, the signatures on the consent forms were collected with either the participant's real name or a name that the interviewee preferred to be called by during the interviews in order to ensure that the participants felt safe and anonymous when participating in the study. During the interview process, the privacy and confidentiality of the interview setting were managed carefully. As mentioned, when the interview was conducted at a cafe, tea room or restaurant, the researcher went to the location 30 minutes earlier and took a more secluded table. Before the interview started, the researcher asked the participant whether the place was appropriate to discuss the topics associated with breast cancer, breast screenings and their views on their own breasts. All of the interviewees who chose to have their interview at a coffee or a tea room agreed to stay in the same places and expressed that they felt comfortable enough to talk about the topics in those settings.

Each participant was given an identification number and their data was coded using this ID instead of their name or pseudonym. In addition, any identifying details in the transcripts and reports were changed in order to maintain the participants' privacy and confidentiality. The written consent forms were stored in a locked cabinet. Information stored on the researcher's laptop and portable hard disk drive was password protected and the passwords were held by the researcher alone.

### **3) Autonomy**

Before the interview started, the participants were informed that they had a right to withdraw at any time from the study without giving a reason. In addition, during the interview, when the participants showed signs of being too uncomfortable to talk or expressed that they did not like to discuss or to think about their own breasts, the researcher asked if they would like to stop the interview, take a break or move on to other questions.

### **4) Potential harm**

Potential harm can occur to both the interviewer and interviewee. Some interview questions may be sensitive for the participants, which can result in emotional distress (Clarke, 2006; Smith, 1992), while the potential risks related to the researcher fall within the area of personal safety (Tod, 2007). Any potential harm which might have been caused to the interviewees was managed by providing them with detailed information regarding the study, obtaining informed consent from the participants, and providing lists of support groups and their contact details in case the participants needed support. During the data collection,

questions associated with breasts and breast cancer might cause the participants distress, embarrassment or anxiety. Therefore, the researcher tried to be sensitive and use words that did not make or express judgments. For example, when the interviewer asked a masculine-identity lesbian's views about her own breasts, she reported that she did not want to think about the issue. It was a 'boring' issue for her to talk about. During that period, the researcher observed the individual's body language and asked the individual whether she would like to move on from the issue. The purpose of stopping the topic was to protect the participant from emotional distress. In addition, two Taiwanese lesbians were consulted to ensure that the topic guide, poster, participant information sheet and consent form did not imply judgments or sexual discrimination.

The interviewer's safety was managed by following the lone worker policy which was proposed by the University of Manchester. For example, when arranging the interviews, no interview was arranged after 5 p.m. in a participant's house or after 7 p.m. at a cafe, tea room or restaurant. The researcher's status was followed by one of her family members when conducting the interview. An address, a mobile phone number and a time when she should call back were given to family member person.

#### **4.8 Rigour in qualitative research**

Arguments in relation to the criteria or standards that should be used to assess the rigour of qualitative research have been proposed by previous researchers. Some researchers argue that qualitative research shares the same philosophical underpinning as quantitative work, and that therefore the same criteria should be applied to both types of research, for example, validity, reliability and generalizability (LeCompte & Goetz, 1982).

However, some qualitative researchers refuse to use the terms 'validity' and 'reliability' due to the association of the terms with the quantitative research tradition, and the assumption implicit in their definition that research can be entirely objective and free from bias (Holloway & Wheeler, 1996). Lincoln and Guba (1985) replaced reliability and validity with the concept of '*trustworthiness*' in qualitative research. The researchers believe that there are multiple, constructed realities which change with time and context and are constructed by both researchers and research samples. Guba and Lincoln therefore reject the use of external validity (generalization) as a means of evaluating qualitative studies because they believe that absolute comparability between different research settings is impossible, even if a similarity

may exist. To reflect the differences between qualitative and quantitative research, in the 1980s, Guba and Lincoln replaced reliability and validity with the concept of ‘*trustworthiness*’ in qualitative research, which contains four aspects: credibility, transferability, dependability and confirmability. The definitions of the four criteria are as follows (Baxter & Eyles, 1997; Lincoln & Guba, 1985):

- (1) *Credibility* (comparable with internal validity) is the authentic representation of experience;
- (2) *Transferability* (comparable with external validity) means that the collected data fits within contexts outside the research situation;
- (3) *Dependability* (comparable with reliability) aims to minimize interpretative idiosyncrasies and can be achieved through an auditing process;
- (4) *Confirmability* (comparable with objectivity) refers to a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivations, interests or perspectives.

Several strategies were suggested to enhance the rigour of the qualitative interviews, including purposive sampling, self-reflection, peer debriefing, negative case analysis, taking field notes and audio-recording (Baxter & Eyles, 1997; Corbin & Strauss, 2008; Flick, 2006; Fossey et al., 2002; Thomas & Magilvy, 2011). In order to enhance the rigour in the present study, purposive sampling, a reflective journal, regularly meeting with the supervisors, negative case analysis, field notes, audio recordings and memos were employed.

Purposive sampling was used to ensure that the participants represented a maximum variation of characteristics. The recruitment took place in the five lesbian organizations and one bookstore, which were located in different areas of Taiwan, and each LGBT organization and community was recruited five to seven lesbians. The sampling strategy was employed to enhance the credibility and transferability of the study.

A reflective journal was used throughout the study’s data collection and analysis to help the researcher to assess her influence, possible misinterpretations of the data and incorrect assumptions. Corbin and Strauss (2008, p. 33) suggest that “*the more we are aware of the subjectivity involved in data analysis, the more likely we are to see how we are influencing interpretations.*” For example, the researcher’s sexual orientation (heterosexual) and gender

identity (feminine) were considered to be influences when the participants reported what their breast healthcare concerns were in relation to their sexual orientation and gender identity, and these might have affected the participants' decisions regarding how much or the depth of the information they were going to disclose. During the data analysis period, sensitivity to the data could be another issue in relation to the researcher's sexual orientation and gender identity. She could have misunderstood or misinterpreted the data provided by the participants. Reflective journalizing helped the researcher to be aware of her own influence and possible misunderstandings, misinterpretations and incorrect assumptions, and so enhanced the credibility of the study.

Regular meetings with supervisors (peer debriefing) were held to enhance the rigour of the study. The data collection and data analysis were discussed with the supervisors so as to understand the interviewer's effects and the interpretation of the data. For example, the researcher initially attempted to understand and explain the masculine lesbians' views about their own breasts by using previous research conducted with 'lesbians' and/or 'women who partnered with women/the same gender'. However, she could not explain why some of the masculine-identity lesbians did not want their own breasts and even felt guilty about her own female characteristics. During a discussion with the supervisors, studies which had been conducted with 'transgender people' (female-to-male; FtM) that explored the relationship between the individuals' gender identities and body image, were suggested in order to assist the researcher to understand how these masculine-identity lesbians viewed their female characteristics and constructed their body image. Their comments corresponded with the existing evidence which showed that some transgender people may identify themselves as heterosexual, homosexual or bisexual (IOM, 2011). Of the masculine lesbians, some of the individuals' views and beliefs about their own female characteristics were found to be similar to those of the ones who self-identified as FtM.

The negative case analysis method was used to examine the reasons for any differences that emerged to enhance the credibility of the study. In addition, field notes, memos and audio recordings were also available for scrutiny to improve the dependability of the study.

Member-checking has been suggested by researchers as a means of validating the analysis by asking the members (participants) to check particular aspects of the interpretation of the data they have been given (Lincoln & Guba, 1985; Doyle, 2007; Merriam, 1998). Some

researchers, on the other hand, have proposed several drawbacks and problems in using member-checking (Angen, 2000; Carlson, 2010; Morse, 1994; Sandelowski, 1993). Member-checking may lead to confusion rather than confirmation because the participants may change their minds about the issue, because the interview itself is seen (which may have an impact on their original assessment), and because new experiences (since the interview was conducted) may have occurred. Both the researchers and the members are stakeholders in the research process and they have different experiences and backgrounds. These differences may result in conflicting ways of making interpretations. The participants may disagree with the researcher's interpretations and then the question of whose interpretation should remain becomes a problem. In addition, the roles of the participants (sample) and the researcher (scholar) are different. Different roles may result in different ways of interpreting and reacting to data. In the present study, member-checking was not used. In addition to the drawbacks and the problems proposed by previous researchers, the main reason for not using this approach concerned the characteristics of the target population as a vulnerable group. When designing this study, one of the main ethical issues was the participants' confidentiality. In order to protect the interviewees' confidentiality, the researcher deleted the participants' personal information after each interview had been conducted; for example, their email addresses and mobile phone numbers. On the information sheet, the researcher assured the participants that she would not contact them again after the interview was conducted so as to increase the participation rates. Therefore, this method was not actually appropriate for the study population and the study design.

#### **4.9 Summary**

A total of 37 Taiwanese lesbians were recruited from five lesbian organizations and one feminist bookstore in North, South, West and East Taiwan. Purposive sampling and snowball sampling were used to recruit participants with varied characteristics. The data collection and analysis were carried out concurrently using constant comparative analysis with NVivo 10's audio-coding. The ethical issues involved in the study were considered and the researcher attempted to manage them throughout. These issues included informed consent, confidentiality, autonomy and potential harm. In order to enhance the rigour of the study, methods such as purposive sampling, self-reflection, peer debriefing, negative case analysis, field notes, memos and audio recordings were employed.

## **Chapter 5: Phase one – findings**

### **5.1 Introduction**

This chapter presents the factors that significantly affected the lesbians' breast healthcare behaviour and intentions due to their sexual orientation. Four themes emerge from the analysis, namely: 1) gender identity; 2) gender role expression; 3) partner support; and 4) patient-provider interaction. Other factors, such as the perceived benefits of breast cancer screenings, are not presented in this chapter because they were also factors influencing Taiwanese heterosexual women's breast healthcare behaviour. However, these factors served as references when the researcher developed a questionnaire for the online survey (see Chapter 7: instrument development).

At the beginning of this chapter, the participants' demographics and their breast healthcare behaviours are described, followed by a presentation of the findings under the four themes. At the end of this chapter, a summary is provided.

### **5.2 Demographics and breast healthcare behaviour**

A total of 37 self-identified lesbians and women who partnered with women participated in the qualitative interviews. Of these women, 20 were recruited from North Taiwan, five from Central Taiwan, five from South Taiwan and seven from East Taiwan. Details of the participants' demographics and their reported breast healthcare behaviour can be seen in Appendix 12 (p.300).

The age range of the women was between 21 and 57 years, with a mean age of 32.4 years. Over 90% of the women were aged between 20 and 44 years and were not eligible for free mammograms. Six out of the 37 women had a family history of breast cancer and one was uncertain. Twenty-five women were employed full-time while five were students, two were employed part-time, two were retired and three were unemployed. Around three-quarters had been educated to a high level, with a college or graduate degree. Almost half of the women in this study had no religion and two-fifths were Buddhists or Taoists. Regarding their relationship status, 22 women were partnered with women, 14 were single and one was married to a woman. As gay marriage has not been legalized in Taiwan, the woman who reported her relationship status as 'married to a woman' did not have legal marriage status in Taiwan.

Of the 37 participants, eight reported that they performed BSEs regularly, while one reported that she had performed it once, 15 reported that they had performed it irregularly and 13 reported that they had never performed it. Thirty-one of the women reported that they had never had a CBE and one reported that she had undergone it regularly. Among the 37 participants, only one woman reported that she had had mammograms regularly, although she was not eligible for free mammography. Of the three women who met the free mammography criteria, one reported that she had had the screenings irregularly, while one reported that she had had a mammogram only once and the other reported that she had never had one.

### 5.3 Gender identity

Interviewee (ID05, T, 23 yrs): If I need to take off my clothes and to be examined by a physician, I will not have a screening.

Interviewer (YC): Why? Can you explain why you do not want to have a breast screening performed by a physician? Because you need to take off your clothes?

ID 05: Um...I think this is because I am a T. The screening will make me to feel very uncomfortable.

YC: What makes you to feel the most uncomfortable?

ID 05: My body needs to be seen or touched by others. Because I am a T.

YC: Can you please explain what means by being a T? Why is it so important for you?

ID 05: Both I and my girlfriend think I am a man. But, some of my body parts cannot be changed and they might cause problems and need to be screened, I will leave these problems.

It has been suggested that gender identity helps lesbians to structure expectations regarding personal identity, social interactions and romantic exchanges within lesbian culture (Halberstam, 1998; Levitt et al., 2003; Levitt & Hiestand, 2004). Among those participating in the qualitative interviews, gender identity was found to be an important factor influencing the lesbians' breast healthcare behaviour and intentions.

Four categories of gender identity were reported by the lesbians in this study: T, Po, Bufen and Bufen pian T. These gender labels were described to help these women not only in structuring their personal identity, social interactions and relationship with their partners but also to help them in making decision regarding their daily life and health care. These gender identities were found to be strongly related to the participants' body image and attitudes

towards and beliefs about breast cancer and breast cancer screenings. These attitudes and beliefs were identified as inhibitors or factors that facilitated the women's breast healthcare behaviour and intentions.

### **5.3.1 Self-identification as a T**

The majority of the participants self-identified as T in the study. Two different groups of Ts were noted among these participants: 1) those who identified themselves and constructed their gender role based on the mainstream Taiwanese lesbian culture in order to meet social expectations (masculine-identity lesbians within a lesbian relationship); and 2) those who identified themselves as male and constructed their masculine role in order to meet their own expectations (transgender butch). Whether their gender identification or appearance was constructed in order to meet social expectations or their own expectations, both groups of Ts were found to have negative intentions in relation to breast cancer screenings and any relevant information due to their masculine identity.

In the first group of Ts, strict codes for being a T within lesbian communities were identified as a barrier for these masculine-identity lesbians to obtaining information related to their own breasts:

*"I have never tried to look for any information about that [my breasts], because I am a T."*

*(ID 10, T, 36 yrs)*

Chao's (2000; 2001) research found that strict codes for being a T were adhered to by masculine-identity lesbians in constructing their gender roles and meeting social expectations within the lesbian community (for example, masculine acts and a de-feminized appearance). In the current study, the codes for being a T were found to not only influence the Ts' appearance and acts, but also to affect their body image and their views about their own breasts, breast cancer and breast cancer screenings. Seeking information relating to their female characteristics was considered to go against the codes for being a T, and it led to the masculine-identity lesbians developing negative intentions as regards breast cancer screenings, whether BSE, CBE or mammograms.

Among the second type of Ts, inconsistent notions of masculine identity and their physical sex were found to be barriers to breast cancer screenings:



*“I am a man with a female body.”*

*(ID 22, T, 47 yrs)*

*“Sometimes, Ts have a very bad relationship with their own bodies. Some Ts are transgender – transgender in mind. They try to ignore their own female characteristics.”*

*(ID 12, T, 30 yrs)*

Lee (2009) has suggested that butch lesbians play a substantial role in transgender communities. Transgenderism is a state whereby an individual’s gender identity differs from the sex originally assigned to that individual at birth or whereby an individual’s gender expression varies from what is traditionally related to or typical for that individual’s sex (IOM, 2011). The term ‘transgender butch’ was proposed by Halberstam (1998), who argued that transgender butch describes a form of gender transition that was found to be strongly associated with the individual’s sexual subjectivity, sense of embodiment and even gender legitimacy. Transgender butch lesbians are different from those individuals who are FtM due to the women’s anatomy. Butch lesbians do not undergo sex reassignment surgery in order to alter their female anatomical traits. All of the transgender butch lesbians in the current study maintained their female characteristics, whether this was because of traditional Chinese culture or societal expectations (this will be discussed in Section 5.4). The individuals possessed a masculine identity and constructed their male appearance in order to meet their own expectations and to avoid body image disturbance. However, these expectations and the actions taken to avoid body image disturbance were found to inhibit them in thinking about issues relating to their female characteristics or in obtaining relevant information and approaching the relevant services.

Whether the Ts identified themselves as masculine within their relationships and constructed their male appearance in order to meet social expectations or their own expectations, masculine identity was found to be strongly associated with the Ts’ body image. ‘Body image’ refers to a person’s cognitive perceptions and attitudes about his or her own body, particularly his or her physical appearance (Cash & Pruzinsky, 2002). Kraemer et al. (2007) found that transgender people, particularly preoperative transgender people, felt insecure and unattractive due to their concerns about their body image. In this study, both groups of Ts tended to feel disconnected from their female body characteristics because of the discordance between their female body and their masculine identity, especially their breasts and genitalia.

In addition, such discordance could cause physical or emotional discomfort and lead to negative intentions in relation to breast cancer screenings:

*“I feel annoyed when I think about breast cancer screenings. Why do we need the screenings? I do not want to think about them.”*

*(ID 17, T, 22 yrs)*

Emotional discomfort was reported by this participant (ID 7) when thinking about breast cancer screenings. The woman’s body did not meet her expectations regarding being a man, and the discordance between her female body and her masculine identity was found to lead to an emotional reaction and a negative intention regarding screenings.

Due to the inconsistency between the female characteristics and masculine identities of the Ts, the risk of revealing their physical sex was reported as an inhibitor in relation to breast cancer screenings. The Ts in this study constructed and maintained their gender identity by adopting a masculine appearance in daily life. However, the procedure for breast cancer screenings and the title ‘*breast screening*’ forced the women to acknowledge their physical sex, which they were trying to hide:

*“When I walk in the street, most people will think that I am a man and it will make me happy. But if I walk into a hospital, I suddenly become a woman. I cannot pretend that I am a man in a hospital. Physically, I cannot change it.”*

*(ID 05, T, 23 yrs)*

*“....any title but ‘breast screenings’. Probably, ‘physical examination’ or something else. I think the title [breast screenings] ... To be honest, I do not know which title would be better, but the title should not be so obvious. For me, it is very difficult to walk into a hospital and have a screening with the title ‘**breast screening**’.”*

*(ID 02, T, 27 yrs)*

Concerns about the risk of revealing their physical sex among the Ts were found to be related to the lesbians’ body image and concerns about stigmatization. Having a breast screening might cause the individuals to experience body image disturbance, because the action was considered to be a symbol of the indirect acknowledgement of their physical sex, which the lesbians sought to hide. In addition to the lesbians’ body image, another concern associated

with the risk of revealing their physical sex was stigma. It was also a factor that inhibited the women's use of breast cancer screenings, and this issue will be presented in Section 5.4.

In order to avoid the physical or emotional discomfort caused by a negative body image, denial was reported by the lesbians as a method to avoid body image disturbance:

*“Because I am a T; I dress like a man... Although we look like men, something [my breasts] that we cannot change can cause problems, and we have to have examinations for those problems. We will leave them alone. We prefer to be blind on this issue and not to think about it.”*

*(ID 05, T, 23 yrs)*

Denial was employed as a self-defence mechanism to maintain the balance between the individual's physical and psychological characteristics and to reduce the anxiety caused by body image disturbance. For the participant, being a T was the same as being a man – or at least being ‘like’ a man. Physically, the individual could do nothing to change her body due to traditional Chinese culture and societal expectations (which will be discussed in Section 5.4); as such, she rejected or ignored the relevant information and services in order to maintain her gender identity and body image. However, this self-defence mechanism resulted in low utilization and a negative intention regarding breast cancer screenings, and even not seeking medical help if she needed it.

In addition, among the individuals who ignored the available breast healthcare resources (information and the screenings) and their symptoms, some of them reported that they had a similar – or the same – risk of getting breast cancer as men, due to their masculine identity:

*“I do not think I will have breast cancer. It is very strange to think that I have a chance of getting breast cancer, because breast cancer is a disease for women. I do not want to admit that I have a chance of getting the disease.”*

*(ID 05, T, 23 yrs)*

*“What I think is that women have a bigger chance of getting breast cancer than men. We (Ts) identify as masculine, so we do not even want to know about it [breast cancer].”*

*(ID 02, T, 27 yrs)*

Even though the individuals had female body parts and could not change them, they adapted their thoughts and actions according to what they perceived to be men's thoughts and actions

in order to avoid body image disturbance. They did not simply ignore external resources and symptoms; the women chose to believe that they had the same (or similar) breast cancer risk as men, and internalized the idea of perceiving a lower risk of having breast cancer than women (whether temporarily or permanently). Due to them perceiving a lower risk of getting breast cancer than ‘women’, the Ts tended to express negative intentions regarding breast cancer screenings.

On the other hand, although the Ts held negative breast healthcare intentions and suggested that they would never have a breast cancer screening, feelings of discomfort and pain in their breasts were found to be reasons that might encourage some of the Ts in the study to have CBEs or mammograms:

*“I will not have a screening unless I feel pain or discomfort.”*

*(ID 22, T, 47 yrs)*

For this T (ID 22), feelings of pain and discomfort in her breasts were thought to be signs of breast cancer. Breast pain is not normally a sign of breast cancer (Breast cancer care, 2013); however, it was found to motivate the T’s breast healthcare behaviour. For the T, the benefits of breast cancer screenings and the risks of possible harm were weighed against each other when the individual had to decide whether she would like to have a breast screening in a hospital. For example, having a mammogram in a hospital might help with the early detection of breast cancer (i.e., a benefit), but her gender identity would be revealed due to the procedure and, consequently, cause the woman body image disturbance (i.e., harm). However, when feeling pain or discomfort (which meant that the individual perceived her susceptibility to getting breast cancer), the T would tend to choose to have a breast screening, although it depended upon how the individual weighed the various benefits and risks of harm.

### **5.3.2 Self-identification as a Po**

As a counterpart to Ts, Pos play a ‘female’ role within lesbian couple relationships. Gender role and identity among Pos were suggested as being similar to those of heterosexual women in Taiwan (Chao, 2000; 2001). In the present study, the Pos played a female role in their relationships and presented themselves with a feminine appearance and actions. Body image disturbance did not appear to be a barrier to breast cancer screenings among the Pos.

Regarding the Pos’ attitudes towards and beliefs about breast cancer and breast cancer

screenings, their susceptibility to breast cancer was reported to be the same as for heterosexual women:

*“I check my breasts at least once a month. I do it when I take a shower... I think I have a high chance of getting breast cancer in the future because it is the most common cancer among Taiwanese women.”*

*(ID 31, Po, 28 yrs)*

In Taiwan, monthly BSEs are recommended to women to detect breast cancer early by the Taiwan Breast Cancer Foundation, the Taiwan Clinical Oncology Research Foundation and the Taiwan Breast Cancer Alliance. As she is a ‘woman’, this participant believed that she had the same chance of getting breast cancer as heterosexual women, and therefore she followed the recommendation and performed monthly BSEs just like women in general.

On the other hand, perceiving a lower risk of getting breast cancer was identified as a barrier in relation to some of the Pos’ breast healthcare behaviour and intentions. Being too young to get breast cancer and having no family history of breast cancer were reported by the Pos:

*“I do not think it will happen to me. I am only 21 years old.”*

*(ID 15, Po, 21 yrs)*

*“I do not have a family history of breast cancer. I do not need a breast examination... I do not think I have a chance of getting breast cancer.”*

*(ID 36, Po, 33 yrs)*

Whilst the barriers for the Ts were strongly associated with their masculine identity and body image, the barriers for the Pos were mainly related to the risk factors of breast cancer rather than their feminine identity. Age (Bouwens et al., 2012; Hankinson et al., 2004; Héry et al., 2008; Rossi, 2008) and a family history of breast cancer (Claus et al., 1994; Newman et al., 1995; Thompson, 1994) are known risk factors for breast cancer and these resulted in the participants’ negative intentions regarding BSE.

Feeling embarrassed about the procedures for CBEs and mammograms were described as barriers to the Pos having screenings:

*“Breast examinations would make me feel embarrassed. It is very strange for my breasts to be touched by someone I am not familiar with.”*

*(ID 08, Po, 26 yrs)*

*“I do not want to be screened. Although I do not feel embarrassed about my own body, I do not like to be naked in front of strangers.”*

*(ID 13, Po, 30 yrs)*

In the present study, feeling embarrassed was reported by both the Ts and the Pos as an inhibitor of their breast healthcare behaviour and intentions. For the Ts, feeling embarrassed was significantly related to their masculine identity, the potential risk of revealing their physical sex and their body image. Among the Pos, embarrassment was found to be mainly related to the screening procedures, in particular where the women were required to take off their clothes during the procedure, whereby their female characteristics would be seen and touched by a physician whom they were not familiar with. In contrast to the Ts, the Pos’ feeling of embarrassment about the screening procedure might be associated with the women’s body boundaries instead of their gender identity. As the participant (ID 13) reported that she did not feel embarrassed about her own body, nonetheless she did not feel comfortable being naked in front of a physician she was not familiar with. Gender identity as a Po, therefore, might have no or else a slight influence on Pos’ breast healthcare behaviour and intentions according to the interview data.

### **5.3.3 Self-identification as a Bufen**

The gender identity ‘Bufen’ was proposed in the 1990s by feminists and has been suggested with a view to adopting equal roles and sharing responsibilities in lesbian couple relationships (Cheng, 1997). However, in the present study, three different ways in which to be a Bufen were proposed by the participants, and different body images, attitudes towards and beliefs regarding breast cancer and breast cancer screenings were found among the lesbians based on their own definitions of being a Bufen. In addition, their breast healthcare behaviour and intentions were found to vary with the women’s views regarding breast cancer and breast cancer screenings.

The first type of Bufen is similar to the definition proposed in the previous research of Cheng (1997). Bufens share equal roles and responsibilities in lesbian couple relationships. Usually, these women are feminists:

*“Within a relationship, my partner does not have to be a T or a Po. I present my appearance with feminine characteristics and I still wear a bra.”*

*(ID 33, Bufen, 28 yrs)*

*“The issues relating to women’s breasts are very obscure. In Taiwanese society, women cannot talk about their breasts openly and they do not have the right to control their own bodies. I would rather be a lesbian than a heterosexual woman. I have full control of my own body.”*

*(ID 18, Bufen, 35 yrs)*

Two out of the four Bufen-identity lesbians were in this group. The individuals did not categorize themselves according to rigid, dichotomous identities, and the gender roles among the women were flexible. In addition, the Bufens were found to not only emphasize their femininity but also take control of their own bodies and go against traditional cultural ideas of men being superior to women. Taking control of her own body by paying attention to relevant information was reported by one Bufen:

*“I have read information about breast cancer in a hospital. I do not want to get breast cancer, so I pay attention to relevant information and services.”*

*(ID 18, Bufen, 35 yrs)*

Because of the participant’s views regarding her own body, her feminine identity and her perceived right to take care of her own body, she expressed a positive intention in relation to breast cancer screenings.

The second type of Bufen was proposed by one Bufen who was 39 years old and who was partnered with a T at the time of the interview:

*“My appearance changes based on my partner’s gender identity. If my partner is a Po, I will wear breast bindings and have an androgynous appearance. During that time, I am a T and I feel fine if my friends (Ts) touch my breasts... If my partner is a T, I will wear a bra and have a feminine appearance. During that time, I do not allow my friends (Ts) to touch my breasts.”*

*(ID 20, Bufen, 39 yrs)*

A changeable gender identity and gender role were reported by this Bufen. The participant's gender role and appearance were mainly affected by her partner's gender identity. Defined by the traditional T/Po-identity, the Ts or Pos identified themselves first and then found a partner according to their gender identity; the Bufen (ID 20) found a partner first and, consequently, modified her role and actions as a counterpart to her partner. The Bufen did not have a fixed gender identity.

Based on the description provided, the lesbian's views regarding her own body also varied with her identity. The participant described how, when she was a T (being a 'male' within a relationship), she felt fine being touched by other Ts (not sexually, more like play between friends). However, when she was a Po (female), her breasts could not be touched by other Ts (i.e., 'males'). In other words, when being a woman (Po), and based on traditional Chinese cultural norms, her female characteristics could not be touched by 'men' (Ts) except for her own 'husband' (the Po's partner) (Young, 2005). It seemed that the individual still followed the strict codes for being a T or a Po within a relationship, although the identity could be changed. Mainstream lesbian culture and the wide use of the T/Po-identity among Taiwanese lesbians were considered to be associated with this woman's fluid gender identification.

In addition, the Bufen's views regarding her own body were found to vary with her gender identity; therefore, this woman's body image, attitudes and beliefs regarding breast cancer and breast cancer screenings could also differ according to her adoption of a feminine identity or a masculine identity. This woman's breast healthcare behaviour and intentions, therefore, were considered such that they could be varied when the individual changed her identity from one to the other.

The third type of Bufen was described as being mainly associated with the participant's unchangeable female characteristics:

*"When I was young, I felt conflict. I identified myself as a T, initially, but I realized that I could not change them [my breasts]. They were there."*

*(ID 27, Bufen, 30 yrs)*

Due to the unchangeable nature of her female characteristics, the lesbian changed her gender identity from T to Bufen. As mentioned already, Ts maintain a masculine identity, gender role and body image by constructing a masculine appearance and acting accordingly in daily



life. However, this Bufen realized that no matter how hard she tried in constructing her gender role and masculine appearance, she was still a ‘woman’ physically. Hence, she changed her gender identity from T to Bufen in order to avoid body image disturbance (“*felt conflict*”). The participant’s attitudes and beliefs regarding breast cancer and breast cancer screenings were found to be positive. However, they were strongly related to the individual’s family history of breast cancer. The individual’s mother was diagnosed with breast cancer three months before she undertook the interview, and it was considered to affect not only her views regarding breast cancer and breast cancer screenings, but also her breast healthcare behaviour and intentions.

The identity ‘Bufen’ in the context of relationships in Taiwan is obscure. There were no specific codes to follow in order to be a Bufen. Although equal roles among Bufens have been suggested by feminists, exactly what should be construed as ‘equal’ was difficult to define. This obscure identity was found to be associated with varying views regarding breast cancer and breast cancer screenings, and different patterns of behaviour and intentions regarding breast cancer screenings.

#### **5.3.4 Self-identification as a Bufen pian T**

Gender identity as a Bufen pian T was also found to be obscure among the lesbians. Of the three Bufen pian Ts in this study, one identified herself as being in the middle between a T and a Bufen. In other words, she played a male role within her relationship but did not follow all of the strict codes associated with being a T. Although she constructed her gender role using a masculine appearance, she shared her masculine rights and duties with her partner; for example, making decisions or wearing breast bindings if her partner (Po) would like her to wear them. This participant’s views regarding breast cancer screenings were more positive than those of the Ts:

*“I check my breasts every month, after my period... It is my body. I have to take care of myself first, and then I can take care of my partner.”*

*(ID 32, Bufen pian T, 33 yrs)*

In contrast to the Ts, the Bufen pian T was found to exhibit more positive attitudes towards her own body as well as more flexible views regarding masculine identities and gender roles

within lesbian couple relationships. These views were identified as factors that facilitated the individual's breast healthcare behaviour.

In addition to the above participant (ID 32), two factors were reported by other participants as being related to their decision to self-identify as Bufen pian T. One of the two factors was described as being associated with patriarchy:

*"When I was young, I wanted to be a boy. I was born in a traditional farming family and my parents always thought that boys were superior to girls. I wanted to be a boy, but that did not mean that I wanted to have male sexual organs. I just thought, if I was a boy, my parents would expect me to do more for my family."*

*(ID 25, Bufen pian T, 24 yrs)*

The individual's gender identity was found to be strongly related to masculine privileges according to traditional Chinese culture. In the description, the participant wanted her parents to pay more attention to her. Although no further information about the lesbian's views regarding her own family and her relationship between herself and her family was provided, familial and traditional Chinese culture were found to influence the participant's masculine identity and, therefore, her intentions in relation to breast cancer screenings. She continued:

*"I do not want to think about it [breast cancer] specifically."*

*(ID 25, Bufen pian T, 24 yrs)*

The lesbian's views regarding her body and breast cancer were found to be in conflict. Although she expressed that she did not want to have male sexual organs, she denied her female characteristics and the risk of getting breast cancer. The individual's body image was found to be similar to that of Ts. Her views regarding her own breasts and breast cancer were considered to be barriers in her breast healthcare behaviour and intentions.

Another factor associated with the identity Bufen pian T was reported by a lesbian who was 25 years old, and concerned androphobia:

*"I do not want any men looking at my breasts. I feel uncomfortable about them looking. Usually, I feel comfortable when I wear a sports bra to make my breasts invisible. I do not like men looking at my breasts. It terrifies me. I am scared if I am alone with a man in a room... Probably, it is because of my father. He was not nice to us [the participant and her sisters]..."*

*(ID 29, Bufen pian T, 25 yrs)*

Due to her fear of men, the lesbian identified herself as Bufen pian T and presented a masculine appearance by making her breasts invisible. The lesbian connected her androphobia with her childhood experiences. Having a masculine role within a relationship was not the key issue for the lesbian – rather, it was to keep men away by identifying as a Bufen pian T and presenting a masculine appearance. The identity and constrictions of the male role were found to be associated with the woman’s views regarding breast cancer and breast cancer screenings:

*“I have never thought about it [performing BSEs]. I do not think I will get breast cancer.”*

*(ID 29, Bufen pian T, 25 yrs)*

The lesbian’s views regarding breast cancer inhibited her intentions in relation to BSE. Denial was also employed to avoid possible harm caused by issues or services related to her female characteristics.

According to the three Bufen pian Ts, the identity was found to be as obscure as the identity of Bufen. There were no specific rules or norms which needed to be followed by the lesbians. However, all three of the women were found to have a masculine appearance and two of the three denied their risk of getting breast cancer and breast cancer screenings. These attitudes and views were similar to the lesbians who identified as T.

#### **5.4 Gender role expression**

YC: You mentioned you do not want to have a screening at a hospital because of your sexual orientation. Can you tell me more about this?

ID 21 (T, 52 yrs): Because my appearance is not so feminine and I am always be asked about my gender at a hospital. Last time, I went to a hospital. When I went to a examine room, the physician kept asking me whether I was the person they just called the name (feminine name). I felt very uncomfortable about the situation but I did not have another choice but accepted it, because I was the one asking for the physician’s help.

Gender expression was found to be strongly associated with the participants’ behaviour and intentions regarding breast cancer screenings. Gender expression refers to “*the presentation of characteristics in one’s personality, appearance and behaviour that are culturally defined as masculine or feminine*” (IOM, 2011, p. 26). It was suggested to help lesbians in finding a ‘suitable’ partner and identifying as an insider (Cheng, 1997). In the previous section, gender

identity was identified as a significant factor influencing the lesbians' intrapersonal world (how they viewed and identified themselves) and beliefs about and attitudes towards breast cancer and breast cancer screenings. Gender role expression, however, was found to be not only associated with the lesbians' internal world (themselves) but also their external world (the community, society and healthcare system).

This section describes how the lesbians constructed their gender roles based on their gender identities and how their masculine or feminine appearance affected their interactions between communities (the lesbian and non-lesbian communities) and society and their breast healthcare behaviour and intentions. The lesbians' interactions with healthcare providers will be described in Section 5.6: patient-provider interaction.

#### **5.4.1 Masculine appearance**

##### **5.4.1.1 Masculine-identity lesbians' views about their own breasts**

The lesbians' masculine appearance (or their so-called 'androgynous' appearance) was identified as a barrier in relation to the T-, Butch and FTM-identity lesbians' breast healthcare behaviour and intentions. The term 'masculine-identity lesbians' is used to represent these three groups in this section.

The construction of a masculine identity was found to be associated with the process of de-feminization (Chao, 2000; 2001). For the Ts in Chao's research, breasts were seen as female characteristics which should be hidden in order to construct a male gender identity. Various negative views about their own breasts were reported by the masculine-identity lesbians in this study. These negative views were considered to inhibit the women's breast healthcare behaviour and intentions:

*"I do not like the feeling when I look at myself in the mirror."*

*(ID 16, T, 21 yrs)*

*"I have had them [my breasts] since I was born. I cannot change them. But in my mind, I feel there is a conflict between my body and my mind."*

*(ID 17, T, 22 yrs)*

Butch lesbians are considered to be a part of the transgender subgroup (Lee, 2009). A transgender person's gender identity is different from his or her physical sex, assigned to

them at birth. With the two masculine-identity lesbians, the discordance between their female characteristics and their masculine identity led to negative feelings about their own breasts.

In addition to feelings of embarrassment and a sense of contradiction, feeling guilty was reported by one T who was 47 years old:

*“Most Ts feel guilty about their own body. Although I have already accepted that I am a woman, I cannot accept my female characteristics.... When I was young, my parents blamed themselves and asked God why they had a child different from other children.... I felt sorry about who I was... I did not know how to face my parents during that period....”*

*(ID 22, T, 47 yrs)*

A disturbed body image and traditional cultural obligations were related to the lesbian's (ID 22) feelings of guilt. Not only did the woman feel guilty because of the inconsistency between her female characteristics and her masculine identity, but she also acknowledged that she could not satisfy the traditional Taiwanese cultural obligations of requiring women to obey (for example, being an obedient daughter or wife and having children). The individual's feelings of guilt were felt in relation to herself and her family. On the one hand, she could not be who she really was – a man. On the other hand, she could not satisfy what her family expected or required of her.

Despite prior negative views, living peacefully with their female characteristics was reported by some of the masculine-identity lesbians:

*“I spent some time identifying myself. I have learnt to try to accept my own female body and live with it peacefully.”*

*(ID 12, T, 30 yrs)*

*“I have already accepted who I am – so my breasts, for me, are a part of my body.”*

*(ID 32, Bufen pian T, 33 yrs)*

A long-term negative body image could lead to emotional disturbance and even mental health problems, such as depression (Hamilton, 2008). In order to avoid body image disturbance, the lesbians appeared to begin a concordance process, either consciously or unconsciously. The purpose of this concordance process among the lesbians appeared to solve the contradictions between their female bodies and their masculine identities, to integrate the women's

expectations and experiences of their physical and psychological aspects and to develop new body image perceptions. Although these women's (ID 12 and 32) views regarding their own breasts were positive, they had all experienced a process of concordance between their physical and psychological characteristics and had developed new body image perceptions.

Three key factors were found to motivate the process among the individuals, namely traditional Chinese culture, increasing age and social stigma. Based on traditional Chinese culture (Classic of Filial Piety), a person's body, along with their hair and skin, is derived from their parents; accordingly, they are prohibited from hurting their own body in any situation. Traditional Chinese culture forbids a person from making any changes to his or her own body. Due to traditional Chinese culture, the impossibility of having sex reassignment surgery to remove their breasts was reported as a reason motivating the concordance process:

*"When I was young, I felt embarrassed about my breasts. But it was for a very short period of time. They are already there, and I cannot change them. So, be content with them! I do not like or dislike them – they are just parts of my body."*

*(ID 27, Bufen, 30 yrs)*

The participant self-identified as Bufen throughout the interview, but her gender role expression was mainly presented as masculine, such as wearing a shirt and short hair. According to the participant's description, it seemed that she identified herself as masculine and that she felt embarrassed about her own breasts when she was young. However, she realized that there was nothing she could do to change it; accordingly, she passively accepted her female characteristics and changed her gender identity from T to Bufen. Hence, the Bufen-identity lesbian began the concordance process and changed her gender identity from T to Bufen in order to avoid body image disturbance.

In addition, ageing was found to be one of the reasons for beginning the concordance process:

*"I could not accept my breasts when I was young. I wanted to be a handsome boy. But I accept my own body because they are impossible to hide. I accept my breasts but I do not like them."*

*(ID 10, T, 36 yrs)*

*“If I was in my 20s, I would probably have surgery to remove my breasts. But I am old now – I do not have to pretend to be somebody else. I do not dislike them, but I do not like them either.”*

*(ID 21, T, 52 yrs)*

As the lesbians aged, they might realize that their female characteristics could not be removed because of traditional Chinese culture, and also that no matter how hard they tried to hide their breasts, they were still women physically. With the older T (ID 21), external identification might have become less important to her as she grew older, which might be because the lesbian had a stable relationship and belonged to various social groups. As such, she might not need to be identified by her appearance in order to find a partner or to merge into a lesbian community. In order to maintain a balance between their physical and psychological characteristics, they began a concordance process; however, although they accepted their female characteristics passively, they did not have positive views regarding their female characteristics.

Social stigma was also expressed as a reason motivating the concordance process:

*“I have accepted my female body because I am getting older and I do not want to make life too difficult for myself. A few years ago, I looked for a job, but it was very difficult to find one because I was not sure what kind of a job I was looking for – a job for a woman or a job for a man? If I did not acknowledge that I was a woman, I could not find a job. During that time, I was forced to identify myself as a woman in order to find a job in this society.”*

*(ID 37, T, 27 yrs)*

In addition to traditional Chinese culture and increasing age, stigma was found to motivate the concordance process. The masculine lesbians dressed as males were easily recognized as homosexual by others (i.e., non-lesbians) in society. ‘Transgender stigma’, which refers to the stigma attached to those whose gender expression or comportment differs from societal gender norms (IOM, 2011), was considered to be what motivated the concordance process in order to live in Taiwanese society and avoid body image disturbance.

The reasons motivating the women’s concordance process were specifically found to meet the expectations of the family and Taiwanese society rather than their own. Hence, the individuals expressed the view that they had accepted their breasts due to them becoming older, society or their culture, but they still did not like them.

#### **5.4.1.2 Constructions of masculine appearance: breast-binding**

Based on the above description, the majority of the masculine-identity lesbians were found to hold negative views regarding their own breasts. In order to avoid body image disturbance, constructing a masculine appearance in their daily lives was considered by these lesbians to be important to them. For the masculine-identity lesbians, wearing breast bindings was found to be the most common method to make their breasts invisible. Three reasons for wearing breast bindings were reported by the masculine-identity individuals. Responding to social expectations was reported as a reason for the masculine lesbians to wear breast bindings:

*“I wear breast bindings because I would like to make them (my breasts) smaller. I do not know why I want to make them smaller, but this is what Ts do.”*

*(ID 16, T, 21 yrs)*

In order to meet social expectations, this young participant (ID 16) wore breast bindings to construct her masculine identity, even though she stated that she did not really know or understand why she did it. The mainstream lesbian culture (i.e., using the binary labels), strict codes for being a T and social surroundings might have affected the individual’s way of constructing her masculine role and male identity in order to meet social expectations.

In addition, strengthening gender identity was expressed as another reason for wearing breast bindings:

*“My partner is a Po; so, I do not like my female characteristics to be seen. It will make me feel uncomfortable.”*

*(ID 17, T, 22 yrs)*

Within her relationship, the T-identity lesbian (ID 17) played a male role and presented a masculine appearance to strengthen her male identity. This action might aim to follow the body codes of being a T and therefore be identified as masculine by other lesbians (insiders) and the community. As Chao (1997) has suggested, Ts’ breasts are bound not only in order to distance themselves from heterosexual love but also as important and visible signals to distinguish between T and Po.

Finally, promoting the identification of their sexual orientation and the promotion of their sexual attraction were reported as two of the reasons for wearing breast bindings:



*“...Because other Ts have a flat chest and it looks good when they wear a suit. It is easier for them to find a partner. So, I think of how I want to dress like them and how this will probably help me to find girlfriends.”*

*(ID 19, T, 37 yrs)*

As in the description, the participant (ID 19) wore breast bindings to promote her masculine identity and increase her sexual attraction. She followed the codes for constructing gender roles within her relationships and for finding a partner. Except for two Bofens, who played an undifferentiated role within their relationships and shared equal roles and responsibilities with their partners, the masculine-identity lesbians mainly partnered with feminine-identity lesbians. There were no T-T or Po-Po lesbian couples reported in the study. Therefore, the identification of their gender role was very important to the lesbians in finding a ‘suitable’ partner. Wearing breast bindings was the most common and widely-used method of helping the masculine-identity lesbians to construct their gender roles.

#### **5.4.1.3 Masculine appearance as a barrier to having breast cancer screenings**

The lesbians’ masculine appearance and de-feminized acts were identified as a major inhibitor of the women’s breast healthcare behaviour and intentions in this study due to social stigma. In Taiwanese society, Ts’ anti-feminine acts are seen as symbols against traditional Chinese culture. Hence, masculine-identity lesbians were more likely than feminine-identity lesbians to face sexist insults and homophobic comments in their social surroundings (Chao, 2000; Kuang et al., 2004). Previous medical or social experiences of being discriminated by others or physicians due to the lesbians’ masculine appearance were reported as barriers to breast cancer screenings by some of the masculine-identity lesbians. Even if the women had never had a screening, they reported their concerns about having a breast screening in a hospital.

Discrimination by others and by healthcare providers regarding the lesbians’ masculine appearance were reported by one T in relation to negative experiences of having a mammogram in a hospital:

*“I went to a hospital and had a screening last year. In the waiting room, there were many women waiting for their mammograms or to have other examinations. They looked at me several times. Even the physician looked at me, and checked my identity more than once. Checked your... I felt very angry... If I go to a gynaecological clinic, other women would probably wonder: ‘Why is a man going to a gynaecological clinic?’... You just want to see a doctor... If you are seen as a freak, would you feel comfortable?... During the time while I was waiting*

*for a mammogram, I went to the ladies room and the other women in the room discussed my appearance. They said: 'Why has that man come into the ladies room?' ... I was in there...*

*(ID 21, T, 52 yrs)*

Sexual stigma, which refers to the stigma relating to any non-heterosexual identity, behaviour, relationship or community (Herek, 2009), was found to be an influencing factor in the woman's re-attendance to have a mammogram. The past experience of discrimination by the other women and the physician when having a mammogram was reported by the T; for example, the physician checking her identity multiple times and doubting her physical sex, and the other women challenging her gender identity and gender role expression. Details about discrimination by healthcare providers will be provided in Section 5.6.

Internalized sexual stigma ("*seen as a freak*") was also reported by the participant and was associated with her breast healthcare intentions. This is suggested as leading to the denigration of the self and is associated with the healthcare provider's attitudes towards sexual minority people (IOM, 2011). Sexual minority people might feel that they do not deserve respect from healthcare providers or the same access to healthcare as heterosexual people. Therefore, they might avoid seeking medical help or disclosing key information to healthcare providers, or else they might hold back challenging discrimination and other forms of enacted stigma. For the participant (ID 21), self-stigma was not only caused by the healthcare provider's attitudes but also by the other women, and it was found to inhibit the individual's intention to have a mammogram. The past negative experience caused by her masculine appearance was reported as leading to non-re-attendance at mammography screenings by the T:

*"I will never have a screening again unless I feel pain or uncomfortable."*

*(ID 21, T, 52 yrs)*

A negative intention in relation to re-attending mammography screenings was expressed by the lesbian. However, the individual's intention to have the screening was reported to be influenced by her perceived risk of getting breast cancer. Although feeling pain or discomfort are not signs of breast cancer, as mentioned previously, the woman connected these to the strong possibility of having breast cancer. They motivated the lesbian to have a mammography screening even though she was concerned about sexual stigma in the hospital.

Among the lesbians in this study who were eligible for a free mammogram every two years and who had a masculine appearance, only this individual had had the experience of having screenings. There were no other participants who were also eligible for free mammograms and who had a masculine appearance for comparison with the individual in question. Although the sexual stigma was found to be associated with the masculine-identity lesbian's intention to have breast cancer screenings, more lesbians with a male appearance and who are eligible for free mammograms would be needed in order to understand whether or not the finding is peculiar to this single case.

The masculine-identity lesbians who did not meet the free breast screening criteria also reported their concerns about having breast cancer screenings in a hospital. Possible discrimination in relation to their masculine appearance was expressed as being a barrier to undergoing CBEs and mammograms:

*"It is not easy for me to have breast screenings. It is very difficult to change others' perceptions... I would worry about others' judgments while waiting for the examination. I would probably worry that others might talk about me."*

(ID 05, T, 23 yrs)

*"I think it is because of others' perceptions. I do not know. I worry about how others might think that my appearance is not OK. I worry about how others might feel confused because of my appearance: 'Are you a man or a woman?' Or others might look at me judgementally. I feel uncomfortable about that. All of these concerns will discourage me from having breast screenings."*

(ID 30, T, 41 yrs)

As previously mentioned, the lesbians with a male appearance were often targeted for being homosexual and, therefore, they were more likely to be subject to discrimination by others than those who were not. Although neither of the lesbians had undergone a CBE or a mammogram at a hospital, fear of stigmatization because of their male appearance was described as inhibiting each individual's intention to have the screening. Past negative experiences of society or the healthcare system might cause the women to anticipate discrimination by others when having a breast screening at a hospital.

Among the masculine-identity lesbians, previous stigma in a specific situation was described and was connected to the individuals' intentions regarding CBEs and mammograms, namely discrimination by others when using a public toilet:

*"...Because my appearance means I look like a man... Like walking into a ladies room, and everyone looks at me. The feeling is the same. We [Ts] look like who we are, but we have to put up with others' looking at us. So, I might not... have breast screenings."*

(ID 02, T, 27 yrs)

*"...Like being asked to leave the ladies room, or sometimes just being reminded that it is the ladies room. It is very strange. People might think: 'Why has a man come in here?' I feel embarrassed about the situation. You will try to explain to them, but they will not believe that you are a woman. When I go into a new environment, I meet the same situation every time."*

(ID 35, T, 24 yrs).

Due to the participants' masculine appearance, they had had the negative experience of being asked to leave the toilet by other women or being challenged as regards their physical sex and gender identity. The lesbians connected such discrimination from their previous experiences of using a toilet with possible situations that might arise should they have a CBE or a mammogram at a hospital, because both settings were mainly for women. Such previous sexual stigma was found to inhibit the women's intentions in relation to having breast cancer screenings at a hospital.

## **5.4.2 Feminine appearance**

### **5.4.2.1 Feminine-identity lesbians' views about their own breasts**

In the present study, the Pos and some of the Bufens (particularly those who were feminists and who emphasized their femininity) represented themselves in terms of their feminine characteristics. In this section, the term 'feminine-identity lesbians' was used to represent both the Pos and the Bufens.

The feminine-identity lesbians' breasts represented their female characteristics. Their views regarding their own breasts were found to be more positive than was the case for the Ts. The important sexual function of their breasts was reported by two Pos:

*“I like my breasts the most in comparison with other parts of my body.... My breasts are my female characteristics.... My ex-partners liked my breasts too.”*

*(ID 13, Po, 30 yrs)*

*“My current partner, she likes my breasts very much. They [the participant’s breasts] bring a great deal of feeling and pleasure for both of us. For sexual attraction, they are very important.”*

*(ID 23, Po, 57 yrs)*

The function of the women’s breasts was mainly understood in terms of the sexual attraction of the Pos’ partners. Unlike the Ts, who bound their breasts to construct a masculine identity and promote sexual attraction, the Pos increased their sexual attraction and strengthened their feminine identity by representing their female characteristics (their breasts) in order to find the ‘right’ partner and to maintain a relationship.

In addition to sexually attracting the Pos’ partners, breastfeeding was reported as another function in relation to the Pos’ own breasts:

*“For me, breasts are used to feed babies.”*

*(ID 06, Po, 42 yrs)*

Given that she had a female role within her relationship, the participant connected her breasts’ function with the traditional motherhood function (breastfeeding) perceived among heterosexual women (even though she was 42 years old and did not have any children). The participant adhered to the code of having a female role within a relationship and held the belief that her breasts had a function associated with motherhood. Although breastfeeding was reported as one of the functions in relation to the lesbian’s breasts, it was perhaps unlikely to be a factor influencing the woman’s breast healthcare behaviour or intentions.

Similar to heterosexual women in Taiwan, the feminine-identity lesbians saw their breasts as a part of their own body, which represented female characteristics:

*“They are part of my body.”*

*(ID 33, Bufen, 28 yrs)*

*“They are parts of my body. I do not feel embarrassed or anything bad about them. Usually, I touch them and look for any changes in them every two or three days.”*

*(ID 08, Po, 26 yrs)*

Not only were their views on their own bodies found to be similar to those of heterosexual women, some of the feminine-identity lesbians also seemed to have more positive views regarding their own breasts than heterosexual women. In the existing evidence, feeling embarrassed was found to be a barrier to the heterosexual women in performing or having breast cancer screenings due to the procedures involved (Chiang et al., 2011; Tsai et al., 2011). The individual (ID 08) in question viewed her own female characteristics positively and promoted her breast awareness without feeling embarrassed or discomfort. The Po’s view that ‘breasts are parts of my body’ was found to facilitate the woman’s breast awareness.

### **5.5 Partners’ support**

YC: Have you ever heard of BSEs? Have you ever performed the examinations?

ID 01(Po, 30 yrs): Yes, I’ve heard about it and I know the procedure, but I just do not feel I want to do it, except that my partner asks me to do so. Because I had some problems about my breasts and had a surgery before, so she usually reminds me to practice the examinations. She worries I might have “bad things” (breast cancer) in my breasts in the further.

YC: So, you mean you will be more likely to practice BSEs if your partner reminds you to do so?

ID 01: Yes, I think my partner’s willingness about me to practise BSEs is much more important than my own willingness.

The lesbians’ partners’ support was identified as an important factor influencing breast healthcare behaviour and intentions among the participants in the present study. As mentioned, the erotic roles and responsibilities within a T/Po couple in Taiwan were indicated as being similar to those shared by heterosexual couples (Chiang, 2008; Shieh, 2010). Among the participants, different gender roles were found to affect the perceived support provided by their partners in relation to performing or having a breast cancer screening.

In this section, the associations between relationship status and the lesbians' breast healthcare behaviour and intentions are introduced firstly, followed by the methods for perceiving support from a partner.

### **5.5.1 Relationship status: single or partnered**

Being single was reported as a barrier to the masculine-identity lesbians performing BSEs:

*“Usually, I do not do it [BSE] every day and I do not do it purposively. If I have a partner, I will do it more often. Now, I am less likely to do it because I am single.”*

*(ID 30, T, 41 yrs)*

The majority of the masculine lesbians had negative intentions in relation to breast cancer screenings due to their masculine identity and/or male role expression, but their breast healthcare behaviour and intentions were found to be encouraged by their partners. This participant (ID 30) was less likely to perform BSEs when she was single, but she expressed her positive intention to perform the examination when she had a partner. Having no partner was found to be a barrier in the T's breast healthcare behaviour and intentions.

On the other hand, being partnered and having the support of a partner were identified as facilitating both the Ts' and the Pos' breast healthcare behaviour and intentions:

*“For me, I do not want to do the examination [BSE]. But, if my girlfriend asks me to do it, I will do it.”*

*(ID 05, T, 23 yrs)*

*“My partner's support and her willingness are reasons for me to do the examinations [BSEs].”*

*(ID 06, Po, 42 yrs)*

The former participant (ID 05) had no intention to perform a BSE, but she would do it with her partner's support (for example, when asked by her partner). Her partner was found to facilitate the T in performing BSEs. Based on the frequency of performing BSEs among the masculine lesbians in this study, the partnered Ts were found to be more likely to perform BSEs than the single Ts. This echoes the previous description in which the T's partner was found to be a facilitator of her behaviour and intentions in relation to BSE. However, one problem among Ts in Taiwan regarding partners' support is that there are fewer Pos than Ts. Some of the Ts may have difficulty in finding a Po and, consequently, there is no partner who

can support them to perform BSEs or undergo breast cancer screenings. This is considered to be an inhibitor of undergoing breast cancer screenings among Ts in Taiwan.

For the Po (ID 06), her partner motivated her to perform BSEs. It seems as though the lesbians' partners facilitated the women in performing BSEs, whether the individuals were masculine- or feminine-identity lesbians. However, according to the frequency of performing BSEs among the Pos in this study, the single Pos were more likely to report that they performed BSEs regularly than the partnered Pos. Nearly all of the single Pos performed BSEs regularly, although one who was 24 years old had never performed the examination. This Po expressed how she was too young to perform a BSE. In contrast to the single Pos, the majority of the partnered Pos performed BSEs irregularly. Only one partnered Po, who was 28 years old, performed BSEs regularly; however, the factor that facilitated her regular performance was mainly related to her knowledge of the high incidence of breast cancer among young women in Taiwan. Although the Pos' partners were reported to facilitate BSE, their actual influence was uncertain.

The partners of the Ts played an important role in encouraging these masculine lesbians to perform BSEs, even though the women did not want to perform the examinations due to their sense of gender identity and body image. The Pos' partners seemed to affect the women's breast healthcare behaviour, but with an uncertain influence.

### **5.5.2 Support from a partner**

Being asked by a partner was reported to facilitate the T's performance of BSEs:

*“My girlfriend worries about my health status. If she [the participant's partner] really wants me to do a breast examination, I will go to a toilet and do it.”*

*(ID 05, T, 23 yrs)*

The T who was 23 years old (ID 05) expressed her negative intention in relation to BSE, but she would perform the examination if her partner asked her to do so. A prerequisite proposed by the lesbian in accepting her partner's request was that she needed to know or feel that her partner cared about her and her health status. Therefore, she would do the examination even though she did not want to pay any attention on her own breasts, breast cancer and breast cancer screenings. In addition, doing the examination in a private space was reported by the



participant. Although the lesbian accepted her partner's request and performed a BSE, she still needed to maintain her masculine role, and the action was performed to avoid revealing her physical sex in front of her partner and to maintain her body image.

In addition to BSE, being asked by a partner was also found to encourage the T's utilization of mammograms:

*"I really do not want to have the screenings. But, if my partner asks me to have it, I probably will have one."*

*(ID 22, T, 47 yrs)*

The participant (ID 22) who was 47 years old and eligible for a free mammogram every two years expressed how her behaviour in relation to mammograms would probably be motivated by her partner. As with the younger lesbian (ID 05), the participant expressed negative intentions in relation to mammograms, but she reported that she would probably have one if her partner asked her to. The individual had never had a mammogram, and the word 'probably' was used when she described this condition. Based on this description, it was considered that the lesbian's partner might have an influence on the woman's breast healthcare behaviour, but that other factors might mediate her action in undergoing a screening at a hospital. During the screening procedure, other factors might include discrimination by others due to the masculine lesbian's appearance and fear of revealing her true sex. As mentioned previously, the T would weigh the possible benefits and risk of harm involved in having a mammogram; hence, although she might take her Po's advice to have a mammogram, the lesbian could change her mind if the harm was considered to be too great before taking action.

In terms of the Pos, reminders from a partner were described as a facilitating factor:

*"When she [the lesbian's partner] reminds me to do the examination, I will do it."*

*(ID 01, Po, 30 yrs)*

In contrast to the masculine lesbians, whose partners needed to put pressure on them in order for them to take care of their own breast health, a reminder might be sufficient to prompt the Pos' behaviour in performing BSEs due to the Pos' positive views on their own body, breast cancer and breast cancer screenings.

Being accompanied by a partner was reported by the Ts, the Bufen pian Ts and the Pos as a facilitating factor of their breast healthcare behaviour and intentions:

*“If she [the participant’s girlfriend] can accompany me, she can ask questions which I would not know how to ask. Because she understands me, I would like her to accompany me.”*

*(ID 05, T, 23 yrs)*

*“If it is possible, I would like someone who I am familiar with to go with me and to have an examination together. In particular, if my partner accompanies me, I will feel at ease, because she knows how I feel.”*

*(ID 29, Bufen pian T, 25 yrs)*

*“I would like my partner to accompany me to have a breast screening, because it will be much better if there is someone who you are familiar with to go with you.”*

*(ID 06, Po, 42 yrs)*

These lesbians reported that being accompanied by a partner would facilitate their behaviour and intentions to have a breast screening at a hospital. The masculine-identity lesbians believed that their partners understood or knew them well; therefore, if anything unexpected were to happen, they could help the masculine-identity lesbians to respond or to deal with it during the screening procedure in order to avoid the risk of body image disturbance. This finding corresponded with the findings in Wang’s (2013) lesbians’ medical experience study. The lesbians’ partners in Wang’s study were found to have an important role, acting between the physician and the patient, especially when the issues were sensitive. In contrast, the reasons for needing a partner to accompany them to have a breast screening were considered to be different to those of the Pos. Regarding the Pos, the women who would like their partner to accompany them to have a breast screening were considered to be mainly concerned with the sense of safety during the screening procedure. Some of the Pos had never had a relationship with a man; therefore, they might have been concerned about the screening procedure and the healthcare provider’s gender. The influencing factors associated with the healthcare provider’s gender will be described in Section 5.6.1.

In addition, performing BSEs for one another was reported as a facilitating factor by one Bufen:

*“My partner and I check each other’s breasts every two or three days. Just for checking the breasts themselves – it is not a part of sexual activity. If there are any changes in our breasts, I believe we will notice.”*

*(ID 20, Bufen, 39 yrs)*

The Bufen (ID 20) might change her gender role based on her partner’s gender identity, and her views regarding her own breasts were considered to be flexible. When she played a masculine role within a relationship, she might allow her Po partner to touch her breasts. Therefore, during such periods, performing BSEs for each other was a facilitating factor for both the Bufen and her partner. However, this was not considered to be possible when the Bufen’s partner was a T – her partner might adhere to the code for Ts, and therefore the Bufen would not be allowed to touch her partner’s breasts. Examples of Ts’ views in relation to performing BSEs for one another and the barriers are provided in the following.

In Fish’s UK national lesbian survey (2003<sub>b</sub>), conducted between 1997 and 1998, performing BSEs for one another as a part of sexual activity was noted among British lesbians. One T (ID 07) reported that she did BSEs for her partner as a part of sexual activity; however, she did not specify whether she and her partner did BSEs for one another or whether she did BSEs for her partner alone:

*“I do it [BSE] for my partner as a part of sexual activity. Sometimes, I do it for her when we take a shower together.”*

*(ID 07, T, 38 yrs)*

As previously mentioned, the masculine lesbians were found to be more likely to have a negative view of their own breasts because they were a symbol relating to their physical sex that they were trying to hide, and which they felt might damage their masculine role within their relationship. The Ts in this study indicated that they did not like or allow their partners to touch or look at their breasts:

*“Usually, I do not like my partner touching my breasts.”*

*(ID 10, T, 36 yrs)*

*“During sexual activity, I do not allow my partner to touch my breasts, I do not like it. I think this is because I am a T. If she touches my breasts, I feel very uncomfortable.”*

*(ID 14, T, 31 yrs)*

Among these Ts, touching or looking at their breasts was to go against their masculine identity, and might result in the individuals developing body image disturbance. Hence, it seemed impossible for these Ts to allow their partners to perform BSEs for them. However, where a T-identity lesbian and her partner were in a long-term relationship, she might allow her partner to touch her breasts:

*“I do not like my partner touching or looking at my body. I have to ensure that she really likes me, and then I will decide whether she can touch my body or not.”*

*(ID 22, T, 47 yrs)*

The loyalty of Pos was often challenged by Ts (Zhang, 2011). Pos' gender identity, gender expression and their responsibilities and roles within a relationship were considered by Ts to be no different from those of heterosexual women. In contrast, Ts had to adhere to the strict codes for being masculine within their relationships, which led to a significant likelihood of being recognized as homosexual and being discriminated against by non-homosexual people. For the participant (ID 22), allowing her partner to touch her breasts was considered to be related to how certain she was that the Po belonged to this subgroup and the extent to which the T trusted that the Po would not challenge her masculine identity and her male privileges.

In addition, whether touching her partner's breasts was for BSE or for pleasure, one T-identity lesbian reported that any changes in her partner's breasts would be noticed because of long-term and frequent contact:

*“I had a partner who was diagnosed with breast cancer. Initially, the mass was small and hard to notice, but I touched her breasts frequently and I found that the mass was getting bigger. So, I accompanied her to see a doctor and then she was diagnosed with cancer. Touching a partner's breasts frequently should enable me to notice any changes in her breasts.”*

*(ID 30, T, 41 yrs)*

A change in her partner's (Po's) breasts was noticed by one T (ID 30) due to long-term and frequent contact. However, among the Ts in this study, the efficacy of breast examinations and breast awareness (not being conducted step-by-step) was unclear. Although the Ts might touch their partners' breasts frequently, some might not notice changes in their partners' breasts because the touching was for pleasure rather than for examination, and the sensitivity of individuals regarding the changes would vary. Hence, it might be wrong to assert that a T

touching her partner's breasts is a facilitating factor in a Po's breast health, but it could be that in touching her partner's breasts a T might find changes.

As mentioned, one of the responsibilities of having a masculine role within a relationship was to take care of her partner (Su, 2005). In addition to performing BSEs for a partner (her Po) and noticing any changes in her partner's breasts, taking note of relevant information for a partner was reported as a method for taking care of her partner's breast health by one T:

*"I will pay attention to relevant information for my girlfriend and take care of her and her health. I think it is normal for my girlfriend to have a breast screening."*

*(ID 05, T, 23 yrs)*

Adopting a male role within their relationship, this participant (ID 05) took care of her partner's breast health by paying attention to any relevant information. As previously mentioned, the participant expressed negative intentions in relation to breast cancer screenings; however, by disconnecting the association between herself and breast screenings, the individual preferred to pay attention to any relevant information or else approach services relating to her Po's female characteristics.

### **5.5.3 The impact of breast cancer in relation to lesbian couple relationships**

When the lesbians were asked questions relating to the seriousness of breast cancer, some of the women reported their concerns about their relationships with their partners. Having breast cancer would endanger their relationship with a partner, as was reported by the Bufens, the Pos and the Ts:

*"Having breast cancer would affect my life because I would have to be treated. Also, my relationship with my partner would probably be changed, especially sexual activity."*

*(ID 18, Bufen, 35 yrs)*

*"The disease would change me physically and psychologically, and even my relationship with my partner would be changed too. Some people do not accept partners who are incomplete."*

*(ID 36, Po, 33 yrs)*

*"I do not believe in long-term relationships. There is no one who can stay with you forever, especially when you are sick."*

*(ID 30, T, 41 yrs)*

As with previous descriptions, two of the lesbians (the T and the Po) expressed the negative consequences that would probably result if they had breast cancer, and the Bufen reported that sexual activity with her partner would change. However, it was uncertain whether this factor facilitated or inhibited the lesbians' behaviour and intentions in relation to breast cancer screenings.

## 5.6 Patient-provider interaction

YC: What are you concerned with when you have a breast screening at a hospital?

ID 12 (T, 30 yrs): Usually, we do not have much choice but to choose a female physician, because at least we feel safe while being examined by someone of the same gender. It is very difficult to find a physician who has knowledge about multiple gender diversity in Taiwan.

YC: So, physicians' knowledge about multiple gender diversity will encourage you to have a breast screening at a hospital?

ID12: Yes, if they understand us, we will be very happy to have a screening at hospital.

The influencing factors regarding patient-provider interaction were found to be strongly related to the participants' behaviour and intentions regarding CBE and mammography in this study. Details of the influencing factors are presented in the following sections, under the headings: 1) healthcare provider's (HCP's) gender; 2) HCP's knowledge about multiple gender diversity and lesbian healthcare needs; and 3) HCP's acceptance of lesbians.

### 5.6.1 HCP's gender

The preferred gender of their HCP was reported as female by the majority of the participants in this study, whether the individuals self-identified as a masculine, undifferentiated or feminine lesbian. Traditional Chinese culture was expressed as a reason for choosing a female HCP:

*"We live in a patriarchy. Women have been taught that their breasts or vagina cannot be seen."*

*(ID 18, Bufen, 35 yrs)*

For this Bufen (ID 18), in order to promote her breast health and to avoid going against traditional Chinese culture, she would prefer a female HCP to perform the breast screening for her. In Yalom's (1998) *A history of the breast*, she indicated that the meanings associated with

breasts have always been bound up with societal values and cultural norms. In a male-dominated society, a woman's breasts are not thought of as her own – her breasts belong to others, such as her husband, her lover or her baby (Young, 2005). Hence, it is not acceptable for a woman's breasts to be seen by another man (male HCP), even if it is for a breast screening.

Another reason for preferring a female HCP was related to the women's sexual orientation. Never having had a relationship with a man was reported by one Po:

*“Some of us do not have any experience with men. So, if the screening is performed by a male physician and we have to take off our clothes, I feel it would be a very... I do not know how to describe it... very uncomfortable...”*

*(ID 01, Po, 30 yrs)*

This was considered to be related to the lesbian's feelings towards or views about men (biological males). Based on the information given by the participant (ID 01), it was hard to understand why she held the views she had regarding men and, consequently, her preferences. However, previous experiences within the family or social surroundings were considered to affect the lesbian's views regarding men. Androphobia, which refers to the abnormal fear of men, was expressed by the two Bufen pian Ts in Section 5.3.4 and affected the individuals' gender identification. In this case, androphobia might be a reason for preferring a female HCP and, probably, her sexual orientation.

In addition to the feminine-identity lesbians preferring a female HCP, the majority of the masculine-identity lesbians also reported that they preferred a female HCP. Having the same sexual characteristics was expressed as a reason for the individuals' preference for a female HCP:

*“What I have, she [the female HCP] has too.”*

*(ID 10, T, 36 yrs)*

As previously mentioned, the Ts' masculine identity was found to be negatively associated with their actions and intentions regarding CBEs and mammograms. However, in circumstances where the individuals suspected that they might get breast cancer (such as feeling pain or discomfort in their breasts), they would probably have a breast screening. In this case, the individuals reported that they preferred a female HCP to provide the screening

for them. The idea of having the same sexual characteristics was considered to be related to the lesbians' unchangeable female characteristics. Whether because of traditional Chinese culture or societal expectations, the lesbians thought that they were still women. Hence, a HCP of the same gender would meet expectations in terms of culture and society.

As they had the same sexual features as female HCPs, one masculine lesbian considered that female HCPs might be more familiar with breasts and breast disease than male HCPs:

*"In my opinion, female physicians might have more knowledge about breasts because they have breasts too."*

*(ID 02, T, 27 yrs)*

The idea was considered to be related to the T's (ID 02) masculine identity. As already mentioned, some of the Ts thought that breasts belonged to women. These Ts disconnected themselves from their female body parts in order to avoid body image disturbance. This participant, who self-identified as male, might refer her views to male HCPs' views regarding female breasts. She assumed that male HCPs would have less relevant knowledge because they had no reason to approach issues about women's breasts. Therefore, if the T needed a breast screening, she would prefer a female HCP.

In contrast to the preference for a female HCP, two Ts reported that they preferred male HCPs to provide breast screenings for them:

*"...if the physician is female, I would probably feel embarrassed. If the physician is male, I would feel more comfortable."*

*(ID 17, T, 22 yrs)*

*"I would feel much more embarrassed if the physician were female. I do not want a female physician to perform it [breast screening] for me.... I like women, so a female physician will make me feel very... strange.... If the physician were male, I would feel that it is just a physical examination."*

*(ID 22, T, 47 yrs)*

Feeling embarrassed was verbalized by both these lesbians if they had a female physician provide breast cancer screenings for them. The lesbians might view themselves as men, hence, having a breast screening performed by a female physician could be intrusive for these lesbians. In addition, the Ts were attracted to women and it might be another reason for them



preferring a male HCP. The participants' masculine identities were also considered to be associated with their preferences relating to the HCP's gender. Being a T required the construction of a masculine role and appearance based on the codes within lesbian communities. Some of the traditional Ts did not allow their partner to look at or touch their breasts in order to maintain their male identity and masculine role. Therefore, having a female HCP (a potential Po) perform a breast screening for them would be to go against their masculine identity, and would probably lead to body image disturbance.

Having no HCP gender preference was also expressed by some of the lesbians:

*"A male or female physician is fine for me. I am concerned more about their skills and knowledge."*

*(ID 31, Po, 28 yrs)*

For this lesbian (ID 31), the efficacy of CBE and mammography was considered to be more important than her preference as to the HCP's gender. In addition to the efficacy of the screenings, the HCP's knowledge and skills in terms of providing care with cultural competence might also be more important than his or her gender. In the following section, the influencing factors regarding the HCP's knowledge about multiple gender diversity are presented.

### **5.6.2 HCP's knowledge about multiple gender diversity and lesbian healthcare needs**

The HCP's knowledge about multiple gender diversity and lesbian healthcare needs were identified as factors influencing the participants' breast healthcare behaviour and intentions. Poor patient-provider communication was reported by the participants as being associated with HCPs' lack of knowledge regarding multiple gender diversity and inadequate skills in providing culturally competent care:

*"We usually hope that physicians will understand us. This makes us feel comfortable and safe. We do not want to deal with a physician's lack of knowledge or nervousness. Sometimes, physicians are not impolite on purpose – they just don't know how to communicate with lesbians. They have a lack of knowledge and skills regarding multiple gender diversity. If they had more knowledge about it, I would probably have a screening."*

*(ID 12, T, 30 yrs)*

For this T (ID 12), a HCP's lack of skills in communicating with LGBT patients and inadequate relevant knowledge were reported as being associated with the lesbian's

satisfaction with the quality of the service. Culturally competent care was related to high-quality care by the lesbian. Cultural competence is an important aspect of care and it refers to a set of skills that allows HCPs to give culturally appropriate care to individuals of cultures different from their own (IOM, 2011). The individual expressed her anticipation that HCPs should be trained to provide proper care to sexual minority people and, therefore, that it would encourage her to have a CBE or a mammogram in a hospital.

In addition, HCPs' knowledge about multiple gender diversity was related to their sensitivity in the areas of concern for sexual minorities and the acceptance of lesbians, according to one Bufen pian T:

*"If the physician understands lesbians, I will have a screening. I'd think that it's not such a scary matter to have a screening, because at least someone knows we exist and they understand and respect us."*

*(ID 29, Bufen pian T, 25 yrs)*

In Taiwan, medical students are not specifically trained to provide healthcare services to sexual minority individuals. A lack of training among HCPs might result in low sensitivity to sexual minority groups and, consequently, they might provide poor quality care, which could lead to lesbians' non-attendance for mammograms or low re-attendance and low satisfaction with the service.

The most common example noted by the participants regarding HCPs' lack of sensitivity towards sexual minority women was their heterosexual assumptions:

*"Once, I went to see a doctor because my period had not arrived. The doctor kept asking me about my sexual activities and whether I had gotten pregnant or not. Although I told her that it was impossible for me to get pregnant, she insisted that I needed a pregnancy test to check for it."*

*(ID 31, Po, 28 yrs)*

In this study, being asked to have a pregnancy test was reported by some of the Pos in relation to HCPs' lack of sensitivity regarding the subgroup, even though the women provided clues to disclose their sexual orientation to the HCP. For example, the participant (ID 31) told the HCP *"it was impossible for me to get pregnant"*. Robertson (1992) indicated that HCPs would too often assume that their patients were heterosexual. HCPs' heterosexual assumptions were found to result in feelings of not being accepted, of exclusion and of

neglect among sexual minority individuals (Rondahl et al., 2006). The heterosexual assumptions of HCPs were reported by the Po when she described the healthcare system in Taiwan, and it was considered to be a concern in relation to the individual's breast healthcare behaviour and intentions.

In addition, a lack of knowledge regarding multiple gender diversity and a lack of sensitivity towards the subgroup were expressed as leading to low satisfaction with the care given to the lesbians:

*"The healthcare provider treated me just as a number, I felt that they did not provide me with what I needed."*

*(ID 13, Po, 30 yrs)*

HCPs' neglect of sexual minority individuals and providing care without cultural competence could cause the lesbians to feel excluded. Therefore, the Po (ID 13) reported that she was treated as a 'number' instead of being accepted as an 'individual' by the HCP, and the feeling of being excluded resulted in the woman's low level of satisfaction with the service.

Although the majority of the participants were not eligible to have a free mammogram, the women referred to past experiences of seeing a HCP and to possible scenarios that might occur if they had one. HCPs' lack of knowledge regarding multiple gender diversity and healthcare needs were identified as barriers in the women's breast healthcare behaviour and intentions. In addition, heterosexual assumptions of HCPs were also found to be associated with the individuals' intention to have CBEs and mammograms, especially the feminine-identity lesbians. Feeling excluded from the healthcare system was considered to be associated with not only the women's low satisfaction with the healthcare services they used but also their actions and intention to obtain breast cancer screenings.

### **5.6.3 HCP's acceptance of lesbians**

The HCP's acceptance of lesbians was identified as the most important factor associated with the women's utilization of and intentions regarding CBE and mammograms. 'Acceptance' refers to whether a HCP shows an interest in the individual as well as the health problem that has brought them together. Lesbians decide what level or degree of acceptance is shown in the interaction due to certain attitudes of the HCP (Hitchcock & Wilson, 1992). An 'attitude'

is a subjective phenomenon whereby the use of verbal behaviours or nonverbal factors may have different meanings for the provider and the patient (van Dam et al., 2001).

Eye contact and silence were reported as the most common nonverbal factors helping the lesbians to assess HCPs' acceptance of them:

*"We [the participant and her partner] worry about how they see us.... It is just like how they use very unfriendly attitudes and looks to judge and treat us."*

*(ID 01, Po, 30 yrs)*

*"I had a breast screening when I was 24 years old because I felt some changes in my breasts. The physician kept silent during the whole procedure. He was so cold and uncaring."*

*(ID 09, T, 35 yrs)*

Hitchcock and Wilson (1992) suggested that nonverbal factors provided clues to lesbians regarding HCPs' acceptance of them. These factors helped the lesbians to assess how 'safe' the HCPs would be (i.e., in terms of not being discriminated against by the HCPs). The Po (ID 01) reported her concerns about being subjected to discrimination by HCPs in terms of a lack of eye contact between herself and the HCP. In addition, the T (ID 09) referred to her past experiences of having breast screenings. The HCP's silence during the screening procedure resulted in the T's dissatisfaction with the service. These clues were reported as being associated with how the lesbians detected the level of acceptance of the subgroup among the HCPs and the possibility of discrimination by the HCPs should they have a CBE or a mammogram.

On the other hand, statements that revealed a judgmental attitude and a feeling of being excluded were reported by the participants as verbal factors in helping the women to assess HCPs' acceptance of lesbians, based on the lesbian's previous medical experience of having gynaecological examinations:

*"A doctor asked me about my sexual activities. I answered: 'Yes, using fingers.' He/she told me it was not.... During that time, I felt that what the physician had said was very inappropriate."*

*(ID 20, Bufen, 39 yrs)*

Verbal factors were suggested as being very important in maintaining 'safe' patient-physician interaction (Hitchcock & Wilson, 1992). The Bufen took a risk and gave a clue regarding her sexual orientation; the HCP's verbal response indicated a low level of acceptance of the lesbian and his/her lack of knowledge and skill in communicating with sexual minority groups. This scenario was considered to be a 'non-safe' interaction between the HCP and the individual. The lesbian might be concerned of possible perceived misunderstandings or discrimination by the HCP, and therefore she might choose not to reveal more information related to her sexual orientation and this might influence her decision in using future medical services. The woman's intention to receive breast healthcare services from HCPs might also be affected because of such a negative past experience.

Whether a HCP presents his or her attitudes and acceptance of the lesbians verbally or nonverbally, concern about being discriminated against by HCPs was reported by the participants as an important barrier in the women's breast healthcare behaviour and intentions:

*"I worry about being discriminated against by physicians if I need a breast cancer screening."*

*(ID 32, Bufen pian T, 33 yrs)*

In the case of this lesbian, although she had no experience of breast cancer screenings in a hospital, she reported her concerns regarding the HCP's attitudes. It was considered to be associated with previous experiences of being discriminated against in public and the individual's masculine appearance, as previously mentioned in Section 5.4. The lesbians who had a masculine appearance were more likely to be identified as homosexual and to have received harassment from others than the lesbians with a feminine appearance. This finding echoes the previous studies. Sexual minority individuals reported experiencing verbal abuse and disrespectful verbal or nonverbal behaviour on the part of HCPs (Eliason & Schope, 2001; Kenagy, 2005). Jillson (2002) found that providers' attitudes towards sexual minority patients could be an inhibitor to care.

In order to avoid possible discrimination by HCPs and to meet the expectation that the HCP should have knowledge regarding multiple gender diversity and the skills to provide culturally appropriate care, the lesbians reported that they would scout a suitable HCP out:

*“Last time, when I needed to see a doctor, I found one who was familiar with issues of gender diversity and who had published books about multiple gender diversity. The doctor knew about how sexual orientation is varied and also diverse. He/she did not ask lots of questions, nor too few – the information was just enough for what he/she needed to know.”*

*(ID 20, Bufen, 39 yrs)*

The participant (ID 20) sought to amass information about HCPs before deciding whether she would go to see one in ‘safe’ circumstances. Hitchcock and Wilson (1992) proposed two methods to scout a suitable HCP out: screening and networking. Screening is an action involving interviewing a provider to assess his or her attitude towards lesbians. Networking is a process of gathering information about a HCP by asking friends for a referral – usually HCPs who friends and partners use – and looking in gay-orientated media for advertisements (Hitchcock & Wilson, 1992). The lesbian (ID 20) searched and reviewed the HCPs’ backgrounds online. The HCP whom the lesbian saw had a background involving and knowledge of multiple gender diversity – the participant believed that the HCP was ‘safe’ because of his or her acceptance of the subgroup and his/her knowledge and skills in dealing with sexual minority women. This finding was echoed in the lists of gay-friendly doctors which were provided by some LGBT organizations in Taiwan in order to help the sexual minority individuals to receive care with cultural competence and avoid possible discrimination by HCPs.

## **5.7 Summary**

The aim of the study was to explore the factors associated with Taiwanese lesbians’ breast healthcare behaviour and intentions. Four themes were identified from the qualitative interviews, which were gender identity, gender role expression, partner support and patient-provider interaction.

Gender identity was found to be an important factor influencing the lesbians’ breast healthcare behaviour and intentions and their views regarding breast cancer and breast cancer screenings, whether the individuals self-identified as T, Bufen or Bufen pian T. For

the Pos, gender identity was not considered to be a factor influencing these individuals' breast healthcare behaviour and intentions. The majority of the Ts held negative intentions in relation to breast cancer screenings due to their masculine identity, while the Pos were found to have similar views to heterosexual women regarding breast cancer and breast cancer screenings. Three different definitions of 'Bufen' were reported by the four Bufen-identity lesbians and these definitions were found to vary the individuals' breast healthcare behaviour and intentions. The Bufen pian Ts' views regarding breast cancer and breast cancer screenings and breast healthcare behaviour and intentions were found to be affected by the individuals' reasons for self-identifying as Bufen pian T, comprising contemporary lesbian culture, traditional Chinese culture and androphobia.

Gender role expression was also identified as a key factor influencing the lesbians' breast healthcare behaviour and intentions, in particular those individuals with a masculine appearance. This factor was mainly related to the lesbians' behaviour and intentions in relation to breast cancer screenings performed by a HCP because of concerns about sexual stigma attached by society or else the HCP. The lesbians' practices regarding BSE and breast awareness were found to be affected by the women's views of their own breasts. Negative views were held by the majority of the masculine-identity lesbians and they led to the non-utilization of and negative intentions regarding breast cancer screenings. On the other hand, a number of the Pos had positive views regarding their own breasts, and these views were found to motivate their actions in relation to BSE and breast awareness.

The partner's support was identified as an important factor facilitating the lesbians' breast healthcare behaviour and intentions. The partner's reminders or requests, being accompanied by a partner, and performing BSEs for one another, were found to be common methods that would motivate the participants' breast healthcare behaviour. The belief that having breast cancer would endanger their relationship with their partner was proposed by the participants as an influencing factor in relation to perceiving the seriousness of breast cancer, although this factor's effect was uncertain in influencing the women's breast healthcare behaviour and intentions.

Patient-physician interaction was identified as a factor affecting the lesbians' behaviour and intentions in relation to CBE and mammography. HCPs who are female and who have knowledge and skills regarding multiple gender diversity and lesbian health needs might

encourage the lesbians to have breast cancer screenings. HCPs' acceptance of lesbians was assessed by the participants based on their verbal and nonverbal behaviour when interacting with the women. Whether the lesbians had a breast screening in a hospital or not, their previous experience of interacting with HCPs influenced the individuals' breast healthcare intentions and behaviour. Those lesbians who felt accepted by the healthcare system would be more likely to have a breast screening than those who experienced 'unsafe' interactions with HCPs.



## **Chapter 6: Phase one – discussion**

### **6.1 Introduction**

In Chapter 5, four themes associated with Taiwanese lesbians' breast healthcare behaviour and intentions were generated from the findings of the qualitative interviews, which were: 1) gender identity; 2) gender role expression; 3) partners' support; and 4) patient-provider interaction.

This chapter aims to compare the findings with existing evidence and to discuss the possible reasons for the influencing factors among the Taiwanese lesbians. The findings which are different from existing evidence will be described and discussed in terms of how and why they are related to the lesbians' breast healthcare behaviour and intentions. In addition, the purpose of the qualitative interviews was to identify the influencing factors in order to develop an online questionnaire, which was employed to collect data from a larger target population in the second phase of this PhD study. Hence, the factors which were chosen and included in the questionnaire's design are also presented and discussed in this chapter. At the end, a conceptual framework is provided to give a general idea of how these factors might be associated with Taiwanese lesbians' breast healthcare behaviour and intentions, and also to offer a preliminary framework for the online questionnaire.

### **6.2 Gender identity**

Gender identity was identified as an important factor influencing the Taiwanese lesbians' breast healthcare behaviour and intentions. The T and Po gender identities were found to be mainly and widely used by the participants in this study, while the identities Bufen and Bufen pian T were only employed by a small number of the participants. Gender identity was not only related to the individuals' breast healthcare behaviour and intentions but also affected the women's views on their own breasts, breast cancer and breast cancer screenings.

#### **6.2.1 Self-identification as a T**

The rigid gender roles within the lesbian subculture parallel the relatively staid gender roles of men and women in the dominant heterosexual culture of Taiwan (Hong et al., 2003; Kuang et al., 2004). As mentioned, there were more Ts than Pos in Taiwan. Ts would thus try to maintain their relationships by devoting as much time as possible to taking care of their partners (Pos) (Chiang & You, 2011; Su, 2005; Zhang, 2011). The gender identities and roles

among the Ts in this study were found to be similar to those in previous studies. The majority of the participants self-identified as T. Their identity, however, was found to be strongly related to not only their roles within their lesbian couple relationships but also their views about their own body, breast cancer and breast cancer screenings.

The women's body image is suggested as being related to the individuals' cancer screening behaviour (Ridolfi & Crowther, 2013). In this study, being a T was reported as being a man or being "*like*" a man by the T-identity lesbians. This identity was mainly adopted based on the lesbians' own expectations (transgender butch) or by following the codes of being a T within lesbian communities. Avoiding body image disturbance was found to be a key reason for the individuals not finding information or thinking about issues related to their female body and not performing or having breast cancer screenings in this study.

A similar finding about body image can also be seen in Kelly's (2007) study. The researcher conducted 20 qualitative interviews with lesbians in order to explore how the sociocultural contexts in which lesbians belong influence their perceptions of body image. She found that the process of creating a body image perception was affected by two sociocultural contexts: (1) the dominant culture (outsider expectations); and (2) lesbian cultural norms (insider expectations). When the lesbians adopted an identity, their perceptions of body image were affected by lesbian cultural norms. Body silence was expressed as a method by which the lesbians in Kelley's study dealt with their bodies, because the participants reported that they had difficulties speaking to others or soliciting feedback from others about their bodies, and they were unsure how they felt about their bodies or how they were supposed to feel. This finding in Kelly's study echoes the finding in the present study. The Ts disconnected from their female bodies by staying silent or else distant from related information and healthcare services.

In addition to staying silent or distant, denial was also proposed as a method to help the lesbians to maintain their body image and to minimize the risk of revealing their true sex. For example, perceiving a lower risk of getting breast cancer was expressed as a barrier in relation to the masculine lesbians' breast healthcare behaviour and intentions. In Fish's UK lesbian health survey, a lower perceived risk of having breast cancer inhibited the lesbians' use of mammograms (Fish, 2006) and performance of BSEs (Fish & Wilkinson, 2003<sub>b</sub>). However, the reasons for the perceived lower risk were reported to be related to the British

lesbians' age (such as being too old or too young), having no family history of breast cancer or else having no symptoms. The masculine identity of the Ts in the current study was found to mainly contribute to the individuals' perceived risk of having breast cancer. Some of the lesbians believed that they had a similar risk of getting breast cancer as Taiwanese men, while some reported that they "*preferred to think*" that they had a similar risk of having breast cancer as men in Taiwan. These individuals maintained a masculine identity and body image by disconnecting any association between themselves and "*women*" (including both Pos and heterosexual women).

Brown (1987) indicated that lesbians who accepted their sexual orientation had a positive body image. She believed that the process of the self-acceptance of a woman's lesbianism and the process of the self-acceptance of her body were simultaneous processes, and that working through one supports the resolution of the other. In contrast, in the current study, the Ts' acceptance of their sexual orientation and gender identity were not positively associated with their body image. Self-stigma (internalized homophobia) may have explained the individuals' body image perceptions (IOM, 2011). Due to the long-term perception of discrimination by Taiwanese society, the lesbians might begin to develop negative views about themselves and begin to integrate with common stereotypes. The women's negative body image and self-stigma might inhibit their breast healthcare behaviour and intentions.

### **6.2.2 Self-identification as a Po**

Among the Pos, gender identity was not identified as a factor influencing the women's breast healthcare behaviour and intentions. The key influencing factors among these individuals were found to be similar to those for heterosexual women, such as being too young (Chiang et al., 2011; Lopez et al., 2009; Kratzke et al., 2010) and a family history of breast cancer (Chiang et al., 2011; Lai, 2011; Gierisch et al., 2009). Moreover, the Pos' views about CBE and mammography were also found to be similar to those of heterosexual women in Taiwan. Feeling embarrassed about the screening procedures was identified as a barrier to having a CBE or mammogram too, which was also found in heterosexual women by Chiang et al. (2011) and Tsai et al. (2011). Traditional cultural norms and body boundaries were considered to be associated with the finding. Taiwanese women are taught that they should hide their breasts from a young age onwards, and hence taking off their clothes and being examined by a physician are considered to go against the traditional culture, especially when the examination is performed by a male.

In contrast to the body boundaries among the Pos in this study, body shame and body avoidance were found to be associated with cancer screening behaviour among heterosexual women (Ridolfi & Crowther, 2013). Body shame includes the belief that one is morally and physically inferior as a consequence of having objectionable, unattractive or unfavourable physical traits in comparison to the dominant cultural standard for beauty (Bessenoff & Snow, 2006). When women engage in body avoidance, they try to avoid perceiving their body's shape or weight; for example, avoiding examining their reflection in mirrors and avoiding weighing themselves (Fairburn, 2008; Trautmann et al., 2007). Among the Pos in this study, body shame and body avoidance were not found to relate to the lesbians' breast healthcare behaviour and intentions. The women were more likely to hold positive views about their own breasts due to the influences of US gay culture in the 1960s and feminism in the 1990s. Instead of body shame and body avoidance, the personal distance (body boundaries) between the physician and the lesbian, and the procedures of breast screenings, were considered to be more likely to be associated with the Pos' breast healthcare behaviour and intentions.

### **6.2.3 Self-identification as a Bufen**

'Bufen' originally referred to a lesbian who adopted equal roles and shared responsibility in her relationship (Cheng, 1997). In this study, however, three different definitions of 'being a Bufen' were proposed by the four Bufen-identity participants and the different definitions were found to vary the lesbians' views regarding their female body, breast cancer and breast cancer screenings, and consequently their actions and intentions regarding breast cancer screenings. These varied definitions were considered to be used to meet the individuals' expectations and emotional needs. For example, one Bufen who changed her gender role according to her partner's gender identity, and another Bufen who changed her gender identity from T to Bufen because she realized that she could not change her female body. There is limited extant evidence which can be used to compare with this finding in the present study or to help understand the relationship between gender-identity and breast healthcare behaviour and intentions among Bufen-identity lesbians. Therefore, it needs to be investigated further. In the second phase of this study, a question about gender identity was asked in order to understand whether the identity of Bufen was associated with Bufens' behaviour and intentions regarding breast cancer screenings in Taiwan.

#### **6.2.4 Self-identification as a Bufen pian T**

The identity Bufen pian T was found to be used among a small number of Taiwanese lesbians who mainly identified themselves as lying between T and Bufen (Chiang & You, 2011). A total of three participants in this study self-identified as Bufen pian T. Except for one who held Chiang and You's (2011) definition of Bufen pian T, the other two lesbians' identities were found to be associated with traditional Chinese culture and androphobia. Their views about their own body, breast cancer and breast cancer screenings were found to be similar to those of the Ts. Both of the Bufen pian Ts were found to have a negative body image and negative views about breast cancer and breast cancer screenings, and consequently this led to reversed breast healthcare behaviour and intentions.

This identification is employed by Taiwanese lesbians specifically. In the existing evidence exploring lesbian gender identities, no other lesbians used it outside of Taiwan. There is limited evidence that can be used to understand the relationship between gender identity and breast healthcare behaviour and intentions among Bufen pian Ts. Hence, it needs to be investigated further. In the second phase of the study, a question about gender identity was asked in order to understand whether the identity of Bufen pian T was related to Taiwanese lesbian behaviour and intentions regarding breast cancer screenings.

Previously, gender identity was discussed in relation to the existing evidence and how it is associated with Taiwanese lesbians' breast healthcare behaviour. However, in contrast to the studies reviewed in Section 2.6, gender identity was not identified as a factor influencing lesbians' breast healthcare behaviour or intentions in the US or the UK. Comparing contemporary lesbians' identities in the US, the UK and Taiwan, the lesbians' identities were found to be different among the women in these three countries. The following paragraphs describe gender identity and its history among lesbians in the US, the UK and Taiwan, and discuss the possible reasons for the different findings.

In the US, the butch/femme lesbian gender role divisions appeared in the 1940s and the 1950s during the aftermath of WWII. Butch and femme labels were widely used among poor and working-class lesbians. However, between the 1950s and the 1960s, these divisions began to be rejected by middle-class lesbians, who preferred to adopt the behaviour and dress that was acceptable to society (Faderman, 1992). In the 1970s, with the start of the feminist movement, the butch/femme divisions remained out of favour among middle-class lesbians,

who preferred an androgynous appearance, because the dichotomous identities were seen as mimicking the heterosexual marriages that feminists were challenging (Gibson & Meen, 2002; Faderman, 1992). In the 1980s, the butch/femme divisions began to re-emerge in some lesbian communities as women reclaimed their identities (Faderman, 1992). However, new combinations of butch/butch and femme/femme couples were increasingly visible (Faderman, 1985; Inness & Lloyd, 1995). As a result, there was greater flexibility in constructing modern butch and femme identities (Levitt et al., 2003; 2004).

Today, lesbians in the US do not usually fall neatly into the butch/femme identities in their gender presentation (Peplau et al., 2004). When lesbians have a partner and live together, they typically share responsibilities equally, such as housework, financial responsibilities and decision-making (Kurdek, 1993). Peplau and Huppin (2008) have argued that the gender expressions and identities of lesbians are fluid across social classes, social contexts, time and ethnicities. Although the butch/femme divisions are familiar labels for contemporary lesbians, many lesbians in the US do not see themselves as falling into rigidly gendered categories. In a more recent survey conducted in the US with 214 lesbian-identified women (Walker et al., 2012), the researchers found that the butch/femme labels do not fully include the multiplicity, fluidity or complexity of individual women's identities. The results in Walker's study did not support the stereotypes about lesbian gender labels, and suggested that behaviours in the lesbian community were fluid across labels.

A similar progression of lesbians' identities can also be seen among British lesbians. Before the 1990s, the butch/femme identities were mainly employed by British lesbians, and they were associated with assimilation in a heterosexual society. After the 1990s, contemporary lesbians in the UK rejected the rigid dichotomous labels and lesbians' identity was suggested as being flexible and fluid (Farquhar, 2000).

The Taiwanese lesbian culture was constructed mainly following the American lesbian culture between the 1960s and the 1980s. As mentioned, during that time, Taiwan was incorporated into the Cold War structure as a US military base in the Asia-Pacific (Chao, 2000; 2001). The dichotomous identities were introduced to Taiwanese lesbians in the 1960s and have become a norm since the 1980s, when the first T-bar opened in Taipei. The butch/femme labels have been modified in terms of T/Po labels by Taiwanese lesbians because of the massive media influence and by referring to Chinese meanings (Chao, 2000;

2002). Different from lesbians in the US and the UK, the T/Po identities were suggested to be continuously used by contemporary lesbians in Taiwan so as to distinguish the gender roles within their relationships and to find partners (Kuang et al., 2004).

According to the existing evidence, this finding was considered to be related to the mainstream Taiwanese lesbian culture and the favourable dichotomous identities used by the lesbians in Taiwan. In contrast, for contemporary lesbians in the US and the UK, women's identities have become much more flexible and fluid compared to the rigid dichotomous identities, and this might be a reason why gender identity was not identified as a factor influencing the individuals' breast healthcare behaviour and intentions in these two countries.

Although gender identity was not identified as a factor influencing lesbians' breast healthcare behaviour and intentions in the studies reviewed in Section 2.6, it was found to be strongly related to the lesbians' breast healthcare behaviour and intentions in this study. The identities T and Bufen pian T were found to be barriers, while the identity Po was considered not to be an influencing factor. The Bufen-identity's relationship with the women's breast healthcare behaviour and intentions was uncertain due to the various definitions. In order to understand whether gender identity affected Taiwanese lesbians' breast healthcare behaviour and intentions significantly, questions regarding the lesbians' gender identification were included in the questionnaire.

## **6.3 Gender role expression**

### **6.3.1 Masculine appearance**

Gender role expression was identified as a factor inhibiting the lesbians' breast healthcare behaviour and intentions, particularly the individuals with a masculine appearance. It was found to be related to three key issues, namely the individuals' views about their own breasts, constructions of gender roles and sexual stigma in society or the healthcare system.

#### **6.3.1.1 Masculine-identity lesbians' views about their own breasts**

Negative views about their own breasts among the masculine-identity lesbians were found to be barriers in the women's breast healthcare behaviour and intentions. Fish and Wilkinson (2003<sub>b</sub>) explored how feelings of embarrassment or psychological discomfort when performing BSEs inhibited the individuals in undergoing breast cancer screenings. Although the lesbians reported that they knew that BSE was a good idea, they still felt discomfort about

their body in general or else specifically about their breasts. The participants in Fish and Wilkinson's study reported that, sometimes, strong negative feelings (for example, nausea) were induced by the prospect of BSE. However, their study did not explore why these women held negative views regarding their own breasts. The researchers only indicated that a negative attitude towards their own breasts inhibited British lesbians' practice of BSE.

In the present study, the negative views that some participants held regarding their own breasts were found to be related to the women's gender identities, in particular those who self-identified as T or Butch. Morrison and McCutcheon (2011) found that bodily discomfort among lesbians might be due to a variety of factors, including a lack of conformity to the cultural expectation of having a female appearance, particularly by those identifying as androgynous. In addition, Zeng (2004) has indicated that the more that a lesbian behaves like a man, the more dissatisfaction she will have towards her own physiological structure. Most masculine-identity lesbians were dissatisfied with their female physiological structure, and disliked being touched by their partners. Similar findings are also found in Gunkel's (2009) study. Masculine lesbians in Bulgaria expressed how they felt as though they were trapped in the wrong body and that they attempted to hide or ignore their breasts, which served as a signifier for female identity.

In addition to the masculine-identity lesbians' negative views about their own breasts, the lesbians were also found to have fluid views on their own breasts in a previous Taiwanese study (Peng, 2008). Peng conducted qualitative interviews with five T-identity lesbians. She found that although the Ts' views about their own breasts were influenced by the dominant culture and that they held negative views about their own female characteristics initially, these masculine lesbians adopted their views through peer learning, their body experiences and their partners' support. The Ts developed new body image perceptions which varied from the traditional binary sex concept. Different definitions of body beauty were expressed by the participants in Peng's study; for example, breasts being not too big and of the same size. The researcher, however, did not specify the reasons for the Ts' varied views and how these views were related to their body image or their life experience. In addition, this study was conducted with only five lesbians aged around 25 years, and they were all recruited through friends (snowball sampling). The participants were considered to have high homogeneity. The findings in the present study somewhat echo those in Peng's (2008) study. The masculine-identity lesbians' attitudes towards their own breasts were found to vary as the



individuals aged. The younger masculine lesbians were in the process of developing concordance between their female bodies and gender identities, but they still had contradictory feelings. As they aged, the lesbians reported that they accepted their bodies but did not like them, because they realized that they could not be changed. Traditional Chinese culture and expectations in Taiwanese society were considered to motivate the women to begin the concordance process in order to avoid body image disturbance. Those masculine lesbians who did not integrate their physical and psychological aspects might have feelings of guilt and embarrassment. Those who went through the concordance process and maintained their body image might live with their breasts peacefully or else accept their breasts passively.

In Hong's (2013) Taiwanese study, living with their female characteristics peacefully was also found among the masculine-identity lesbians. A total of seven lesbians who had experience of wearing breast bindings were interviewed to understand their experiences of wearing the bindings. Hong indicated that the inclusion criteria did not require the women's sexual orientation; however, all of the participants were found to be masculine-identity lesbians. The participants' age range was 18-30 years and they were recruited by using purposive sampling and snowball sampling. The participants were considered to be young. Based on the information provided in Hong's (2013) study, it was not known whether the use of the word 'peacefully' meant that the participants accepted their female characteristics actively or passively, or whether their attitude towards their breasts was positive or negative. The meaning of 'peacefully' and how this view was related to the participants' life experiences were not specified by the researcher. Compared with Hong's study, some of the Ts in the present study were also found to live with their female features peacefully, but these women mainly held these views because they realized they could not make any changes in relation to their primary sexual characteristics.

### **6.3.1.2 Constructions of masculine appearance: breast binding**

The construction of a masculine identity requires a process of body modification. Building a masculine body includes a whole series of de-feminizations, comprising breast-binding, shortening hair and wearing masculine/androgynous outfits. Breast binding for Ts is an action taken to de-feminize themselves and mimic the masculine (Chao, 1997). In Kuang et al.'s (2004) Taiwanese online survey, over 70% of the masculine lesbians had tried to hide their

breasts. In the present study, a number of T-identity lesbians reported using breast bindings to construct a masculine identity.

The reasons for using breast bindings among the Ts in this qualitative study echoed those found in previous studies in Taiwan (Hong, 2013; Su, 2005), including: 1) to promote the identification of their sexual orientation and sexual attraction; 2) to strengthen their gender identity; and 3) to respond to social expectations. Breast bindings were found to be used by those masculine-identity lesbians and heterosexual women who were born before the 1960s. Both groups of women were more likely to hold negative views regarding their own breasts than Pos, although heterosexual women and Pos had similar ideas as to their breasts' function: sexuality and motherhood. However, the reasons for using breast bindings were different for these two groups. Masculine-identity lesbians used breast bindings to construct a masculine identity, to maintain their body image and to increase their sexual attraction. In contrast, heterosexual women who were born before the 1960s wore breast bindings because of the obligations of traditional Chinese culture and views on female beauty in Taiwanese society (Chen, 2007; Chin, 2003).

### **6.3.1.3 Masculine appearance as a barrier to having breast cancer screenings**

A masculine appearance was identified as a barrier to accessing breast healthcare services by the Ts and Bufen pian Ts. For the lesbians with a masculine appearance, the actions of constructing a masculine role were seen to go against traditional Chinese culture by Taiwanese society. In Taiwan, women's roles and obligations are regulated and conceptualized mainly within conventional Confucian ideology. Constructed around principles of patrilineal piety, Chinese society stresses conformity to the family. A woman is asked to pay three forms of respect to: 1) her own family; 2) her husband; and 3) her first son (if she has any) following her spouse's death. To be a lesbian in Taiwan, the woman might have to deal with all kinds of hostility because patrilineal obligations and maternal productivity cannot be satisfied by the individual (Chao, 2000; 2001).

In addition, the lesbians' anti-feminine acts and masculine appearance were found to have several consequences. For example, Ts were suspected of spying and were either imprisoned or killed during the *White Terror* period in Taiwan. In Chao's (2000) study, Ts constantly faced sexist insults, homophobic comments and even sexual harassment in their social surroundings, such as being asked to leave women's rest rooms. Kuang et al. (2004) also

found that Taiwanese masculine-identifying lesbians perceived more oppression than Taiwanese feminine or androgynous lesbians.

Lesbian identity has been suggested as a social identity to which stigma was generally attached (Kelly, 2007). Evidence from Western countries indicates that butch lesbians more often reported being perceived as lesbian than femme lesbians and that they were obvious targets for homophobic attacks (Levitt & Hiestand, 2004). Butch women were discovered to experience more discrimination based upon their sexual orientation than femme women or women with non-traditional gender expressions, and faced significantly more discrimination based upon their gender expression (Levitt, 2012; Levitt & Horn, 2002). Mitra and Globerman (2014) and Baker (1993) also indicated that anti-gay violence and a lack of an adequate lesbian-supportive environment were barriers in lesbian healthcare.

Sexual stigma, which refers to the stigma relating to any non-heterosexual identity, behaviour, relationship or community, was suggested as a barrier to accessing healthcare among sexual and gender minorities (Herek, 2009; IOM, 2011). There are three types of sexual stigma which have been identified, namely enacted sexual stigma, felt sexual stigma and internalized sexual stigma. Enacted sexual stigma refers to explicit acts that express discrimination or violence towards members of a sexual minority group. Felt stigma consists of the fear that one might have of being labelled with a sexual stigma according to the views and stereotypes that society has placed on sexual minority members. The awareness of the possibility that stigma will be present in particular situations is related to felt stigma. Compared to the other types of social stigma, it was found to be strongly associated with individuals' behaviour – an individual may seek to avoid situations where a stigma might be enacted. Fear of stigmatization or previous negative experience of the healthcare system might cause sexual minority people to not access healthcare services or else delay seeking care. Finally, internalized sexual stigma refers to a person's self-identity, such that they start to accept a given sexual stigma. The individual's self-concept supports the idea of a specific stigma that society has created through negative actions, which as a result leads to the possession of a negative attitude towards his or her own sexuality or personality. This means that the stigmatized individual starts to believe the negative views held about them and so begins to integrate with common stereotypes (IOM, 2011). In Polek et al.'s (2008) study, self-stigmatization and a lack of self-esteem were also found to be barriers in lesbians' healthcare. The finding in the present study echoed the existing evidence. For the masculine

lesbians, concerns about sexual stigma from society and the healthcare system regarding their appearance were reported as inhibiting the women in undergoing CBEs or mammograms, although the majority of the Ts in this study were not eligible for free mammograms.

There was a lack of evidence to explore the association between gender role expression and lesbians' breast healthcare behaviour; however, previous studies on Taiwanese lesbians explored how concerns about being judged by other patients might delay them in seeing a physician or else cause them to avoid physicians entirely (Wang, 2013). The findings in Wang's study echo the findings in the present study. The T-identity lesbians reported that they would not go to a hospital and see a doctor if there were no (serious) symptoms due to their concern about being discriminated by other patients or physicians.

### **6.3.2 Feminine appearance**

#### **6.3.2.1 Feminine-identity lesbians' views about their own breasts**

Compared to the masculine-identity lesbians, the feminine-identity lesbians' views regarding their own breasts were more like those of Taiwanese heterosexual women (for example, relating to sexuality and motherhood).

The construction of Taiwanese women's views about their own female characteristics is suggested as being associated with their culture (Bloomfield & Illinois, 1994; Kwok, 2006). In Chinese society, Confucian moral and ethical teachings have been maintained as a guideline for gender hierarchies, honoured as a norm for evaluating women's behaviour, and used as a tool for gender division for approximately 2,000 years. The Confucians saw human desire as the opposite of the heavenly order, and argued that human desire would break the natural order for ordinary people and even disorder the cosmological principle. Therefore, all kinds of human desire – including sexual desire – were discouraged. In Chinese culture, the breasts were a body part that was associated with sex due to their capacity for sexual arousal, as an alluring temptation for men. In opposition to this background, breast binding was encouraged so that men should remain in a calm mood (Zhang, 2011).

While regulating moral behaviour, Confucianism advocated an ideal of feminine beauty and facilitated the popularization of breast-binding in the nineteenth century. Before the 1960s, breast bindings were still employed widely among Taiwanese women. Women's feelings about their breasts were expressed in terms of shame and embarrassment (Chen, 2007). At the

end of the 1980s, the Taiwanese women's liberation movement was established by modern artists. At the time, feminism was emphasized in art works in order to free women's bodies. For example, Yan, a famous female artist in Taiwan, drew fruit in images of women's breasts and vulvas (Chen, 2005). In Lu's (2001) article, although Taiwanese women have not bound their breasts in recent decades because of the influence of Western culture, their views regarding their bodies still relate to the ideas of 'shame' and 'uncleanliness'. The word 'unclean' mainly refers to feminine submission and traditional Chinese culture. In Taiwanese society, women are taught that the female body (i.e., their own bodies) is 'unclean' from childhood onwards. Women cannot go to temples during their menstrual periods because they are 'unclean' or else they have to hide their underwear because it is a symbol of 'shame'.

Yang et al. (2010) conducted qualitative interviews with 66 Taiwanese women and the researchers found that Taiwanese women's negative views about their female characteristics influenced their intentions regarding BSEs and led the women to avoid discussing related issues with others. However, it was not only Taiwanese women who were found to hold a negative body image affecting the individuals' intentions regarding breast examinations, as similar findings can also be seen in Ridolfi and Crowther's (2013) review. Body shame and body avoidance were found to be predictors of women's cancer screening behaviours. In contrast to heterosexual women, the majority of the Pos in this study reported positive views regarding their own breasts. These views were considered to be associated with US lesbian culture and feminism, which started in the early 1990s in Taiwan. Both the culture and the feminism mainly emphasized 'femininity', and they were considered to influence the Pos' views on their own breasts positively.

### **6.3.2.2 Criticism regarding feminine appearance (stigma from other lesbians)**

Unlike the lesbians with a masculine appearance in this study, the lesbians with a feminine appearance did not report that their appearance was a barrier to having breast cancer screenings. Levitt et al. (2002) found that feminine-identity lesbians experienced less discrimination and harassment from society than other lesbians. In addition, Kelly (2007) found that if a feminine-identity lesbian did not disclose her sexual orientation to heterosexuals, she would experience less discrimination from others because the lesbian's body presentation met with the dominant culture's expectations of what a woman should look like.

However, a feminine appearance was found to cause discrimination by other lesbians. Kelly (2007) found that the participants with a feminine appearance faced discrimination from insiders (non-feminine-identity lesbians) due to their non-apparent sexual orientation. Hence, some of the feminine-identity lesbians in Kelly's (2007) study expressed that they felt unsafe talking about their body image concerns with other lesbians. In addition, Pitman (2000) found that feminine-identity lesbians were unwilling to discuss their bodies with other lesbians because they were concerned about non-acceptance.

Similar findings can also be seen in this study. Pos' loyalty was challenged by some of the Ts because the Pos' sexual orientation was invisible and these women's sexual orientations seemed to be changeable from homosexual to heterosexual. Unlike the masculine-identity lesbians, who needed to go through a process of de-feminization in order to construct their gender identity and role, feminine lesbians maintained their original gender characteristics and roles, and therefore it was difficult to distinguish feminine lesbians from heterosexual women. In contrast to the findings in Kelly's (2007) and Pitman's (2000) studies, the Pos in this study did not report any concerns about discussing their bodies with their partners or others, but some of the Ts did express their concerns in terms of the Pos' loyalty, which was associated with how the Ts viewed their partners' support in performing or having breast cancer screenings. Details of how and why Pos' loyalty was associated with the Ts' breast healthcare behaviour and intentions will be discussed in the next section.

In order to understand if the lesbians' appearance relates to their breast healthcare behaviour and intentions, questions associated with their concerns about receiving discrimination from others regarding their appearance were included in the questionnaire.

#### **6.4 Partners' support**

Partners' support was found to be associated with the Taiwanese lesbians' breast healthcare behaviour and intentions. Similar findings can also be seen in the UK lesbian health survey (Fish & Wilkinson, 2003<sub>b</sub>). As mentioned, Fish and Wilkinson (2003<sub>b</sub>) found that the lesbians' partners were an influencing factor in the participants' breast examination practices. However, they did not specify whether the lesbians were more likely or less likely to perform breast examinations with their partners' support or its efficacy. Hence, it was difficult to identify whether a lesbian's partner was a barrier or whether it facilitated each individual's breast healthcare behaviour.

#### **6.4.1 Relationship status: being partnered as a facilitating factor**

Their partners' support was identified as being an important factor in encouraging Taiwanese lesbians to undergo breast cancer screenings, especially the masculine-identity lesbians.

Social support was found to be positively related to BSEs among heterosexual women (Jacob et al., 1989). Social support, which was defined as “*emotional support, advice, guidance and appraisal, as well as the maternal aid and services, that people obtain from their social relationships*” (Ell, 1984, p. 134), has been suggested to be beneficial to the health of individuals by increasing their use of preventive health practices, especially for women (Hurdle, 2001). A number of health models have linked human behaviour to social support; for example, the theory of reasoned action (TRA), diffusion theory and social learning theory (Brieger, 2006). Healthy individuals' healthcare behaviour is not simply related to their own personal characteristics, attitudes or beliefs, but is also associated with their social networks. Previous studies have shown that a partner's influence and support affects a person's health behaviour (Coppotelli & Orleans, 1985; Missinne et al., 2013; Park et al., 2004), although the definitions of ‘partner’ and types of health behaviour have varied. In addition, Prestwich et al. (2005) suggested that a partner's involvement was found to enhance the utilization of BSEs among women in general in the UK. The finding in the present study echoes the existing evidence. The ‘partnered’ lesbians were found to be more likely to perform BSEs or undergo breast cancer screenings than those who were single.

#### **6.4.2 Support from a partner**

In addition to relationship status, the lesbians' partners were found to affect the individuals' breast healthcare behaviour and intentions in several ways, mainly associated with the lesbians' gender identity and gender role expression. Taiwanese lesbian gender-role presentation was suggested as reflecting rigid gender differences in mainstream Taiwanese society (Kuang et al., 2004). Although some researchers have argued that there are no differences between the responsibilities and decision-making rights according to the gender role division in lesbian relationships (Tseng et al., 2008; Chao, 2006), homosexual love was indicated as being as attractive and romantic as ‘heterosexual love’ and it was felt that both types of relationships shared similar features (Shieh, 2010).

The Ts and the Bufen pian Ts reported their responsibilities in taking care of their partners' (Pos') breast health. The lesbians performed BSEs for their partners either as a part of sexual

activity or as a regular breast examination. Whether the Ts touched their partners' (Pos') breasts just for fun or for the examination, the lesbians reported that if there were any changes in their partners' (Pos') breasts, they would notice. In addition to performing BSEs for their partners, the Ts also reported that they would pay attention to any relevant information for their partners. The Ts emphasized their responsibilities in taking care of their partners' breast health instead of their own. The utilization rates of BSE might increase among the Pos because their partners (Ts) performed the examinations for them. However, this influencing factor was found to be inappropriate for some of the Ts in this study. As previously mentioned, the Ts' masculine identity, masculine role expression and negative views regarding their own female characteristics stopped their partners (Pos) from performing BSEs for them. Touching the Ts' breasts might cause the Ts to suffer body image disturbance. The findings in Levitt and Hiestand's (2004) and Singh et al.'s (1999) studies correspond with the findings in the interviews. The butch lesbians expressed their reluctance in letting their partners touch them due to them feeling vulnerable and gender incongruence.

However, not all of the Ts refused their Pos' touching them. Some Ts reported that if they had a stable relationship with their Pos, they "*might*" allow their partners to touch and look at their breasts. Zhang (2011) indicated that the "*Po's loyalty*" within a lesbian couple relationship was commonly challenged by Ts. As previously mentioned in Section 6.3.2.2, feminine-identity lesbians were criticized by other insiders due to the invisibility of their sexual orientation. "*Trust*" is a main factor for these Ts in allowing their partners to touch their breasts. If the Ts trust their partners (Pos), the Pos play a very significant role in encouraging the Ts' behaviour in performing BSEs or having CBEs or mammograms. In addition, being asked by Pos was also indicated by the Ts as factor in facilitating their breast healthcare behaviour.

#### **6.4.3 The seriousness of breast cancer in relation to lesbian couple relationships**

Some of the lesbians, including Ts, Pos and Bufens, reported that having breast cancer might affect the relationship between themselves and their partners. It was considered to be a factor in relation to these lesbians' breast healthcare behaviour and intentions, although it was uncertain whether this factor was a barrier or whether it facilitated them based on the data in this study. An assumption was made that the physical, emotional and social distress caused by breast cancer would affect the lesbian couple's relationship, but this assumption still led to an uncertainty in the direction of the lesbians' breast healthcare behaviour and intentions.



In order to know what the partners' influence is regarding the lesbians' breast healthcare behaviour and intentions, questions related to the partners' support were asked in the questionnaire, which included relationship status, the period of being in the relationship (stable relationship), support from a 'current' partner (during the data collection period of the second-phase online survey) and perceived influences of the partner (whether the lesbian was single or partnered). In addition, a question about the seriousness of breast cancer in relation to lesbian couple relationships was also included in the questionnaire in order to understand whether this factor was associated with the lesbians' breast healthcare behaviour and intentions.

## **6.5 Patient-provider interaction**

Patient-provider interaction refers to the relationship between a lesbian and her healthcare provider. It has been defined by Sparks and Villagran (2010, p. 5) as 'creating shared meaning' in terms of healthcare and conditions in patient-provider encounters. The researchers point out that 'shared meaning' is important for competent communication; however, it can be hard to achieve because of differences in culture, experiences and, sometimes, language. Stevens and Hall (1988) found that the majority of the lesbians in their study had personally experienced inappropriate or negative interactions with HCPs in the past. In Stevens' more recent study (1996), past negative interactions with physicians were reported by a number of the lesbians. Feeling belittled, intimidated, angry, humiliated, vulnerable, intruded upon, shamed and silenced were expressed by the lesbians after they had negative interactions with HCPs; some of the lesbians even felt that they had to terminate their interactions with a HCP following disclosure of their sexual orientation due to the negative reactions of the provider (Stevens, 1996). Cortes et al. (2009) and Stewart (1995) suggested that poor physician-patient communication was associated with adverse health behaviour (for instance, a decreased level of adherence to physician advice) as well as with decreased rates of satisfaction. In this study, although the majority of the participants were not eligible for free breast screenings, the women reported their concerns about the HCP's gender, their knowledge in terms of LGBT issues and lesbian healthcare needs, and his or her attitudes towards the subgroup.

### **6.5.1 HCPs' gender**

#### **6.5.1.1 Female HCPs**

In DeHart's (2008) US survey, lesbians were found to be more comfortable discussing their

healthcare with female HCPs. The majority of the lesbians in Hitchcock and Wilson's (1992) study also reported their preference for a female HCP because these individuals believed that female HCPs would be more sensitive, more open to alternative lifestyles and less judgemental than male HCPs. The findings in this study were found to be similar to the findings in the previous studies. The majority of the lesbians preferred a female physician to provide their breast cancer screenings, whether they self-identified as T, Po, Bufen or Bufen pian T.

A number of reasons were proposed in terms of the lesbians' preference for a female HCP, including the influences of traditional Chinese culture, never having had a relationship with a man, having the same physical characteristics, and having more knowledge regarding breasts than male HCPs. As previously described in Section 5.4, women's views about their own breasts were mainly influenced by Taiwanese society (patriarchy) and traditional Chinese culture (women were taught to hide their female characteristics). Taking off their clothes and being examined by a male HCP seemed to go against traditional Chinese culture and might result in emotional discomfort, whether they were a masculine- or feminine-identity lesbian. In addition, some of the lesbians in this study connected their sexual orientation and gender identity to androphobia; hence, having a female HCP to provide healthcare services to these lesbians was considered to be associated with their feelings of safety and being comfortable during the procedure. Regarding the masculine-identity lesbians, having the same physical characteristics and having more knowledge regarding breasts than male HCPs were reported as reasons for their preference. However, the majority of the Ts tried to disconnect their female features and ignore related information or healthcare services, except when they perceived a higher risk of getting breast cancer. A perceived higher risk of getting breast cancer motivated the Ts starting to think about their preference in relation to a HCP's gender, for example, someone with the same sexual features or with more knowledge in relation to breasts.

#### **6.5.1.2 Male HCPs**

Masculine identity was found to be related to the Ts' preference for a male HCP. Two Ts reported that they preferred male HCPs to provide breast screenings for them because they would feel embarrassed if the HCP was female. In contrast to the existing evidence, where the lesbians were more likely to prefer female HCPs to provide the services to them than male HCPs (DeHart, 2008; Hitchcock & Wilson, 1992), these two Ts' preferences were

considered to be associated with their masculine identity and the codes for being a T within lesbian communities. As part of being a T, the lesbians had to go through a process of de-feminization in order to construct their gender role and masculine identity. Revealing a T's female characteristics to female physicians (potential Pos) might go against their masculine identity and masculine role, and it could result in body image disturbance. Hence, it was considered to be a reason why the Ts preferred a male HCP. In addition, some of the Ts were transgender butches and they viewed themselves as men; therefore, if a female HCP performed the examination, revealing the lesbians' private body parts might be seen as inappropriate as men's private parts being seen by a female HCP.

### **6.5.1.3 Having no preference as to the HCP's gender**

Eight lesbians reported that they had no preference as to the physician's gender. The lesbians who had no preference as to the physician's gender expressed the view that the physician's skills and knowledge were much more significant than their gender. By these eight participants, the efficacy of breast screenings was considered to be more important than the HCP's gender. Similar findings can be seen in Chang's (2000) study, where 632 (43.9%) of the Taiwanese heterosexual women reported that they preferred a female physician to perform their breast examinations, while 791 (54.9%) women thought that the physician's skills and attitudes were much more important than their gender.

### **6.5.2 HCPs' knowledge about multiple gender diversity and lesbian healthcare needs**

Barriers to accessing healthcare services resulting from physicians' lack of knowledge of multiple gender diversity and the healthcare needs of lesbians were indicated by the participants in the interviews. This finding echoes the existing evidence. A lack of knowledge and sensitivity regarding multiple gender diversity were suggested as specific provider-level barriers to adequate care for lesbians (Hutchinson et al., 2006). Mravcak (2006) also indicated that physicians' lack of comfort and knowledge in relation the health issues specific to lesbian healthcare was a significant barrier, which inhibited primary and preventative healthcare delivery to lesbians and bisexual women. On the other hand, Rankow and Tessaro (1998) found that lesbians who felt that their HCP was knowledgeable and sensitive to lesbian issues and needs were more likely to engage in preventive screening over the course of a year.

Cortes et al. (2009) suggested that poor patient-provider communication was strongly associated with adverse health behaviour, such as decreased rates of satisfaction and reduced levels of adherence to HCPs' recommendations. IOM (2011) indicated that many HCPs had not been trained to provide care for sexual minority individuals, and even HCPs themselves reported a lack of knowledge about the issues facing their sexual minority patients. White and Dull (1997) have pointed out that improving communication skills and obtaining adequate knowledge about sexual orientation were a significant first step in providing good quality care to healthy lesbians. In Taiwan, although obtaining training for providing services to sexual minority individuals has been suggested to improve patient-provider interaction and the quality of care (TAPWR, 2007; Wang, 2013), the healthcare providers' training does not include courses associated with LGBT people's health issues or knowledge of multiple gender diversity. In this study, HCPs' inadequate knowledge and skills were reported as a factor influencing the lesbians' behaviour and intentions in relation to healthcare services and were related to the participants' low satisfaction with the services. The participants did not mention HCPs' lack of training directly, but they reported their concerns regarding HCPs' knowledge, skills and acceptance of sexual minority groups. These concerns strongly reflect the importance of HCPs obtaining relevant training.

In addition to HCPs' lack of knowledge about multiple gender diversity, HCPs' lack of sensitivity to sexual minority women were also reported as an influencing factor in the participants' breast healthcare behaviour and intentions, in particular HCPs' heterosexual assumptions. A qualitative study conducted in Canada found that the assumption of female heterosexuality continued among physicians in the medical environment (Daley, 2003). In DeHart's (2008) US survey, 25% of the 173 lesbians believed that assumptions about heterosexuality by healthcare providers influenced the care the women received. Among the lesbians in the interviews, the Pos connected previous gynaecology experiences with breast screening services. The heterosexual assumptions of the physicians were a barrier to the lesbians having screenings, because some of the questions asked by the physicians might be difficult to answer (for example, concerning their relationship status). This situation appeared to prevent some of the lesbians from going to hospitals and having screenings.

The participants expressed that culturally competent care was a factor facilitating their breast healthcare behaviour and intentions in this study. Cultural competence is a significant aspect of care (IOM, 2011). In this study, it was connected to HCPs' knowledge, skills (particularly

communication skills), sensitivity and acceptance of sexual minority groups by the participants. Some of the participants reported that they searched for a HCP with a related background on the Internet or made their choice from lists of friendly HCPs who were proposed by Taiwanese LGBT organizations in order to ensure that the HCP had the knowledge and abilities to provide culturally competent care and to eliminate the risk of being discriminated by the HCP. In Hiestand et al.'s (2008) study, the butch lesbians expressed the importance of finding LGBT-positive providers, and it may be that they took greater precaution in identifying LGBT-positive providers before seeking healthcare. The researchers argued that:

*"...as their (butch lesbians') sex might have been the site of lifelong questioning, harassment and discrimination for these women, the act of a simple exam might provoke discomfort, especially if mismanaged."*

*(Hiestand et al., 2008, p. 25)*

In contrast to the finding in Hiestand et al.'s (2008) study, identifying a HCP who had the ability to provide culturally competent care was mainly reported by the feminine-identity lesbians in this study. It was interesting that the feminine lesbians were more concerned about this, because they experienced less discrimination than masculine-identity lesbians as it was difficult to identify their sexual orientation from their feminine appearance. Lesbians with a masculine appearance might be thought to be more concerned about the HCP's ability to provide culturally competent care. However, the masculine-identity lesbians in this study rarely mentioned how they would find a LGBT-positive provider in order to meet their expectations. Instead of finding an LGBT-positive provider, some of the masculine lesbians emphasized that they had negative intentions regarding breast cancer screenings due to their masculine identity, role and body image, no matter what abilities, knowledge and skills the HCP might have. Avoiding body image disturbance seemed to be more important. This perception only varied if the individuals perceived a higher risk of getting breast cancer. In future, if they were to think that they might have breast cancer, the individuals might start to consider their preferences in relation to HCPs' knowledge and skills.

### **6.5.3 HCPs' acceptance of lesbians (discrimination from a HCP)**

Concerns about HCPs' acceptance of lesbians were identified as an important factor associated with the lesbians' utilization of CBE and mammography. As mentioned, fear of stigmatization or previous negative experiences of the healthcare system might cause sexual

minority members to not access healthcare services or else to delay seeking care (IOM, 2011). Sexual stigma was also identified as a factor associated with lesbians' healthcare behaviour in the existing evidence. Fear of discrimination – including homophobia and heterosexism – by healthcare providers was found to be a barrier to lesbians discussing their healthcare needs with physicians (Clark et al., 2003) and their use of cancer screenings (Bowen et al., 2004; McNair, 2003; O'Hanlan et al., 2004).

In Clark et al.'s (2003) study, fear of discrimination was explored as not only preventing lesbians and bisexual women from seeking care, but also preventing them from disclosing relevant information once in care. Compared to heterosexual women, lesbians were found to have lower rates of recommended screening services (Roberts et al., 2004; Valanis et al., 2000). McNair (2003) has indicated that when judgmental and negative attitudes were experienced by lesbians, their patterns of health-seeking behaviour were influenced. In addition, a US survey considered whether homophobia or heterosexism on the part of providers affected lesbians' frequency of use of breast cancer screenings (DeHart, 2008). These findings echo the finding in the present study. Fear of discrimination by HCPs was also reported as a barrier to having breast screenings (CBEs and mammograms) by the lesbians in the interviews.

The participants' concerns regarding discrimination by HCPs were found to reflect how HCPs in Taiwan viewed sexual minority groups. In Yen et al.'s (2007) study, a total of 1,824 nurses from a medical centre and two regional teaching hospitals in southern Taiwan were recruited into their study. The researchers used the Attitudes Towards Homosexuality Questionnaire (ATHQ) to examine four concepts (dimensions of contact, stereotypes, morality and condemnation/tolerance of homosexuality among nurses). They found that the nurses held negative views of gay men and lesbians, especially those who had worked for a longer period of time, who labelled themselves as being absolutely heterosexual and who were religious. The finding showed that some Taiwanese HCPs held negative attitudes towards LGBT patients and that these attitudes might influence the quality of the services provided by these HCPs. However, Yen's study mainly recruited participants from South Taiwan. There might be differences in HCPs' acceptance of LGBT individuals between South Taiwan and North Taiwan. The people living in South Taiwan are usually considered to be more conservative than those living in North Taiwan. The gay culture in Taiwan started in North Taiwan, and the first lesbian bar was also opened there. Nevertheless, in this study the

participants, whether they were recruited from North Taiwan or South Taiwan, reported their concerns about sexual discrimination by HCPs.

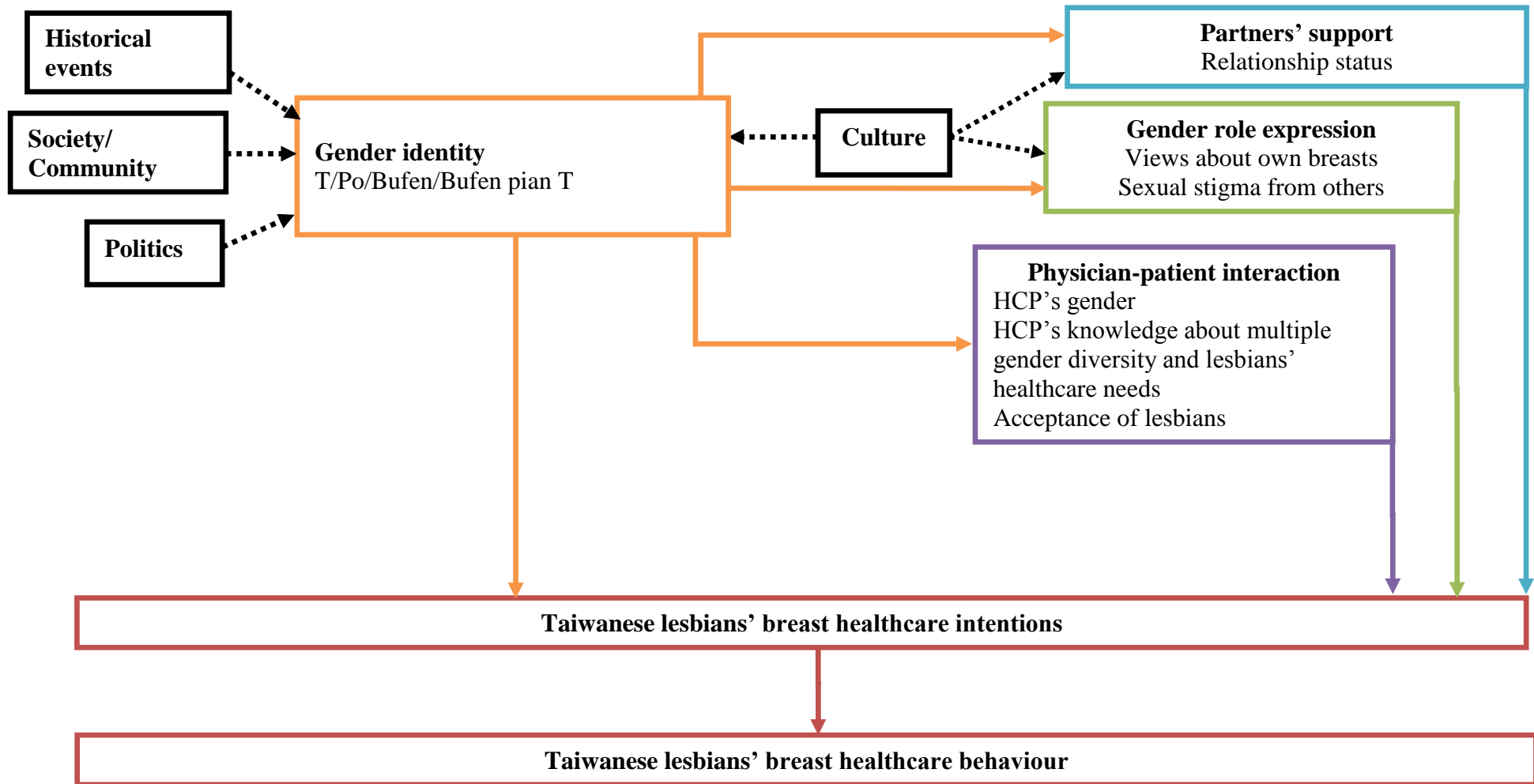
In addition, Levitt and Horne (2002) have pointed out that gender identity contributes to the healthcare experiences and healthcare-seeking behaviour of sexual minority women. Butch lesbians thought that they received poorer treatment from medical healthcare practitioners than femme-identified lesbians. In Hiestand et al.'s (2008) study, the researchers found that both gender identity and gender role presentation impacted upon sexual minority women's experiences in the healthcare setting. The researchers examined the experience of discrimination in the healthcare setting among a sample of 220 butch-identified women and 296 femme-identified women. The butch women reported poorer treatment within the healthcare setting and greater difficulty in finding lesbian-affirmative physical healthcare practitioners. The findings in the present study echo Hiestand et al.'s study. The masculine-identity lesbians reported their concerns about having a breast screening in a hospital due to their gender identity and male appearance. Fear of discrimination from the HCP, whether verbal or nonverbal, inhibited the individuals' breast healthcare behaviour and intentions.

In order to understand whether lesbians' concerns regarding HCPs' gender, knowledge about multiple gender diversity and lesbian healthcare needs, and acceptance of lesbians, affect the women's breast healthcare behaviour and intentions, questions about these factors were asked in the questionnaire and compared with lesbians with different gender identities in the second phase of the study.

## **6.6 Summary and development of a conceptual framework**

Gender identity was found to be significantly associated with the lesbians' breast healthcare behaviour and intentions due to the cultural and historical background, politics and Taiwanese society. It not only influenced the women's breast healthcare behaviour and intentions directly, but it also affected their appearance, their views about their own breasts, their perceived support from their partners and their considerations about patient-provider interaction, which were also found to be mainly associated with the women's breast healthcare behaviour and intentions. Hence, a conceptual framework of the factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions was developed based on the findings and the existing evidence (see Figure 6.1), and it was employed preliminarily for designing the online questionnaire.

Figure 6.1: Factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions



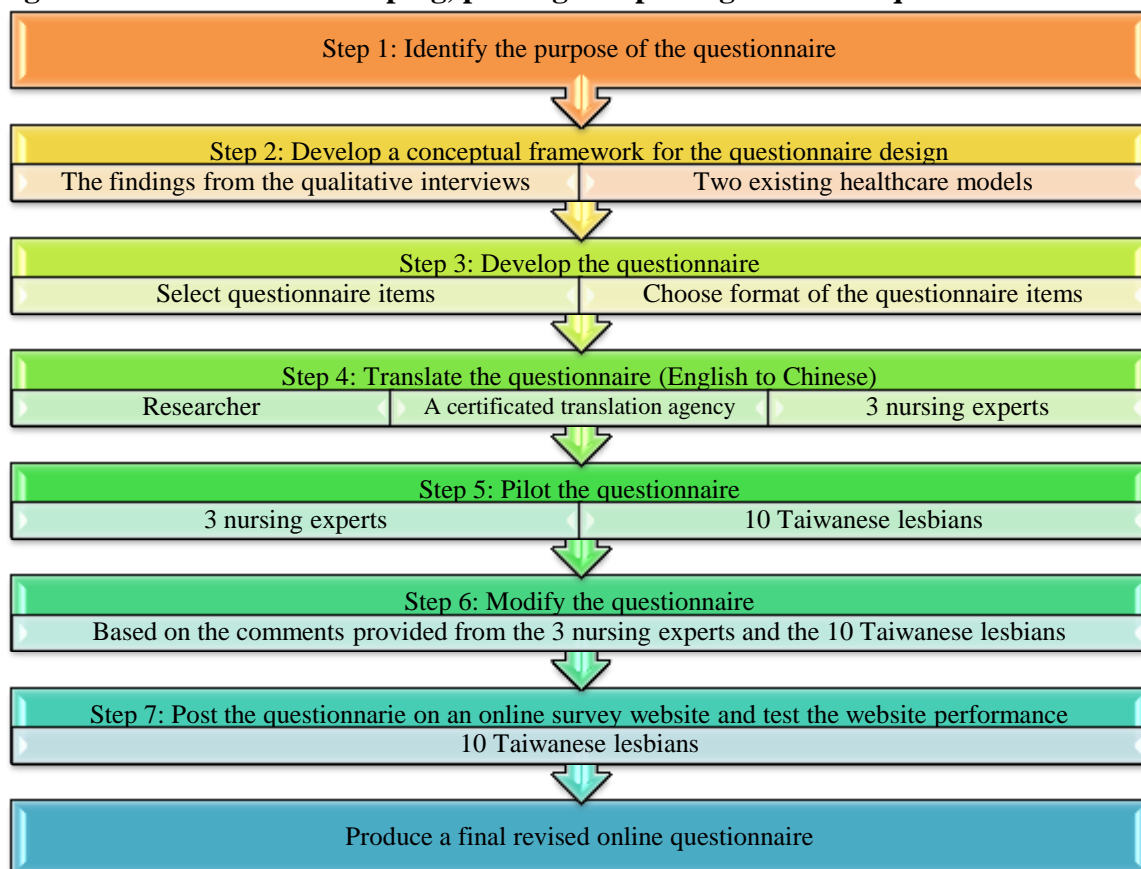


## Chapter 7: Instrument development and pilot studies

### 7.1 Introduction

Creswell and Clark (2011) state that instrument development represents a ‘mixing’ of the qualitative and quantitative phases or an explicit relationship between qualitative and quantitative data in a mixed-methods framework. In the development of an instrument, the qualitative data analysis serves as the foundation for the quantitative data collection. The phases within a mixed-methods study design are ‘connected’ via the process of transforming the qualitative themes and/or subthemes into quantitative items. The factors associated with Taiwanese lesbians’ breast healthcare behaviour and intentions were identified in Chapter 5 and discussed in Chapter 6. In this chapter, based on the sequential exploratory mixed-methods study design, the main aims are to introduce the development of the instrument that was employed in the second phase of the PhD study, the piloting and conducting of the online survey, and to present the process of transforming the qualitative findings into quantitative variables. Figure 7.1 shows the process of developing, piloting and posting the online questionnaire. The details of each step are provided in the following sections.

**Figure 7.1: Process of developing, piloting and posting the online questionnaire**



(Based on Georgy, 2011, p. 59; Onwuegbuzie et al., 2010, p. 62)

## **7.2 Identify the purpose of the questionnaire**

In accordance with the purposes of this PhD study, the questionnaire was mainly developed to assess whether the findings from the first-phase qualitative interviews can be applied to a larger target population.

## **7.3 Develop a conceptual framework for the questionnaire's design**

The importance of having a well-defined construct as the foundation for any instrument development has been noted by researchers (DeVellis, 2003; Worthington & Whittaker, 2006). Developing a conceptual framework was the first step in designing the questionnaire to help the researcher to conceptualize the construct of interest, including the concepts chosen for investigation and their relationships.

The constructs of the conceptual framework were chosen according to the qualitative interview findings and the existing literature review (see Section 2.6). The interview findings provided the core theoretical foundation for the development of the questionnaire in order to be able to test whether findings were generalizable to a larger target population and to understand the associations with lesbians' behaviour and intentions (see Figure 6.1, p.160). All of the four themes identified from the interview data were included: 1) gender identity; 2) gender role expression; 3) the lesbians' partners' support; and 4) patient-provider interaction.

As mentioned in Chapter 5, in addition to the four themes, other influencing factors which were shared with Taiwanese heterosexual women were also identified from the interview findings. For example, the benefits of performing BSEs and having a mammogram ("*will help protect me against breast cancer*"). These factors were chosen and included in the questionnaire so as to understand the similarities and differences among the influencing factors for lesbians and women in general in Taiwan. However, it was not feasible to consider every factor that was found from the interview data. A long questionnaire might lead to a decrease in response rates (Iglesias & Torgerson, 2000). Hence, theoretical approaches were employed to help the researcher to identify important influencing factors and to assist the researcher to obtain a more comprehensive picture of the factors associated with Taiwanese lesbians' breast healthcare behaviour and intentions.

To this purpose, the HBM and the TRA were included in the conceptual framework. These are social cognition models for predicting behaviours and can also be termed 'health

psychology models'. Based on the literature review in Section 2.6.7, the HBM has been used mainly and successfully in investigating breast healthcare behaviour among Taiwanese heterosexual women (Change & Nien, 2003; Chiang et al., 2011; Ku, 2004; Luo et al., 2001). In order to understand the similarities and differences in the influencing factors among lesbians and heterosexuals in Taiwan, the HBM was chosen and was involved in the conceptual framework's design. In addition to the HBM, the TRA was also included in the conceptual framework because it has been suggested that it can be used to overcome the limitations of the HBM (Poss, 2001). The following subsections introduce the HBM and the TRA briefly along with their limitations. The rationales for choosing the constructs from the models are also discussed. At the end of this section, the conceptual framework and its constructs are provided.

### **7.3.1 The health belief model**

The HBM was developed firstly by Rosenstock during the 1950s to predict health-related behaviours. A total of six constructs are included in the HBM: 1) perceived susceptibility to health threats; 2) perceived severity of health threats; 3) perceived benefits of health behaviour; 4) perceived barriers to health behaviour; 5) cues to action; and 6) self-efficacy.

The original model hypothesizes that health-related action depends upon the simultaneous occurrence of three classes of factors (Rosenstock et al., 1998). Firstly is the existence of sufficient motivation or health concerns to make health issues irrelevant or relevant to a person. Secondly, the person must believe that he or she is susceptible to a specific disease that can cause serious health effects. This mainly refers to the person's perceived threat. Thirdly, the person must believe that following a particular health recommendation would be beneficial in reducing the perceived threat, and he or she must overcome barriers that could inhibit the adoption of such behaviour.

Cues to action were originally described under the heading of perceived susceptibility and severity, as well as the variables that explained the perceived benefits and barriers to taking action. The variables were believed to complete the HBM. They serve as triggers to encourage a person to engage in health maintenance. Examples of such cues include advice from friends or relatives and reminders from physicians (Becker, 1974). Self-efficacy, which was added to the model's core concepts more recently in order to improve the model's

explanation of health behaviour, indicates a person's faith in his or her ability to act in a specific way (Green & Kreuter, 2005; Rosenstock et al., 1988).

Several limitations of the HBM have been proposed in previous studies (Armitage & Conner, 2000; Naidoo & Wills, 2010; Poss, 2001; Stroebe, 2000; Stroebe & de Wit, 1996). For example, neglect of social and cultural factors. The HBM mainly explains a person's health behaviour in terms of his or her attitudes and beliefs. Social factors, such as social support from family members or friends, are not included in the model. Although Rosenstock (2005) – the model's developer – points out that a person's beliefs about risk-reducing behaviours are affected by the norms and pressures of his or her social groups, the concept is not included in the HBM. Other researchers also question whether the HBM can explain behaviour in a variety of cultural settings due to it lacking culture-specific concepts (Rubel & Carro, 1992).

Regardless of the limitations, based on the literature review in Section 2.6.7, the HBM has been used successfully in investigating breast healthcare behaviour among Taiwanese heterosexual women (Change & Nien, 2003; Chiang et al., 2011; Ku, 2004; Luo et al., 2001). Poss (2001) suggests that the HBM is useful in explaining health behaviours and that it is generalizable to a variety of settings, despite the criticisms that arose in previous studies. Poss comments that, instead of abandoning the HBM because of its limitations, adapting it by constructing a second model which includes social factors might be a better option.

In this study, all of the HBM's constructs were included in the conceptual framework's design because the researcher aimed to compare the results between heterosexual women, as reported in the literature (see Section 2.6), and lesbians in Taiwan. In terms of the limitations of the HBM, the TRA was added to the present conceptual framework's design in order to overcome the HBM's limitations.

### **7.3.2 The theory of reasoned action**

The TRA was introduced by Fishbein and was further developed and tested by Fishbein and Ajzen (1975). It has been widely used to predict women's breast healthcare behaviour in previous studies (Michels et al., 1995; Montano & Taplin, 1991; 1997). Three main components are included in the model (Miller, 2005): 1) attitudes; 2) subjective norms; and 3) behavioural intentions.

The TRA proposes that a person's intention to adopt a particular form of behaviour is influenced by the person's attitude towards that behaviour and their subjective norms. The model attempts to explain the relationship between beliefs, attitudes, intentions and behaviours, and is based on the assumption that a person's behaviour is mainly influenced by his or her intentions. A person's attitude towards a given form of behaviour and the subjective norm adopted regarding that behaviour comprise the two predictors of a behavioural intention. A person's attitude is affected by their belief that a particular form of behaviour will result in an expected outcome and whether the person evaluates that outcome positively or negatively. A subjective norm has been defined broadly as "*the perceived social pressure to perform or not to perform the behaviour*" (Ajzen, 1991, p. 188) and has been defined more precisely as "*an individual's perception or opinion about what important others believe the individual should do*" (Finlay et al., 1999, p. 2005). It is affected by normative beliefs, which refer to a person's belief as to whether significant others support or oppose that behaviour and his or her own motivation to follow his or her opinions (Ham, 2005; Montano et al., 1997).

The TRA has been used successfully by researchers to explain individuals' health behaviour and to develop programmes targeted to modify individual behaviour (Bosompra, 2001; Trost et al., 2002). Previous studies employing the TRA as a theoretical framework found that the subjective norm was positively related to the utilization of mammography. Women with friends and significant others who supported them in using mammography were more likely to have screenings (Maxwell et al., 1997). On the other hand, the TRA has been criticized by previous researchers. The model omits the fact that behaviour may not always be under volitional control and the impacts of past behaviour on current behaviours (Stroebe, 2000). Behavioural control was therefore included in the model by the original authors and the new model was termed the 'theory of planned behaviour' (Ajzen, 2005). Behavioural control represents the perceived difficulty or ease of performing a behaviour and is a foundation of control beliefs. It was suggested as being very similar to 'self-efficacy' (Stroebe, 2000) and to include knowledge of relevant skills, experience, emotions, past track-record and external circumstances (St Claire, 2003). However, the TPB was not employed in the present study because the limitation of the TRA was overcome by including the construct of 'self-efficacy' from the HBM, and the main purposes of including the TRA in the conceptual framework were: 1) to overcome the HBM's limitation (i.e., a lack of social factors); and 2) to know

whether the lesbians' breast healthcare behaviour and intentions would be affected by their partners' expectations, and also to know their motivations to comply with their partners' wishes, based on the interview findings. The TRA was considered to be enough to meet these two purposes.

Although the TRA was included in the conceptual framework, not all of the TRA constructs were included in the conceptual framework because some of them overlap with the HBM's concepts. As mentioned previously, both the HBM and the TRA are cognitive theories. In some respects, the TRA is seen as refining and taking forward the approaches embodied in the HBM (Taylor et al., 2006). In the present study, the constructs 'subjective norms' and 'behavioural intentions' from the TRA were added to the conceptual framework so as to deal with the HBM's limitation and to understand the relationship between the lesbians' breast healthcare behaviour and intentions and their perceived partner's influence. The 'attitudes' construct from the TRA was excluded because it was parallel to the 'perceived benefits of and barriers to preventive action' constructs from the HBM. In previous research, which also used both the HBM and the TRA as the theoretical underpinning to explore healthcare behaviour and its influencing factors, the researchers also viewed that the construct 'attitudes' was similar to the 'perceived benefits of and barriers to preventive action' constructs. One study combined both the HBM and the TRA to understand the factors that influence future intentions in relation to mammography and to differentiate the factors influencing such future intentions among those who have had past experience of mammography and those who have not (Ham, 2005). Ham retained all of the constructs in the HBM while adding subjective norms and removing attitudes from the TRA in an attempt to understand the factors relating to the intention to have a mammogram among individuals. In addition, Poss (2001) also combined the HBM and the TRA to study the factors that affect Mexican migrant workers' participation in tuberculosis screenings. She excluded the perceived barriers and benefits from the HBM. She explained that the perceived barriers and benefits are parallel to the attitudes towards behaviour in the TRA.

### **7.3.3 Conceptual framework of the questionnaire**

The conceptual framework can be seen in Figure 7.2, which was developed based on the qualitative findings, the two healthcare models and the literature review (Section 2.6). The constructs in the framework include background information, gender identity, patient-provider interaction, gender role expression, subjective norms, perceived benefits of

preventive action, perceived barriers to preventive action, perceived susceptibility to breast cancer, perceived seriousness of breast cancer, cues to action, self-efficacy and behavioural intentions. The gender identity, patient-provider interaction and gender role expression constructs were identified and chosen according to the interview findings (see Chapters 5 and 6).

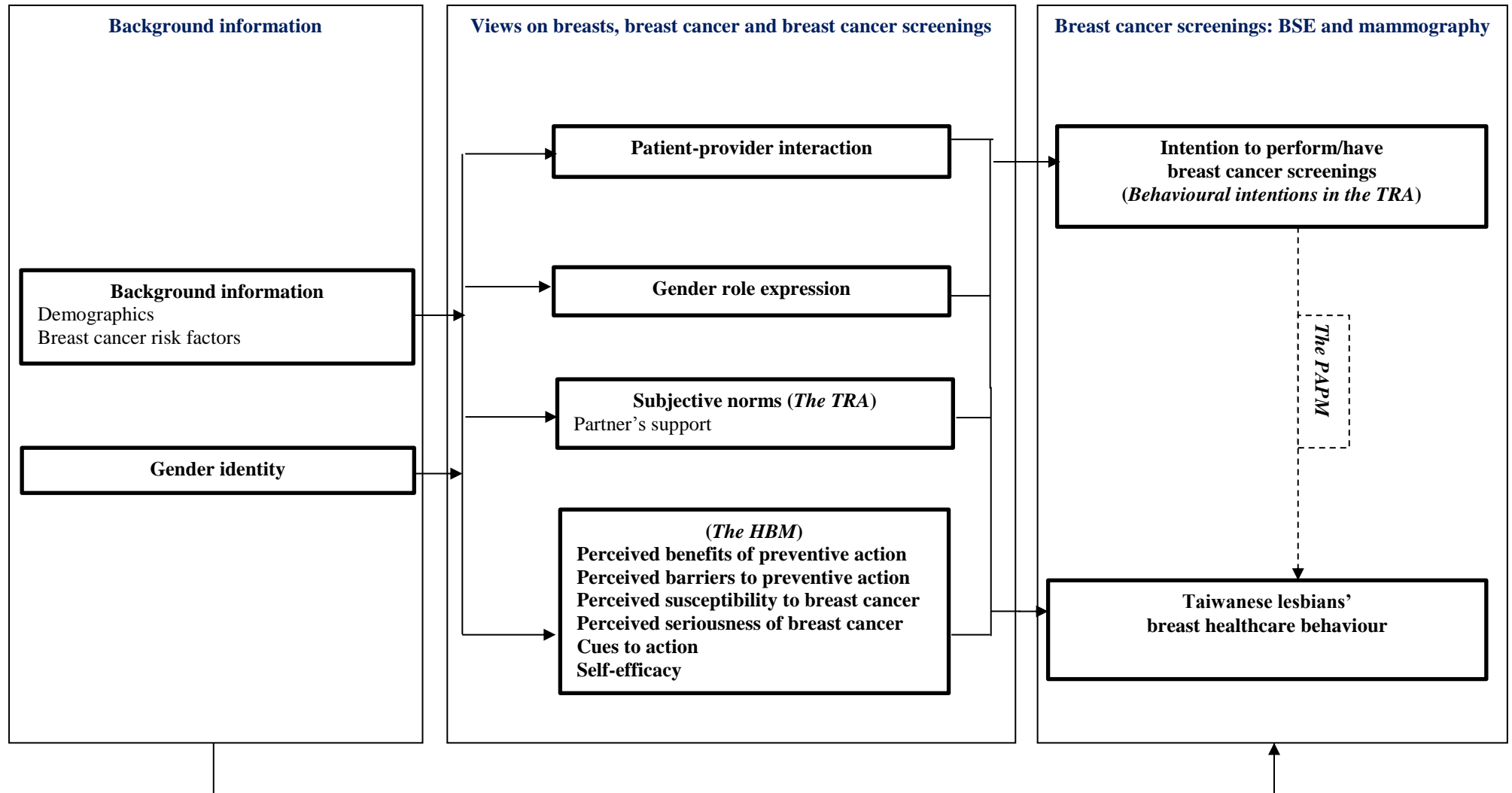
The background information construct comprised demographics and breast cancer risk factors. One limitation shared among the HBM and the TRA is that neither model includes demographic characteristics and personal factors. These variables are considered to be potentially important but are not incorporated into the core of the theories. Instead, they are thought of as external variables that may affect a person's beliefs but which influence behaviour only through the major variables that are included in the models (Poss, 2001). Based on the interview findings and literature review in Section 2.6, the demographic characteristics and the risk factors of breast cancer were found to be strongly related to women's breast healthcare behaviour and intentions and their attitudes and beliefs about breast health. Hence, they were included in the framework.

The constructs 'subjective norms' and 'behavioural intentions' were derived from the TRA and they were also included in the conceptual framework. Partners' support served as a topic under the construct 'subjective norms' because the lesbian's partner was found to be an important factor motivating the women's breast healthcare behaviour in the interview findings.

All of the constructs from the HBM were included in the conceptual framework, namely perceived benefits of preventive action, perceived barriers to preventive action, perceived susceptibility to breast cancer, perceived seriousness of breast cancer, cues to action and self-efficacy.

In addition to the HBM and the TRA, the precaution adoption process model (PAPM) was also employed to assist in the questionnaire's design because a person's intended health behaviour could be divided into several different levels. Therefore, this model acted as a guideline when designing the answers to the questions in relation to the participants' intentions regarding breast cancer screenings. Details of the model will be introduced in 7.4.1.

Figure 7.2: Conceptual framework of the online questionnaire





## **7.4 Developing the questionnaire**

During this stage, two issues were focused on in order to develop an optimal tool for investigating Taiwanese lesbians' breast healthcare behaviour and intentions, namely selecting the questionnaire items and choosing the format of the questionnaire items.

### **7.4.1 Selecting the questionnaire items**

This step sought to 'connect' the qualitative findings with the quantitative items. As can be seen in Figure 7.2, three sections were included in the questionnaire: 1) background information; 2) lesbians' views on breasts, breast cancer and breast cancer screenings; and 3) breast cancer screenings: BSE and mammography. The process of selecting the questionnaire items and transforming the qualitative findings into questions/statements in the instrument is described as follows.

#### **1) Background information**

The background section aimed to investigate the participants' demographics, gender identity and risk factors for breast cancer. The variables in this section mainly served as independent variables (IVs).

Demographic characteristics were collected, including age, religion, employment status, occupation and level of education. In the studies reviewed in Section 2.6, these variables were found to be associated with women's breast healthcare behaviour in addition to employment status and occupation. Income was identified as an influencing factor in women's breast healthcare behaviour in the reviewed studies. However, questions relating to the participants' income could raise sensitive issues (Colosi, 2006), and therefore the participants' employment status and occupation were queried instead of their income directly. In addition, the question about age was included not only to examine the relationship between this variable and the women's breast healthcare behaviour and intentions, but also to exclude any individuals who were younger than 20 years old.

Two questions about the lesbians' sexual orientation and gender identity were also asked in this section. The question about sexual orientation aimed to exclude those who did not self-identify as a lesbian or as a woman who had a partner of the same gender. It was used to assist the researcher to identify the target population. In the qualitative interviews, gender

identity was found to be an important influencing factor for Taiwanese lesbians, not only in their breast healthcare behaviour and intentions but also in their views on their own breasts, breast cancer and breast cancer screenings. Thus, the participant's gender identity was asked about in order to explore the relationship between this variable and breast healthcare behaviour and intentions, and to understand whether the participants with different gender identities held different or similar views on their own breasts, breast cancer and breast cancer screenings. However, the gender identity choices (gender labels) included in the questionnaire were designed not only based on the interview findings but also on current evidence. There was no lesbian who identified herself as a 'Bufen pian Po' in the qualitative interviews. Based on Chiang and You (2011) study, Bufen pian Po was found to be used among some Taiwanese lesbians. Hence, this gender label was included in the questionnaire to help the researcher to understand whether the label was actually used among the subgroup and whether the women's breast healthcare behaviour and intentions and its influencing factors were similar to or different from the women who self-identified as T, Po, Bufen or Bufen pian T.

In addition, as mentioned in Chapter 4, the research indicates that the breast healthcare behaviours, beliefs and expectations of women who have been diagnosed with breast cancer differ from those who have no personal history of breast cancer (Clark et al., 2003; Lopez et al., 2009; Luo et al., 2001; Nekhlyudov et al., 2003). This online survey aimed to investigate healthy lesbians in Taiwan and to generalize the qualitative findings to the target population; thus, a question about the experience of being diagnosed with breast cancer was asked to exclude any individuals who currently have or previously had the disease.

Breast cancer risk factors were identified as important factors related to women's breast healthcare behaviour in previous studies (see Section 2.6), comprising having previous non-malignant breast disease and having a family history of breast cancer. Reproductive factors and behavioural risk factors were found to be common risk factors of breast cancer among lesbians, and they were suggested as factors that lead to lesbians' higher risk of getting breast cancer when compared to heterosexual women (see Section 2.4). Hence, a total of six questions were asked comprising their personal history of non-malignant breast disease, family history of breast cancer, reproductive factors (if they have any children and the number of children) and behavioural risk factors (smoking and drinking). The quantities of

cigarette and alcohol consumption were asked if the participant reported that she was a current user.

## **2) Lesbians' views on their own breasts, breast cancer and breast cancer screenings**

In this section, the constructs included patient-provider interaction, gender role expression, subjective norms, perceived benefits of preventive action, perceived barriers to preventive action, perceived susceptibility to breast cancer, perceived seriousness of breast cancer, cues to action and self-efficacy. They were derived from the qualitative findings, the HBM and the TRA. The questionnaire items under these constructs were chosen according to the first-phase qualitative interviews and the literature review. The main findings in the qualitative interviews were transformed into quantitative items in this section. An example of the transformation process can be seen in *physician-patient interaction*, and it was also applied to the other constructs in this section.

These items served as IVs or dependent variables (DVs) based on the hypotheses being tested. All of these items served as IVs when testing whether they were influencing factors in relation to the participants' breast healthcare behaviour and intentions. On the other hand, when examining whether the participants with different gender identities held different or similar views on their own breasts, breast cancer and breast cancer screenings, they served as DVs.

### ***Patient-provider interaction***

There were four items under this construct, namely the HCPs' gender, heterosexual assumptions, knowledge about multiple gender diversities and attitudes towards lesbians. All of these items were derived from the qualitative findings (see Chapters 5 and 6).

In terms of how the researcher transformed the qualitative findings into quantitative items, NVivo 10 was used to help select the variables because of its ability to allow the researcher to extract the relevant data for each of the identified factors. These data groups were then divided and reviewed for themes, subthemes and relevant concepts. A matrix showing the themes, subthemes and representational quotes was developed to guide the item-writing process and to ensure that all the elements of the construct were included. An example of

how the qualitative findings were transformed into questionnaire items can be seen in Table 7.1.

**Table 7.1: Item generation matrix**

Themes and subthemes	Quotes	Questionnaire items
<b>Patient-provider interaction</b>		
HCPs' gender	<p><i>"In my opinion, female physicians might have more knowledge about breasts because they have breasts too."</i> (ID 02, T, 27 yrs)</p> <p><i>"If the physician is female, I would probably feel embarrassed. If the physician is male, I would feel more comfortable."</i> (ID 17, T, 22 yrs)</p>	<p>I would be more likely to have a mammogram if the healthcare provider was a female.</p> <p>I would be more likely to have a mammogram if the healthcare provider was a male.</p>
Heterosexual assumptions	<p><i>"Once, I went to see a doctor because my period had not arrived. The doctor kept asking me about my sexual activities and whether I had gotten pregnant or not. Although I told her/him that it was impossible for me to get pregnant, she/he insisted that I needed a pregnancy test to check for it."</i> (ID 31, Po, 28 yrs)</p>	<p>Concerns that a healthcare provider would assume that I was a heterosexual would make me less likely to have a mammogram.</p>
Knowledge about LGBT issues	<p><i>"Sometimes, physicians are not impolite on purpose – they just don't know how to communicate with lesbians. They lack the knowledge and skills regarding multiple gender diversities. If they had more knowledge about it, I would probably have a screening."</i> (ID 12, T, 30 yrs)</p>	<p>Concerns that a healthcare provider would lack knowledge about LGBT issues would make me less likely to have a mammogram.</p> <p>Concerns that a healthcare provider would feel uncomfortable with lesbians would make me less likely to have a mammogram.</p>
HCPs' acceptance of lesbians	<p><i>"I worry about discrimination by physicians if I need a breast cancer screening."</i> (ID 32, Bufen pian T, 33 yrs)</p>	<p>Concerns that a healthcare provider would discriminate against me would make me less likely to have a mammogram.</p>

In order to design questionnaire items suitable for the target population and ensure that the relevant vocabulary was used in the item, the qualitative data were reviewed by the researcher at least four times. Whenever possible, *in vivo* codes or the participants' own words were employed when constructing the items. These *in vivo* items give richness and depth to the final measurement instrument that would not otherwise be possible with an instrument established based solely on the literature. The items were written with a focus on providing useful information relevant to the target population.

After the transformation process, the statements for collecting the participants' views in relation to patient-provider interaction and their breast healthcare behaviour and intentions were developed. In this questionnaire, the participants were asked to indicate whether a female or male healthcare provider would encourage them to have a mammogram. The participants were then asked to indicate whether their healthcare provider's possible heterosexual assumptions, lack of knowledge about LGBT issues and attitudes towards lesbians would make them less likely to have a mammogram. These statements were designed specifically to collect data from the target population.

### ***Gender role expression***

Based on the qualitative findings, two topics were included in this construct: lesbians' views about their own breasts and their appearance. In the qualitative interviews, they were found to be associated with the individuals' BSE practices, mammography attendance/re-attendance and their intention to have screenings.

With regard to lesbians' views about their own breasts, several views were identified from the qualitative interviews. However, these views were not all included in the questionnaire in order to avoid it from becoming too long. Longer questionnaires have been suggested to have lower response rates (Roszkowski & Bean, 1990). Thus, in order to choose representative variables and to have a reasonable number of questions in the instrument, the five most commonly reported views (variables) were included in the questionnaire. However, all of these items were reported as inhibitors: not wanting their own breasts, feeling embarrassed, feeling uncomfortable when thinking about their own breasts, binding their own breasts in daily life, not liking their breasts to be touched or to be seen (whether by a HCP or their partner). According to the qualitative interviews, not all of the lesbians viewed their own

breasts negatively and as such a positive view was included under this construct: have an important sexual function.

In addition, the number of masculine-identity lesbians was found to be more than the number of feminine- and Butch-identity lesbians in both the qualitative interviews and the studies in the literature review. One of the most commonly reported concerns about having a mammogram among the masculine lesbians in the qualitative study was others' judgments in relation to their gender identity and gender role expression. Thus, one statement, 'worrying about my appearance being judged by other women in the waiting room would make me less likely to have a mammogram', was included to investigate the relationship between this concern and the women's behaviour and intentions to have mammograms and to compare this factor among the lesbians with different gender identities.

### ***Subjective norms (partners' support)***

This construct was derived from the TRA and the qualitative interviews. As mentioned, subjective norms refer to a person's belief as to whether significant others support or oppose certain behaviour and his or her motivation to follow their opinions. From the qualitative interviews, the lesbian's partner was found to be an important factor in the women's actions and intentions to have breast cancer screenings. Hence, questions addressing subjective norms were put in the questionnaire in order to understand whether the lesbian's partner influences the lesbian's breast healthcare behaviour and intentions.

A total of five questions and three statements were included under this construct which were developed based on the findings from the qualitative interviews. Their relationship status was asked to find out whether the participants had a partner to support them. If the lesbian was partnered or married (to a same-gender partner), she they would be asked about the duration of the current relationship, her current partner's support in relation to BSE and mammography, and her perception of the influence of her partner on her breast healthcare behaviour and intentions. On the other hand, if the individual was single, she would be asked to predict how she would behave 'if she had a partner' and to answer statements about the perceived influence of her partner on her breast healthcare behaviour and intentions. These questions/statements aimed to discover: 1) how many partners had talked about issues relating to breast healthcare with the participants and actually supported them to perform

BSEs or to have mammograms, if the women were partnered or married; and 2) any differences in the perceived influence of their partner on their breast healthcare behaviour and intentions among the lesbians with different gender identities.

### ***Constructs from the HBM***

All of the six constructs from the HBM were included in the questionnaire, namely: 1) perceived benefits of preventive action; 2) perceived barriers to preventive action; 3) perceived susceptibility to breast cancer; 4) perceived seriousness of breast cancer; 5) cues to action; and 6) self-efficacy.

The questionnaire items under these headings were selected based on the qualitative findings and existing evidence. In order to choose the most representative variables that are associated with Taiwanese lesbians' breast healthcare behaviour and intentions and to compare the results with those for heterosexuals in Taiwan, the most commonly reported items which were also reported by Taiwanese heterosexuals were chosen.

During the process of transforming the qualitative findings into statements in the questionnaire, Champion's Health Belief Model Scale (CHBMS) for breast cancer screenings was modified to meet the purposes of the questionnaire and to measure what the study was investigating accurately and consistently. The CHBMS was revised and validated by Victoria Champion (Champion, 1984; 1993) and is a commonly used instrument to measure the HBM variables associated with beliefs about breast cancer and breast cancer screenings. This scale has also been used successfully to investigate Taiwanese women's breast healthcare behaviour and intentions (Lien, 2006; Tsou, 2013). Table 7.2 shows the statements modified from the CHBMS. The items were chosen and modified based on the interview findings and current studies conducted with Taiwanese heterosexual women so as to make the Chinese statements understandable by Taiwanese women and also to focus on what had been found from the qualitative interviews.

**Table 7.2 Modifications from the CHBMS**

<b>Items in the CHBMS</b>	<b>Statements included in the questionnaire</b>
<b>Perceived benefits of preventive action</b> *Performing a BSE can help me find lumps in my breast *Having a mammogram will help me find breast lumps early	<b>Perceived benefits of breast cancer screenings</b> *BSE will help protect me against breast cancer  *Mammograms will help protect me against breast cancer
<b>Perceived barriers to preventive action</b> * It is embarrassing for me to do monthly breast exams * Having a mammogram is too embarrassing * Having a mammogram takes too much time * Having a mammogram is too painful * I have other problems more important than getting a mammogram * I am afraid to have a mammogram because I might find out something is wrong  *I do not know how to go about getting a mammogram	<b>Perceived barriers to breast cancer screenings</b> *Performing BSE would be embarrassing for me  * Having a mammogram would be embarrassing * Having a mammogram would take too much time * Having a mammogram would be painful * Having mammograms is not a high priority for me  * Having a mammogram would make me worry about having breast cancer  <i>Self-efficacy in the questionnaire</i> *I know how to have a mammogram
<b>Perceived susceptibility to breast cancer</b> * My chances of getting breast cancer are great * I worry a lot about getting breast cancer	<b>Perceived susceptibility to breast cancer</b> * My chances of getting breast cancer are great * I worry about having breast cancer in the future
<b>Perceived seriousness of breast cancer</b> *Breast cancer is a hopeless disease	<b>Perceived seriousness of breast cancer</b> * Breast cancer is a life-threatening disease
<b>Motivation</b> *I have recommended yearly physical exams in addition to visits related to illness	<i>Cues to action in the questionnaire</i> * A physician’s recommendations would encourage me to have a mammogram

Based on the purpose of the screenings and the qualitative findings, ‘will help protect me against breast cancer’ was included to discover the individuals’ beliefs about the perceived benefits of breast cancer screenings. In terms of barriers to having breast cancer screenings, ‘embarrassing’, ‘not a high priority’ and ‘would make me worry about having breast cancer’ were identified as important barriers to having both BSE and mammography. Hence, these three variables were asked separately in relation to the lesbians’ views on performing BSEs and having mammograms. In addition, ‘unpleasant’ was identified as another barrier to the lesbians performing BSEs in the qualitative interviews, which was considered to be related to their gender identities and their views on their own female characteristics (breasts). In the previous research (Fish, 2003<sub>b</sub>), feeling discomfort was found to inhibit British lesbians in performing BSEs. Hence, the variable ‘unpleasant’ was used to learn whether the participants would find it unpleasant to perform BSEs. With regard to perceived barriers to mammography, ‘takes too much time’ and ‘pain’ were also identified as important barriers to having mammograms for Taiwanese lesbians from the qualitative interviews. These two



variables were found to inhibit women's actions and intentions in relation to having a screening in the studies reviewed. These two variables were put in the questionnaire to discover whether there were any differences between the lesbians and the women in the previous studies.

Statements under the topics of susceptibility to and seriousness of breast cancer, self-efficacy and cues to action were also established based on the interview findings, current Taiwanese evidence and the CHBMS. In order to compare the factors between the lesbians and heterosexuals in Taiwan, the researcher selected the variables shared by both groups of women in order to know what the similarities and differences were among the lesbians and women in general. In addition to the factors shared among both groups of women, one item under the construct 'perceived susceptibility to breast cancer' was included in the questionnaire: 'having breast cancer would endanger the relationship between my partner and me', although it was found to be specific to the lesbians. The variable was reported as an important influencing factor among some of the women in the qualitative interviews. Based on the qualitative interviews, however, it was uncertain whether the variable was a barrier or a motivator. Hence, it was included in the questionnaire in order to understand whether – and in what way – it was related to the women's breast healthcare behaviour and intentions.

### **3) Breast cancer screenings: BSE and mammography**

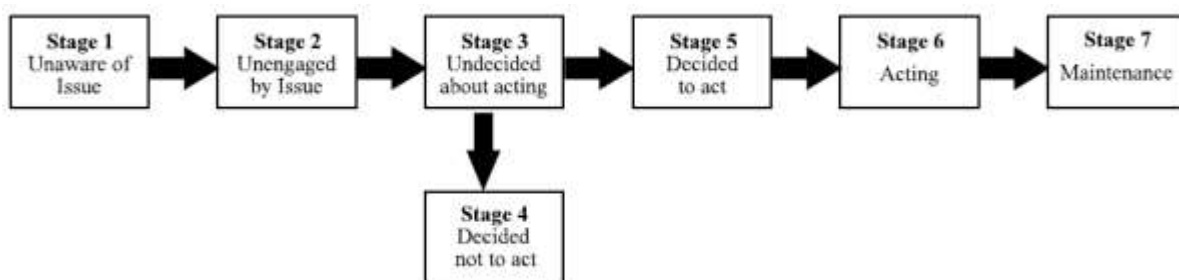
This section aimed to measure Taiwanese lesbians' behaviour and intentions in relation to breast cancer screenings. In the first-phase qualitative interviews, the questions regarding breast cancer screenings covered BSE, CBE and mammography. In 2012, however, the breast healthcare programme of Taiwan was changed. CBE is no longer offered in the programme. Hence, in the questionnaire breast cancer screenings referred to BSE and mammography only.

In the first-phase qualitative interviews, the majority of the participants had never had a mammogram, with only 2.7% of the lesbians having had regular mammograms. These results were considered to be affected by the age of the individuals (not being eligible for the screenings) and potential barriers. However, in previous research (TAPWR, 2008), the utilization rate of mammography screenings among Taiwanese lesbians was only 2%, which corresponds with the utilization rate of mammography in this qualitative study. In terms of

BSE, in the interviews only about 20% of the women did it regularly, while 45% did it irregularly or once, and 35% had never done it. Hence, the low utilization rates of breast cancer screenings were considered within the target population. According to the TRA, behavioural intentions were pointed out as being related to a person's health behaviour. Ajzen and Fishbein (1980) have indicated that intentions are the immediate determinants of behaviour, and when a proper measure of intentions is obtained it will give the most accurate prediction of behaviour. Therefore, in addition to investigating Taiwanese lesbians' breast healthcare '*behaviour*' (actions), if the women did not have experience of having/performing breast cancer screenings, they were asked to indicate their intentions regarding the screenings. All of these variables (behaviour and intentions regarding BSE and mammography) served as DVs based on the study's purposes.

In order to identify what factors are associated with the lesbians' positive or negative intentions regarding breast cancer screenings and their experiences and frequencies of performing and having the screenings, the PAPM was employed to develop choices for the participants' breast healthcare intentions and actions in the questionnaire. The PAPM attempts to explain how a person comes to a decision to take action and how he or she translates that decision into action (Weinstein et al., 2008). The PAPM distinguishes between the seven stages involved in the process of adopting a preventive health behaviour, with Figure 7.3 showing the stages of the PAPM.

**Figure 7.3: Stages of the PAPM**



Source: Weinstein et al. (2008, p. 4)

Initially, people are unaware of a given health issue (Stage 1). When they first learn something about it, they are no longer unaware but they are not yet engaged by it either (Stage 2). People who approach the decision-making stage (Stage 3) have become engaged

by the issue and are considering their response. This decision-making process can result in one of three outcomes: they may suspend judgment, thereby remaining in Stage 3 for the moment; they may decide to take no action and move to Stage 4; or they may decide to adopt a precaution, moving to Stage 5. For those who decide to adopt the precaution, the next step is to begin acting (Stage 6). The last stage (Stage 7) indicates that the behaviour has been maintained over time (Weinstein et al., 2008). The most potentially useful aspect of the model is the assumption that the variables that determine the progress towards an action varies from stage to stage (Weinstein & Sandman, 1992).

In this study, the PAPM was used to develop choices for the lesbians' intentions to perform BSEs and to have mammography screenings in order to identify the differences among the influencing factors corresponding to Stages 2, 3, 4, 5 and 6 in the PAPM. The group of lesbians not planning to perform BSEs or to have a mammogram is of particular interest, because it represents individuals who may have difficulty in screening their own breasts or in going to be screened. The model was used to assess in greater detail the earlier stages of adoption prior to action. In addition, the participants who reported having experience of performing a BSE or having a mammogram were then asked about how frequently they did so. The choices for the two questions were designed based on the recommendations made by the breast cancer screening programme in Taiwan and previous relevant studies. These questions can help the researcher to understand what factors influence the women's maintenance of breast healthcare behaviour (PAPM Stage 7).

In this questionnaire design, the number of questions/statements under each construct was mainly decided by the interview findings, as the purpose of the online survey was to understand whether the interview findings could be applied to a larger target population. Hence, all of the influencing factors relating to the lesbians' sexual orientation were included in order to meet the study's purposes (the detailed rationale for the factors chosen can also be seen in Chapter 6).

In terms of the other constructs in the questionnaire, the number of questions/statements was decided based upon both the interview findings and the current evidence. The number of statements under the HBM constructs was decided by the interview findings and the relevant studies conducted in Taiwan. The most commonly shared variables among the two groups of

women were included in the questionnaire. Each construct included no more than five statements so as to avoid having a long questionnaire but also to include the most commonly shared factors among the two groups of women.

The number of questions under the constructs of the demographic variables and breast cancer risk factors was also decided by current evidence and the interview findings. The previous structured questionnaire used in the qualitative interviews for collecting the lesbians' demographic information was used in this questionnaire design, so as to correspond with the first-phase study. The shared variables regarding the risk factors of breast cancer, reported by the participants in the qualitative interviews, heterosexual women in relevant Taiwanese studies (see Section 2.6) and lesbians in international studies (see Section 2.4), were included in the questionnaire so as to compare the similarities and differences among these women. In terms of actions and intentions regarding breast cancer screenings, two questions addressed BSE and two addressed mammograms.

Although a longer questionnaire in a web survey might lead to fewer respondents starting and completing it (Galesic & Bosnjak, 2008), the researcher included all of the main findings from the qualitative interviews and the factors shared among lesbians and women in general in Taiwan in order to meet the study's purpose and to compare the factors among the two groups of women. The number of questions/statements under each construct was mainly decided based on the interview findings, but the length of the questionnaire was designed to be answered over the course of 20 minutes by a participant (see Section 7.6 pilot of the questionnaire and its modifications)

#### **7.4.2 Choosing the format of the questionnaire items**

The choice of format depended upon what information was needed and how specific it needed to be. The questionnaire items in the 'background information' section mainly consisted of three types of questions: filling in a blank space, yes/no questions and multiple-choice questions (only one answer). In order to obtain the respondent's specific age and occupation, blank spaces were provided. Yes/no questions were used to collect information about the respondents' breast cancer risk factors. The majority of the questions were designed as multiple-choice questions (only one answer), which asked the respondents to select the best answer out of the choices on a list. This format was suggested as an effective assessment

technique and it is commonly used to collect demographic information (Case & Swanson, 2002).

The format of the questionnaire items in the ‘breast cancer screenings’ section comprised multiple-choice questions (only one answer) to investigate the participants’ intentions to have breast cancer screenings and the frequency with which they perform BSEs and have mammograms. Due to the choices within these questions being designed based on the literature review and the policy of the breast health services in Taiwan, multiple-choice questions with one answer were considered to represent the most appropriate format for collecting data.

A Likert scale was used for the items in the core instrument: ‘views on breasts, breast cancer and breast cancer screenings’. This kind of measure was invented by Rensis Likert in 1932 and has been widely used for decades. Although it has been criticized for its lack of reproducibility (the same total score of a scale may be obtained in many different ways) and inconsistent response options, the scale is suggested as being able to capture and describe the complexity of respondents’ attitudes and opinions by providing more precise information about the degree of agreement or disagreement (Oppenheim, 1992). Oppenheim has indicated that having more than five options exhibits no advantage over having five. In this section, a five-point Likert-type scale was employed as the question format, ranging from strongly disagree (1), disagree (2), neither agree nor disagree (3), agree (4) to strongly agree (5). It has been suggested that the ‘neutral’ and ‘undecided’ options in a Likert scale encourage avoiding false responses or increase the number of people reporting they have no opinion when they actually do (Edwards & Smith, 2011). In this study, the ‘neutral’ option (neither agree nor disagree) was included because the researcher attempted to avoid forcing respondents into expressing agreement or disagreement when they may have lacked confidence in expressing their views, particularly when answering some sensitive statements (for example: “I do not want my breasts”). In addition, people with a Chinese culture background were taught to follow “the doctrine of the mean” (中庸; *zhongyong in Chinese*) when they were young. *Zhong* represents bent neither one way or another, and *yong* means unchanging. Excluding the neutral option might be inappropriate as it may indicate disregard towards the nature of Chinese people and society.

### **7.5 Translating the questionnaire from English to Chinese**

The initial questionnaire design was in English because it was necessary to discuss the content and format of the questionnaire's design with supervisors (who are based in the UK and cannot read or speak Chinese). In order to apply it to Taiwanese lesbians, it was necessary to translate the questionnaire into a Chinese version.

The language of the translated questionnaire must be understandable and meaningful to the subject (Greco et al., 1987). Differences in grammatical and syntactical styles have been pointed out as difficulties when translating (Yu et al., 2004). In order to ensure the accuracy of the translation, a six-step translation process was employed. Firstly, the English version of the questionnaire was translated into Chinese by the researcher. The initial translation was done by the researcher because she was most familiar with the findings from the first-phase qualitative study and the rationale behind the questionnaire's development. Secondly, a qualified translator (without a nursing background) made a separate translation of the questionnaire. Transcribing is a profession that requires training and qualifications – it requires specific skills and procedures to make good-quality translations. In addition, the translator usually has no understanding of survey practices and needs; hence, he or she may use the same view as the target population to read and explain the questionnaire (Harkness, 2013). Thirdly, the researcher compared both translated questionnaires (the one made by the researcher herself and the other by the qualified translator) and then modified the Chinese-language questionnaire. Fourthly, three experts (who were bilingual and had nursing backgrounds) were invited to check the accuracy of the translation by using the English questionnaire and the modified Chinese questionnaire. Fifthly, the researcher discussed the translation with the experts and modified the Chinese questionnaire based on the discussion's results. This step was repeated two or three times before obtaining agreement on the translation between the researcher and the experts. Finally, a final revised Chinese language questionnaire was produced.

### **7.6 Pilot of the questionnaire and its modification using the comments provided by the participants**

Questionnaires are usually piloted on a small sample of people with similar characteristics to those in the full study in order to pick up questions that are misinterpreted or items that are frequently missed out (Gerrish & Lacey, 2007). Punch (2007) has suggested that newly

written items and questions need to be tested for comprehension, clarity, ambiguity and any difficulties in responding. This process aims to ensure that the questions can be understood by the participants as well as to test the questionnaire's length and the time and difficulty involved in completing it.

A pilot study was conducted with 10 Taiwanese lesbians before the main study in order to check the readability and wording of the questionnaire. The 10 women were invited and recruited from four Taiwanese lesbian organizations and the study advisory group. The Taiwanese lesbian organizations were approached previously to conduct the qualitative interviews in 2012. The staff in the organizations were invited to take part in the pilot study. The advisory group, which included four Taiwanese lesbians, was organized by the researcher when advice was needed for conducting the study on Taiwanese lesbians in 2012 and 2013. Members of this group were also invited to take part in the pilot study.

A comment sheet (which can be seen in Appendix 13, p.301) was prepared before the pilot study and was filled in by the lesbians after they had completed the questionnaire. All of the comments were discussed with the supervisors. Modifications were made using the comments provided by the participants which did not go against the rationale of the questionnaire design.

Higher response rates have been suggested as resulting if the questionnaire's length is 15-30 minutes compared to 30-45 minutes (Deutskens et al., 2004). For the 10 participants (age range: 29-53 years), the mean time to complete the questionnaire was about 12 minutes. The length of time to complete it was markedly different among the 10 participants, ranging from five to 24 minutes. Those who spent a relatively long time (more than 20 minutes) filling in the questionnaire were more likely to provide detailed comments and were older (39-58 years). Only one reported that the questionnaire was too long and that it had too many questions, but the time she took to complete the questionnaire was around five to eight minutes. All of the participants reported that none of the questions were objectionable and that none of the items in the questions produced irritation or embarrassment. These participants also felt comfortable in answering the questions. In addition, they reported that the choices contained within the questions could reflect the individuals' feelings or ideas.

Several modifications were made based on the comments provided by the participants. Firstly, definitions for breast cancer screenings were added to the questionnaire in order to help the participants to understand what BSE and mammography meant and to assist them to answer the questionnaire. Secondly, some of the questions were reported as being too ambiguous to answer by the participants. For example, the question ‘My partner thinks that I should perform BSE’ asked the lesbians to rate how much the women agreed or disagreed with the statement by using a five-point Likert-type scale. Some of the participants reported that it was too ambiguous to answer because they did not know what their partner thought. The rationale behind the use of this question was that it aimed to assess the support offered by the lesbian’s current partner, not the lesbian’s views on her partner’s support. Hence, the question format was modified to multiple-choice questions (with one answer) or yes/no questions, if applicable. Thirdly, the directions of some questions were modified to help the participants to understand the aims of these questions. For instance, the directions for the question relating to the lesbians’ views on the perceived benefits and barriers to having breast cancer screenings instructed the lesbians to indicate how much they agreed or disagreed with the statements, and some of the participants reported that they did not know how to rate the statements because they lacked experience of having breast cancer screenings. The purpose of the questions was to assess the lesbians’ views or beliefs, not their experiences or knowledge. Thus, the directions for these questions were modified in order to help the women to understand the aims of the questions and to obtain the information that the questions aimed to assess. The modified questionnaire can be seen in Appendix 14 (see p.303).

### **7.7 Posting the questionnaire on an online survey website and piloting its performance**

Following the revision of the questionnaire, a final version of the Chinese language questionnaire was posted online via SurveyMonkey (an online survey program). Currently, a number of online survey software solutions are available. SurveyMonkey was chosen as the platform for data collection because it provides a state-of-the-art security infrastructure to ensure that the data collected are safe via an enhanced SSL encryption package to protect the survey during transmission. In addition, it supports Chinese characters and has been used successfully for the collection of survey data via the Internet by Taiwanese researchers (Spence & Liu, 2013). The price of the software (£299 per year) was also affordable for the researcher compared to other online survey software (Wright, 2005).



The participant information sheet and the questionnaire were posted online via the survey software. ‘*Question logic (the sequence of the questions)*’ was edited to redirect the participants to the next question automatically and to help the participants to answer the questionnaire more easily. Before testing the website’s performance, an English language online questionnaire was posted on the website (the Chinese language online questionnaire was designed with the same format and question logic) in order to discuss the website’s performance with supervisors. The participant information sheet was added as a link on the welcome page to avoid too many words appearing on the first page, which might decrease the response rate. If a participant wanted to view the sheet, they could then click the link and be redirected to the website page, which contained the full contents of the participant information sheet.

A pilot study was conducted with 10 Taiwanese lesbians, who also took part in the previous pilot study to test the questionnaire (their recruitment can be seen in Section 7.6), in order to check the website’s performance, and to diminish any risks that might occur during the main study’s collection period.

Nielsen (2000) has suggested that testing with five users should reveal 85% of a website’s usability problems. In this pilot study, 10 participants were recruited to check its navigation, for typographical errors, its appearance and its readability. A comment sheet (which can be seen in Appendix 15, p.311) was provided to the participants to help them to examine the online questionnaire and assess its performance. Overall, the participants reported that the performance of the online questionnaire was good. The participants did not report any specific technical issues that might cause difficulties in connecting to the website. In addition, its navigation, appearance and readability were also reported as being good.

## **7.8 Summary**

In this chapter, the process of the questionnaire’s development was described. Two pilot studies were conducted with 10 Taiwanese lesbians in order to test the questionnaire and to check the website’s performance. Modifications were made based on the comments proposed by the participants to ensure that the online questionnaire was readable and understandable. After the online questionnaire was developed, the main study – an online survey – was then conducted. In the next chapter, the methods of the online survey are presented.

## **Chapter 8: Phase two – online survey**

### **8.1 Introduction**

Based on the sequential exploratory mixed-methods study design in this PhD study, a cross-sectional online survey was conducted after the instrument was developed and piloted. The survey is not only a research approach but also a research process, in which a set of scientifically rigorous procedures are included, from selecting a suitable research question, identifying the target population and research samples, systematically collecting data, to choosing appropriate methods of analysing the data. As each procedure is planned and conducted rigorously, a relatively accurate conclusion can be obtained (Nardi, 2003). It is suggested, therefore, that the reporting of every study must contain sufficient information to allow the reader to justify the quality of the findings with reference to the study methods (Mann, 2003).

This chapter aims to present an overview of the methods employed in the survey and the survey results. At the end of this chapter, a summary of the results is provided.

### **8.2 Purposes of the study**

The purposes of this survey were to assess whether the findings from the first-phase qualitative interviews could be applied to a larger target population, to understand the associations between the influencing factors and the lesbians' breast healthcare behaviour and intentions, and to identify the similarities and differences in the influencing factors of BSE and mammograms between lesbians and heterosexual women when comparing the survey results to those of previous studies conducted with women in general in Taiwan.

### **8.3 Methods**

This section provides details of the methods used in this online survey, including the sampling, data collection, data analysis and ethical considerations.

#### **8.3.1 Sampling**

##### **8.3.1.1 Inclusion and exclusion criteria**

Consistent with the target population in the first phase of this study, the target population in this survey was women who: 1) were twenty years of age or over; 2) who self-identified as lesbian or women who had a partner of the same gender; and 3) who had the ability to access, read and answer the online questionnaire, due to the online survey design. The exclusion

criteria for this study also corresponded with the exclusion criteria in the interview study. Women who were not Taiwanese lesbians and had been diagnosed with breast cancer were excluded from the study.

### **8.3.1.2 Sampling and recruitment**

Due to the characteristics of the target population, as a hidden population, non-probability sampling was used to recruit the participants in the online survey. Usually, quantitative studies tend to use probability sampling because the errors and biases can be more easily calculated and thus accounted for in the sampling procedure and data analysis. It allows for generalization to the target population more readily than non-probability sampling (Procter & Allan, 2007). However, it can only be employed when an accurate and up-to-date sampling frame is available. As lesbians are a hidden group in Taiwanese society, probability sampling was considered to be inappropriate because there was no sampling frame available.

Based on the previous international studies (see Section 2.6), the most commonly used sampling strategies for recruiting lesbians have been convenience sampling and snowball sampling. Although sampling errors and limitations in terms of the representativeness of the population were pointed out (IOM, 2011), they had been widely used due to the subgroup's features. Different from the previous studies, purposive sampling and snowball sampling were used in the present survey, employing similar sampling strategies to those for the qualitative interviews, in order to recruit participants with a maximum variation of characteristics and older lesbians (aged 45 years or over). However, in addition to the organizations approached during the qualitative interviews, several access points on websites, for example lesbian-associated groups on Facebook, were also approached to target a larger population.

#### **1) Purposive sampling**

Although it is not always possible to be certain about the characteristics of participants approached and recruited via the Internet, in the present study, the researcher attempted to approach a larger group of participants with varied characteristics. Therefore, the participants were recruited via six lesbian/LGBT-associated groups on Facebook and one bulletin board system (which is a terminal-based bulletin board system based in Taiwan) on the Internet.

The study was also advertised on the websites of three LGBT organizations that had previously assisted with recruitment for the qualitative interviews and were located in North, West and South Taiwan (one North, one South and one covering both North and South). Lesbians who lived in East Taiwan were recruited through one of the Facebook forums run from East Taiwan. A summary of the access points can be seen in Table 8.1.

**Table 8.1: A summary of the access points**

<b>Facebook</b>	
女子聚會	<a href="https://www.facebook.com/groups/nicewoman/">https://www.facebook.com/groups/nicewoman/</a>
三十以上找拉伴	<a href="https://www.facebook.com/groups/127264710684542/">https://www.facebook.com/groups/127264710684542/</a>
非成勿擾	<a href="https://www.facebook.com/groups/295576180477890/">https://www.facebook.com/groups/295576180477890/</a>
博拉圖 (Libro Central)	<a href="https://www.facebook.com/libro.central.handbook?fref=hovercard">https://www.facebook.com/libro.central.handbook?fref=hovercard</a>
陽光酷兒中心 (Sunshine queer centre)	<a href="https://www.facebook.com/sqc.tw">https://www.facebook.com/sqc.tw</a>
林寒玉 (Must Muster Publisher, East Taiwan)	<a href="https://www.facebook.com/profile.php?id=528545100">https://www.facebook.com/profile.php?id=528545100</a>
<b>Bulletin board system</b>	
PTT Bulletin Board System (Lesbian chat room)	<a href="https://www.ptt.cc/index.html">https://www.ptt.cc/index.html</a>
<b>LGBT organizations</b>	
Taiwan LesHand Association (North Taiwan)	<a href="http://lalahand.xxking.com/">http://lalahand.xxking.com/</a>
Taiwan Tongzhi Hotline Association (North Taiwan)	<a href="http://hotline.org.tw/english">http://hotline.org.tw/english</a>
Taiwan Tongzhi Hotline Association (South Taiwan)	<a href="http://hotline.org.tw/english">http://hotline.org.tw/english</a>
GisneyLand (West Taiwan)	<a href="http://www.gisneyland.org/">http://www.gisneyland.org/</a>

An invitation (see Appendix 16, p.313) and an online questionnaire link were posted on the lesbian forums on Facebook, the bulletin board system on the Internet and the LGBT organizations' websites. If a potential respondent was interested in taking part in the study, they could click the link, which would redirect them to the welcome page of the online questionnaire. The welcome page contained the study's purpose, the inclusion and exclusion criteria, and a link which redirected the respondents to a homepage, which included detailed information on the study's purpose, methods, potential harm, benefits and the researcher's contact information (participant information sheet, see Appendix 17, p.314). The potential respondents were reminded that it was important for them to click the link and read the participant information sheet in order to ensure that they knew their rights and understood the study before they started to answer the online questionnaire.

If the participant decided to take part in the study, they could click the 'Next' button on the welcome page, which would indicate that she understood the research and agreed to participate (see Appendix 18, p.317). Once the 'Next' button was clicked, the respondent was redirected to the survey questionnaire and the main body of the online questionnaire was presented. Although the inclusion and exclusion criteria were presented on the invitation and the welcome page, the respondents were also included or excluded based on their answers to the first three questions in the online questionnaire, which asked for the respondent's age, sexual orientation and personal history of breast cancer. If the respondent met any of the exclusion criteria of the study (that is, being younger than 20 years of age, heterosexual or diagnosed with breast cancer), she was redirected to the 'Thank you' page.

## **2) Purposive and snowball sampling to recruit older lesbians**

In addition to purposive sampling, snowball sampling was also employed because of the challenge that was met in the first-phase qualitative interview: the difficulty in recruiting older lesbians (aged 40 years or over). This sampling strategy mainly uses human networks to gather a sample or identify informants (Procter & Allen, 2007). It relies on an initial core group of participants to recruit others into the study through their social networks; those individuals, in turn, may be asked to recruit additional participants from their networks, and so on (Binson et al., 2007; Meyer & Wilson, 2009). One lesbian group, Old Lady (where only lesbians who were aged 40 years and above could participate in this group), in the Taiwan Tongzhi Hotline Association, was contacted and the study was advertised during the group's regular meetings with permission. The members were invited to participate in the study and were asked to introduce the survey to other potential respondents. The study was advertised in the group again four weeks after the survey began because there was only one participant who was 45 years or over (i.e., the criterion for free mammograms in Taiwan), and in addition to a web-based questionnaire, a paper-pencil questionnaire was also added so as to recruit participants who might not have the ability to access the online questionnaire. The process of data collection using a paper-pencil questionnaire is provided in the following section.

## **3) Incentives**

Incentives were employed to increase the response rates. Although it has been suggested that incentives may be unethical or a form of undue influence or coercion (Singer & Bossarte, 2006), others have suggested that the use of incentives to recruit research participants is

innocuous (Grant & Sugarman, 2004). In line with Taiwanese traditional culture, the researcher's experience when conducting the first-phase qualitative interviews in 2012 was that some of the participants expected a small gift after the study was completed. The value of the gift (cheap or expensive) is not the major issue in the action of gift-giving. In the Taiwanese gift-giving culture, the meaning of the action is to show appreciation for a respondent's participation. The incentive was a short study summary and entering the respondents who participated in the survey into a prize draw. The respondents needed to agree to leave their email addresses. Three prizes were provided. The value of each prize was about £20 and the prize winners were decided by a random draw. In addition to the incentives, clear instructions on how to complete the questionnaire, the university mark and the ethical approval reference number were posted on the welcome page in order to validate the researcher's identity and to increase the response rates.

### **8.3.1.3 Sample size**

This survey was mostly descriptive and it established whether the findings from the first-phase qualitative interviews appeared to hold true for a larger population, but some relationships between the influencing factors and Taiwanese lesbians' breast healthcare behaviour and intentions were considered, for instance associations between the women's views on their own breasts, breast cancer and breast cancer screenings and the participants' breast healthcare behaviour and intentions.

The sample size in the study was mainly calculated to compare proportions in two equally-sized groups. A sample of  $N = 200$  was considered to be adequate to investigate the relationships of interest. For example, lesbians who had an unskilled/skilled job were expected to be less likely than lesbians who had a professional/management job to have a mammogram (for example, 40% versus 60%). A sample of  $N = 190$  would give 80% power to detect such a small effect-size of 0.20 at  $\alpha = 0.05$ , which would require 95 people to be recruited per study site (Whitley & Ball, 2002). A smaller sample would be sufficient to detect moderate to large effect-sizes.

## **8.3.2 Data collection methods**

### **8.3.2.1 Online survey**

The data collection began in August 2013 and lasted for two months (August 2013-October 2013). Data were collected using the questionnaire described in Chapter 7, Appendix 14, and

p.303, consisting of 70-75 questions and covering three sections: background information, breast cancer screenings (behaviour and intentions regarding BSE and mammograms) and views on breasts, breast cancer and breast cancer screenings. The questionnaire was posted via online survey software (SurveyMonkey).

The participant was asked to follow the instructions on filling in the online questionnaire. No question was highlighted as a required question. Therefore, the participant did not have to answer every question in the questionnaire if she did not want to and/or she felt uncomfortable about the question(s). At the end of the survey, the participant was reminded to click the 'Done' button to record her responses and participation. A 'thank you' page followed the main body of the questionnaire in order to show the researcher's appreciation and also to remind the respondent that, if she wanted to receive a short study summary and enter a free prize draw, an email address needed to be provided and her personal information would remain confidential. A comment box was also provided at the end of the questionnaire if the respondent wanted to leave comments about the survey and/or the questionnaire.

#### **8.3.2.2 Challenges in recruiting older lesbians and amendments**

As mentioned, during the first four weeks of the data collection period, there was some difficulty in recruiting older lesbians, although the study was advertised during the Old Lady group's regular meetings and snowball sampling was employed during the data collection period. Only one out of the 105 lesbians who participated in this study was aged 45 years or over. With only one participant who was eligible for a free mammogram every two years in Taiwan, it was considered to be difficult to understand the associations between the influencing factors and the women's breast healthcare behaviour, including their experiences and frequencies of having mammograms. Hence, paper-pencil questionnaires were used to attempt to improve the response rate among older lesbians who might not know how to use a computer. Amendments were made to the ethical approval application before the paper-pencil questionnaire was used to recruit older lesbians. The leader of the Old Lady group in the Taiwan Tongzhi (Homosexual) Hotline Association agreed to advertise the study again during their regular meetings and to invite older lesbians to participate in the study using paper-pencil questionnaires.

The following is the process by which the data were collected using a paper-pencil questionnaire and amendments were approved by the ethical committee at the University of Manchester (Appendix 22, p. 322):

- (1) If a potential participant was interested in taking part in the study, they would receive a participant information sheet, a paper-pencil questionnaire and a stamped envelope from the manager.
- (2) A minimum of 24 hours to as much time as they wished to take during the study's data collection period (12<sup>th</sup> September 2013-10<sup>th</sup> October 2013) was given for the participants to read the information sheet and to decide whether or not they wished to participate.
- (3) If a potential participant agreed to take part in the study, she was asked to answer the questionnaire and mail it back to the researcher. Alternatively, they sent the questionnaire back (in an envelope) to the manager and the researcher went to the organization and collected the questionnaires herself.

One business card (which can be seen in Appendix 19, p.318) was also attached to each envelope. It contained the study's purposes, the inclusion and exclusion criteria, the online questionnaire link, a quick response (QR) code and the researcher's contact information. The respondents could easily scan the QR code on the business card using their smart phones and they would be redirected to the online questionnaire website. During the Old Lady group meeting, the researchers asked if the group members could help to hand the business cards out to other potential respondents that they knew.

At the end of the data collection, no paper-pencil questionnaires were returned. The characteristics of the target population (as a hidden group), the short data-collection period (approximately four weeks) and the possible barriers for older lesbians (such as illiteracy, whereby 17.6% of Taiwanese women who are 65 years or over cannot read; Ministry of the Interior, Department of Statistics, 2013) were considered to be the causes for the absence of responses. Moreover, the business cards might be another reason for the non-response of the paper-pencil questionnaires, because scanning a QR code and answering the questions directly on the respondent's phone might be much more convenient than answering a paper-pencil questionnaire and returning/ mailing it back to the organization or the researcher. Therefore, all of the data were collected by using the online questionnaire in this study. The difficulty in recruiting older Taiwanese lesbians and possible solutions to this challenge will be discussed in Chapter 9.



### **8.3.3 Data management and analysis**

#### **8.3.3.1 Preparation of the data for statistical analysis**

The key tasks of data preparation were performed before any statistical analyses were conducted. The main targets of the data preparation in this survey included: 1) reviewing the raw data and examining any missing data; 2) defining and labelling variables; and 3) checking for errors and inaccuracies in the data. Due to the online survey design and the tools of SurveyMonkey, the researcher did not have to enter the data manually. SurveyMonkey has the ability to integrate with SPSS and to assist the participants in answering questions with specific item formats (set when designing the online questionnaire). Hence, situations such as double-answers or answers that were marked between two categories had a very small chance of occurring.

Before the data preparation, the responses from the online questionnaires (SurveyMonkey) were exported and inserted into IBM SPSS Statistics 21. The data preparation and data analysis were all done using SPSS.

#### **1) Reviewing the data and examining any missing data in the responses**

Any missing data and/or irrelevant answers were examined. Two types of missing data can occur in an online questionnaire: 1) the answer box may be empty because the respondent could not or would not provide a response; and 2) an inappropriate answer may have been provided (Bowling, 2009). Missing values are often the main issue with data analysis and interpretation in a survey study. In a self-completion questionnaire, missing data may be the result of: 1) poor recall by the participants; 2) a question being misunderstood; 3) a lack of a proper category for an unanticipated answer; and 4) problems with privacy (Silman & Macfarlane, 2002).

The amount of missing data for each question/statement can be seen in Appendix 20 (see p.319). One reason for missing data in this study can be associated with the number of questions. The response rates were poorer for Section 3 compared to the rates for Sections 1 and 2. Therefore, the questionnaire might have been too long for some of the respondents. The sensitivity of the questions/statements was a second factor. The statements in Section 3 aimed to learn about the lesbians' views on their own breasts, breast cancer and breast cancer screenings. According to the findings from the first-phase qualitative interviews, some lesbians, particularly those who self-identified as masculine lesbians, would like to ignore

their female characteristics due to their gender identity and gender role expression, for example, not thinking about or not discussing issues about their own breasts. Hence, the statements in Section 3 may be considered to be too sensitive for some of the participants to answer. The third factor was the lack of proper choices for the questions/statements.

Although pilot studies with 10 Taiwanese lesbians were conducted before the instrument was employed in the main study and all of these participants expressed that they thought the questions and the answer choices could represent their views or beliefs and that they were not too sensitive, these women might not represent the larger population. Hence, the choice of questions/statements might not be appropriate for some of the participants in representing their views on a specific issue. The amount of missing data in the questionnaires was discussed with the supervisors in order to decide whether to keep or to delete the cases. Details regarding the omitted cases will be provided in Section 8.4.1.

## **2) Labelling and recoding variables**

As the online survey was designed and conducted in Chinese, the variables were renamed based on the purpose of the designed question and translated into English following the researcher's discussion of the statistical methods and variables with her supervisors. For example, the first question sought to ask the respondent's age, and so the variable was labelled 'Age' (in English).

The majority of the data were numeric responses. Data regarding occupation and the length of the respondents' current relationship with her partner were collected using blank spaces; hence, they were recorded as numbers by the researcher. Decisions about categorizing the data were made based on previous research and the statistics on monthly salaries by occupation published by the Taiwanese government. The purpose of asking for the respondent's occupation was to indirectly know what their income was. Hence, according to the report on monthly salaries by occupation (National Statistics ROC, 2013), the variable was coded into four categories: '1' as unskilled (\$20,000-\$38,000), '2' as skilled (\$38,000-\$50,000), '3' as professional (\$50,000-\$66,000) and '4' as management (> \$66,000). In terms of the length of the current relationship with the respondent's partner, the data were coded with four categories: '1' as 1-12 months, '2' as 13 months to two years, '3' as 25 months to three years and '4' as more than three years. These categories were established based on previous research which aimed to explore Taiwanese lesbians' long-term relationship maintenance and the main goals at different stages of the relationship (Huang, 2012).

### **3) Checking the data for errors and inaccuracies**

Although it has been pointed out that human error in data entry and coding could be reduced by employing an online questionnaire (Restore-National Centre for Research Methods), the frequency distributions, with minimum and maximum values, were estimated for all categories and ordinal data before the data analysis. Any values that were not expected were checked. Age, as a continuous variable, was estimated using its minimum and maximum values, and mean and standard deviation. SPSS was used to search for errors after finding 'out-of-range' responses. Any unreasonable responses were examined and compared with the original data in SurveyMonkey and the data in SPSS.

#### **8.3.3.2 Data analysis**

Descriptive and difference inferential statistics were used for analysing the survey data.

##### **1) Descriptive statistics**

The first step in the analysis was to describe and summarize the collected information using descriptive statistics. The variables for the demographics, breast cancer risk factors and gender identity were summarized using descriptive methods as appropriate. Age, as the only continuous variable, was described using means, standard deviations and ranges. The other demographic variables were all categorical (nominal) variables and were summarized with numbers and percentages.

The respondents' behaviour and intentions regarding breast cancer screenings were treated as categorical variables, and numbers and percentages were used to describe and summarize the data. Although the answer choices of the questions regarding 'BSE intentions' and 'mammogram intentions' were designed based on the PAPM and these two variables could be seen as ordinal variables, they were categorized into several groups in this study (details can be seen in Section 8.4.2). Hence, these variables were treated as categorical variables in the data analysis.

Views about breasts, breast cancer and breast cancer screenings (health psychology variables) were treated as ordinal variables, but these variables were estimated using means and standard deviations in the data analysis. The appropriate descriptive statistics for an ordinal variable are the median and interquartile range (Morgan, 2011). However, the researcher found that when presenting the health psychology variables with medians and interquartile

ranges, it was difficult to see the differences among the groups. For example, the variable ‘performing a BSE would be unpleasant to me’ was found to be significantly different among the participants who had never performed a BSE and those who had performed a BSE ( $p \leq 0.001$ ). When presenting the data with medians (interquartile ranges), they were 2 (1) and 2 (1), respectively. On the other hand, when presenting the data with means (standard deviations), they were 2.39 (0.97) and 1.74 (0.78), respectively. The means and the standard deviations would make it easier for readers to compare the data and to see the differences among the groups.

## **2) Difference inferential statistics: comparing two groups**

Difference inferential statistics are used for approaches that test for differences between groups. When comparing the difference between two independent groups, the independent-samples  $t$ -test, Mann-Whitney U test and Pearson’s chi-squared test were used, as appropriate. The independent-samples  $t$ -test is used when the DV is continuous. It assumes that the variances in the DV in the two populations are equal, that the DV is normally distributed within each population and that the data are independent (Morgan, 2011). For example, this approach was employed to test the differences in age between the respondents who performed BSEs regularly and those who performed them irregularly.

If the data are not sufficiently normally distributed or else if they are ordinal variables, the Mann-Whitney U-test (where the test statistic is denoted by ‘Z’) can be used to compare the distribution between the two groups. This test is a non-parametric version of the two-sample  $t$ -test based on ranked values (Bland, 2000). One disadvantage is that the Mann-Whitney U-test is slightly less powerful than the  $t$ -test when the data distributions are normal (Bland, 2000). However, the Mann-Whitney U-test is more powerful when the distributions are not normal (Vickers, 2005). The Mann-Whitney U-test does not provide an estimate of the size of the difference, such as a 95% confidence interval for the difference between means (Bland, 2000). This method, for instance, was employed in the study to investigate the differences in the individuals’ views about their own breasts and the women’s experience of performing a BSE.

Pearson’s chi-squared test can be used to examine the association between a pair of categorical variables when 20% of the expected counts under the null hypothesis are higher than five and none are less than one (Bland, 2000); for example, when comparing the breast

cancer risk factors within the respondents who performed BSEs regularly and irregularly. Cells were combined as necessary to meet the assumptions for the test. Fisher's exact test can be used to analyse data arranged in a 2\*2 table if the previous assumptions are not satisfied (Bland, 2000). This method was employed when comparing the experience of having children between women who performed BSEs regularly and those who performed them irregularly, because two cells (50.0%) had an expected count that was less than five.

### **3) Difference inferential statistics: comparing three groups**

To compare three groups in this study, one-way ANOVA, the Kruskal-Wallis test and Pearson's chi-squared test were used, as appropriate. The usual method for comparing the means of three or more groups is one-way analysis of variance (Munro, 2004). This usually assumes normal distributions within each group. To compare three or more groups, one-way ANOVA can be used to compare the means of the samples or groups in order to make inferences about the population means. It is also called 'single factor analysis of variance' because there is only one IV, which has nominal levels or a few ordered levels (Morgan, 2011). This method, for example, was employed when comparing the ages between the respondents who were not planning to perform BSEs, those who were undecided about performing BSEs and those who were planning to perform BSEs.

A non-parametric alternative that does not assume normality is the Kruskal-Wallis test (where the test statistic will be denoted by Kruskal-Wallis  $\chi^2$ ) (Munro, 2004). The Kruskal-Wallis test can be used when the DVs are ordinal variables when comparing three or more groups (Morgan, 2011). This method, for example, was employed to compare cues to action among the three groups of respondents with varied intentions regarding breast cancer screenings.

When the DVs are nominal variables, Pearson's chi-squared test can be used to compare the differences among two and more groups. The Monte Carlo method was used when comparing more than two groups and where more than 20% of the cells have an expected count that is less than five. This was employed to investigate the reproductive factor (having children or not) among the respondents with different intentions regarding breast cancer screenings.

#### **4) The problem with multiple comparisons: the Bonferroni method**

The more tests that are performed on a set of data, the higher the probability of making one or more false positive discoveries – or type I errors – among all the hypotheses when performing multiple-hypotheses tests, known as the familywise error rate (McDonald, 2014). In other words, when a researcher performs a large number of statistical tests, it becomes more likely that some will produce  $p$ -values of less than 0.05 purely by chance (Abdi, 2007) and that the null hypothesis is rejected in error. The most common way to control the problem is by using the Bonferroni method. This method is used to obtain the values that should be considered as significant for individual tests by dividing 0.05 by the number of tests (Bender & Lange, 2001; McDonald, 2014) such that we only consider results significant if equal to or below this threshold. With the 47 exploratory variables in our study, the threshold for significance would be  $0.05/47 = 0.00106$ .

#### **8.3.4 Ethical considerations**

Ethical issues are considered below under the following headings: confidentiality, autonomy and potential harm (the ethical approval can be seen in Appendix 21, p.321).

##### **1) Confidentiality**

Although it has been suggested that the anonymity provided by an online questionnaire is helpful for approaching small, specific population subgroups, protecting the respondent's privacy and confidentiality have been seen as significant ethical issues when conducting an online survey. When conducting a web survey, data security is important to protect the anonymity and confidentiality of the participants.

In the present study, the online software SurveyMonkey was used as a tool to collect online data. The data were kept privately and confidentially in the online system (Security Statement, SurveyMonkey, 2013). The online survey system was set to allow anonymous users to answer the survey, and the survey results could only be viewed by the researcher. The respondents might worry that their answers on an online survey could be traced back to them via their email addresses, their IP addresses or other information that the researcher could attempt to elicit from them while they are visiting the website (Fenlason et al., 2002; Information Technology Services, ITS, 2008). The researcher ensured that no information about specific individuals and their visits was tracked and recorded. '*Force Anonymous*' was set up in the survey system, which meant that any information that could potentially identify

respondents was removed no matter how they answered the survey. If the respondent did not click the 'Done' button at the end of the survey, the fact she participated and her responses were not recorded.

If a respondent provided her email address to obtain a short study summary and enter a free prize draw, the researcher clarified that she had saved the personal information provided in a separate file, separate from the other responses, by creating two data collection files in the online survey system. The first file was used to collect the main study data and the second was used to collect the participants' email addresses. By separating the data collection files, the participants' responses could not be linked back to their email addresses. Each respondent was given a participant number, and only that number appeared with the participant's survey responses in the online survey system. In addition, if the respondent did not complete the survey and click the 'Done' button, her responses and participation were not recorded.

During the process of the data analysis, the SPSS software was used. Each respondent was given a participant number, and only that number appeared with the participant's survey responses when using SPSS. The participant's email address was not saved in the SPSS file but in an Excel file. The email addresses saved in the Excel file and in SurveyMonkey were destroyed after the summary was sent. The participants' responses saved in the SPSS file and the SurveyMonkey system will be destroyed after five years. The information stored on the researcher's laptop and external hard drive was password protected and the passwords were held by the researcher alone. In addition, the researcher's laptop was encrypted.

## **2) Autonomy**

During the data collection period, the participants were reminded on the welcome page that they had the right to withdraw at any time during the study. There was an 'Exit this survey' button on every page of the online questionnaire. If a participant wanted to withdraw from the study, they could click the button at any time.

## **3) Potential harm**

A web survey was used to collect the data in this study. It should not cause any harm to the participants. However, some questions might have been sensitive for some of the participants. Participant distress might have been caused during the study. On the welcome page, the researcher reminded the participants that they had the right to withdraw from the study at any

time by clicking the 'Exit this survey' button, and the researcher assured the participants that she would not track their information. The telephone numbers of the Taiwanese gay/lesbian support hotline were provided to the participants. The researcher also provided her phone number and an email address on the participant information sheet, and the participants could contact the researcher if they had any questions or concerns about the study.

## **8.4 Results**

This section aims to present the study's recruitment and to compare the influencing factors among the participants who had varied breast cancer behaviour and intentions. In order to distinguish the two different breast screening methods and the influencing factors clearly, the results are presented under the two titles: BSE and Mammography.

Based on the qualitative interview findings, the Taiwanese lesbians' gender identity was found to be associated with the individuals' views on their own breasts, breast cancer and breast cancer screenings, and consequently their behaviour and intentions regarding BSE and mammography. Hence, at the end of this section, health psychology variables (variables associated with patient-provider interaction, partner support, views towards the woman's own breasts and beliefs about breast health) are compared within different gender identity groups in order to determine whether participants with different gender identities held different views on these variables.

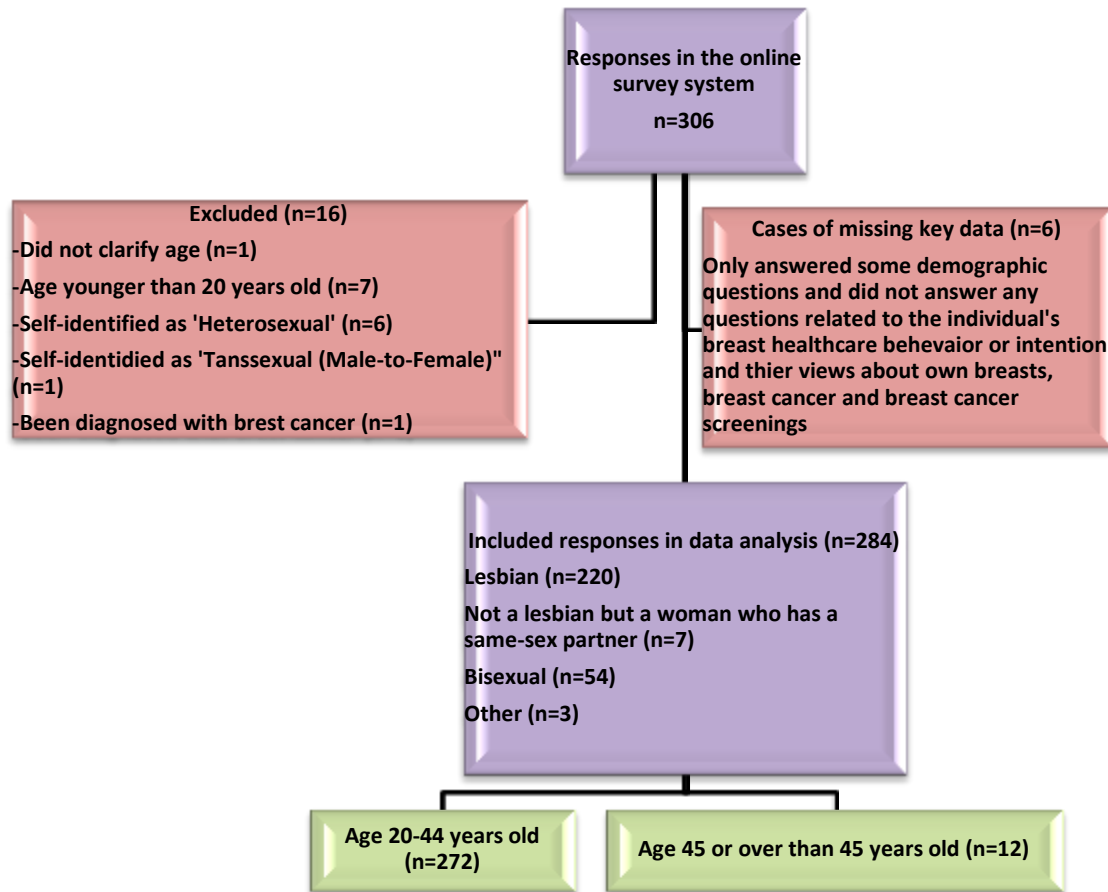
### **8.4.1 Study participation**

Figure 8.1 provides details of the recruitment. All of the participants were recruited using the online questionnaire. A total of 306 responses were recorded in the online survey system. Sixteen participants were excluded, comprising one respondent who did not clarify her age, seven lesbians who were younger than 20 years old, six women who self-identified as 'Heterosexual', one individual who self-identified as 'Male-to-Female Transsexual' and one lesbian who had been diagnosed with breast cancer. In addition, six participants only answered some of the demographic questions but did not answer any questions about their behaviour and intentions regarding BSE and mammography, or their views on their own breasts, breast cancer and breast cancer screenings. For example, one respondent (ID 150) only answered the first two questions (age and sexual orientation) and did not answer any of the other questions in the questionnaire. These six responses were considered not to meet the study's purposes and did not contribute knowledge in terms of lesbians' breast healthcare



behaviour and intentions or the influencing factors. Hence, they were excluded from the analysis. A total of 284 women were included in the data analysis.

**Figure 8.1: Recruitment of participants**



Respondents who self-identified as ‘Lesbian’, ‘Not a lesbian but a woman who has a partner of the same gender’, ‘Bisexual’ or ‘Other (no specific identification and ambisexual)’ were all included in the study. Although the inclusion criteria aimed to recruit individuals who self-identified as ‘Lesbian’ or ‘Not a lesbian but a woman who has a partner of the same gender’, ‘Bisexual’ and ‘Other’ participants were included in the analysis because the majority of these women (93%) reported that they used gender labels (as a masculine (T/Bufen pian T), feminine (Po/Bufen pian Po) or undifferentiated (Bufen) lesbian) to construct their gender roles within their relationships. As mentioned in the interview findings, gender identity was an important factor that affected the lesbians’ breast healthcare behaviour and intentions and their views about their own breasts, breast cancer and breast cancer screenings. Even though these ‘Bisexual’ and ‘Other’ participants did not self-identify as a lesbian or a woman who partnered with the same gender, they were included in order to assist

the researcher to understand the associations between the women's gender identity, their behaviour and intentions regarding having breast cancer screenings, and the health psychology variables.

Among the 284 participants, there were 12 individuals aged 45 years or over and 272 aged 20 to 44 years. In other words, only 4% (12/284) of the participants were eligible for free mammograms every two years, based on the breast healthcare programme in Taiwan. Most of the participants were not eligible for the breast screening in the present survey.

#### **8.4.2 BSE**

The associations between the influencing factors and the participants' behaviour and intentions regarding BSE were investigated in this subsection. As mentioned in Chapter 7 (see Figure 7.2, p.168), the influencing factors in the present study included demographic characteristics, the risk factors of breast cancer, partners' support and psychological health variables. The psychological health variables contained the variables found from the qualitative interviews and the HBM and the TRA variables.

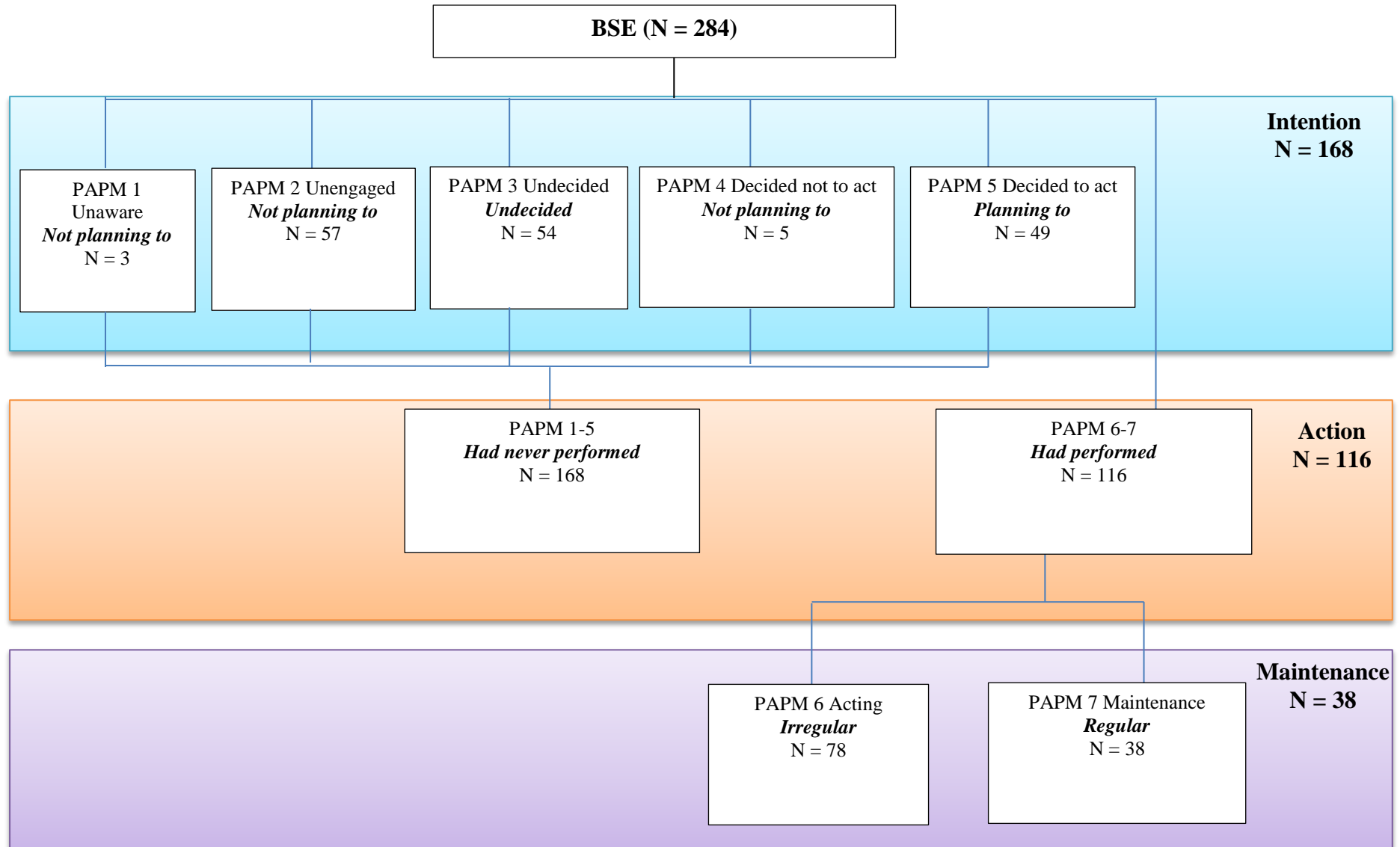
The participants' behaviour and intentions regarding BSE were categorized mainly based on the PAPM. As mentioned in Chapter 7, the model includes seven stages: Stage 1: unaware; Stage 2: unengaged; Stage 3: undecided; Stage 4: decided not to act; Stage 5: decided to act; Stage 6: acting; and Stage 7: maintenance.

Of the 284 participants, there were 168 women who had never performed a BSE. Women's intentions to perform the examination were categorized into three groups based on the PAPM (see Figure 8.2) and a study by Clemow et al. (2000) to facilitate analysis and enable the comparison of groups which contained equal numbers of participants. Clemow et al. (2000) categorized participants' intentions regarding mammograms into three groups: 1) not planning; 2) thinking about; and 3) definitely planning. Clemow stated that the participants who selected PAPM Stages 1, 2 or 4 were categorized into the 'not planning' group. The 'thinking about' group in her study corresponded to PAPM Stage 3 and the 'definitely planning' group to PAPM Stage 5. In the present study, the participants' intentions were also categorized into three groups: 1) not planning to (PAPM Stages 1, 2 and 4); 2) undecided (PAPM Stage 3); and 3) planning to (PAPM Stage 5). To investigate predictors of intentions to perform BSE, the influencing factors were compared among these three PAPM groups.

A total of 116 participants in this study had performed a BSE. To understand the predictors of actual behaviour, participants were divided into those who had performed (PAPM 6 and 7) and those who had not performed BSE (PAPM 1-5).

Furthermore, to investigate the factors associated with women's regular and irregular BSE practice, those who performed BSE regularly (N = 38) and those performing it irregularly (N = 78) were compared using the categories PAPM 6 (acting) and PAPM 7 (maintenance)

**Figure 8.2: PAPM stages and comparable group descriptions in this study (BSE)**



The results of the comparisons of the variables among the women with different actions and intentions regarding performing BSEs can be seen in Tables 8.2 (demographic characteristics), 8.3 (breast cancer risk factors), 8.4 (partners' support) and 8.5 (health psychological variables). There were no significant differences at  $p \leq 0.001$  regarding the demographic characteristics and risk factors of breast cancer among the women with different actions and intentions regarding BSEs.

The partners' support was associated with the participants' experience of performing BSEs. The women who had performed a BSE were significantly more likely to report that their partners thought they should perform BSEs ( $p = .001$ ) and that their partners performed BSEs for them ( $p < .001$ ) than those who had never performed a BSE.

In terms of the psychological health variables, there were significant differences in the perceived barriers to performing BSEs, self-efficacy and cues to action between the women who had never performed a BSE and those who had performed one. The women who had never performed a BSE were also more likely to feel that performing a BSE would be embarrassing ( $p \leq .001$ ), would be unpleasant ( $p \leq .001$ ) and was not a high priority for them ( $p = .001$ ). In terms of self-efficacy and cues to action, the participants who had performed a BSE were more likely to report that they knew how to perform a BSE ( $p \leq .001$ ) and felt confident about the examination results ( $p \leq .001$ ) than the women who had never performed a BSE. Campaigns ( $p = .001$ ) and symptoms ( $p \leq .001$ ) were also more likely to be reported as facilitating these women's actions regarding BSE.

The women's intentions regarding performing BSEs were found to be associated with their perceived barriers to BSE and perceived susceptibility to breast cancer, in particular that performing a BSE was not a high priority for them ( $p \leq .001$ ), that they were more likely to have breast cancer than the average woman ( $p \leq .001$ ), and that they worried about having breast cancer in the future ( $p \leq .001$ ).

The participants' continuing to perform BSEs was found to be related to their perceived barriers to performing BSEs. The women who performed BSEs irregularly were more likely to report that performing BSEs was not a high priority for them ( $p \leq .001$ ) than the women who performed the examinations regularly.

**Table 8.2: Demographic characteristics and BSE**

		<b>Had never performed a BSE</b>	<b>Had performed a BSE</b>	<i>p</i> -value	<b>Not planning to perform a BSE</b>	<b>Undecided</b>	<b>Planning to perform a BSE</b>	<i>p</i> -value	<b>Performing BSEs irregularly</b>	<b>Performing BSEs regularly</b>	<i>p</i> -value
<b>Age</b>		<b>N = 168</b>	<b>N = 115</b>		<b>N = 65</b>	<b>N = 54</b>	<b>N = 49</b>		<b>N = 78</b>	<b>N = 38</b>	
	Mean (SD)	28.53 (6.79)	31.18 (7.80)	.003	29.52 (8.11)	28.28 (5.72)	27.49 (5.83)	.272	31.26 (7.90)	30.74 (7.79)	.739
	Range	20-56	20-58		20-56	20-44	20-43		20-58	20-55	
<b>Gender identity</b>		<b>N = 164</b>	<b>N = 111</b>		<b>N = 63</b>	<b>N = 53</b>	<b>N = 48</b>		<b>N = 75</b>	<b>N = 37</b>	
	Masculine-identity lesbian	89 (66.4%)	45 (33.6%)		39 (43.8%)	25 (28.1%)	25 (28.1%)		29 (64.4%)	16 (35.6%)	
	Buten-identity lesbian	35 (52.2%)	32 (47.8%)	.080	13 (37.1%)	12 (34.3%)	10 (28.6%)	.495	22 (66.7%)	11 (33.3%)	.847
	Feminine-identity lesbian	40 (54.1%)	34 (45.9%)		11 (27.5%)	16 (40%)	13 (32.5%)		24 (70.6%)	10 (29.4%)	
<b>Religion</b>		<b>N = 151</b>	<b>N = 89</b>		<b>N = 60</b>	<b>N = 51</b>	<b>N = 40</b>		<b>N = 60</b>	<b>N = 30</b>	
	None	85 (60.3)	56 (39.7%)		31 (36.5%)	29 (34.1%)	25 (29.4%)		42 (73.7%)	15 (26.3%)	
	Buddhism	35 (62.5%)	21 (37.5%)	.373	18 (51.4%)	10 (28.6%)	7 (20%)	.572	12 (57.1%)	9 (42.9%)	.164
	Taoism	31 (72.1%)	12 (27.9%)		11 (35.5%)	12 (38.7%)	8 (25.8%)		6 (50%)	6 (50%)	
<b>Employment status</b>		<b>N = 164</b>	<b>N = 110</b>		<b>N = 63</b>	<b>N = 53</b>	<b>N = 48</b>		<b>N = 75</b>	<b>N = 36</b>	
	Student	45 (67.2%)	22 (32.8%)		15 (33.3%)	12 (26.7%)	18 (40%)		16 (69.6%)	7 (30.4%)	
	Employed	109 (58.3%)	78 (41.7%)	.288	43 (39.4%)	37 (33.9%)	29 (26.6%)	.317	51 (65.4%)	27 (34.6%)	.632
	Unemployed	10 (50%)	10 (50%)		5 (50%)	4 (40%)	1 (10%)		8 (80%)	2 (20%)	
<b>Occupation</b>		<b>N = 109</b>	<b>N = 78</b>		<b>N = 43</b>	<b>N = 37</b>	<b>N = 29</b>		<b>N = 51</b>	<b>N = 27</b>	
	Skilled/Unskilled (< \$50,000)	65 (62.5%)	39 (37.5%)		25 (38.5%)	22 (33.8%)	18 (27.7%)		30 (76.9%)	9 (23.1%)	
	Professional/Management (> \$50,000)	44 (53%)	39 (47%)	.191	18 (40.9%)	15 (34.1%)	11 (25%)	.946	21 (53.8%)	18 (46.2%)	.032
<b>Level of education</b>		<b>N = 165</b>	<b>N = 113</b>		<b>N = 64</b>	<b>N = 52</b>	<b>N = 49</b>		<b>N = 77</b>	<b>N = 36</b>	
	High school/associate degree	16 (59.3%)	11 (40.7%)		6 (37.5%)	6 (37.5%)	4 (25%)		5 (45.5%)	6 (54.5%)	
	College degree	105 (59.7%)	71 (40.3%)	.989	40 (38.1%)	36 (34.3%)	29 (27.6%)	.642	23 (31.9%)	49 (68.1%)	.600
	Postgraduate degree	44 (58.7%)	31 (41.3%)		18 (40.9%)	10 (22.7%)	16 (36.4%)		9 (29%)	22 (71%)	

**Table 8.3: Breast cancer risk factors and BSE**

	Had never performed a BSE	Had performed a BSE	<i>p</i> -value	Not planning to perform a BSE	Undecided	Planning to perform a BSE	<i>p</i> -value	Performing BSEs irregularly	Performing BSEs regularly	<i>p</i> -value
<b>Non-malignant breast disease</b>	<b>N = 166</b>	<b>N = 115</b>		<b>N = 64</b>	<b>N = 53</b>	<b>N = 49</b>		<b>N = 78</b>	<b>N = 38</b>	
Yes	18 (42.9%)	24 (57.1%)	.020	8 (44.4%)	2 (11.1%)	8 (44.4%)	.108	11 (45.8%)	13 (54.2%)	.012
No	148 (61.9%)	91 (38.1%)		56 (37.8%)	51 (34.5%)	41 (27.7%)		67 (72.8%)	25 (27.2%)	
<b>Family history of breast cancer</b>	<b>N = 168</b>	<b>N = 114</b>		<b>N = 65</b>	<b>N = 54</b>	<b>N = 49</b>		<b>N = 77</b>	<b>N = 38</b>	
Yes	24 (57.1%)	18 (42.9%)	.319	4 (16.7%)	9 (37.5%)	11 (45.8%)	.018	8 (44.4%)	10 (55.6%)	.024
No	112 (57.7%)	82 (42.3%)		53 (47.3%)	31 (27.7%)	28 (25%)		61 (74.4%)	21 (25.6%)	
Unsure	32 (69.6%)	14 (30.4%)		8 (25%)	14 (43.8%)	10 (31.3%)		8 (53.3%)	7 (46.7%)	
<b>Have children</b>	<b>N = 168</b>	<b>N = 115</b>		<b>N = 65</b>	<b>N = 54</b>	<b>N = 49</b>		<b>N = 78</b>	<b>N = 38</b>	
Yes	7 (70%)	3 (30%)	.745	3 (42.9%)	4 (57.1%)	0 (0%)	.151	2 (66.7%)	1 (33.3%)	1.000
No	161 (59%)	112 (41%)		62 (38.5%)	50 (31.1%)	49 (30.4%)		76 (67.3%)	37 (32.7%)	
<b>Smoking</b>	<b>N = 168</b>	<b>N = 115</b>		<b>N = 65</b>	<b>N = 54</b>	<b>N = 49</b>		<b>N = 78</b>	<b>N = 38</b>	
Yes, currently	41 (61.2%)	26 (38.8%)	.936	14 (34.1%)	20 (48.8%)	7 (17.1%)	.088	19 (73.1%)	7 (26.9%)	.360
Ex-smoker	25 (58.1%)	18 (41.9%)		9 (36%)	8 (32%)	8 (32%)		14 (77.8%)	4 (22.2%)	
Never	102 (59%)	71 (41%)		42 (41.2%)	26 (25.5%)	34 (33.3%)		45 (62.5%)	27 (37.5%)	
<b>Drinking</b>	<b>N = 168</b>	<b>N = 114</b>		<b>N = 65</b>	<b>N = 54</b>	<b>N = 49</b>		<b>N = 77</b>	<b>N = 38</b>	
Yes, currently	124 (61.1%)	79 (38.9%)	.620	48 (38.7%)	40 (32.3%)	36 (29%)	.365	24 (30%)	56 (70%)	.340
Ex-drinker	8 (50%)	8 (50%)		2 (25%)	5 (62.5%)	1 (12.5%)		2 (25%)	6 (75%)	
Never	36 (57.1%)	27 (42.9%)		15 (41.7%)	9 (25%)	12 (33.3%)		12 (44.4%)	15 (55.6%)	

**Table 8.4: Partners' support and BSE**

	<b>Had never performed a BSE</b>	<b>Had performed a BSE</b>	<i>p</i> -value	<b>Not planning to perform a BSE</b>	<b>Undecided</b>	<b>Planning to perform a BSE</b>	<i>p</i> -value	<b>Performing BSEs irregularly</b>	<b>Performing BSEs regularly</b>	<i>p</i> -value
<b>Relationship status</b>	<b>N = 161</b>	<b>N = 114</b>		<b>N = 62</b>	<b>N = 53</b>	<b>N = 46</b>		<b>N = 77</b>	<b>N = 38</b>	
Single	64 (63.4%)	37 (36.6%)	.216	25 (39.1%)	22 (34.4%)	17 (26.1%)	.893	23 (60.5%)	15 (39.5%)	.303
Partnered	97 (55.7%)	77 (44.3%)		37 (38.1%)	31 (32%)	29 (29.9%)		54 (70.1%)	23 (29.9%)	
<b>Length of the relationship</b>	<b>N = 94</b>	<b>N = 74</b>		<b>N = 36</b>	<b>N = 29</b>	<b>N = 29</b>		<b>N = 51</b>	<b>N = 23</b>	
1-12 months	29 (56.9%)	22 (43.1%)	.627	10 (34.5%)	8 (27.6%)	11 (37.9%)	.200	14 (63.6%)	8 (36.4%)	.566
1 yr 1 m-2 yrs	16 (66.7%)	8 (33.3%)		4 (25%)	9 (56.3%)	3 (18.8%)		6 (75%)	2 (25%)	
2 yrs 1 m -3 yrs	20 (50%)	20 (50%)		7 (35%)	5 (25%)	8 (40%)		16 (80%)	4 (20%)	
> 3 yrs	29 (54.7%)	24 (45.3%)		15 (51.7%)	7 (24.1%)	7 (24.1%)		15 (62.5%)	9 (37.5%)	
<b>Partner thinks that I should perform BSEs</b>	<b>N = 95</b>	<b>N = 77</b>		<b>N = 35</b>	<b>N = 31</b>	<b>N = 29</b>		<b>N = 54</b>	<b>N = 23</b>	
Yes	22 (36.7%)	38 (63.3%)	.001	6 (27.3%)	5 (22.7%)	11 (50%)	.201	22 (57.9%)	16 (42.1%)	.049
No	8 (53.3%)	7 (46.7%)		3 (37.5%)	4 (50%)	1 (12.5%)		5 (71.4%)	2 (28.6%)	
I do not know	65 (67%)	32 (33%)		26 (40%)	22 (33.8%)	17 (26.2%)		27 (84.4%)	5 (15.6%)	
<b>Partner performs BSEs for me</b>	<b>N = 96</b>	<b>N = 77</b>		<b>N = 36</b>	<b>N = 31</b>	<b>N = 29</b>		<b>N = 54</b>	<b>N = 23</b>	
Yes	16 (31.4%)	35 (68.6%)	.000	3 (18.8%)	5 (31.3%)	8 (50%)	.117	22 (62.9%)	13 (37.1%)	.203
No	80 (65.6%)	42 (34.4%)		33 (41.3%)	26 (32.5%)	21 (26.3%)		32 (76.2%)	10 (23.8%)	



**Table 8.5: Psychological health variables and BSE**

	<b>Had never performed a BSE</b>	<b>Had performed a BSE</b>	<i>p</i> -value	<b>Not planning to perform a BSE</b>	<b>Undecided</b>	<b>Planning to perform a BSE</b>	<i>p</i> -value	<b>Performin g BSEs irregularly</b>	<b>Performin g BSEs regularly</b>	<i>p</i> -value
	<b>Mean (SD) N =</b>	<b>Mean (SD) N =</b>		<b>Mean (SD) N =</b>	<b>Mean (SD) N =</b>	<b>Mean (SD) N =</b>		<b>Mean (SD) N =</b>	<b>Mean (SD) N =</b>	
<b>Perceived influences of a partner</b>										
I am more likely to perform a BSE if my partner thinks I should do so	4.16 (0.87) N = 161	4.32 (0.64) N = 115	.275	3.97 (0.91) N = 61	4.17 (0.75) N = 53	4.40 (0.90) N = 47	.007	4.26 (0.63) N = 78	4.45 (0.65) N = 38	.105
<b>Views about own breasts</b>										
Important sexual function	3.48 (1.08) N = 155	3.75 (0.93) N = 115	.036	3.40 (1.04) N = 58	3.43 (1.08) N = 51	3.63 (1.14) N = 46	.401	3.72 (0.90) N = 78	3.82 (0.98) N = 38	.518
Do not want my breasts	2.30 (1.24)	2.11 (1.32)	.166	2.47 (1.34)	2.24 (1.23)	2.15 (1.13)	.580	2.05 (1.28)	2.23 (1.38)	.490
Feel embarrassed	2.55 (1.17)	2.13 (1.14)	.004	2.57 (1.23)	2.55 (1.06)	2.52 (1.22)	.984	2.09 (1.14)	2.21 (1.12)	.504
Feel uncomfortable	2.35 (1.16)	2.03 (1.00)	.023	2.33 (1.19)	2.45 (1.19)	2.28 (1.11)	.775	1.99 (1.00)	2.11 (0.98)	.468
Bind breasts in daily life	2.22 (1.42)	2.05 (1.40)	.254	2.22 (1.33)	2.24 (1.53)	2.20 (1.42)	.888	2.00 (1.37)	2.16 (1.46)	.725
Do not like my partner touching them	2.05 (1.15)	1.65 (0.80)	.019	2.22 (1.24)	2.02 (1.12)	1.84 (1.05)	.326	1.68 (0.76)	1.61 (0.86)	.427
Do not like my partner looking at them	2.10 (1.14)	1.83 (1.00)	.086	2.26 (1.16)	2.10 (1.15)	1.89 (1.10)	.274	1.87 (1.04)	1.74 (0.92)	.549
<b>Perceived benefits and barriers to performing BSEs</b>										
Help protect me against breast cancer	4.13 (0.81) N = 158	4.27 (0.72) N = 113	.165	3.97 (0.77) N = 61	4.13 (0.89) N = 52	4.36 (0.74) N = 45	.023	4.26 (0.67) N = 78	4.28 (0.85) N = 36	.582
Embarrassing	2.53 (1.09)	1.79 (0.82)	.000	2.75 (1.03)	2.63 (1.10)	2.11 (1.05)	.008	1.94 (0.86)	1.50 (0.65)	.009
Unpleasant	2.39 (0.97)	1.74 (0.78)	.000	2.62 (1.02)	2.46 (0.94)	1.98 (0.81)	.004	1.87 (0.81)	1.50 (0.65)	.014
Not a high priority for me	2.29 (0.88)	1.93 (0.85)	.001	2.61 (0.99)	2.37 (0.74)	1.78 (0.60)	.000	2.18 (0.86)	1.42 (0.55)	.000
Makes me worry about having breast cancer	2.73 (1.03)	2.60 (1.18)	.344	2.61 (1.00)	2.90 (1.03)	2.69 (1.04)	.191	2.67 (1.16)	2.47 (1.23)	.380
<b>Susceptibility to and seriousness of breast cancer</b>										
Great chance of getting breast cancer	2.60 (0.81) N = 153	2.53 (0.97) N = 111	.555	2.49 (0.86) N = 59	2.51 (0.77) N = 49	2.84 (0.74) N = 45	.040	2.42 (0.91) N = 76	2.81 (1.06) N = 36	.077
More likely than the average woman to get breast cancer	2.69 (0.89)	2.81 (1.07)	.349	2.34 (0.84)	2.90 (0.90)	2.91 (0.82)	.000	2.72 (1.04)	3.03 (1.13)	.094
Worry about having breast cancer in the future	3.33 (0.94)	3.38 (0.94)	.637	3.03 (1.03)	3.29 (0.87)	3.76 (0.74)	.000	3.28 (0.99)	3.64 (0.83)	.066
Breast cancer is a life-threatening disease	3.78 (0.92)	3.95 (0.92)	.119	3.86 (0.78)	3.73 (1.08)	3.73 (0.91)	.824	3.99 (0.76)	3.86 (1.20)	.881
Feel anxious when thinking about breast cancer	3.23 (1.06)	3.42 (1.06)	.165	2.92 (1.07)	3.31 (1.08)	3.56 (0.92)	.008	3.32 (1.05)	3.67 (1.04)	.065
Having breast cancer would endanger the relationship between my partner and me	3.04 (1.11)	3.33 (1.09)	.059	2.90 (1.06)	3.16 (1.12)	3.09 (1.14)	.588	3.20 (1.02)	3.64 (1.17)	.032

**Table 8.5: Psychological health variables and BSE (con.)**

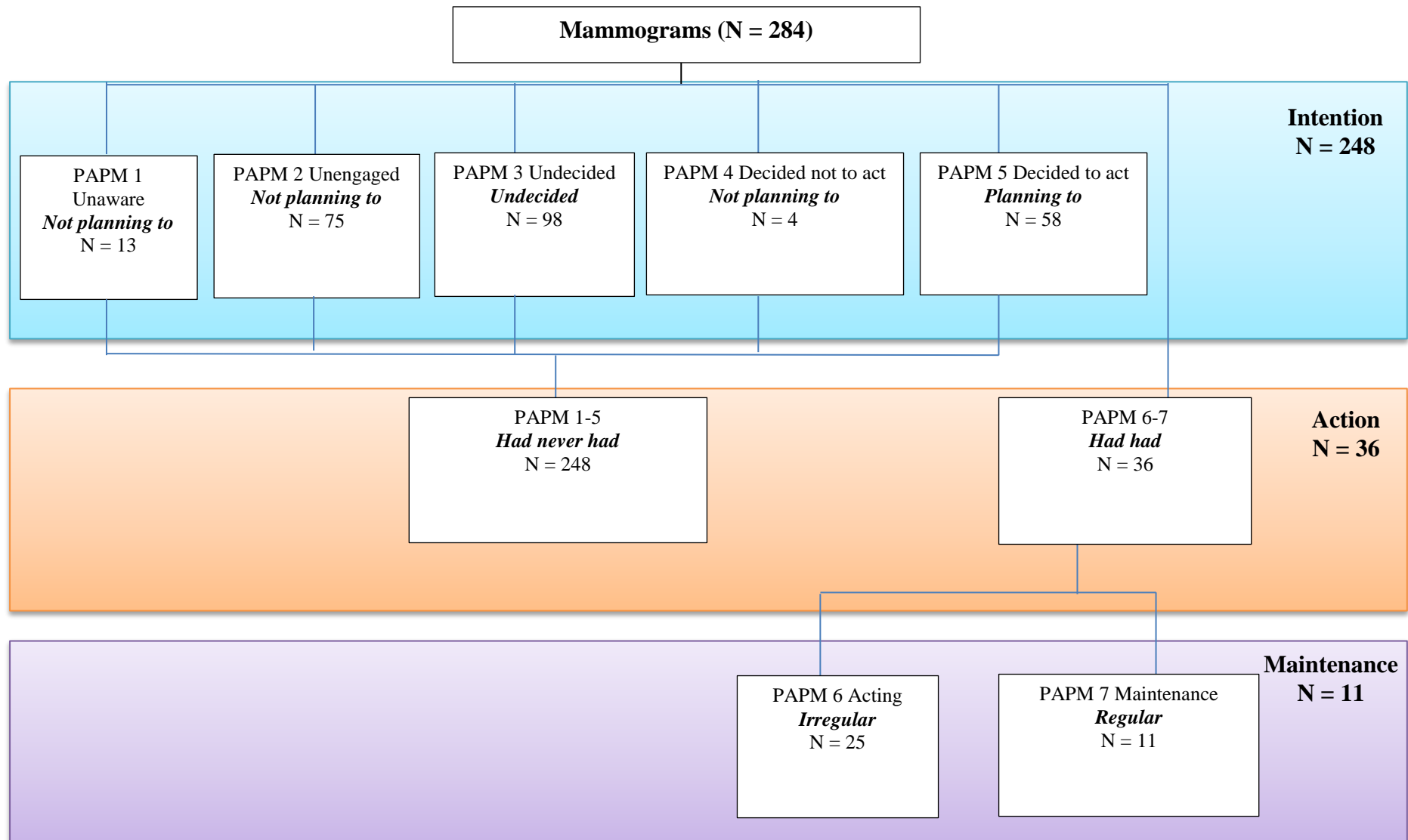
	<b>Had never performed a BSE</b>	<b>Had performed a BSE</b>	<i>p</i> -value	<b>Not planning to perform a BSE</b>	<b>Undecided</b>	<b>Planning to perform a BSE</b>	<i>p</i> -value	<b>Performin g BSEs irregularly</b>	<b>Performin g BSEs regularly</b>	<i>p</i> -value
<b>Self-efficacy</b>	<b>N = 156</b>	<b>N = 112</b>		<b>N = 60</b>	<b>N = 51</b>	<b>N = 45</b>		<b>N = 77</b>	<b>N = 36</b>	
Know how to perform a BSE	2.69 (1.01)	3.86 (0.79)	<b>.000</b>	2.57 (0.89)	2.76 (1.09)	2.76 (1.09)	.551	3.70 (0.80)	4.11 (0.85)	.003
Feel confident about the examination results	2.50 (0.93)	3.16 (0.95)	<b>.000</b>	2.35 (0.80)	2.65 (0.93)	2.53 (1.08)	.251	3.03 (0.90)	3.39 (1.08)	.059
<b>Cues to action</b>	<b>N = 153</b>	<b>N = 112</b>		<b>N = 59</b>	<b>N = 49</b>	<b>N = 45</b>		<b>N = 77</b>	<b>N = 36</b>	
Campaigns	3.29 (0.93)	3.65 (0.85)	<b>.001</b>	3.10 (1.09)	3.31 (0.80)	3.53 (0.79)	.075	3.49 (0.88)	3.94 (0.71)	.012
Symptoms	4.04 (0.79)	4.39 (0.62)	<b>.000</b>	3.93 (0.91)	4.08 (0.76)	4.13 (0.63)	.521	4.29 (0.70)	4.56 (0.50)	.064
Other people I knew had breast cancer	3.94 (0.82)	4.10 (0.77)	.116	3.76 (0.93)	3.96 (0.79)	4.16 (0.64)	.094	3.99 (0.80)	4.28 (0.74)	.074

### **8.4.3 Mammograms**

This subsection aims to investigate the associations between the influencing factors and the participants' behaviour and intentions regarding the performance of mammograms. The rationale and methods of grouping the participants in relation to their experiences and intentions regarding having mammograms (Figure 8.3) were the same as when grouping the participants' BSE experiences and intentions (Figure 8.2).

The associations between the IVs and the participants' frequencies of having mammograms were not investigated in this analysis because there were only 36 women who had had a mammogram (including 11 women who had mammograms regularly and 25 who had screenings irregularly), while the majority of the participants (272/284; 95.8%) were not eligible to have free mammograms every two years.

**Figure 8.3: PAPM stages and comparable group descriptions in this study (mammograms)**



Tables 8.6 (demographic characteristics), 8.7 (risk factors of breast cancer), 8.8 (partners' support) and 8.9 (the health psychological variables) provide the results of the comparisons of the variables between the women with different actions and intentions regarding having mammograms.

There were significant differences regarding age and non-malignant breast disease between the women who had never had a mammogram and those who had had one. The women who were older ( $p \leq .001$ ) and who had a personal history of non-malignant breast disease ( $p \leq .001$ ) were more likely to have had a mammogram.

The partners' support was associated with both the women's experiences of having mammograms ( $p \leq .001$ ) and their intentions regarding having screenings ( $p \leq .001$ ). The women who had had a mammogram were more likely to report that their partner thought they should have a mammogram. With the women's partners' support, the participants who had never had a mammogram were more likely to be planning to have the screening in the future.

In terms of the psychological health variables, the women who had never had a mammogram were more likely to report that they worried about their appearance being judged by other women in the waiting room ( $p = .001$ ) than those who had had a mammogram. On the other hand, the women who had had a mammogram were more likely to report that they knew how to have the screening ( $p \leq .001$ ) than those who had never had one.

Patient-provider interaction, perceived influences from a partner, perceived benefits and barriers to mammograms, perceived susceptibility to breast cancer and cues to action were associated with the participants' intentions to have mammograms. For the women who were not planning to have a mammogram, their breasts needing to be seen and touched were barriers. They were more likely to report that their breasts needing to be seen ( $p \leq .001$ ) and touched ( $p = .001$ ) by a HCP put them off from having a mammogram than those who were undecided and those who were planning to have a mammogram. In addition, the women who were planning to have a mammogram were more likely to report that if their partner thought they should have a mammogram ( $p \leq .001$ ), they were more likely to have the screening.

The perceived benefits of mammograms were more likely to be reported by the participants who were planning to have the screening in the future ( $p \leq .001$ ) when compared to those

who were undecided and those who were not planning to have a mammogram. The women who were not planning to have a mammogram were more likely to perceive barriers to having the screenings, in particular that they felt embarrassed about having a mammogram ( $p \leq .001$ ) and that having the screening was not a high priority for them ( $p \leq .001$ ). The women who were undecided on whether they wanted to have a mammogram in the future or not were more likely to believe that having a mammogram would be painful ( $p = .001$ ).

The women who were planning to have a mammogram were more likely to believe that they were more likely to get breast cancer than the average woman ( $p = .001$ ) and were also more likely to worry about having breast cancer in the future ( $p < .001$ ). Cues, including campaigns ( $p \leq .001$ ), symptoms ( $p \leq .001$ ), others they knew who had breast cancer ( $p \leq .001$ ) and a physician's recommendations ( $p \leq .001$ ) were more likely to be reported as what encouraged them to have a mammogram.

**Table 8.6: Demographics characteristics and mammograms**

		Have never had a mammogram	Have had a mammogram	<i>p</i> -value	Not planning to have a mammogram	Undecided	Planning to have a mammogram	<i>p</i> -value
<b>Age</b>	N	248	36		92	98	58	
	Mean (SD)	28.53 (6.191)	36.78 (10.134)	<b>.000</b>	27.49 (6.144)	29.37 (6.548)	28.76 (5.465)	.107
	Range	20-47	22-58		20-47	20-47	21-43	
<b>Gender identity</b>		<b>N = 243</b>	<b>N = 33</b>		<b>N = 89</b>	<b>N = 96</b>	<b>N = 58</b>	
	Masculine-identity lesbian	119 (88.8%)	15 (11.2%)		49 (41.2%)	36 (30.3%)	34 (28.6%)	
	Butch-identity lesbian	61 (89.7%)	7 (10.3%)	.655	24 (39.3%)	27 (44.3%)	10 (16.4%)	.025
	Feminine-identity lesbian	63 (85.1%)	11 (14.9%)		16 (25.4%)	33 (52.4%)	14 (22.2%)	
<b>Religion</b>		<b>N = 213</b>	<b>N = 28</b>		<b>N = 82</b>	<b>N = 86</b>	<b>N = 45</b>	
	None	124 (87.3%)	18 (12.7%)		48 (38.7%)	52 (41.9%)	24 (19.4%)	
	Buddhism	48 (85.7%)	8 (14.3%)	.276	19 (39.6%)	20 (41.7%)	9 (18.8%)	.710
	Taoism	41 (95.3%)	2 (4.7%)		15 (36.6)	14 (34.1%)	12 (29.3%)	
<b>Employment status</b>		<b>N = 245</b>	<b>N = 30</b>		<b>N = 91</b>	<b>N = 96</b>	<b>N = 58</b>	
	Student	64 (94.1%)	4 (5.9%)		30 (46.9%)	20 (31.3%)	14 (21.9%)	
	Employed	163 (87.2%)	24 (12.8%)	.287	54 (33.1%)	69 (42.3%)	40 (24.5%)	.413
	Unemployed	18 (90%)	2 (10%)		7 (38.9%)	7 (38.9%)	4 (22.4%)	
<b>Occupation</b>		<b>N = 163</b>	<b>N = 24</b>		<b>N = 54</b>	<b>N = 69</b>	<b>N = 40</b>	
	Skilled/Unskilled (< \$50,000/month)	92 (88.5%)	12 (11.5%)		31 (33.7%)	41 (44.6%)	20 (21.7%)	
	Professional/Management (> \$50,000/month)	71 (85.5%)	12 (14.5%)	.553	23 (32.4%)	28 (39.4%)	20 (28.2%)	.624
<b>Level of education</b>		<b>N = 243</b>	<b>N = 36</b>		<b>N = 89</b>	<b>N = 97</b>	<b>N = 57</b>	
	High school/associate degree	24 (88.9%)	3 (11.1%)		10 (41.7%)	8 (33.3%)	6 (25%)	
	College degree	155 (87.6%)	22 (12.4%)	.852	58 (37.4%)	65 (41.9%)	32 (20.6%)	.633
	Postgraduate degree	64 (85.3%)	11 (14.7%)		21 (32.8%)	24 (37.5%)	19 (29.7%)	

**Table 8.7: Breast cancer risk factors and mammograms**

		<b>Have never had a mammogram</b>	<b>Have had a mammogram</b>	<i>p</i> -value	<b>Not planning to have a mammogram</b>	<b>Undecided</b>	<b>Planning to have a mammogram</b>	<i>p</i> -value
<b>Non-malignant breast disease</b>		<b>N = 246</b>	<b>N = 36</b>		<b>N = 92</b>	<b>N = 96</b>	<b>N = 58</b>	
	Yes	26 (61.9%)	16 (38.1%)	<b>.000</b>	9 (34.6%)	10 (38.5%)	7 (26.9%)	<b>.905</b>
	No	220 (91.7%)	20 (8.3%)		83 (37.7%)	86 (39.1%)	51 (23.2%)	
<b>Family history of breast cancer</b>		<b>N = 247</b>	<b>N = 36</b>		<b>N = 92</b>	<b>N = 98</b>	<b>N = 57</b>	
	Yes	36 (85.7%)	6 (14.3%)	<b>.945</b>	10 (27.8%)	12 (33.3%)	14 (38.9%)	<b>.030</b>
	No	170 (87.6%)	24 (12.4%)		67 (39.4%)	64 (37.6%)	39 (22.9%)	
	Unsure	41 (87.2%)	6 (12.8%)		15 (36.5%)	22 (53.7%)	4 (9.8%)	
<b>Have children</b>		<b>N = 248</b>	<b>N = 36</b>		<b>N = 92</b>	<b>N = 98</b>	<b>N = 58</b>	
	Yes	6 (60%)	4 (40%)	<b>.026</b>	0 (0%)	6 (100%)	0 (0%)	<b>.007</b>
	No	242 (88.3%)	32 (11.7%)		92 (38%)	92 (38%)	58 (24%)	
<b>Smoking</b>		<b>N = 248</b>	<b>N = 36</b>		<b>N = 92</b>	<b>N = 98</b>	<b>N = 58</b>	
	Yes, currently	63 (94%)	4 (6%)	<b>.117</b>	18 (28.6%)	32 (50.8%)	13 (20.6%)	<b>.167</b>
	Ex-smoker	35 (81.4%)	8 (18.6%)		12 (34.3%)	16 (45.7%)	7 (20%)	
	Never	150 (86.2%)	24 (13.8%)		62 (41.3%)	50 (33.3%)	38 (25.3%)	
<b>Drinking</b>		<b>N = 247</b>	<b>N = 36</b>		<b>N = 92</b>	<b>N = 98</b>	<b>N = 57</b>	
	Yes, currently	183 (89.7%)	21 (10.3%)	<b>.098</b>	63 (34.4%)	76 (41.5%)	44 (24%)	<b>.050</b>
	Ex-drinker	14 (87.5%)	2 (12.5%)		3 (21.4%)	9 (64.3%)	2 (14.3%)	
	Never	50 (79.4%)	13 (20.6%)		26 (52%)	13 (26%)	11 (22%)	



**Table 8.8: Partners' support and mammograms**

	Have never had a mammogram	Have had a mammogram	<i>p</i> -value	Not planning to have a mammogram	Undecided	Planning to have a mammogram	<i>p</i> -value
<b>Relationship status</b>	<b>N = 242</b>	<b>N = 34</b>		<b>N = 89</b>	<b>N = 98</b>	<b>N = 55</b>	
Single	91 (89.2%)	11 (10.8%)	.553	39 (42.9%)	34 (37.4%)	18 (19.8%)	.305
Partnered	151 (86.8%)	23 (13.2%)		50 (33.1%)	64 (42.4%)	37 (24.5%)	
<b>Length of the relationship</b>	<b>N = 145</b>	<b>N = 23</b>		<b>N = 49</b>	<b>N = 61</b>	<b>N = 35</b>	
1-12 months	45 (88.2%)	6 (11.8%)	.732	10 (22.2%)	23 (51.1%)	12 (26.7%)	.055
1 yrs 1 m-2 yrs	22 (91.7%)	2 (8.3%)		5 (22.7%)	13 (59.1%)	4 (18.2%)	
2 yrs 1 m-3 yrs	34 (85%)	6 (15%)		12 (35.3%)	11 (32.4%)	11 (32.4%)	
> 3 yrs	44 (83%)	9 (17%)		22 (50%)	14 (31.8%)	8 (18.2%)	
<b>Partner thinks that I should have a mammogram</b>	<b>N = 150</b>	<b>N = 23</b>		<b>N = 50</b>	<b>N = 64</b>	<b>N = 36</b>	
Yes	23 (65.7%)	12 (34.3%)	<b>.000</b>	2 (8.7%)	6 (26.1%)	15 (65.2%)	<b>.000</b>
No	23 (88.5%)	3 (11.5%)		9 (39.1%)	14 (60.9%)	0 (0%)	
I do not know	104 (92.9%)	8 (7.1%)		39 (37.5%)	44 (42.3%)	21 (20.2%)	

**Table 8.9: Psychological health variables and mammograms**

	Have never had a mammogram	Have had a mammogram	<i>p</i> -value	Not planning to have a mammogram	Undecided	Planning to have a mammogram	<i>p</i> -value
	M (SD) N = 243	M (SD) N = 34		M (SD) N = 89	M (SD) N = 98	M (SD) N = 56	
<b>Patient-provider interaction</b>							
Female HCP	4.26 (0.84)	4.41 (0.86)	.171	4.23 (0.90)	4.19 (0.77)	4.43 (0.87)	.061
Male HCP	1.95 (0.90)	1.82 (0.94)	.306	1.92 (0.96)	1.93 (0.83)	2.05 (0.94)	.643
The HCP's heterosexual assumptions	2.71 (1.00)	2.21 (0.84)	.007	2.80 (1.05)	2.73 (0.91)	2.52 (1.08)	.276
The HCP would discriminate against me	3.04 (1.20)	2.41 (1.28)	.005	3.07 (1.17)	2.97 (1.11)	3.11 (1.42)	.831
The HCP would lack knowledge about LGBT issues	3.08 (1.17)	2.56 (1.19)	.019	3.13 (1.17)	3.13 (1.07)	2.89 (1.33)	.433
The HCP would feel uncomfortable with lesbians	2.85 (1.12)	2.56 (1.21)	.171	2.96 (1.11)	2.78 (1.03)	2.82 (1.28)	.514
Breasts needing to be seen by a HCP	2.98 (1.14)	2.50 (1.35)	.018	3.21 (1.12)	3.12 (1.03)	2.34 (1.13)	<b>.000</b>
Breasts needing to be touched by a HCP	3.09 (1.17)	2.71 (1.38)	.100	3.28 (1.14)	3.22 (1.03)	2.54 (1.29)	<b>.001</b>
<b>Perceived influences from a partner</b>	N = 242	N = 35		N = 89	N = 98	N = 55	
I am more likely to have a mammogram if my partner thinks I should have one	4.19 (0.76)	4.31 (0.68)	.436	4.17 (0.71)	4.05 (0.71)	4.49 (0.84)	<b>.000</b>
I am more likely to have a mammogram if my partner accompanies me	4.29 (0.84)	4.17 (1.01)	.684	4.21 (0.85)	4.19 (0.81)	4.56 (0.86)	.002
<b>Views on own breasts</b>	N = 236	N = 35		N = 88	N = 94	N = 54	
Important sexual function	3.55 (1.02)	3.91 (1.04)	.048	3.42 (1.08)	3.63 (0.93)	3.61 (1.05)	.377
Do not want my breasts	2.27 (1.26)	1.86 (1.33)	.023	2.48 (1.28)	2.14 (1.24)	2.17 (1.24)	.131
Feel embarrassed	2.43 (1.16)	1.97 (1.15)	.028	2.60 (1.12)	2.35 (1.18)	2.28 (1.19)	.147
Feel uncomfortable	2.27 (1.11)	1.86 (0.97)	.041	2.36 (1.02)	2.22 (1.17)	2.19 (1.17)	.356
Bind breasts in daily life	2.21 (1.43)	1.71 (1.15)	.061	2.38 (1.50)	1.94 (1.31)	2.43 (1.47)	.045
Do not like my partner touching them	1.92 (1.02)	1.63 (1.06)	.055	2.11 (1.04)	1.84 (1.00)	1.72 (1.00)	.037
Do not like my partner looking at them	2.03 (1.10)	1.66 (0.94)	.061	2.31 (1.21)	1.90 (1.02)	1.81 (0.99)	.021

**Table 8.9: Psychological health variables and mammograms (con.)**

	Have never had a mammogram	Have had a mammogram	<i>p</i> -value	Not planning to have a mammogram	Undecided	Planning to have a mammogram	<i>p</i> -value
<b>Perceived benefits and barriers to having mammograms</b>	<b>N = 232</b>	<b>N = 34</b>		<b>N = 84</b>	<b>N = 93</b>	<b>N = 55</b>	
Helps protect me against breast cancer	3.91 (0.86)	4.15 (1.02)	.037	3.73 (0.87)	3.85 (0.81)	4.27 (0.87)	<b>.000</b>
Embarrassing	2.96 (1.15)	2.71 (1.49)	.302	3.19 (1.04)	3.14 (1.15)	2.31 (1.10)	<b>.000</b>
Takes up too much time	2.78 (1.01)	2.71 (1.29)	.550	2.98 (0.96)	2.81 (0.95)	2.44 (1.13)	.008
Not a high priority for me	2.29 (0.83)	2.00 (1.26)	.007	2.56 (0.84)	2.35 (0.76)	1.76 (0.67)	<b>.000</b>
Painful	3.19 (1.13)	2.88 (1.47)	.215	3.14 (1.05)	3.49 (1.09)	2.74 (1.17)	<b>.001</b>
Makes me worry about having breast cancer	2.66 (1.09)	2.26 (1.11)	.045	2.61 (1.02)	2.74 (1.11)	2.58 (1.17)	.565
I worry about my appearance being judged by other women	2.61 (1.23)	1.91 (1.14)	<b>.001</b>	2.75 (1.13)	2.66 (1.22)	2.33 (1.35)	.065
<b>Perceived susceptibility to and seriousness of breast cancer</b>	<b>N = 231</b>	<b>N = 34</b>		<b>N = 85</b>	<b>N = 92</b>	<b>N = 54</b>	
Great chance of getting breast cancer	2.58 (0.88)	2.59 (0.92)	.947	2.45 (0.82)	2.53 (0.86)	2.85 (0.94)	.021
More likely than the average woman to get breast cancer	2.73 (0.93)	2.82 (1.27)	.841	2.49 (0.85)	2.74 (0.90)	3.09 (0.98)	<b>.001</b>
Worry about having breast cancer in the future	3.35 (0.94)	3.41 (1.02)	.569	2.94 (0.91)	3.29 (0.91)	3.76 (0.91)	<b>.000</b>
Breast cancer is a life-threatening disease	3.83 (0.93)	4.03 (0.87)	.206	3.84 (0.86)	3.73 (0.95)	3.98 (0.98)	.206
Feel anxious when thinking about breast cancer	3.31 (1.05)	3.35 (1.15)	.790	3.13 (1.02)	3.32 (1.03)	3.57 (1.09)	.041
Having breast cancer would endanger the relationship between my partner and me	3.14 (1.09)	3.35 (1.23)	.222	2.94 (1.07)	3.23 (1.00)	3.30 (1.22)	.139
<b>Self-efficacy</b>	<b>N = 233</b>	<b>N = 34</b>		<b>N = 86</b>	<b>N = 93</b>	<b>N = 54</b>	
Know how to have a mammogram	2.79 (1.07)	3.97 (0.97)	<b>.000</b>	2.59 (1.03)	2.90 (1.02)	2.93 (1.16)	.053
Feel confident about the screening results	3.15 (0.96)	3.47 (1.02)	.108	3.07 (1.00)	3.10 (0.86)	3.35 (1.05)	.121
<b>Cues to action</b>	<b>N = 232</b>	<b>N = 33</b>		<b>N = 87</b>	<b>N = 91</b>	<b>N = 54</b>	
Campaigns	3.29 (0.87)	3.61 (1.06)	.023	3.07 (0.83)	3.21 (0.82)	3.78 (0.82)	<b>.000</b>
Symptoms	4.15 (0.70)	4.36 (0.74)	.048	4.05 (0.65)	4.05 (0.75)	4.48 (0.61)	<b>.000</b>
Other people I knew had breast cancer	3.93 (0.84)	4.21 (0.78)	.024	3.82 (0.84)	3.78 (0.85)	4.37 (0.65)	<b>.000</b>
A physician's recommendations	3.94 (0.83)	4.03 (1.05)	.167	3.84 (0.83)	3.75 (0.84)	4.43 (0.60)	<b>.000</b>

#### **8.4.4 Associations between gender identity and the psychological health variables**

Table 8.10 shows comparisons of the health psychology variables among the masculine-, Buten- and feminine-identity lesbians.

All of the variables regarding the women's views about their own breasts were found to be significantly different among these three groups of women ( $p \leq .001$ ). In addition, the variable 'worry about my appearance being judged by other women' was also found to be significantly different among these women ( $p \leq .001$ ).

In addition to the variables regarding the women's views about their own breasts and their gender role expression, there were no significant differences in the other psychological variables among the masculine-, Buten- and feminine-identity lesbians in this study.

**Table 8.10: Psychological health variables and gender identity**

	<b>Masculine-identity lesbian</b>	<b>Bufen-identity lesbian</b>	<b>Feminine-identity lesbian</b>	<b>p-value</b>
<b>Patient-provider interaction</b>	<b>M (SD) N = 128</b>	<b>M (SD) N = 67</b>	<b>M (SD) N = 74</b>	
Female HCP	4.28 (0.84)	4.16 (0.86)	4.39 (0.81)	.182
Male HCP	1.91 (0.93)	1.97 (0.78)	2.03 (0.98)	.591
The HCP's heterosexual assumptions	2.59 (1.02)	2.81 (1.00)	2.61 (0.98)	.266
The HCP would lack knowledge on LGBT issues	3.09 (1.23)	3.06 (1.18)	2.82 (1.10)	.340
The HCP would feel uncomfortable with lesbians	2.87 (1.19)	2.93 (1.11)	2.68 (1.09)	.349
The HCP would discriminate against me	2.98 (1.22)	3.04 (1.27)	2.88 (1.23)	.711
Breasts needing to be seen by a HCP	2.84 (1.22)	2.93 (1.06)	2.97 (1.17)	.644
Breasts needing to be touched by a HCP	2.98 (1.23)	3.04 (1.15)	3.05 (1.19)	.907
<b>Perceived partner's influence</b>	<b>N = 128</b>	<b>N = 67</b>	<b>N = 74</b>	
If my partner thinks I should perform BSEs	4.25 (0.87)	4.07 (0.72)	4.31 (0.68)	.063
If my partner thinks I should have a mammogram	4.24 (0.84)	4.06 (0.60)	4.27 (0.69)	.035
If my partner accompanies me to have a mammogram	4.26 (0.92)	4.12 (0.81)	4.42 (0.79)	.037
<b>Views about own breasts</b>	<b>N = 124</b>	<b>N = 65</b>	<b>N = 74</b>	
Important sexual function	3.12 (1.07)	3.91 (0.82)	4.04 (0.77)	<b>.000</b>
Do not want my breasts	2.88 (1.30)	1.98 (1.10)	1.43 (0.74)	<b>.000</b>
Feel embarrassed	2.89 (1.18)	2.20 (1.02)	1.74 (0.89)	<b>.000</b>
Feel uncomfortable	2.72 (1.13)	1.97 (0.93)	1.65 (0.82)	<b>.000</b>
Bind breasts in daily life	3.07 (1.47)	1.65 (0.90)	1.15 (0.36)	<b>.000</b>
Do not like my partner touching them	2.31 (1.16)	1.63 (0.78)	1.45 (0.69)	<b>.000</b>
Do not like my partner looking at them	2.41 (1.20)	1.71 (0.93)	1.59 (0.77)	<b>.000</b>
<b>Perceived benefits and barriers to having breast cancer screenings/BSE</b>	<b>N = 123</b>	<b>N = 64</b>	<b>N = 71</b>	
Help protect me against breast cancer	4.18 (0.85)	4.16 (0.80)	4.23 (0.61)	.860
Embarrassing	2.37 (1.13)	1.97 (0.80)	2.18 (1.06)	.082
Unpleasant	2.19 (1.01)	1.98 (0.77)	2.07 (0.92)	.536
Not a high priority for me	2.20 (0.94)	2.19 (0.85)	2.01 (0.82)	.472
Make me worry about having breast cancer	2.60 (1.11)	2.70 (1.02)	2.76 (1.09)	.420

**Table 8.10: Psychological health variables and gender identity (con.)**

	Masculine-identity lesbian	Buten-identity lesbian	Feminine-identity lesbian	<i>p</i> -value
<b>Perceived benefits and barriers to having breast cancer screenings/mammograms</b>	<b>N = 126</b>	<b>N = 66</b>	<b>N = 72</b>	
Help protect me against breast cancer	3.98 (0.91)	3.95 (0.74)	3.82 (0.96)	.383
Embarrassing	2.96 (1.24)	2.90 (1.09)	2.83 (1.20)	.880
Take up too much time	2.67 (1.04)	2.92 (1.03)	2.80 (1.10)	.396
Painful	2.88 (1.10)	3.38 (1.24)	3.37 (1.20)	.002
Not a high priority for me	2.28 (0.96)	2.30 (0.81)	2.15 (0.86)	.822
Make me worry about having breast cancer	2.43 (1.08)	2.59 (1.05)	2.86 (1.10)	.018
Worry about my appearance being judged by other women	2.89 (1.24)	2.20 (1.12)	2.17 (1.15)	<b>.000</b>
<b>Susceptibility to and seriousness of breast cancer</b>	<b>N = 122</b>	<b>N = 65</b>	<b>N = 71</b>	
Great chance of getting breast cancer	2.61 (0.93)	2.40 (0.75)	2.72 (0.90)	.093
Worry about having breast cancer in the future	3.29 (0.97)	3.34 (0.91)	3.49 (0.97)	.257
More likely than the average woman to get breast cancer	2.84 (0.99)	2.52 (0.85)	2.82 (1.06)	.094
Breast cancer is a life-threatening disease	3.95 (0.90)	3.80 (0.77)	3.68 (1.05)	.127
Feel anxious when thinking about breast cancer	3.09 (1.09)	3.34 (0.83)	3.62 (1.10)	.002
Having breast cancer would endanger the relationship between my partner and me	3.06 (1.11)	3.32 (1.02)	3.23 (1.17)	.313
<b>Self-efficacy</b>	<b>N = 125</b>	<b>N = 66</b>	<b>N = 72</b>	
Know how to perform a BSE	3.09 (1.21)	3.26 (1.00)	3.37 (1.05)	.206
Feel confident about the examination results	2.74 (1.05)	2.81 (0.96)	2.81 (1.01)	.861
Know how to have a mammogram	3.07 (1.19)	3.21 (1.06)	2.83 (1.15)	.109
Feel confident about the screening results	3.06 (0.92)	3.19 (0.98)	3.12 (1.02)	.984
<b>Cues to action</b>				
<b>BSE</b>	<b>N = 124</b>	<b>N = 66</b>	<b>N = 72</b>	
Campaigns	3.26 (1.02)	3.77 (0.68)	3.49 (0.76)	.221
Symptoms	4.21 (0.84)	4.30 (0.64)	4.08 (0.72)	.362
Other people I knew had breast cancer	4.07 (0.89)	4.19 (0.63)	3.98 (0.79)	.853
<b>Mammograms</b>	<b>N = 123</b>	<b>N = 66</b>	<b>N = 72</b>	
Campaigns	3.24 (0.93)	3.53 (0.74)	3.41 (0.80)	.514
Symptoms	4.27 (0.78)	4.16 (0.69)	4.25 (0.63)	.912
Other people I knew had breast cancer	3.88 (0.92)	4.05 (0.65)	4.10 (0.81)	.358
A physician's recommendations	3.96 (0.97)	4.02 (0.67)	4.12 (0.74)	.399

## 8.5 Summary

This online questionnaire survey aimed to understand whether the first-phase interview findings can be applied to a larger target population. A total of 284 participants were recruited in the study by using purposive sampling and snowball sampling. In this study, the results at  $p \leq .001$  were considered to be significant differences. The differences found at  $p < 0.05$  may well reflect real differences (i.e., not be due to chance). However, due to the higher number of statistical tests and the increased likelihood that they are due to chance, the researcher only focused on results at  $p \leq .001$ , which she can trust are more robust and less likely to be due to chance.

Tables 8.11 and 8.12 provide the significant variables associated with the women's actions and intentions regarding breast cancer screenings. Table 8.11 summarizes the significant variables that are associated with the women's actions and intentions regarding performing BSEs. The perceived barriers to performing BSEs ('performing a BSE is not a high priority for me') and the perceived susceptibility to breast cancer ('I am more likely than the average woman to have breast cancer' and 'I worry about having breast cancer in the future') were found to be associated with the women's intentions regarding the examinations. The participants' experiences of performing BSEs were found to be significantly associated with their current partners' support ('my partner thinks that I should perform BSEs'; 'my partner performs BSEs for me'), the perceived barriers to performing BSEs ('performing a BSE would be embarrassing for me; would be unpleasant; and is not a high priority for me'), self-efficacy ('I know how to perform a BSE; I feel confident about the examination results') and cues to action ('campaigns; symptoms would encourage me to perform BSEs'). In terms of the women's continuance of performing BSEs, their perceived barriers to performing BSEs were found to be significant factors influencing their regular or irregular performance of BSEs, in particular that performing BSEs was not a high priority for them.

Table 12 provides a summary of the significant factors associated with the participants' behaviour and intentions regarding mammograms. The women's intentions regarding having a mammogram were found to be significantly associated with their current partners' support ('my partner thinks that I should have a mammogram'), patient-provider interaction ('my breasts needing to be seen/touched by a HCP puts me off having mammograms'), the perceived influences of their partners ('I am more likely to have a mammogram if my partner thinks I should have one'), the perceived benefits of having mammograms ('mammograms

will help me go against breast cancer'), the perceived barriers to having mammograms ('having a mammogram would be embarrassing; painful; is not a high priority for me'), the perceived susceptibility to breast cancer ('I am more likely than the average woman to have breast cancer; I worry about having breast cancer in the future') and cues to action ('campaigns; symptoms; other people I knew had breast cancer; a physician's recommendation would encourage me to have a mammogram'). Age, previous non-malignant breast disease, the current partners' support ('my partner thinks I should have a mammogram'), worrying about their appearance being judged by other women and knowing how to have a mammogram were found to be significantly associated with the women's actions regarding having a mammogram.

Comparing the factors influencing the women's actions and intentions regarding BSEs and mammograms, 'not a high priority for me' was found to be strongly associated with not only the women's actions and intentions regarding performing BSEs but also their intentions regarding having a mammogram. The participants' intentions regarding both types of screening were also significantly related to their perceived susceptibility to breast cancer; in particular, when the women thought that they were more likely than the average woman to have breast cancer and were worried about having breast cancer in the future.

In addition to the perceived barriers to having/performing breast cancer screenings and their perceived susceptibility to the disease, the women's intentions regarding having a mammogram were also found to be facilitated by their partners (partners' support), the perceived benefits of having mammograms and triggers (including campaigns, symptoms, others they knew who had breast cancer and a physician's recommendation). 'Breasts needing to be seen and/or touched by a HCP' and 'having a mammogram would be embarrassing and/or painful' were barriers to having the screening. In contrast to their intentions regarding performing BSEs, the women's intentions regarding having a mammogram were found to be affected not only by their attitudes and beliefs about breast cancer and breast cancer screenings but also by their interactions with the outside world.

The variables associated with the women's decisions to act regarding BSEs were found to be different from those for mammograms. Although their partners' support and knowing how to have/perform the screenings were shared motivators, the women's actions regarding performing BSEs were also found to be facilitated by their confidence about the examination



results and cues (campaigns and symptoms). On the other hand, feeling that 'performing a BSE would be embarrassing and/or unpleasant for me' inhibited the women's actions regarding performing BSEs.

The women's actions regarding having a mammogram, however, were found to be motivated by their perceived susceptibility to breast cancer. The women's age (being older) and having a personal history of non-malignant breast disease were positively associated with their actions regarding having a mammogram. Similar to their intentions regarding having a mammogram, concerns about interactions with others were also barriers to the women's actions. 'Worry about my appearance being judged by other women in the waiting room' was significantly associated with the women's actions regarding having a mammogram.

**Table 8.11: A summary of the significant factors associated with the participants' behaviour and intentions regarding BSE**

<b>PAPM/ Categories of the influencing factors</b>	<b>Intentions</b>	<b>→ Acting</b>	<b>→ Maintenance</b>
<b>Partners' support</b>		<ul style="list-style-type: none"> <li>▪Partner thinks that I should perform BSEs</li> <li>▪Partner performs BSEs for me</li> </ul>	
<b>Psychological health variables</b> Perceived barriers to performing BSEs	▪Not a high priority for me	<ul style="list-style-type: none"> <li>▪Not a high priority for me</li> <li>▪Embarrassing</li> <li>▪Unpleasant</li> </ul>	▪Not a high priority for me
Perceived susceptibility to breast cancer	<ul style="list-style-type: none"> <li>▪More likely than the average woman to have breast cancer</li> <li>▪Worry about having breast cancer in the future</li> </ul>		
Self-efficacy		<ul style="list-style-type: none"> <li>▪Know how to perform a BSE</li> <li>▪Feel confident about the examination results</li> </ul>	
Cues to action		<ul style="list-style-type: none"> <li>▪Campaigns</li> <li>▪Symptoms</li> </ul>	

**Table 8.12: A summary of the significant factors associated with the participants' behaviour and intentions regarding mammograms**

<b>PAPM/Categories of the influencing factors</b>	<b>Intentions</b>	<b>→</b>	<b>Acting</b>
<b>Background information</b>			▪Age
Demographic characteristics			
Risk factors of breast cancer			▪Non-malignant breast disease
<b>Partners' support</b>	▪Partner thinks that I should have a mammogram		▪Partner thinks that I should have a mammogram
Current partner's support			
<b>Health psychology variables</b>	▪Breasts needing to be seen by a HCP		
Patient-provider interaction	▪Breasts needing to be touched by a HCP		
Perceived influences of a partner	▪I am more likely to have a mammogram if my partner thinks I should have one		
Perceived benefits of having mammograms	▪Help protect me against breast cancer		
Perceived barriers to having mammograms	▪Embarrassing ▪Not a high priority for me ▪Painful		▪Worry about my appearance being judged by other women in the waiting room
Perceived susceptibility to breast cancer	▪More likely than the average woman to have breast cancer ▪Worry about having breast cancer in the future		
Self-efficacy			▪Know how to have a mammogram
Cues to action	▪Campaigns ▪Symptoms ▪Other people I knew had breast cancer ▪A physician's recommendations		

## **Chapter 9: Synthesis and conclusion**

### **9.1 Introduction**

This chapter firstly synthesizes the PhD findings and is followed by recommendations and implications. A reflection upon the strengths and limitations of the research, directions for future research and a conclusion are provided towards the end of the chapter.

### **9.2 Synthesizing the PhD findings**

This section aims to: 1) synthesize the main findings from the first-phase qualitative interviews and the second-phase online survey in order to understand whether the interview findings can be applied to a larger population (see Sections 9.2.1-9.2.3); and 2) to compare the survey results regarding the variables from the HBM with current Taiwanese studies so as to know whether these variables are shared between heterosexual women and lesbians in Taiwan (see Section 9.2.4).

Within the two sets of findings, the findings correspond with each other partially (see Table 9.1). Overall, partner support and gender role expression (appearance) were found to be important factors in relation to the participants' actions in performing BSE and having a mammogram in both studies, while gender identity (how they view themselves) was not found to be a factor influencing the women's breast healthcare behaviour in the survey. Patient-provider interaction was a factor affecting the women's intentions in having a mammogram in both studies. The survey and the interviews both found that lesbians' gender identity affected the women's views regarding their own breasts and their appearance.

The findings are synthesized and discussed under the headings of: 1) gender identity and gender role expression; 2) patient-provider interaction; 3) subjective norms (partners' support) – the TRA; and 4) attitudes and beliefs about breast cancer and breast cancer screenings, self-efficacy and cues to action – the HBM.

**Table 9.1: The main findings from the two studies**

Breast cancer screenings/Gender identity The influencing factors		Qualitative interviews			Online survey					
		BSE	CBE	Mammogram	BSE			Mammogram		Gender identity
Intentions	Action				Maintenance	Intentions	Action			
<b>Gender identity</b>		√	√	√						
<b>Gender role expression</b>		√	√	√						√
Views about own breasts										
Appearance			√	√					√	√
<b>Patient-provider interaction</b>			√	√				√		
<b>TRA</b>	<b>Subjective norms</b> Partner's support	√	√	√		√		√	√	
<b>HBM</b>	<b>Perceived benefits</b>							√		
	<b>Perceived barriers</b>				√	√	√	√		
	<b>Perceived susceptibility</b>				√			√	√	
	<b>Perceived seriousness</b>									
	<b>Self-efficacy</b>					√			√	
	<b>Cues to action</b>					√		√		

### **9.2.1 Gender identity and gender role expression**

In this PhD study, gender identity and gender role expression were found to be associated with the individuals' breast healthcare behaviour and intentions directly and/or indirectly.

Dichotomous gender labels (masculine/feminine; T/Po) were used by the majority of the participants in both the qualitative and quantitative studies, 90% and 73% respectively. Most of the participants self-identified as masculine lesbian (T and Bufen pian T; 63% in the interviews and 47% in the survey), followed by feminine lesbian (Po and Bufen pian Po; 27% and 26%). The proportions of gender identities among the Taiwanese lesbians were found to be similar to Zhang's (2011) findings: there are more Ts than Pos. The gender label "Bufen" (undifferentiated lesbians) was the least likely to be employed among the participants, with only 10% in the interviews and 24% in the survey.

Gender identity and gender role expression were found to be associated in this PhD study. A lesbian's gender identity affected her appearance (constructions of gender identity) and her body image. The woman's appearance strengthened her gender identity and may well help her to avoid identity crises. In the qualitative interviews, gender role expression was related to lesbians' views about their own breasts and constructions of gender identity (masculine, feminine or neutral appearance). The masculine lesbians (Ts and Bufen pian Ts) tended to hold negative views about their female characteristics and negative intentions regarding having breast cancer screenings. Some of these individuals even attempted to ignore any information and/or healthcare services in relation to their female features. Based on the survey results, the masculine lesbians were more likely to hold negative views about their own breasts and to worry about their appearance being judged by other women in the waiting room if they had a mammogram compared to feminine and Bufen lesbians. These survey results agree with the qualitative results and also echo previous evidence. In Wang's (2013) study, she found that Taiwanese lesbians' concerns about being judged by other patients might delay them in seeing a physician or else cause them to avoid physicians entirely. Other research conducted in the US also found that butch lesbians experienced more discrimination than feminine lesbians or lesbians with non-traditional gender expression (Levitt et al., 2012; Levitt & Hiestand, 2002; 2004).

Feminine lesbians (Pos and Bufen pian Pos) were more likely to hold positive views about their own breasts than the masculine- and Bufen-identity lesbians in this PhD study. Based on the interview findings, these positive views might encourage the Pos to perform BSEs and have mammograms. In contrast, in the survey, there was no association between the women's breast healthcare behaviour and intentions and their views about their own breasts. Therefore, although the feminine lesbians held positive views about their own breasts, these views were still not able to motivate them to perform or have breast cancer screenings, and were not even able to affect their intentions in relation to the screenings.

In addition, as in the discussion in Chapter 6 (see Section 6.3.2.1), the Pos' positive views about their own breasts might be influenced by US gay culture and feminism, which started in the early 1990s in Taiwan. These Pos' views about their own breasts were considered to be likely to be more positive than Taiwanese heterosexual women when compared to previous studies (Yang et al., 2010). The women in Yang et al.'s (2010) study reported that feelings of embarrassment and vulnerability about their own breasts stopped them from performing BSEs and/or to learn the examination procedure. In contrast, there were no Pos in the qualitative interviews who reported that they held negative views about their own breasts and, based on the survey findings, nearly 80% of the feminine lesbians agreed that their breasts had an important sexual function. Therefore, the findings suggest that the feminine lesbians might hold more positive views about their own breasts than heterosexual women in Taiwan, at least when compared to the findings in Yang's study. A further study is needed to understand their views about their own breasts and the associations between these views and breast healthcare behaviour and intentions among lesbians and heterosexual women in Taiwan.

In terms of Bufens, the qualitative interviews found that the Bufens' breast healthcare behaviour and intentions and the influencing factors were unclear because their gender identities were fluid and sometimes affected by their partners' gender identities. According to the survey results, it was not possible to identify whether the Bufens' gender identity and gender role expression were influenced by their partners; rather, their views on their own breasts were found to lie in the middle between the views of the masculine and feminine lesbians. The findings echo previous Taiwanese research that found that Bufens play neither masculine nor feminine gender roles (Kuang et al., 2004) and that their roles and responsibilities lie between T and Po (Cheng, 1997).

Based on the synthesized findings, gender identity (how they saw themselves) and gender role expression (how this was acted out) were found to be factors influencing the lesbians' breast healthcare behaviour and intentions both indirectly and directly, in particular for those who self-identified as masculine lesbian. As mentioned, in the US and the UK, gender identity was not identified as a factor influencing lesbians' actions in having breast cancer screenings (see Sections 2.6 and 6.2). It might relate to the disfavour of butch/femme labels among the lesbians in recent decades. Gender identity among contemporary lesbians in these two countries was suggested as being flexible and fluid (Farquhar, 2000; Levitt et al., 2003; Peplau et al., 2004; Peplau & Huppin, 2008; Walker et al., 2012). In Taiwan, the majority of Taiwanese lesbians still use the binary labels to find the 'right' partner and construct their gender roles within their relationships. Although there was no direct evidence to suggest that gender identity was associated with the lesbians' breast healthcare behaviour and intentions in the survey, it was considered that the women's gender identity might be indirectly related to their actions in relation to breast cancer screenings via their gender role expressions, particularly when interactions with the outside world were needed, for example, interactions with other women and/or physicians (details can be found in the following subsection).

### **9.2.2 Patient-provider interaction**

The influence of patient-provider interaction on the online survey results partially agreed with the interview findings. Based on the interview findings, eight variables were found to be related to the lesbians' behaviour and intentions regarding mammograms. The variables included female provider, male provider, heterosexual assumptions and discriminations of HCPs, HCPs' lack of knowledge about LGBT issues, HCPs feeling uncomfortable with lesbians, and breasts needing to be seen and/or touched by a HCP.

In the online survey, two of the above variables were found to be associated with the participants' intention to have a mammogram, namely 'my breasts needing to be seen and/or touched by a healthcare provider put me off having mammograms'. These barriers to having mammograms are also found in previous research conducted with heterosexual women in Taiwan (Chiang et al., 2011; Tsai et al., 2011) and in the US (Kratzke et al., 2010), and lesbians in the UK (Fish & Anthony, 2005).



The physician's gender was not associated with the women's actions and intentions regarding mammograms in the online survey. This finding corresponds with previous Taiwanese evidence. In Chang et al.'s (2000) study, the majority of the participants had no preference as to the HCP's gender. The HCP's skills and attitudes were reported to be more important than their gender.

The other factors regarding patient-provider interaction were found to have no associations with the women's actions and intentions in relation to having a mammogram in the survey. These results differed from the interview findings and findings in previous evidence. In the qualitative interviews, HCPs' lack of knowledge about LGBT issues, HCPs feeling uncomfortable with lesbians, and the heterosexual assumptions and discrimination by HCPs were found to be barriers to the lesbians' actions and intentions in relation to having a mammogram. In previous evidence, lack of knowledge about LGBT issues (Hutchinson et al., 2006; Mravcak, 2006; Rankow & Tessaro, 1998), HCPs' lack of comfort (Mravcak, 2006), concerns about discrimination (Bowen et al., 2004; Clark et al., 2003; McNair, 2003; O'Hanlan et al., 2004) and the heterosexual assumptions (DeHart, 2008) of HCPs were barriers in lesbians' healthcare behaviour.

These divergent survey results might be associated with the participants' age (mean age: 29.57). Over 95% of the participants were not eligible for a free mammogram. Having a mammogram and its influencing factors might be not high priority for the women to consider, as the most common perceived barrier to breast cancer screenings among the participants was 'not being a high priority for me' (see Figures 8.11 and 8.12, p.p.226-227). Moreover, the participants might have been new-generation lesbians who were more confident with their own sexual orientation, according to the mean age. In addition, among these women, these factors might not really be barriers in their intentions and actions in relation to having the screenings. The participants recruited in the online survey might have been more likely to respond to the questionnaire and to have positive attitudes towards and beliefs about breast cancer screenings and the healthcare system in Taiwan. More detailed discussion regarding the characteristics of the participants can be seen in Section 9.4: Strengths and Limitations.

Although the majority of the variables regarding patient-physician interaction seemed to have no associations with the women's actions and intentions in relation to having a mammogram, their actions and intentions were still considered to be affected by their interactions with the

outside world: 1) concerns about their breasts needing to be seen and/or touched by a HCP (intentions); and 2) concerns about their appearance being judged by other women in the waiting room (actions), based on the survey results. These barriers influenced the women to hold negative views regarding the screenings or else inhibited them from acting.

In terms of the relationships between gender identity and the variables regarding patient-provider interaction, there were no significant differences among the masculine-, feminine- and Butch-identity lesbians in the online survey. These findings echo the qualitative interview findings and the existing evidence. The lesbians' concerns about healthcare providers' attitudes were mainly related to their 'sexual orientation' (Clark et al., 2003; DeHart, 2008; Hart & Bowen, 2009).

### **9.2.3 Subjective norms (partners' support) – the TRA**

In this PhD study, partner support was found to be an important factor influencing the lesbians' breast healthcare behaviour and intentions. In the qualitative interviews, the lesbians' partners' were found to be a factor that was positively associated with the women's actions and intentions in relation to performing BSEs and/or to having CBEs and mammograms. In the online survey, the current partners' support was a significant factor facilitating the women's actions in relation to performing BSEs and/or having a mammogram and also their intentions in relation to having a mammogram. In addition, the perceived influence of a partner ('more likely to have a mammogram if my partner thinks I should have one') was also found to be related to the women's intentions in relation to having a mammogram.

Similar findings can also be seen in previous research which was conducted with heterosexual women in Taiwan (Chang et al., 2000; Li, 2013). In Li's (2013) unpublished Master's thesis, the researcher investigated 321 Taiwanese women's intentions in relation to mammograms and the influencing factors based on the TPB (which was developed from the TRA). She found that the women's intentions in relation to having mammograms were significantly associated with their subjective norms, attitudes towards the behaviour, and perceived behavioural control. In contrast, Fish and Wilkinson (2003<sub>b</sub>) found that the lesbian's partner was a barrier to the women's performance of BSE because their partner did the examinations for them as a part of their sexual activity. In Fish's (2003<sub>b</sub>) study, the researchers suggested that the lesbians' partners were a barrier because the women did not do

the examinations themselves (*'self'-examination*). However, it was unclear whether a participant's breast awareness had increased or decreased because their partner did the examinations for them, and the efficacy of the BSE being performed by their partner was also unknown.

In the interview findings, the lesbians' relationship status (single/partnered) and the length of their relationship with their partner were related to the women's breast healthcare behaviour and their intentions. For example, lesbians who were partnered were more likely to perform a BSE than those who were not. However, this finding was not replicated in the online survey. Having a partner or not having a partner and the length of any such relationship were not associated with the lesbians' breast healthcare behaviour and intentions directly. The factors that encouraged the women's breast healthcare behaviour and intentions were found to be mainly associated with their perceived support from their partners (social pressure) and their motivations to comply with their partners' thoughts. These findings echo the construct "subjective norms" from the TRA that refers to a person's belief as to whether significant others support or oppose that behaviour and his or her motivation to follow their opinions (Ham, 2005; Montano et al., 1997).

In addition, according to the online survey, the partners' support variables did not differ significantly between women with different gender identities. Therefore, their perceived social pressure from a partner and their motivations to comply their partners' thoughts were considered to be similar among the masculine-, feminine- and Buten-identity lesbians. These survey results correspond with the interview findings.

#### **9.2.4 Attitudes and beliefs about breast cancer and breast cancer screenings, self-efficacy and cues to action – the HBM**

As mentioned in Chapter 7, the HBM variables were chosen based on the interview findings and the reviewed Taiwanese studies. In this subsection, the survey findings will be compared with the relevant research conducted with Taiwanese heterosexual women so as to identify the similarities and differences between lesbians and women in general in Taiwan.

Overall, in the survey (see Table 9.1, p.227), the women's intentions to perform BSEs were associated with perceived barriers to performance and a perceived susceptibility to breast cancer. Their actions in relation to BSEs were related to their perceived barriers to

performing the examinations, self-efficacy and cues to action. As can be seen in Table 8.11 (see p.224), the variable ‘performing a BSE is not a high priority for me’ inhibited the women’s intentions, actions and maintaining performing the examinations. Similar findings can be seen in previous studies, although the variables vary slightly. ‘Having no time’ (Chiang et al., 2011; Wu et al., 2012) and ‘feeling that it is unnecessary’ (Luo, 2001) were found to be barriers to performing BSEs among the heterosexual women

The other barriers, ‘performing a BSE would be embarrassing for me’ and ‘performing a BSE would be unpleasant’, prevented women from performing BSEs. However, no previous Taiwanese research has found such that the two variables inhibit heterosexual women’s actions in relation to performing BSEs. Instead of feeling embarrassed about the examinations, heterosexual women were more likely to be influenced by their views about their own breasts (Yang et al., 2010). In Yang et al.’s (2010) study, the researchers reported that the individuals’ views about their own breasts (felt embarrassed about own breasts) inhibited women’s performance of BSEs. The researchers suggested that Chinese culture might have influenced the women’s feelings and their performance of BSEs. As mentioned previously, however, in the survey no relationship was found between the women’s views about their own breasts and their actions and intentions in relation to performing BSEs. Negative attitudes towards the examinations, however, were found to inhibit the women’s actions.

Although in the survey there were no differences as regards negative views towards BSEs among the masculine-, feminine- and Buten-identity lesbians, the masculine lesbians were more likely to hold negative views about their own breasts. In addition, the masculine lesbians reported their negative views and intentions in relation to breast cancer screenings more often than the feminine and Buten lesbians in the qualitative interviews. Therefore, the negative attitudes towards BSEs, ‘embarrassment’ and ‘perceived unpleasantness’, were considered to be possibly related to the women’s gender identity and their body image.

Perceived susceptibility to breast cancer was found to be positively related to the women’s intentions in relation to performing BSEs in the current survey, including the variables ‘I am more likely than the average woman to get breast cancer’ and ‘I worry about having breast cancer in the future’. In previous studies, perceived susceptibility to the disease was found to

be associated with heterosexual women's actions in relation to performing BSEs, but not their intentions. The variables included their personal history of non-malignant breast disease (Chang and Nien, 2003; Chiang et al., 2011; Huang et al., 2012; Lai et al., 2011) and a family history of breast cancer (Chiang et al., 2011; Lai et al., 2011). Interestingly, these two variables were also included in the online questionnaire; however, no relationships were found between the variables and the participants' actions in relation to performing BSEs in the present survey. Therefore, among the women in the survey, their perceived susceptibility to breast cancer might have increased how much attention they paid to breast cancer and BSEs, but it was not enough to motivate them to perform the examinations.

Self-efficacy and cues to action were factors that actually motivated the women to perform BSEs in this survey. When the participants 'knew how to perform BSEs' and 'felt confident about the examination results', they were motivated to perform the examinations. These findings were found to correspond with previous research (Chang & Nien, 2003; Chiang et al., 2011; Luo et al., 2001; Yang et al., 2010).

In addition, campaigns (TV, radio, magazines, etc.) and symptoms (a lump in either breast, pain or a change in the size of one or both breasts) were found to be triggers for the women to perform BSEs in the survey. In Luo's (2001) study, the media also encouraged Taiwanese women to perform BSEs. Symptoms, however, were not identified as a factor facilitating Taiwanese women's actions in relation to performing BSEs in previous research. In both the qualitative interviews and the online survey, having a symptom was reported to be an important factor that motivated the women to perform BSEs. As mentioned in Chapters 5 and 6, some of the lesbians, in particular the masculine-identity lesbians, did not want to perform BSEs. However, if they were to perceive a higher risk of getting breast cancer (such as feeling pain in either breast), they might perform a BSE after they had weighed up whether it was worth it for them to do so (i.e., benefits versus body image alteration).

The perceived benefits of BSEs and the perceived seriousness of breast cancer were not factors affecting the women's actions and intentions in relation to performing BSEs. These two categories were also found to have no associations with heterosexual women's actions in relation to performing BSEs in previous Taiwanese studies (Chang & Nien, 2003; Luo et al., 2001).

In terms of mammograms, in the survey (see Table 9.1, p.227) the perceived benefits and barriers to having mammograms, the perceived susceptibility to breast cancer and cues to action, influenced the women's intentions in relation to having a mammogram. Perceived susceptibility to breast cancer and self-efficacy were found to affect their actions in relation to having the screening. As can be seen in Table 8.12 (see p.225), the perceived benefits of having a mammogram ('having a mammogram will help me protect me against breast cancer') was a factor influencing the women's intentions in relation to having the screening in the survey. To compare with previous Taiwanese studies, the perceived benefits of mammograms were also found to be associated with heterosexual women's actions in relation to having mammograms (Chen, 2009; Chiang et al., 2011; Lin, 2012). As mentioned, most of the participants in the current survey were not eligible for free mammograms. Although the women acknowledged the benefits of having a mammogram and intended to go for a screening, they might not be able to obtain a free screening due to the free mammogram criteria in Taiwan.

The perceived barriers to having breast cancer screenings, in particular 'having a mammogram is not a high priority for me', 'having a mammogram would be embarrassing for me' and 'having a mammogram would be painful', were also associated with whether they intend to have a mammogram. These barriers were found to be associated with whether Taiwanese heterosexual women actually had a mammogram in previous studies. Having no time (Chiang et al., 2011; Wu et al., 2012), embarrassment (Chiang et al., 2011; Tsai et al., 2011) and concerns about pain (Tsai et al., 2011) inhibited the women's behaviour in relation to having the screenings

In the survey, perceived susceptibility to breast cancer was a factor associated with the women's intention to have a mammogram ('more likely than the average woman to have breast cancer' and 'worry about having breast cancer in the future') as well as their actions in relation to having the screening ('age' and 'non-malignant breast disease'). These findings correspond with the previous research. Perceived susceptibility to breast cancer was also found to be a factor that was related to Taiwanese heterosexual women's actions (Chen, 2009; Huang et al., 2012; Lai et al., 2011; Lin, 2012; Lin, 2008) and intentions (Lin, 2012; Lin, 2008) in relation to having mammograms. Based on the survey findings, age and previous breast disease were factors that motivated the participants to act. According to previous research conducted with Taiwanese heterosexual women, being older (Lai et al.,

2011) and having had breast disease (Huang et al., 2012; Lai et al., 2011; Lin, 2012) were also found to be factors facilitating the heterosexual women's behaviour in relation to having mammograms.

Self-efficacy ('know how to have a mammogram') was related to the lesbians' actions in relation to having a mammogram in the survey. In a previous Taiwanese study, self-efficacy was not associated with heterosexual women's behaviour in relation to having mammograms (Chiang et al., 2011) but it was associated with their performance of BSEs (Chang & Nien, 2003; Luo et al., 2001; Yang et al., 2010). In the present survey, however, knowing how to have a mammogram motivated the participants to have the screenings. Therefore, information about how to have a mammogram might be lacking among those who had never had a mammogram in this study. In addition to inadequate information provided by physicians or the Ministry of Health and Welfare, the participants' age, gender identity and gender role expression might affect their willingness in obtaining relevant information. As mentioned previously, based on the interview findings, lesbians of a younger age and/or who had a masculine appearance were less likely to obtain a mammogram. These women might think that having a mammogram was not a high priority for them. Consequently, they might be less likely to approach relevant information, and it therefore might have led to their lack of knowledge of how to having the screening. Hence, this influencing factor should consider that either the women are not being provided with adequate information or else that they prefer to maintain a distance from information about their breasts. Further study is needed to understand whether this factor is associated with the provision of inadequate information or lesbians' intentions to ignore information, so as to facilitate appropriate interventions to help the lesbians in improving their breast health.

In this online survey, campaigns, symptoms, others they knew who had breast cancer and physicians' recommendations were factors that were positively associated with the women's intentions in relation to having a mammogram. In Chiang et al.'s (2011) study, physicians' recommendations were also a factor facilitating the women's behaviour in relation to having mammograms.

Finally, and similarly to BSE, the perceived seriousness of breast cancer was not a factor influencing the participants' actions and intentions in relation to having a mammogram in the survey. This finding corresponds with previous research (Chiang et al., 2011).

### **9.2.5 Summary**

Based on the synthesized findings, gender identity, gender role expression, patient-provider interaction and partner support were found to be factors influencing the women's breast healthcare behaviour and intentions directly or indirectly. In addition, variables from the two healthcare models (the TRA and the HBM) were found to explain the women's breast healthcare behaviour and intentions, and the majority of the HBM variables were shared with heterosexual women in Taiwan. However, although it seemed as though the majority of the HBM variables were shared between lesbians and women in general in Taiwan, some variables regarding the women's attitudes towards breast cancer and breast cancer screenings and self-efficacy were considered that might be associated with their sexual orientations, gender identities and body image.

### **9.3 Recommendations and implications**

Based on the main findings from the two studies, recommendations and implications are provided in order to improve Taiwanese lesbians' breast healthcare behaviour and to promote their breast health.

The social-ecological model proposed by Stokols (1996) was modified and used to assist researchers in providing possible methods for promoting the lesbians' breast health and encouraging the women to perform BSEs and/or have mammograms (see Figure 9.1). This model mainly considers that there are many factors that influence a specific health behaviour, comparing individual (intrapersonal), relationship (interpersonal), community (lesbian community and LGBT organizations) and societal (policy and the healthcare system) factors. It has been employed successfully in previous studies for designing/implementing interventions in order to enhance women's utilization of mammograms (Damron et al., 2010; Earp et al., 1995).



**Figure 9.1: Recommendations for Taiwanese lesbians' breast healthcare behaviour (based on the social-ecological model)**



The social-ecological model emphasizes cross-level analyses of health problems and related intervention strategies. Three approaches are introduced to promote health, including: 1) behaviour changes or lifestyle modifications; 2) environment enhancement and restructuring; and 3) social-ecological approach. Several theoretical or research perspectives associated with each health promotion orientation have been proposed. For example, behavioural change was found to be related to the HBM and the TRA. Environmental enhancement was associated with social support and organizational development. The social-ecological approach is mainly related to policy and community health promotion (Stokols, 1996). The model corresponds with the findings from this PhD study. Taiwanese lesbians' breast healthcare behaviour was related to not only their personal factors (demographic characteristics, perceived risk of getting breast cancer, and views about their own breasts, breast cancer and breast cancer screenings) and relationships (support from their partners), but also the lesbian community (dichotomous gender identity label and constructions of gender identity), Taiwanese society and the healthcare system (attitudes towards lesbians and physicians' knowledge about LGBT issues).

According to the model, four levels of recommendations are provided in order to increase the utilization rates of breast cancer screenings and to improve lesbians' breast health. The first level is the individual; the second level, relationships; the third level, the community; and the fourth level, society/healthcare system. The methods within levels one to three can be used to encourage lesbians to perform BSEs while those between levels one and four, particularly levels three and four, can be employed to motivate lesbians to have a mammogram.

### **Level 1: Individual**

The influencing factors within level one are mainly related to the lesbians' demographic characteristics, the risk factors of breast cancer, gender identity and their views about their own breasts, breast cancer and breast cancer screenings. Modifying a person's health-related attitudes and beliefs is focused on at this level (Stokols, 1996).

As mentioned, being older, perceiving a higher risk of getting breast cancer, self-efficacy and the perceived benefit of having breast cancer screenings facilitated the women's breast healthcare behaviour. Although the women's masculine identity, negative views about their own breasts and perceived barriers to having breast cancer screenings inhibited the individuals in having breast cancer screenings, providing information (education) in relation

to the prevalence and incidence of breast cancer among Taiwanese ‘*people*’ (information providers should avoid using words which relate to dichotomous gender labels, more detailed explanation can be seen in the following), the risk factors, the benefits of having breast cancer screenings, the procedures for BSEs and mammograms, and the importance of self-health management, might encourage lesbians to perform BSEs and to have mammograms.

However, there is one point that should be kept in mind. The terms/words which relate to dichotomous gender labels (male/female; men/women) should be avoided. Based on the interview findings, some of the masculine lesbians might be transgender, and although the number of lesbians who might be transgender was unknown in the online survey, nearly 50% of the participants were masculine-identity lesbians. These individuals did not connect themselves with any issues related to ‘*women*’. Hence, anyone wishing to provide information to the target population should be aware of the wording and the included content.

In terms of the methods of disseminating the information, campaigns (TV, radio or magazines) were found to be a factor that facilitated the lesbians in performing BSEs and in having mammograms in the online survey, although the effectiveness of using campaigns to increase the utilization rates of mammograms was equivocal in previous studies (Fernandez et al., 1999; Flynn et al., 1997; Navarro et al., 1998; Page et al., 2005). However, considering the characteristics of the target population (as a hidden population in Taiwan), campaigns could be a method to encourage Taiwanese lesbians’ breast healthcare behaviour (for instance, the information published in LGBT newspapers or magazines). In addition, website information and workshops might be other possible ways to provide the relevant information to the individuals. Further studies are needed to understand the effectiveness of these methods.

Furthermore, health education based on psychological theories has been suggested to increase women’s utilization of breast cancer screenings effectively (Hajian et al., 2014). The HBM is one of the healthcare models that has been widely and successfully employed as a guiding framework for breast health behaviour intervention (Avci & Gozum, 2009; Farma et al., 2014; Hajian et al., 2011; Lu, 2001; Moodi et al., 2011; Rezaeian et al., 2014). In Taiwan, Lu (2001) explored the effects of nursing intervention on BSE intentions, BSE frequencies and BSE accuracy among 198 beauticians. The researcher used the HBM to design a two-step BSE intervention programme. The first step of the programme included BSE step-by-step

instructions to enhance BSE competence. This part of the intervention focused on individualized strategies and addressed barriers on a personal level. The second step of the intervention involved monthly telephone reminders which were made to each participant for three months after the completion of teaching BSE. The intervention programme was found to significantly increase BSE frequencies, BSE accuracy, the perceived benefits of BSE and the perceived competence in BSE, as well as decreasing the perceived barriers to performing a BSE, although it was also found to decrease the perceived susceptibility to breast cancer. Therefore, the breast health information/knowledge provided based on the HBM is considered to be one possible effective method to encourage lesbians to perform and/or have breast cancer screenings.

### **Level 2: Relationships (partners' support)**

The second level was associated with lesbians' social support (relationships). In this PhD study, social support mainly focused on the lesbians' partners. In both the qualitative and quantitative studies, the partners' support was a significant factor that facilitated the lesbians' breast healthcare behaviour and intentions in relation to BSEs and mammograms. In order to increase the utilization rates of the screenings among the target population, lesbians could be encouraged to perform BSEs for each other. Although the effectiveness of the lesbians' partners performing BSEs was unknown, based on the qualitative interviews, performing BSEs for each other might increase breast awareness.

For lesbians who do not like their partners touching/looking at their breasts, the latter could be encouraged to discuss with them the issues surrounding breast cancer and breast cancer screenings and to express their concerns about the individual's breast health status.

According to the interview findings, although some of the masculine lesbians did not like their breasts to be seen or touched by their partners, if their partners discussed the issues with them and expressed their concerns (i.e., worry) about the lesbians' breast health status, they were encouraged to perform BSEs and/or to have a CBE or a mammogram.

In addition, having a mammogram together might encourage lesbians to have the screening. However, this method needs to consider whether both of the individuals are eligible for free mammograms in Taiwan or whether they would mind paying out-of-pocket for mammograms.

The methods just mentioned were considered for recommendation to lesbian couples via campaigns, workshops and LGBT-related websites.

### **Level 3: Community**

The third level – community – was related to the factors associated with lesbian communities and LGBT organizations in this PhD study. According to the previous literature and the interview findings, Taiwanese lesbians' gender identity and construction of gender identity (gender role expression) were affected by the lesbian's community (in particular gay/lesbian bars). Specific norms were followed by the individuals so as to meet the expectations of the community; for example, masculine lesbians should present a flat chest, short hair and wear t-shirts or shirts, and feminine lesbians should wear their hair long, skirts and make-up. These masculine features might cause the lesbians to be more easily targeted and to receive discrimination from society and/or the healthcare system, and therefore might lead to the non-utilization of mammograms or negative intentions regarding screenings.

It was considered that it would be difficult to change the norms; however, the barriers regarding the strict norms might be overcome via LGBT organizations' support. For example, as previously mentioned, workshops which aim to provide relevant information could be held by the organizations in order to approach the target population and to disseminate the information to as many lesbians as possible. In addition, according to the interview findings, having a mammogram in a hospital with other lesbians who also self-identify as a masculine lesbian and have a masculine appearance might encourage some single masculine lesbians to have the screening, because the setting for having a mammogram might be thought of as a feminine environment and they might feel embarrassed to have a mammogram if they were to go alone. For those who would like to have a mammogram but are concerned about the environment, the LGBT organizations could help to organize for these individuals to have the screenings together. In addition, if the organizations could cooperate with a hospital and provide mammograms for lesbians at a specific time and place for just the target population, it might increase the utilization rates of screenings and decrease their concerns about being judged by other women in the waiting room.

#### **Level 4: Society and the healthcare system**

The last level was associated with society and the healthcare system. The influencing factors at this level included concerns about other women in the waiting room and physicians' attitudes, heterosexual assumptions and their knowledge about LGBT issues. Although the physicians' attitudes towards lesbians, heterosexual assumptions and their knowledge about LGBT issues were not found to be associated with the women's breast healthcare behaviour or intentions in the online survey, these variables were significantly related to the lesbians' breast healthcare behaviour and intentions in the qualitative interviews, and were suggested as important influencing factors among lesbians in previous international studies (see Section 2.6). In the online survey, however, interactions with the outside world (society and the healthcare system) were found to affect the women's actions or intentions in relation to having a mammogram.

As mentioned previously, the masculine lesbians' actions and intentions regarding mammograms were significantly associated with their gender role expression (worrying about being judged by other women in the waiting room). Hence, a safe, protective and private examination environment needs to be provided for these women in order to maintain their identities and to minimize the risk of revealing their true sex. Creating non-judgemental medical environments and posting a non-discrimination policy in waiting areas may help to develop a safe and supportive environment. In order to maintain masculine lesbians' body image, healthcare providers should also consider how to provide a "*safe*" breast screening procedure (for example, how to maintain privacy during the screening procedure) and to develop a trusting relationship with their patient. Developing a trusting relationship should be seen as the first step in improving the lesbians' breast health. Without trust, the lesbians find it difficult to 'come out' and to express what they need for their health.

In addition to the masculine lesbians' concerns about being judged by other women because of their appearance, other factors relating to patient-provider interactions were not significantly different among the masculine, feminine and Butch lesbians in the survey, which included heterosexual assumptions and discrimination by providers and providers' lack of knowledge about LGBT issues. These factors are considered to be common barriers in relation to Taiwanese lesbians' breast healthcare behaviour and intentions, based on the interview findings. Providing culturally competent care and being sensitive to the areas of

concern of sexual minorities might encourage the lesbians' utilization rates for mammograms.

As mentioned, there are no relevant training courses in relation to LGBT health for medical, and nursing students and those of related subjects (such as dentists and social workers) in Taiwan. Providing a relevant training programme for both healthcare providers and students might help them to be more comfortable and open to discussing sexual orientation with their patients. Such training should include issues about: 1) modifying attitudes and methods in collecting patients' histories and not solely basing them on the heterosexual culture; 2) understanding the situation and subculture of LGBTs; and 3) asking rather than making assumptions about sexual behaviour and identity (IOM, 2011).

The recommendations in relation to the policy include: 1) the policy should indicate the importance of providing culturally competent care to the target population; 2) the policy should make it clear that breast cancer screenings are not only for women but also for anyone (LGBTQI; lesbian, gay, bisexual, queer and intersex) who needs the screenings (this recommendation aims to recruit all individuals who need breast cancer screenings but who may have varied sexual orientations and/or gender identities); 3) the policy document should acknowledge that people who need breast cancer screenings may have varied sexual orientations and gender identities; 4) the policy should be designed to encourage hospitals and healthcare providers to provide culturally competent care and support any relevant training courses provided to healthcare providers and students; and 5) the documents used for collecting health information should be LGBT-inclusive. For example, answer choices under the question of relationship statuses in a patient medical history form should include not only the options of 'single', 'married', 'divorced' or 'widowed' but also an option of 'partnered'.

#### **9.4 Strengths and limitations**

This study is the first study of Taiwanese lesbians' public healthcare issues and the first to focus on the target population's health promotion.

It uses a sequential exploratory mixed-methods study design to investigate Taiwanese lesbians' breast healthcare behaviour and intentions and the influencing factors, including qualitative interviews, instrument development and an online survey. The first-phase qualitative interviews were employed to provide an initial but in-depth understanding about

the topic. This approach was useful in eliciting the factors associated with Taiwanese lesbians' breast healthcare behaviour and also helped the researcher to identify dynamic connections among these factors and to compare with the previous relevant studies. The questionnaire used in the online survey was designed based on the interview findings and the two healthcare models. Therefore, the tool was not only suitable for investigating Taiwanese lesbians' breast healthcare behaviour but also able to assist the researcher to understand the similarities and differences in the influencing factors between lesbians and heterosexual women in Taiwan. By using an online survey in the second phase, the generalizability of the interview findings and the associations between the influencing factors were assessed. By combining two research methods to investigate the same phenomenon, the research findings from each method were re-examined. The convergence of the findings from different research methods indicates the mutual verification of the research results, which potentially increases the validity of the research findings (Erzberger & Kelle, 2002). Any differences in the findings would suggest a need to reconsider the findings from each phase to bring out a deeper understanding of the findings.

Purposive sampling was employed in both the qualitative and quantitative studies in order to recruit the participants with a maximum variation in their demographic characteristics. The method was considered to be able to help the researcher to identify a wider range of factors associated with the lesbians' breast healthcare behaviour and intentions. The study was advertised in several organizations located in different areas of Taiwan in order to approach different groups of Taiwanese lesbians during the first and second phases. During the second-phase online survey, the study was also advertised on several lesbian chat rooms via the Internet and lesbian communities on Facebook so as to approach potential participants who were not members of the organizations.

A number of limitations of the two studies should be noted. In the following, the limitations shared by the two studies are discussed first, followed by the individual limitations in each study. The participants were recruited if they self-identified as a lesbian or a woman who had a partner of the same gender, as in previous relevant research which was also conducted with lesbians. However, if a lesbian did not self-identify as a lesbian or a woman who had a partner with the same gender, the lesbian might exclude herself from the study (self-selection bias).



Another challenge in relation to sampling and recruitment was the difficulty in recruiting older lesbians. This was a challenge in both the qualitative interviews and the online survey, although the study was advertised in one older lesbian group and snowball sampling and paper-pencil questionnaires were also employed to attempt to recruit lesbians who were aged 45 years or over in the second-phase survey study. At the end of the online survey, there were only 12 older lesbians who had taken part in the study, and they are therefore underrepresented in this study. As discussed previously in Chapter 8, several reasons might be associated with the non-response: 1) the characteristics of the target population; 2) the short data collection period; and 3) the possible barriers for older lesbians (such as illiteracy). In order to overcome this challenge in a future study, the researcher proposes that possible solutions are: 1) to use both an online questionnaire and paper-pencil questionnaires to collect data from older lesbians; 2) to employ telephone interviews if older lesbians cannot read; 3) to have a longer data collection period (more than two months); and 4) to recruit older lesbians or advertise the study in lesbian/gay bars. Most of the participants in this PhD study were recruited from LGBT organizations and communities. According to the existing evidence (Chao, 1997, 2000, 2001; 2002), the Taiwanese lesbian culture was started in gay/lesbian bars. Recruiting older lesbians from these places might be another way to approach older lesbians.

In addition, there are some specific limitations in each study. After the qualitative interviews, full transcriptions were not used due to time and resource limitations and the sequential mixed-methods study design (a detailed discussion is presented in Section 4.6.2). Instead of using transcriptions, NVivo audio-coding was employed to assist the researcher to analyse the qualitative data directly via the recordings. However, it should be considered that NVivo audio-coding might cause some misinterpretations or misunderstandings because the researcher might miss important information when listening to the recording and coding the data simultaneously. Although the process of audio-coding was repeated at least seven times to ensure the accuracy of the interpretation and understanding of the data, the possible limitations in relation to the method should still be considered.

A number of limitations of the online survey should also be noticed. First of all, it was a cross-sectional study, which means that we cannot really be certain about the causal direction between the study variables and the Taiwanese lesbians' breast healthcare behaviour and

intentions. In addition, changes in the lesbians' breast healthcare behaviour or intentions cannot be measured using this design (only a snapshot). For example, a lesbian's gender identity is fluid or might change based on her partner's gender identity. Different gender identities were associated with varied views about the lesbians' own breasts, breast cancer and breast cancer screenings. These factors might alter the individual's actions and/or intentions regarding breast cancer screenings. Moreover, as they get older, the lesbians' behaviour or intentions might also vary.

Secondly, the findings were not derived from a large, population-based sample; hence, caution should be exercised in generalizing the survey findings. Although non-random samples are usually employed in research on underserved populations, the small purposive and snowball samples may not have been representative of all lesbians and may limit the generalizability of the findings.

Thirdly, the self-reporting methodology might have led to social-desirability biases. For example, lesbians might report that they had a mammogram regularly based on the recommendations of the breast healthcare programme in Taiwan.

Fourthly, the participants who responded to the online survey might have been more likely than the general population to pay attention to breast healthcare issues and information and to hold positive views about breast cancer screenings and the healthcare system. As mentioned previously, no associations were found between the variables regarding physicians' attitudes towards lesbians and the women's breast healthcare actions and intentions in the survey. In contrast, these variables were important influencing factors for the lesbians in the qualitative interviews and the lesbians in previous international studies (see Section 2.6). It was therefore considered that the survey results might be limited in terms of generalizability to the general population. Although both the interviews and the online survey used similar access points to approach potential participants and the same sampling strategies (purposive and snowball sampling) to recruit the participants, different groups of lesbians might have been approached and recruited in the two studies because of the varied methods of data collection. To compare the proportions of the lesbians' gender identity in the two studies, more Ts were recruited in the interviews than in the survey, which were 63% and 47% respectively. As mentioned in Chapter 4, some of the Ts tended to ignore information about their female characteristics. Their participation was mainly encouraged by their partners (Pos; to participate the interview

together) and/or influenced by the interviewer (as a feminine; helping a woman is T's masculine responsibility, based on lesbian norms in Taiwan, see Section 4.5.4), even though they thought that the issue was not a high priority for them or else not relevant to them. Hence, their participations in the interviews gave them time to consider and to express their views about and attitudes towards their own breasts, breast cancer, breast cancer screenings and the healthcare system, and the influences of Taiwanese society. The online survey, however, was completed by the participants individually and mainly alone. There were no external sources, such as their partners or the researcher, to influence these Ts to take part in the survey. Therefore, the participants in the survey might hold more positive views regarding their own breasts, breast cancer, breast cancer screenings and the healthcare system, and therefore they took part in the study and, consequently, these characteristics were reflected in the survey results.

Fifthly, the questionnaire used in the survey study was mainly generated by the researcher based on the interview findings, previous Taiwanese studies or else adopted from a previous scale (CHBMS). The reliability and validity of these measures have not been established. The scale needs to be tested among Taiwanese lesbians.

Sixthly, in the present survey, the data were mainly compared within two or three groups in order to know whether there were any differences regarding the designed variables among the groups (difference inferential statistics). The strength of the relationships between the IVs and DVs was not assessed in this study due to time constraints. However, multivariate regression or correlation could have been used on the survey data to investigate which variables showed the strongest relationships with healthcare behaviours and were most important in predicting such behaviours (Morgan, 2011).

Lastly, this online study did not include heterosexual women as a comparison group; hence, the influencing factors between lesbians and heterosexual women cannot really be compared. Although the researcher attempted to combine the two existing healthcare models (the HBM and the TRA) and use the CHBMS, which has been used to investigate Taiwanese heterosexual women's breast healthcare behaviour when designing the online questionnaire, she can only obtain a superficial understanding of the influencing factors between these two groups of women when comparing the survey results with the previous research conducted with Taiwanese heterosexual women.

## **9.5 Directions for future research**

Due to the challenge of recruiting older lesbians, a study conducted with lesbians who are actually eligible for free mammograms (aged 45 years or over) is needed in order to understand the influencing factors of the individuals' utilization of mammograms.

Based on the qualitative interviews, as they get older, the lesbians' gender identity and gender role expression (appearance and views about their own breasts) might change. Gender identity and gender role expression were found to be associated with the women's breast healthcare behaviour and intentions both directly and indirectly in this PhD study. Hence, further research is needed to investigate the relationship between age, gender identity, gender role expression and lesbians' breast healthcare behaviour and intentions, and to understand whether lesbians' gender identity and gender role expression change as they age and how these changes are associated with the women's breast healthcare behaviour and intentions.

In addition, in order to understand the differences and similarities in the factors associated with women's breast healthcare behaviour and intentions (among lesbians and heterosexuals), both groups of individuals should be recruited in a future study in order to obtain comparable results. These results may help healthcare providers and policy-makers to understand what the differences and similarities are among these two groups of women and how to modify policies in order to encourage lesbians to use breast health services and to improve their breast health.

Finally, there is a lack of evidence for understanding Taiwanese lesbians' breast cancer risk and its risk factors. Compared with the previous studies conducted outside of Taiwan, the risk factors of breast cancer are considered to be different. For example, previous studies conducted in the US have found that behavioural factors were a significant reason for the increase in the risk of breast cancer among lesbians; for instance, smoking and drinking (see Section 2.4). However, when compared with the current online survey, only 20% of the participants were currently smokers and nearly 90% of these smokers smoked less than 10 cigarettes per day. Although 204 out of the 284 participants (about 70%) reported being current alcohol users, 66% of these women reported that they drank alcohol occasionally or that they had less than five drinks per week. In addition, over 20% of the participants used breast bindings over the long-term in the survey study. It was suggested that this might be a risk factor of breast cancer in the target population (Lesbian and Gay Foundation, 2013).

However, there is a lack of evidence to understand the relationship between their binding their chests over the long-term and their breast cancer risk. Therefore, a study is needed to investigate breast cancer and its risk factors among Taiwanese lesbians due to the differences between behavioural risk factors and the target population's cultural background.

## **9.6 Conclusion**

This PhD study aimed to investigate Taiwanese lesbians' breast healthcare behaviour and intentions and their influencing factors by using a sequential exploratory mixed-methods study design. Based on the two studies' findings, gender identity, gender role expression, partners' support and concerns about patient-provider interaction were found to be factors that were directly or indirectly associated with the individuals' breast healthcare behaviour and intentions. In addition, the two healthcare models (the HBM and the TRA) were also used to explain the women's actions and intentions in relation to breast cancer screenings, and most of the HBM variables were shared with Taiwanese heterosexual women despite that some of these variables were considered as possibly being influenced by the lesbians' sexual orientation, gender identity or body image.

Although a number of the limitations of the present PhD study should be noted, it is the first Taiwanese lesbian breast health study and it contributes knowledge about Taiwanese lesbians' breast healthcare behaviour and intentions and their influencing factors.

Recommendations are proposed in order to encourage lesbians' utilization of breast cancer screenings and to promote their breast health.

## References

- Abate, M. A. (2011). Introduction: special issue on tomboys and tomboyism. *Journal of Lesbian Studies*, 15(4), 407-411.
- Abdi, H. (2007). The Bonferonni and Šidák corrections for multiple comparisons. *Encyclopedia of measurement and statistics*, 3, 103-107.
- Ahmed, N. U., Fort, J. G., Fair, A. M., Semanya, K., & Haber, G. (2009). Breast cancer knowledge and barriers to mammography in a low-income managed care population. *Journal of Cancer Education*, 24, 261-266.
- Ajzen, I. (2005). *Attitudes, personality and behaviour* (2 ed.). Berkshire: Open University Press.
- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179-211.
- Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice-Hall.
- Aldridge, A., & Levine, K. (2001). *Surveying the social world: Principles and practice in survey research*. Buckingham: Open University Press.
- Al-Foheidi, M., Al-Mansour, M. M., & Ibrahim, E. M. (2013). Breast cancer screening: review of benefits and harms, and recommendations for developing and low-income countries. *Med Oncol*, 30(2), 471.
- Allmark, P., Boote, J., Chambers, E., Clarke, A., McDonnell, A., & Thompson, A., et al. (2009). Ethical issues in the use of in-depth interviews: Literature review and discussion. *Research Ethics Review*, 5(2), 48-54.
- Altheide, D. L., & Johnson, J. M. (1994). Criteria for assessing interpretive validity in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research*. London: Sage.
- Angen, M. J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. *Qualitative Health Research*, 10(3), 378-395.
- Armitage, C. J., & Conner, M. (2000). Social cognition models and health behaviour: A structured review. *Psychology and Health*, 15(2), 173-189.
- Austin, S. B., Pazaris, M., Nichols, L., Bowen, D., Wei, E., & Spiegelman, D. (2013). An examination of sexual orientation group patterns in mammographic and colorectal screening in a cohort of U.S. women. *Cancer Causes & Control*, 24(3), 539-547.
- Austin, S.B., Pazaris, M. J., Rosner, B., Bowen, D., Rich-Edwards, J., & Spiegelman, D. (2012). Application of the Rosner-Colditz risk prediction model to estimate sexual orientation group disparities in breast cancer risk in a U.S. cohort of premenopausal women. *Cancer Epidemiol Biomarkers Prev*, 21(12), 2201-2208.

- Avci, I. A., & Gozum, S. (2009). Comparison of two different educational methods on teachers' knowledge, beliefs and behaviors regarding breast cancer screening. *European Journal of Oncology Nursing, 13*(2), 94-101.
- Backman, K., & Kyngäs, H. A. (1999). Challenges of the grounded theory approach to a novice researcher. *Nursing & Health Sciences, 1*(3), 147-153.
- Baker, J. A. (1993). Is homophobia hazardous to lesbian and gay health? *American Journal of Health Promotion, 7*(4), 255-262.
- Barry, C. A., Britten, N., Barber, N., Bradley, C., & Stevenson, F. (1999). Using reflexivity to optimize teamwork in qualitative research. *Qualitative health research, 9*(1), 26-44.
- Barter-Godfrey, S., & Taket, A. (2007). Understanding women's breast screening behaviours: A study carried out in South East London, with women aged 50-64 years. *Health Education Journal, 66*(4), 335-346.
- Baxter, J., & Eyles, J. (1997). Evaluating qualitative research in social geography: establishing rigour in interview analysis. *Transactions Institute of British Geographers, 22*, 505-525.
- Becker, M. H. (1974). The health belief model and personal health behavior. *Health Education Monographs, 2*, 324-508.
- Bender, R., & Lange, S. (2001). Adjusting for multiple testing—when and how? *Journal of Clinical Epidemiology, 54*(4), 343-349.
- Bessenoff, G., & Snow, D. (2006). Absorbing society? Influence: Body image self-discrepancy and internalized shame. *Sex Roles, 54*(9-10), 727-731.
- Binson, D., Blair, J., Huebner, D. M., & Woods, W. J. (2007). Sampling in surveys of lesbian, gay and bisexual people. In I. H. Meyer & M. E. Northridge (Eds.), *The health of sexual minorities* (pp. 375-418). Germany: Springer Verlag.
- Bland, M. (2000). *An introduction to medical statistics* (3rd ed.). Oxford: Oxford University Press.
- Bloomfield, R. D., & Illinois, C. (1994). Cultural sensitivity and health care. *Journal of the National Medical Association, 86*(11), 819-820.
- Booth-Kewley, S., Larson, G. E., & Miyoshi, D. K. (2007). Social desirability effects on computerized and paper-and-pencil questionnaires. *Computers in Human Behavior, 23*(1), 463-477.
- Bosompra, K. (2001). Determinants of condom use intentions of university students in Ghana: an application of the theory of reasoned action. *Social Science & Medicine, 52*(7), 1057-1069.

Bouwens, C. S., van Rensburg, S. J., de Kock, L., Apffelstaedt, J. P., Kotze, M. J., Bouwens, C. S. H., et al. (2012). Influence of genetic factors on the development of breast cancer in the older woman. *Current Aging Science*, 5(2), 140-147.

Bowen, D. J., Bradford, J. B., Powers, D., McMorrow, P., Linde, R., Murphy, B. C., et al. (2004). Comparing women of differing sexual orientations using population-based sampling. *Women Health*, 40(3), 19-34.

Bowling, A. (2009). *Research methods in health*: Open University Press.

Brandenburg, D. L., Matthews, A. K., Johnson, T. P., & Hughes, T. L. (2007). Breast cancer risk and screening: a comparison of lesbian and heterosexual women. *Women Health*, 45(4), 109-130.

Breast cancer care. (2013). Breast pain. Retrieved 10<sup>th</sup> Nov., 2014, from [http://www.nhs.uk/ipgmedia/national/breast%20cancer%20care/assets/breastpain\(bcc\).pdf](http://www.nhs.uk/ipgmedia/national/breast%20cancer%20care/assets/breastpain(bcc).pdf)

Brieger, W. R. (2006). Social support. Retrieved 26<sup>th</sup> May, 2014, from <http://ocw.jhsph.edu/courses/socialbehavioralfoundations/PDFs/Lecture8.pdf>

Britten, N. (1995). Qualitative interviews in medical research. *BMJ*, 311(6999), 251-253.

Brown, L. S. (1987). Lesbians, weight and eating: New analysis and perspectives In B. L. P. Collective (Ed.), *Lesbian psychologies: Explorations and challenges* (pp. 294-309). Urbana, IL: University of Illinois Press.

Bryman, A. (2012). *Social research methods* (4 ed.). Oxford: Oxford University Express.

Buchmueller, T., & Carpenter, C. S. (2010). Disparities in health insurance coverage, access, and outcomes for individuals in same-sex versus different-sex relationships, 2000-2007. *Am J Public Health*, 100(3), 489-495.

Burnett, C. B., Steakley, C. S., Slack, R., Roth, J., & Lerman, C. (1999). Patterns of breast cancer screening among lesbians at increased risk for breast cancer. *Women Health*, 29(4), 35-55.

Carey, M. (2012). *Qualitative research skills for social work: theory and practice*: Ashgate Publishing Ltd.

Carlson, J. A. (2010). Avoiding traps in member checking. *Qualitative Report*, 15(5), 1102-1113.

Case, P., Austin, S. B., Hunter, D. J., Manson, J. E., Malspeis, S., Willett, W. C., et al. (2004). Sexual orientation, health risk factors, and physical functioning in the nurses' health study II. *J Womens Health*, 13(9), 1033-1047.

Case, S. M., & Swanson, D. B. (2002). Constructing written test questions for the basic and clinical sciences, Retrieved 12<sup>th</sup> Nov., 2014, from [http://www.nbme.org/PDF/ItemWriting\\_2003/2003IWGindex.pdf](http://www.nbme.org/PDF/ItemWriting_2003/2003IWGindex.pdf)



- Cash, T., & Pruzinsky, T. (2002). *Body Image: A handbook of theory, research, and clinical practice*. New York: Guilford Press.
- Champion, V. L. (1984). Instrument development for health belief model constructs. *Advances in Nursing Science*, 6(3), 73-85.
- Champion, V. L. (1993). Instrument refinement for breast cancer screening behaviors. *Nursing Research*, 42(3), 139-143.
- Chan, L. R. (2000). *Their stories: seven lesbian's life experiences* (Master's thesis, National Pingtung University, Pingtung, Taiwan). 【Chinese version】
- Chang, M. Y., & Nien, C. K. (2003). Factors associated with knowledge, attitude, and behavior of breast self-examination among the community of women attending the screen program in Changhua area. *Show-Chwan Med J*, 4(1), 23-34. 【Chinese version】
- Chang, M. Y., Pan, C. J., & Tsai, C. H. (2000). The Influencing factors of attending county ultrasound breast screening program. *Show-Chwan Med J*, 2(2), 65-73. 【Chinese version】
- Chao, A. (1997). *Sex, conceptions of sex and body constructions*. Paper presented at the Sex/Gender research: 1st LGBT conference. Retrieved 12<sup>th</sup> Nov., 2014, from [http://sex.ncu.edu.tw/publication/1997/4sexpaper\\_1/pdf/01-4.pdf](http://sex.ncu.edu.tw/publication/1997/4sexpaper_1/pdf/01-4.pdf) 【Chinese version】
- Chao, A. (2000). Global metaphors and local strategies in the construction of Taiwan's lesbian identities. *Culture, Health & Sexuality*, 2(4), 377-390.
- Chao, A. (2001). Drink, stories, penis, and breasts: lesbian tomboys in Taiwan from the 1960s to the 1990s. *J Homosex*, 40(3-4), 185-209.
- Chao, A. (2002). 'How come I can't stand guarantee for my own life?': Taiwan citizenship and the cultural logic of queer identity. *Inter-Asia Cultural Studies*, 3(3), 369-381.
- Chao, H. C. (2006). *The past love in between-narrative of lesbian's love* (Master's thesis, Tamkang University, New Taipei City, Taiwan). 【Chinese version】
- Chen, C. C. (2009). *The application health belief model faith pattern discusses the Nantou area woman to sieve using the breast mammography examines the correlation Factor* (Master's thesis, Asia University, Taichung City, Taiwan). 【Chinese version】
- Chen, C. T. (2008). *The utopia of the feeling of stigma – A study about lesbians' unique experiences in sport area* (Master's thesis, National Taiwan Sport University, Taichung, Taiwan). 【Chinese version】
- Chen, C.J., You, S.L., Lin, L.H., Hsu, W.L., & Yang, Y.W. (2002). Cancer epidemiology and control in Taiwan: a brief review. *Japanese journal of clinical oncology*, 32(suppl 1), S66-S81.
- Chen, K. W. (2008). Disciplining Taiwan: The Kuomintang's methods of control during the White Terror era (1947-1987). *Taiwan International Studies Quarterly*, 4(4), 185-210.

Chen, M. H. (2005). Body politics: Art criticisms in 1990s Taiwan. *Journal of Art Forum* (3), 281-305. 【Chinese version】

Chen, Y. H. (2007). *Underwear, body and society: Discursive formations of female bodily aesthetics in Taiwan (1940-1960)* (Master's thesis, National Chiao Tung University, Hsinchu, Taiwan). 【Chinese version】

Cheng, M. L. (1997). *There is a women's community in Taiwan: Taiwan lesbians' gender, family and community life*. Taipei: Nushu. 【Chinese version】

Cherryholmes, C. H. (1992). Notes on pragmatism and scientific realism. *Educational researcher*, 13-17.

Chiang, T. T., Tai, C. S., & Lin, P. C. (2011). To survey the implementation of breast cancer screening behaviors of female medical personnel-based on health belief model. *VGH Nursing*, 28(2), 130-138. 【Chinese version】

Chiang, W. S. (2008). *The experience of self-exploration and intimacy of college lesbian students* (Master's thesis, National Kaohsiung Normal University, Kaohsiung, Taiwan). 【Chinese version】

Chiang, W. S., & You, M. H. (2011). A study on young lesbians' intimate relationships, sexual explorations and sexual practices. *Chinese Journal of Guidance and Counseling*, 31, 159-182. 【Chinese version】

Chin, S. C. (2003). *A sociological analysis of bra wearing* (Master's thesis, National Taiwan University, Taipei, Taiwan). 【Chinese version】

Chur-Hansen, A. (2004). Experience of being gay, lesbian or bisexual at an Australian medical school: a qualitative study. *Iny. J. Inclusive Education*, 8(3), 281-291.

Clark, M. A., Bonacore, L., Wright, S. J., Armstrong, G., & Rakowski, W. (2003). The cancer screening project for women: experiences of women who partner with women and women who partner with men. *Women & Health*, 38(2), 19-33.

Clarke, A. (2006). Qualitative interviewing: encountering ethical issues and challenges. *Nurses Res.*, 13(4), 19-29.

Claus, E. B., Risch, N., & Thompson, W. D. (1994). Autosomal dominant inheritance of early-onset breast cancer. Implications for risk prediction. *Cancer*, 73(3), 643-651.

Clemow, L., Costanza, M. E., Haddad, W. P., Luckmann, R., White, M. J., Klaus, D., et al. (2000). Underutilizers of mammography screening today: characteristics of women planning, undecided about, and not planning a mammogram. *Annals of Behavioral Medicine*, 22(1), 80-88.

Cochran, S. D., Mays, V. M., Bowen, D., Gage, S., Bybee, D., Roberts, S. J., et al. (2001). Cancer-related risk indicators and preventive screening behaviors among lesbians and bisexual women. *American Journal of Public Health*, 91(4), 591-597.

- Colosi, L. (2006). Designing an effective questionnaire Retrieved 12<sup>th</sup> Nov., 2014, from <http://www.human.cornell.edu/pam/outreach/parenting/research/upload/Designing-20an-20Effective-20Questionnaire.pdf>
- Conron, K. J., Mimiaga, M. J., & Landers, S. J. (2010). A population-based study of sexual orientation identity and gender differences in adult health. *Am J Public Health*, 100(10), 1953-1960.
- Coppotelli, H. C., & Orleans, C. T. (1985). Partner support and other determinants of smoking cessation maintenance among women. *Journal of consulting and clinical psychology*, 53(4), 455.
- Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, 13(1), 3-21.
- Corbin, J. M., & Struass, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks, Calif: Sage Publications.
- Cortes, D. E., Mulvaney-Day, N., Fortuna, L., Reinfeld, S., & Alegría, M. (2008). Patient-provider communication: Understanding the role of patient activation for Latinos in mental health treatment. *Health Education & Behavior*. 36 (1), 138-154.
- Coughlin, S. S., Uhler, R. J., Bobo, J. K., & Caplan, L. (2004). Breast cancer screening practices among women in the United States, 2000. *Cancer Causes Control*, 15(2), 159-170.
- Creswell, J. (2009). *Research design: Qualitative, quantitative and mixed methods approaches* (3rd ed.). London: Sage.
- Creswell, J., & Clark, V.L.P. (2007). *Designing and conducting mixed methods research* Thousand Oaks, Calif: SAGE Publications.
- Creswell, J., & Clark, V.L.P. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks: SAGE Publications.
- Critical Appraisal Skills Programme (CASP). (2013). CASP Chencklists. Retrieved 28<sup>th</sup> Oct., 2014, from <http://www.casp-uk.net/#!/casp-tools-checklists/c18f8>
- Daley, A. (2003). Lesbian health and the assumption of heterosexuality: An organizational perspective. *Canadian Journal of Community Mental Health*, 22(2), 105-121.
- Damron, B. I., Helitzer, D. L., Iriart, C., Newbill, S. L., & Cardinali, G. (2010). *Patient navigation for mammography screening: The need for system changes*. Paper presented at the ASCO Annual Meeting Proceedings.
- Davies, N., & Duff, M. (2001). Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research*, 45(3), 253-257.
- DeHart, D. D. (2008). Breast health behavior among lesbians: The role of health beliefs, heterosexism, and homophobia. *Women & Health*, 48(4), 409-427.

- Deutskens, E., de Ruyter, K., Wetzels, M., & Oosterveld, P. (2004). Response rate and response quality of internet-based surveys: An experimental study. *Marketing Letters*, 15, 21-36.
- DeVellis, R. (2003). *Scale development: Theory and applications* (2nd ed.). London: SAGE.
- Diamant, A. L., Schuster, M. A., & Lever, J. (2000). Receipt of prevention health care services by lesbians. *American Journal of Preventive Medicine*, 19(3), 141-148.
- Dibble, S. L., Roberts, S. A., & Nussey, B. (2004). Comparing breast cancer risk between lesbians and their heterosexual sisters. *Women's Health Issues*, 14(2), 60-68.
- Doyle, S. (2007). Member checking with older women: a framework for negotiating meaning. *Health Care for Women International*, 28(10), 888-908.
- Earp, J. A., Altpeter, M., Mayne, L., Viadro, C. I., & O'Malley, M. S. (1995). The North Carolina breast cancer screening program: Foundations and design of a model for reaching older, minority, rural women. *Breast Cancer Res Treat*, 35(1), 7-22.
- Edwards, M. L., & Smith, B. C. (2011). The effects of the neutral response option on the extremeness of participant responses. *Incite*, 6.
- Edwards, P., Roberts, I., Clarke, M., DiGuseppi, C., Pratap, S., Wentz, R., et al. (2002). Increasing response rates to postal questionnaires: systematic review. *BMJ*, 324(7347), 1183.
- Eliason, M. J., & Schope, R. (2001). Original research: Does "don't ask don't tell" apply to health care? Lesbian, gay, and bisexual people's disclosure to health care providers. *Journal of the Gay and Lesbian Medical Association*, 5(4), 125-134.
- Ell, K. (1984). Social networks, social support, and health status: A review. *The Social Service Review*, 133-149.
- Erzberger, C., & Kelle, U. (2002). Making inferences in mixed methods: the rules of intergrations In A. Tashakkori (Ed.), *Handbook of mixed methods in social & behavioral research*. London: SAGE.
- Erzberger, C., & Kelle, U. (2003). Making inferences in mixed methods: the rules of intergrations In A. Tashakkori & C. Teddlie (Eds.), *SAGE handbook of mixed methods in social & behavioral research*. London: SAGE.
- Evers, J. C. (2011). From the past into the future. How technological developments change our ways of data collection, transcription and analysis. *Forum: Qualitative Social Research*, 12. Retrieved 28<sup>th</sup> Oct., 2014, from <http://www.qualitative-research.net/index.php/fqs/article/viewArticle/1636>
- Faderman, L. (1985). *Surpassing the love of men*. London: Women's Press.
- Faderman, L. (1992). The return of butch and femme: A phenomenon in lesbian sexuality of the 1980s and 1990s. *Journal of the History of Sexuality*, 2(4), 578-596.

Fairburn, C. (2008). *Cognitive behavior therapy and eating disorders*. New York: Guilford Press.

Farma, K. K., Jalili, Z., Zareban, I., & Pour, M. S. (2014). Effect of education on preventive behaviors of breast cancer in female teachers of guidance schools of Zahedan city based on health belief model. *J Educ Health Promot*, 3, 77. doi: 10.4103/2277-9531.139240

Farquhar, C. (2000). Lesbian in a post-lesbian world? *Policing Identity, Sex and Image. Sexualities*, 3(2), 219-236.

Fenlason, K. J., Waller, V., & DeMay, C. C. (2002). Key issues and approaches to preserving anonymity and confidentiality in Web surveys. Data Recognition Corporation. Retrieved 23<sup>rd</sup> Feb., 2013, from [http://www.google.com/url?sa=t&rct=j&q=confidentiality+online+survey&source=web&cd=2&ved=0CEgQFjAB&url=http%3A%2F%2Fdrctest.com%2Fsurvey%2Farticles%2Fanon.pdf&ei=KqsoUdCnC-jb0QWs54GIAQ&usg=AFQjCNEtbMF\\_cmSThJ2YPrn2e80c9db-QA&bvm=bv.42768644,d.d2k](http://www.google.com/url?sa=t&rct=j&q=confidentiality+online+survey&source=web&cd=2&ved=0CEgQFjAB&url=http%3A%2F%2Fdrctest.com%2Fsurvey%2Farticles%2Fanon.pdf&ei=KqsoUdCnC-jb0QWs54GIAQ&usg=AFQjCNEtbMF_cmSThJ2YPrn2e80c9db-QA&bvm=bv.42768644,d.d2k)

Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser S, Mathers C, Rebelo M, Parkin DM, Forman D, Bray, F. (2013) GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11 [Internet]. Lyon, France: International Agency for Research on Cancer; 2013. Available from: <http://globocan.iarc.fr>, accessed on 27<sup>th</sup> Oct., 2014.

Ferlay J, Shin HR, Bray F, Forman D, Mathers C & Parkin DM. (2010) GLOBOCAN 2008 v1.2, Cancer Incidence and Mortality Worldwide: IARC Cancer Base No. 10 [Internet]. Lyon, France: International Agency for Research on Cancer; 2010. Available at: <http://globocan.iarc.fr>, accessed on 19<sup>th</sup> Oct., 2011.

Fernandez, M. E., DeBor, M., Candreia, M. J., Wagner, A. K., & Stewart, K. R. (1999). Evaluation of ENCOREplus. A community-based breast and cervical cancer screening program. *Am J Prev Med*, 16(3 Suppl), 35-49.

Fernandez, M. E., Palmer, R. C., & Leong-Wu, C. A. (2005). Repeat mammography screening among low-income and minority women: A qualitative study. *Cancer Control*, 77-83.

Finlay, K. A., Trafimow, D., & Jones, D. (1997). Predicting health behaviors: From attitudes and subjective norms: Between-subjects and within-subjects analyses. *Journal of Applied Social Psychology*, 27(22), 2015-2031.

Fish, J. (2000). Sampling lesbians: How to get 1000 lesbians to complete a questionnaire. *Feminism & Psychology*, 9(2), 224-236.

Fish, J. (2006). Exploring lesbians' health behaviours and risk perceptions. *Diversity in Health & Social Care*, 3(3), 163-169.

Fish, J., & Anthony, D. (2005). UK national lesbians and health care survey. *Women & Health*, 41(3), 27-45.

- Fish, J., & Wilkinson, S. (2003a). Explaining lesbians' practice of breast self-examination: results from a UK survey of lesbian health. *Health Education J*, 62(4), 304-315.
- Fish, J., & Wilkinson, S. (2003b). Understanding lesbians' healthcare behaviour: the case of breast self-examination. *Soc Sci Med*, 56(2), 235-245.
- Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention, and behavior: An introduction to theory and research*. Reading, MA: Addison-Wesley.
- Fishel, T. (1994). Extending the limits of social construction: Female homosexuality in Taiwan. *Historical Reflections/Reflexions Historiques*, 20(2), 267-286.
- Flick, U. (2006). *An introduction to qualitative research* (3 ed.). London: Sage.
- Flynn, B. S., Gavin, P., Worden, J. K., Ashikaga, T., Gautam, S., & Carpenter, J. (1997). Community education programs to promote mammography participation in rural New York State. *Prev Med*, 26(1), 102-108.
- Forbes, L., Atkins, L., Thurnham, A., Layburn, J., Haste, F., & Ramirez, A. J. (2011). Breast cancer awareness and barriers to symptomatic presentation among women from different ethnic groups in East London. *British Journal of Cancer*, 1-6.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, 36(6), 717-732.
- Fox, S. A., Heritage, J., Stockdale, S. E., Asch, S. M., Duan, N., & Reise, S. P. (2009). Cancer screening adherence: Does physician-patient communication matter? *Patient Educ Couns*, 75(2), 178-184.
- Galesic, M., & Bosnjak, M. (2009). Effects of questionnaire length on participation and indicators of response quality in a web survey. *Public Opinion Quarterly*, 73(2), 349-360.
- Georgy, E. E. (2011). Met or matched expectations: What accounts for a successful back pain consultation in primary care? (PhD thesis, Bournemouth University, Dorset, UK).
- Gerrish, K., & Lacey, A. (2007). *The research process in nursing* (5 ed.). Oxford: Blackwell.
- Gibson, M., & Meem, D. T. (2002). Introduction: The way we want to go. *Journal of Lesbian Studies*, 6, 3-8.
- Gierisch, J. M., O'Neill, S. C., Rimer, B. K., DeFrank, J. T., Bowling, J. M., & Skinner, C. S. (2009). Factors associated with annual-interval mammography for women in their 40s. *Cancer Epidemiol*, 33(1), 72-78.
- Glaser, B. G., & Strauss, A. L. (1968). *The discovery of grounded theory: Strategies for qualitative research*. London: Weidenfeld & Nicolson.
- Grant, R. W., & Sugarman, J. (2004). Ethics in human subjects research: Do incentives matter? *Journal of Medicine and Philosophy*, 29(6), 717-738.

- Greco, L. D., Walop, W., & McCarthy, R. H. (1987). Questionnaire development: 2. Validity and reliability. *CMAJ.*, 136(7), 699-700.
- Green, J., & Thorogood, N. (2009). *Qualitative methods for health research* (2nd ed.). Thousand Oaks, CA: Sage.
- Green, L., & Kreuter, M. (2005). *Health program planning: An educational and ecological approach* (4th ed.). Boston: McGraw Hill.
- Greene, J., Speizer, H., & Wiitala, W. (2008). Telephone and web: Mixed mode challenge. *Health services research*, 43(1p1), 230-248.
- Grindel, C. G., McGehee, L. A., Patsdaughter, C. A., & Roberts, S. J. (2006). Cancer prevention and screening behaviors in lesbians. *Women Health*, 44(2), 15-39.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.
- Gummesson, E. (2000). *Qualitative methods in management research*. London: Sage.
- Gunkel, H. (2009). Through the postcolonial eyes: images of gender and female sexuality in contemporary South Africa. *J Lesbian Stud*, 13(1), 77-87.
- Guyatt, G. H., Sackett, D. L., Cook, D. J., Guyatt, G., Bass, E., Brill-Edwards, P., et al. (1993). Users' guides to the medical literature II. How to use an article about therapy or prevention A. Are the results of the study valid? *JAMA*, 270(21), 2598-2601.
- Guyatt, G. H., Sackett, D. L., Cook, D. J., Guyatt, G., Bass, E., Brill-Edwards, P., et al. (1994). Users' guides to the medical literature: II. How to use an article about therapy or prevention B. What were the results and will they help me in caring for my patients? *JAMA*, 271(1), 59-63.
- Hajian, S., Vakilian, K., Najabadi, K. M., Hosseini, J., & Mirzaei, H. R. (2011). Effects of education based on the health belief model on screening behavior in high risk women for breast cancer, Tehran, Iran. *Asian Pac J Cancer Prev*, 12(1), 49-54.
- Halberstam, J. (1998). *Female masculinity*. London: Duke University Press.
- Halcomb, E., & Andrew, S. (2005). Triangulation as a method for contemporary nursing research. *Nurse Res*, 13(2), 71-82.
- Halcomb, E. J., & Davidson, P. M. (2006). Is verbatim transcription of interview data always necessary? *Applied Nursing Research*, 19, 38-42.
- Ham, O. K. (2005). The intention of future mammography screening among Korean women. *Journal of Community Health Nursing*, 22(1), 1-13.
- Hamilton, S. R. (2008). The relationship between perceived body image and depression: How college women see themselves may affect depression. *Student Journal of Psychological Sciences*, 1(1), 13-20.

Hankinson, S. E., Colditz, G. A., & Willett, W. C. (2004). Towards an integrated model for breast cancer etiology: the lifelong interplay of genes, lifestyle, and hormones. *Breast Cancer Res*, 6(5), 213-218.

Hanson, W. E., Creswell, J. W., Clark, V. L. P., Petska, K. S., & Creswell, J. D. (2005). Mixed methods research designs in counseling psychology. *Journal of counseling psychology*, 52(2), 224.

Harkness, J. (2013). VIII. Translation. Cross-cultural survey guideline Retrieved 14th. April, 2014, from <http://ccsg.isr.umich.edu/translation.cfm>

Hart, S. L., & Bowen, D. J. (2009). Sexual orientation and intentions to obtain breast cancer screening. *Journal of Women's Health*, 18(2), 177-185.

Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: Reviewing disparate data systematically. *Qual Health Res*, 12(9), 1284-1299.

Health Promotion Administration-Ministry of Health and Welfare. (2014) Cancer registry annual report, 2011 Taiwan, Retrieved 3<sup>rd</sup> March 2015, from <http://www.hpa.gov.tw/BHPNet/Web/Stat/StatisticsShow.aspx?No=201404160001> 【 Chinese version 】

Health Promotion Administration-Ministry of Health and Welfare. (2013<sub>a</sub>). Cancer prevention and Control. Retrieved 14<sup>th</sup> Jan., 2014, from <http://www.hpa.gov.tw/English/Class.aspx?Sub=application&No=200705180010> 【 Chinese version 】

Health Promotion Administration-Ministry of Health and Welfare. (2013<sub>b</sub>). Taiwan breast cancer, oral cancer and colorectal cancer screening programmes. Retrieved 10<sup>th</sup> Nov., 2014, from <http://www.hpa.gov.tw/Bhpnet/English/ClassShow.aspx?No=201312110001> 【 Chinese version 】

Herek, G. M. (2009). Hate crimes and stigma-related experiences among sexual minority adults in the United States: prevalence estimates from a national probability sample. *J Interpers Violence*, 24(1), 54-74.

Herek, G. M. (2010). Sexual orientation differences as deficits: Science and stigma in the history of American psychology. *Perspectives on Psychological Science*, 5(6), 693-699.

Héry, C., Ferlay, J., Boniol, M., & Autier, P. (2008). Quantification of changes in breast cancer incidence and mortality since 1990 in 35 countries with Caucasian-majority populations. *Ann Oncol*, 19(6), 1187-1194.

Hesse-Biber, S. N. (2010). *Mixed methods research: Merging theory with practice*. New York: Guilford Press.

Hiestand, K. R., Horne, S. G., & Levitt, H. M. (2008). Effects of gender identity on experiences of healthcare for sexual minority women. *Journal of LGBT health research*, 3(4), 15-27.



Hitchcock, J. M., & Wilson, H. S. (1992). Personal risking: Lesbian self-disclosure of sexual orientation to professional health care providers. *Nursing Research*, 41(3), 178-183.

Holliday, A. (2002). *Doing and writing qualitative research*. London: SAGE.

Holloway, I., & Todres, L. (2007). Grounded theory. In K. Gerrish & A. Lacey (Eds.), *The research process in nursing* (5th ed., pp. 192-207). Oxford: Blackwell.

Holloway, I., & Wheeler, S. (1996). *Qualitative research for nurses*. Oxford: Blackwell.

Hong, J. S. (2013). *A study on young lesbians' experiences of wearing breast binders* (Master's thesis, National Kaohsiung Normal University, Kaohsiung, Taiwan). 【Chinese version】

Hong, Z. R., Veach, P. M., & Lawrenz, F. (2003). An investigation of the gender stereotyped thinking of Taiwanese secondary school boys and girls. *Sex Roles*, 48(11/12), 495-504.

Horsburgh, D. (2003). Evaluation of qualitative research. *Journal of Clinical Nursing*, 12(2), 307-312.

Hou, K. H. (2007). White terror in postwar Taiwan. *Bulletin of Academia Historica* (12), 139-203.

Huang, H. H. (2012). *A qualitative exploration of intimate relationship maintainancing in long-term lesbian couples* (Master's thesis, National University of Tainan, Tainan, Taiwan). 【Chinese version】

Huang, H.M. (2006). Do print and Web surveys provide the same results? *Computers in Human Behavior*, 22(3), 334-350.

Huang, S. Y., Hung, T. J., Leu, J. G., Li, C. Y., & Chen, C. C. (2012). A study of mammogram utilization by older women with diabetes. *Journal of Helathcare Management*, 13(2), 95-109.

Hughes, J. (1997). *The philosophy of social research* (3 ed.). London Longman.

Hurdle, D. E. (2001). Social support: a critical factor in women's health and health promotion. *Health Soc Work*, 26(2), 72-79.

Hutchinson, M. K., Thompson, A. C., & Cederbaum, J. A. (2006). Multisystem factors contributing to disparities in preventive health care among lesbian women. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 35(3), 393-402.

Iglesias, C., & Torgerson, D. (2000). Does length of questionnaire matter? A randomised trial of response rates to a mailed questionnaire. *Journal of health services research & policy*, 5(4), 219-221.

Information Technology Services (ITS). (2008). Ethical Issues and "Netiquette". Retrieved 23<sup>rd</sup> February, 2013, from <http://www.utexas.edu/learn/surveys/ethics.html>

- Inness, S. A., & Lloyd, M. (1995). "GI Joes in Barbie Land": Recontextualizing butch in Twentieth-century lesbian culture. *NWSA Journal*, 1-23.
- Institution of Medicine (IOM). (2011). *The health of lesbian, gay, bisexual, and transgender people: Building a foundation for better understanding*. Washington, DC: The National Academies Press.
- International Agency for Research on Cancer (IARC). (2002). Breast cancer screening, IARC handbooks for cancer prevention, volume 7, Lyon, International Agency for Research on Cancer, IARC press.
- Jacob, T. C., Penn, N. E., & Brown, M. (1989). Breast self-examination: knowledge, attitudes, and performance among black women. *Journal of the National Medical Association*, 81(7), 769.
- Jillson, I. A. (2002). Opening closed doors: improving access to quality health services for LGBT populations. *Clinical Research and Regulatory Affairs*, 19(2-3), 153-190.
- Johl, S. K., & Renganathan, S. (2009). Strategies for gaining access in doing fieldwork: Reflection of two researchers. *Electronic Journal of Business Research Methods*, 8(1), 37-46.
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational researcher*, 33(7), 14-26.
- Kavanaugh-Lynch, M. H., White, E., & Daling, J. R. (2002). Correlates of lesbian sexual orientation and the risk of breast cancer. *Journal of the Gay and Lesbian Medical Association*, 6(3/4), 91-95.
- Kays, K., Gathercoal, K., & Buhrow, W. (2012). Does survey format influence self-disclosure on sensitive question items? *Computers in Human Behavior*, 28(1), 251-256.
- Kearney, A. J., & Murray, M. (2009). Breast cancer screening recommendations: is mammography the only answer? *Journal of Midwifery & Women's Health*, 54(5), 393-400.
- Kelly, L. (2007). Lesbian body image perceptions: the context of body silence. *Qualitative Health Research*, 17(7), 873-883.
- Kenagy, G. P. (2005). Transgender health: findings from two needs assessment studies in Philadelphia. *Health Soc Work*, 30(1), 19-26.
- Kerker, B. D., Mostashari, F., & Thorpe, L. (2006). Health care access and utilization among women who have sex with women: sexual behavior and identity. *Journal of Urban Health*, 83(5), 970-979.
- Khatib, O. M. N., & Modjtabai, A. (2006). Guidelines for the early detection and screening of breast cancer. World Health Organization (WHO). Technical Publications Series.
- Kitts, R. L. (2010). Barriers to optimal care between physicians and lesbian, gay, bisexual, transgender, and questioning adolescent patients. *Journal of Homosexuality*, 57(6), 730-747.

- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: the case for reflexivity. *Journal of Advanced Nursing & Health Sciences*, 28(4), 882-890.
- Kösters, J. P., & Gøtzsche, P. C. (2003). Regular self-examination or clinical examination for early detection of breast cancer. *Cochrane Database of Systematic Reviews* (2).
- Kraemer, B., Delsignore, A., Schnyder, U., & Hepp, U. (2007). Body image and transsexualism. *Psychopathology*, 41(2), 96-100.
- Kratzke, C., Garzon, L., Lombard, J., & Karlowicz, K. (2010). Training community health workers: factors that influence mammography use. *J Community Health*, 35(6), 683-688.
- Ku, Y. L. (2004). Chinese cultural beliefs about breast cancer and breast self-examination. *Taiwan Journal of Hospice Palliative Care*, 9(4), 313-335.
- Kuang, M., Mathy, R., Carol, H., & Kazuhiko, N. (2004). The effects of sexual orientation, gender identity, and gender role on the mental health of women in Taiwan's T-Po lesbian community. *Journal of Psychology & Human Sexuality*, 15(4), 163-184.
- Kurdek, L. A. (1993). The allocation of household labor in gay, lesbian, and heterosexual married couples. *Journal of Social Issues*, 49(3), 127-139.
- Kvale, S. (2008). *Interviews : An introduction to qualitative research interviewing* (2 ed.). London: SAGE.
- Kwok, C. (2006). Traditional Chinese health promotion and cancer screening practices among older Chinese women. Paper presented at the TASA Conference 2006. Retrieved 12<sup>th</sup> Nov., 2014, from <http://www.tasa.org.au/conferences/conferencepapers06/papers/Health%20and%20Ageing/Kwok.pdf>
- Lai, C. Y., Lai, C. M., Chen, C. Y., & Koo, M. (2012). Factors associated with non-utilization of mammographic screening services in middle-aged and elderly women in Taiwan. *The Journal of Nursing*, 59(2), 61-71. 【Chinese version】
- Lai, S. Y., Wang, M. C., Chu, L. L., & Hsieh, C. F. (2011). Factors associated with mammography acceptance among younger women in Taoyuan county. *Journal of Nursing and Healthcare Research*, 7(3), 224-232. 【Chinese version】
- Lark, J. S., & Croteau, J. M. (1998). Lesbian, gay, and bisexual doctoral students' mentoring relationships with faculty in counseling psychology: A qualitative study. *The Counseling Psychologist*, 26(5), 754-776.
- Laurilla, J. (1997). Promoting research access and informant rapport in corporate settings: Notes from research on a crisis company. *Scandinavian Journal of Management*, 13(4), 407-418.
- Lauver, D. R., Karon, S. L., Egan, J., Jacobson, M., Nugent, J., Settersten, L., et al. (1999). Understanding lesbians' mammography utilization. *Women's Health Issues*, 9(5), 264-274.

Laws & Regulations Database of the Republic of China. (2013). Act of gender equality in employment. Retrieved 14<sup>th</sup> October 2014, from <http://law.moj.gov.tw/eng/LawClass/LawContent.aspx?pcode=N0030014> 【Chinese version】

Laws & Regulations Database of the Republic of China. (2013). Gender equity education act. Retrieved 14<sup>th</sup> October, 2014, from <http://law.moj.gov.tw/eng/LawClass/LawContent.aspx?pcode=H0080067> 【Chinese version】

LeCompte, M. D., & Goetz, J. P. (1982). Problems of reliability and validity in ethnographic research. *Review of educational research*, 52(1), 31-60.

Lee, A. (2009). The role of butch/femme relationships in transgender activism: A codependent mutualism. *Stanford Undergraduate Research Journal*, 8, 18-23.

Leong, S. P. L., Shen, Z.Z., Liu, T.J., Agarwal, G., Tajima, T., Paik, N.S., et al. (2010). Is breast cancer the same disease in Asian and Western countries? *World Journal of Surgery*, 34(10), 2308-2324.

Levitt, H., & Hiestand, K. (2004). A quest for authenticity: Contemporary butch gender. *Sex Roles*, 50(9-10), 605-621.

Levitt, H. M., Gerrish, E. A., & Hiestand, K. R. (2003). The misunderstood gender: A model of modern femme identity. *Sex Roles*, 48(3-4), 99-113.

Levitt, H., & Horne, S. G. (2002). Explorations of lesbian-queer genders. *Journal of Lesbian Studies*, 6(2), 25-39.

Levitt, H. M., Puckett, J. A., Ippolito, M. R., & Horne, S. G. (2012). Sexual minority women's gender identity and expression: Challenges and Supports. *Journal of Lesbian Studies*, 16(2), 153-176.

Li, C. W. (2013). *Exploring the Behavior Intention of Breast Cancer Screening for Women by Applying the Theory of Planned Behavior*. (Master's thesis, Central Taiwan University of Science and Technology, Taichung, Taiwan) 【Chinese version】

Li, M. Z., & Zhong, Q. Y. (1996). Gender and gender role. *Indigenous Psychological Research in Chinese Societies* (6), 260-299. 【Chinese version】

Lien, M. T. (2006). A study of comparing MammaCare with the traditional breast self-examination education - Female college students in Taipei (Master's thesis, National Taiwan Normal University, Taipei, Taiwan) 【Chinese version】

Lin, H. Y. (2012). *Determining Factors of Mammogram Screening Behaviors Among Middle Age Women Using Health Belief Model*. (Master's thesis, Chia Nan University of Pharmacy and Science, Chia Yi, Tainan) 【Chinese version】

- Lin, S. (2008). Factors influencing the uptake of screening services for breast and cervical cancer in Taiwan. *Journal of the Royal Society for the Promotion of Health*, 128(6), 327-334.
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. London: Sage.
- Linsell, L., Burgess, C. C., & Ramirez, A. J. (2008). Breast cancer awareness among older women. *Br J Cancer*, 99(8), 1221-1225.
- Lopez, E. D., Khoury, A. J., Dailey, A. B., Hall, A. G., Chisholm, L. R., Lopez, E. D. S., et al. (2009). Screening mammography: a cross-sectional study to compare characteristics of women aged 40 and older from the deep South who are current, overdue, and never screeners. *Women's Health Issues*, 19(6), 434-445.
- Lu, M. L. (2001). Is her body "unclean"? Female body and the mass media. *Women's Network* (95). Retrieved 11<sup>th</sup> Nov., 2014, from <http://forum.yam.org.tw/bongchhi/old/body/body5.htm> 【Chinese version】
- Lu, Z. Y. (2001). Effectiveness of breast self-examination nursing interventions for Taiwanese community target groups. *Journal of Advanced Nursing*, 34(2), 163-170.
- Luo, S., Chen, P. L., Lee, T. Y., Chen, C. M., & Hsieh, C. M. (2001). Health beliefs and breast self-examination behaviors among high-risk women. *The Journal of Nursing*, 48(6), 59-68. 【Chinese version】
- Madge, C., & O'Connor, H. (2002). On-line with e-mums: exploring the Internet as a medium for research. *Area*, 34(1), 92-102.
- Makuc, D. M., Breen, N., Meissner, H. I., Vernon, S. W., & Cohen, A. (2007). Financial barriers to mammography: who pays out-of-pocket? *J Womens Health*, 16(3), 349-360.
- Mann, C. (2003). Observational research methods. Research design II: cohort, cross sectional, and case-control studies. *Emerg.Med J*, 20, 54-60.
- Marsh, C. (1982). *The survey method: The contribution of surveys to sociological explanation*. London: Allen & Unwin.
- Marshall, M. N. (1996). Sampling for qualitative research. *Fam Pract*, 13(6), 522-525.
- Mason, J. (1996). *Qualitative researching*. London: Sage.
- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research*, 11(3), Art. 8.
- Matheson, J. L. (2007). The voice transcription technique: Use of voice recognition software to transcribe digital interview data in qualitative research. *Qualitative Report*, 12(4), 547-560.
- Mathy, R. M., Schillace, M., Coleman, S. M., & Berquist, B. E. (2002). Methodological rigor with internet samples: new ways to reach underrepresented populations. *Cyberpsychol Behav*, 5(3), 253-266.

Maxwell, A. E., Bastani, R., & Warda, U. S. (1997). Breast cancer screening and related attitudes among Filipino-American women. *Cancer Epidemiology Biomarkers & Prevention*, 6(9), 719-726.

McAlearney, A. S., Reeves, K. W., Tatum, C., & Paskett, E. D. (2005). Perceptions of insurance coverage for screening mammography among women in need of screening. *Cancer*, 103(12), 2473-2480.

McDonald, J. (2014). *Handbook of Biological Statistics* (3 ed.). Baltimore: Sparky House Publishing.

McKenna, H., Hasson, F., & S., K. (2007). Surveys. In K. Gerrish & A. Lacey (Eds.), *The research process in nursing* (5 ed., pp. 260-273). Oxford Blackwell.

McNair, R. P. (2003). Lesbian health inequalities: a cultural minority issue for health professionals. *The Medical Journal of Australia*, 178(12), 643-645.

McTiernan, A., Kuniyuki, A., Yasui, Y., Bowen, D., Burke, W., Culver, J. B., et al. (2001). Comparisons of two breast cancer risk estimates in women with a family history of breast cancer. *Cancer Epidemiol Biomarkers Prev*, 10(4), 333-338.

Meads, C., & Moore, D. (2013). Breast cancer in lesbians and bisexual women: systematic review of incidence, prevalence and risk studies. *BMC Public Health*, 13(1), 1127.

Merriam, S. (1998). *Qualitative research and case study applications in education* (2nd ed.). San Francisco: Jossey-Bass.

Meyer, H. H., & Wilson, P. A. (2009). Sampling lesbian, gay, and bisexual populations. *American Psychological Association*, 56(1), 23-31.

Michels, T. C., Taplin, S. M., Carter, W. B., & Kugler, J. P. (1995). Barriers to screening: the theory of reasoned action applied to mammography use in a military beneficiary population. *Military medicine*, 160(9), 431-437.

Miller, K. (2005). *Communications theories: perspectives, processes, and contexts*. New York: McGraw-Hill.

Miller, S. J., O'Hea, E. L., Lerner, J. B., Moon, S., & Foran-Tuller, K. A. (2011). The relationship between breast cancer anxiety and mammography: experiential avoidance as a moderator. *Behav Med*, 37(4), 113-118.

Ministry of the Interior-Department of Statistics. (2013). The statistics on the education level of people over 15 years old. Retrieved 12<sup>th</sup> Nov., 2014, from <http://statis.moi.gov.tw/micst/stmain.jsp?sys=100>

Missinne, S., Colman, E., & Bracke, P. (2013). Spousal influence on mammography screening: a life course perspective. *Soc Sci Med*, 98, 63-70.

Mitra, S., & Globerman, J. (2014). *Rapid response: Facilitators and barriers to health care for lesbian, gay and bisexual (LGB) people*. Toronto: Ontario HIV Treatment Network.

Montano, D. E., Kasprzyk, D., & Taplin, S. H. (1997). The theory of reasoned action and the theory of planned behavior. In K. Glanz, F. M. Lewis & B. K. Rimer (Eds.), *Health behavior and health education: Theory, research, and practice* (2nd ed., pp. 85-112). San Francisco: Jossey-Bass.

Montano, D. E., & Taplin, S. H. (1991). A test of an expanded theory of reasoned action to predict mammography participation. *Social Science & Medicine*, 32(6), 733-741.

Moodi, M., Mood, M. B., Sharifirad, G. R., Shahnazi, H., & Sharifzadeh, G. (2011). Evaluation of breast self-examination program using Health Belief Model in female students. *J Res Med Sci*, 16(3), 316-322.

Morgan, D. L. (1998). Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative health research*, 8(3), 362-376.

Morgan, D. L. (2007). Paradigms lost and pragmatism regained methodological implications of combining qualitative and quantitative methods. *Journal of mixed methods research*, 1(1), 48-76.

Morgan, G. (2011). *IBM SPSS for introductory statistics use and interpretation* (4 ed.). Hoboken: Taylor and Francis.

Morris, D. L., Fenton, M. V., & Mercer, Z. B. (2004). Identification of national trends in nursing education through the use of an online survey. *Nursing Outlook*, 52(5), 248-254.

Morrison, T. G., & McCutcheon, J. M. (2011). Gay and lesbian body images. In T. F. Cash & L. Smolak (Eds.), *Body image: A handbook of science, practice, and prevention* (2 ed., pp. 214-220). New York: Guilford Press.

Morrow, S. L. (2007). Qualitative research in counseling psychology conceptual foundations. *The Counseling Psychologist*, 35(2), 209-235.

Morse, J. (1994). Designing funded qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 220-235). Thousand Oaks, CA: Sage Publications.

Mravcak, S. A. (2006). Primary care for lesbians and bisexual women. *Screening*, 100(10), 12-15.

Munro, B. (2004). *Statistical methods for health care research* (5th ed.). London: Lippincott Williams & Wilkins.

Mustanski, B. S. (2001). Getting wired: Exploiting the internet for the collection of valid sexuality data. *Journal of Sex Research*, 38(4), 292-301.

Naidoo, J., & Wills, J. (2010). *Developing practice for public health and health promotion* (3rd ed.). London: Baillière Tindall.

Nardi, P. M. (2003). *Doing survey research: A good guide to quantitative methods*. London: Allyn & Bacon.

National Statistics ROC (Taiwan). (2013). Earning and Productivity. Retrieved 12<sup>th</sup> Nov., 2014, from <http://eng.stat.gov.tw/np.asp?CtNode=1544> 【Chinese version】

Navarro, A. M., Senn, K. L., McNicholas, L. J., Kaplan, R. M., Roppe, B., & Campo, M. C. (1998). Por La Vida model intervention enhances use of cancer screening tests among Latinas. *Am J Prev Med*, 15(1), 32-41.

Nekhlyudov, L., Ross-Degnan, D., & Fletcher, S. W. (2003). Beliefs and expectations of women under 50 years old regarding screening mammography: A qualitative study. *J Gen Intern Med*, 18, 182-189.

Newman, B., Moorman, P. G., & Millikan, R. et al. (1995). The Carolina breast cancer study: integrating population-based epidemiology and molecular biology. *Breast Cancer Res Treat*, 35(1), 51-60.

NHS Breast Screening Programme (NHSBSP). (2010-2016). Retrieved 28<sup>th</sup> Oct., 2014, from <http://www.cancerscreening.nhs.uk/breastscreen/index.html>

Nielsen, J. (2000). Why you only need to test with 5 users. Nielsen Norman Group: Evidence-based user experience research, training and consulting. Retrieved 11<sup>th</sup> Nov. 2014, 2014, from <http://www.nngroup.com/articles/why-you-only-need-to-test-with-5-users/>

Norman, P., & Cooper, Y. (2011). The theory of planned behaviour and breast self-examination: assessing the impact of past behaviour, context stability and habit strength. *Psychol Health*, 26(9), 1156-1172.

O'Hanlan, K. A., Dibble, S. L., Hagan, H. J. J., & Davids, R. (2004). Advocacy for women's health should include lesbian health. *Journal of Women's Health*, 13(2), 227-234.

Onwuegbuzie, A. J., Bustamante, R. M., & Nelson, J. A. (2010). Mixed research as a tool for developing quantitative instruments. *Journal of Mixed Methods Research*, 4(1), 56-78.

Oppenheim, A. (1992). *Questionnaire design, interviewing and attitude measurement*. London: Continuum.

Oxford Dictionaries. (2013). Retrieved 21<sup>st</sup> Dec., 2013, from <http://www.oxforddictionaries.com/definition/english/sexual-orientation?q=sexual+orientation>

Padgett, D. K. (2008). *Qualitative methods in social work research* (2 ed.). Thousand Oaks: CA: Sage.

Page, A., Morrell, S., Tewson, R., Taylor, R., & Brassil, A. (2005). Mammography screening participation: effects of a media campaign targeting Italian-speaking women. *Aust N Z J Public Health*, 29(4), 365-371.

Park, E. W., Schultz, J. K., Tudiver, F., Campbell, T., & Becker, L. (2004). Enhancing partner support to improve smoking cessation. *Cochrane Database Syst Rev*, 3.

Patton, M. (1990). *Qualitative evaluation and research methods* (2nd ed.). London: Sage.



Pealer, L. N., Weiler, R. M., Pigg, R. M., Miller, D., & Dorman, S. M. (2001). The feasibility of a web-based surveillance system to collect health risk behavior data from college students. *Health Education & Behavior*, 28(5), 547-559.

Peng, S. Y. (2008). Love and hate-Lesbian's views towards her own breasts. Paper presented at the Sex, body and relationship: transformation and integration.

Pennant, M., Bayliss, S., & Meads, C. (2009). Improving lesbian, gay and bisexual healthcare: a systematic review of qualitative literature from the UK. *Diversity in Health & Care*, 6(3), 193-203.

Peplau, L., & Huppin, M. (2008). Masculinity, femininity and the development of sexual orientation in women. *Journal of Gay and Lesbian Mental Health*, 12(1/2), 145-165.

Peplau, L. A., Fingerhut, A., & Beals, K. P. (2004). Sexuality in the relationships of lesbians and gay men. In J. Harvey, A. Wenzel & S. Sprecher (Eds.), *Handbook of sexuality in close relationship* (pp. 349-369). Mahwah, NJ: Erlbaum.

Pitman, G. (2000). The influence of race, ethnicity, class, and sexual politics on lesbians' body image. *Journal of Homosexuality*, 40(2), 49-64.

Platzer, H., & James, T. (1997). Methodological issues conducting sensitive research on lesbian and gay men's experience of nursing care. *Journal of Advanced Nursing*, 25, 626-633.

Polek, C. A., Hardie, T. L., & Crowley, E. M. (2008). Lesbians' disclosure of sexual orientation and satisfaction with care. *J Transcult Nurs*, 19(3), 243-249.

Poss, J. E. (2001). Developing a new model for cross-cultural research: synthesizing the health belief model and the theory of reasoned action. *Advances in Nursing Science*, 23(4), 1-15.

Prestwich, A., Conner, M., Lawton, R., Bailey, W., Litman, J., & Molyneaux, V. (2005). Individual and collaborative implementation intentions and the promotion of breast self-examination. *Psychology and Health*, 20(6), 743-760.

Procter, S., & Allen, T. (2007). Sampling. In K. Gerrish & A. Lacey (Eds.), *The research process in nursing* (5 ed., pp. 173-191). Oxford: Blackwell.

Punch, K. F. (2007). *Survey Research: the Basics*. London: SAGE.

Radiological Society of North America. (2011). Mammography. Retrieved 28<sup>th</sup> Oct., 2014, from <http://www.radiologyinfo.org/en/info.cfm?pg=mammo>

Rankow, E. J., & Tessaro, I. (1998). Mammography and risk factors for breast cancer in lesbian and bisexual women. *American Journal of Health Behavior*, 22(6), 403-410.

Reichert, E. 2006. *Understanding human rights: An exercise book*: Pearson Education Ltd.

Restore-National Centre for Research Methods. Online questionnaire. Retrieved 12<sup>th</sup> Nov., 2014, from <http://www.restore.ac.uk/orm/questionnaires/index.html>

Rezaeian, M., Sharifirad, G., Mostafavi, F., Moodi, M., & Abbasi, M. H. (2014). The effects of breast cancer educational intervention on knowledge and health beliefs of women 40 years and older, Isfahan, Iran. *J Educ Health Promot*, 3, 43.

Richardson, L. (1990). *Writing strategies: Reaching diverse audiences*. London: Sage.

Ridolfi, D. R., & Crowther, J. H. (2013). The link between women's body image disturbances and body-focused cancer screening behaviors: A critical review of the literature and a new integrated model for women. *Body Image*, 10(2), 149-162.

Ritchie, J., Lewis, J., & Elam, G. (2003). Designing and selecting samples. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 77-108). Thousand Oaks, CA: Sage.

Roberts, S. A., Dibble, S. L., Scanlon, J. L., Paul, S. M., & Davids, H. (1998). Differences in risk factors for breast cancer: lesbian and heterosexual women. *Journal of the Gay and Lesbian Medical Association*, 2(3), 93-101.

Roberts, S. J., Patsdaughter, C. A., Grindel, C. G., & Tarmina, M. S. (2004). Health related behaviors and cancer screening of lesbians: Results of the Boston lesbian health project II. *Women & Health*, 39(4), 41-55.

Roberts, S. J., & Sorensen, L. (1999). Health related behaviors and cancer screening of lesbians: results from the Boston lesbian health project. *Women & Health*, 28(4), 1-12.

Robertson, M. M. (1992). Lesbians as an invisible minority in the health services arena. *Health Care Women Int*, 13(2), 155-163.

Robson, C. (1993). *Real world research: A resource for social scientists and practitioner researchers*. Oxford: Blackwell.

Robson, C. (2011). *Real world research: A resource for users of social research methods in applied settings* (3 ed.). Chichester: Wiley.

Rondahl, G., Innala, S., & Carlsson, M. (2006). Heterosexual assumptions in verbal and non-verbal communication in nursing. *J Adv Nurs*, 56(4), 373-381.

Rosenstock, I. M. (2005). Why People Use Health Services. *Milbank Quarterly*, 83(4), Online-only. doi: 10.1111/j.1468-0009.2005.00425.x. Retrieved 13<sup>th</sup> Nov., 2014, from <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-0009.2005.00425.x/full>

Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. *Health Education & Behavior*, 15(2), 175-183.

Rossi, D. J., Jamieson, C. H., & Weissman, I. L. (2008). Stems cells and the pathways to aging and cancer. *Cell*, 132(4), 681-696.

Roszkowski, M. J., & Bean, A. G. (1990). Believe it or not! Longer questionnaires have lower response rates. *Journal of Business and Psychology*, 4(4), 495-509.

- Rubel, A. J., & Garro, L. C. (1992). Social and cultural factors in the successful control of tuberculosis. *Public health reports*, 107(6), 626.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16(2), 1-8.
- Schootman, M., & Jeffe, D. B. (2003). Identifying factors associated with disability-related differences in breast-cancer screening. *Cancer Causes Control*, 14, 97–107.
- Seale, C. (1999). Quality in qualitative research. *Qualitative Inquiry*, 5(4), 465-478.
- Shieh, W. Y. (2010). Gay and lesbian couple relationship commitment in Taiwan: A preliminary study. *Journal of Homosexuality*, 57(10), 1334-1354.
- Shin, H. R., Joubert, C., Boniol, M., Hery, C., Ahn, S. H., Won, Y. J., et al. (2010b). Recent trends and patterns in breast cancer incidence among Eastern and Southeastern Asian women. *Cancer Causes & Control*, 21(11), 1777-1785.
- Silman, A. J., & Macfarlane, G. J. (2002). Studies of disease occurrence II: Assessing disease status in study population. In A. J. Silman & G. J. Macfarlane (Eds.), *Epidemiological studies: A practical guide*. Cambridge: University Press.
- Singer, E., & Bossarte, R. M. (2006). Incentives for survey participation: When are they “coercive”?? *American Journal of Preventive Medicine*, 31(5), 411-418.
- Singh, D., Vidaurri, M., Zambarano, R., & Dabbs, J. (1999). Lesbian erotic role identification: behavioral, morphological, and hormonal correlates. *J Pers Soc Psychol.*, 76(6), 1035-1049.
- Skills Website, Faculty of Humanities Study, University of Manchester. (2015). Essays and Reports. Retrieved 20th June, 2015, from <http://www.humanities.manchester.ac.uk/studyskills/essentials/writing/essays.html>
- Smith, L. (1992). Ethical issues in interviewing. *Journal of Advanced Nursing*, 17(1), 98-103.
- Sparks, L., & Villagran, M. (2010). *Patient and provider interaction: A global health communication perspective*. Cambridge: Polity.
- Spence, P., & Liu, G. Z. (2013). Engineering English and the high-tech industry: A case study of an English needs analysis of process integration engineers at a semiconductor manufacturing company in Taiwan. *English for Specific Purposes*, 32(2), 97-109.
- St Claire, L. (2003). *Rival truths : Common sense and social psychological explanations in health and illness*. Hove: Psychology Press.
- Starks, H., & Trinidad, S. B. (2007). Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res*, 17(10), 1372-1380.
- Stevens, P. E. (1996). Lesbians and doctors experiences of solidarity and domination in health care settings. *Gender & Society*, 10(1), 24-41.

- Stevens, P. E., & Hall, J. M. (1988). Stigma, health beliefs and experiences with health care in lesbian women. *Image: The Journal of Nursing Scholarship*, 20(2), 69-73.
- Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: a review. *CMAJ*, 152(9), 1423.
- Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion*, 10(4), 282-298.
- Stonewall. (2013). What is sexual orientation? Retrieved 4<sup>th</sup> January, 2013, from [http://www.stonewall.org.uk/at\\_home/sexual\\_orientation\\_faqs/2695.asp](http://www.stonewall.org.uk/at_home/sexual_orientation_faqs/2695.asp)
- Stroebe, W. (2000). *Social psychology and health* (2nd ed.). Buckingham: Open University Press.
- Stroebe, W., & de Wit, J. (1996). Health impairing behaviours. In G. R. Semin & K. Fiedler (Eds.), *Applied social psychology* (pp. 113-143). London: Sage.
- Su, S. K. (2005). *T/Po identity within a relationship in Taiwan* (Master's thesis, National Dong Hwa University, Hualien, Taiwan). 【Chinese version】
- Sullivan, D., & Losberg, L. (2003). A study of sampling in research in the field of gay and lesbian studies. *Journal of Gay and Lesbian Social Services*, 15(1/2), 147-162.
- Sullivan, S. G., Slack-Smith, L. M., & Hussain, R. (2004). Understanding the use of breast cancer screening services by women with intellectual disabilities. *Sozial- und Präventivmedizin*, 49, 398-405.
- SurveyMonkey. (2013). Security Statement. Retrieved 12<sup>th</sup> Nov., 2014, from <https://www.surveymonkey.com/mp/policy/security/>
- Taipei Association for the Promotion of Women's Rights (TAPWR). (2008). Lesbians' healthcare issues in Taiwan. Retrieved 1<sup>st</sup> October, 2011, from [http://www.tapwr.org.tw/research\\_list.asp?artcatid=4&artcat2id=10&nouse=158](http://www.tapwr.org.tw/research_list.asp?artcatid=4&artcat2id=10&nouse=158) 【Chinese version】
- Taipei Association for the Promotion of Women's Right (TAPWR). (2007). *The handbook of lesbian health*. Taipei: Taipei Association for the Promotion of Women's Right . 【Chinese version】
- Taiwan Alliance to Promote Civil Partnership Rights. (2013). Same sex marriage bill. Retrieved 14<sup>th</sup> October, 2014, from <http://tapcpr.wordpress.com/> 【Chinese version】
- Taiwan Breast Cancer Alliance (TBCA). E-learning: Breast self-examination. Retrieved 14<sup>th</sup> Jan., 2014, from <http://www.tbca-npo.org.tw/activity/elearning2.asp> 【Chinese version】
- Taiwan Breast Cancer Foundation. Retrieved 14<sup>th</sup> Jan., 2014, from <http://www.breastcf.org.tw/> 【Chinese version】

Taiwan Cancer Registry. (2014). Cancer Incidence and Mortality Rates in Taiwan Retrieved 24<sup>th</sup> Dec. 2014, from <http://tcr.cph.ntu.edu.tw/main.php?Page=N2> 【Chinese version】

Taiwan Clinical Oncology Research Foundation. (2010). Breast self-examination handbook. Retrieved 14<sup>th</sup> Jan., 2014, from <http://cisc.twbbs.org/lifetype/index.php?op=ViewArticle&articleId=2727&blogId=1> 【Chinese version】

Tang, T. S., Patterson, S. K., Roubidoux, M. A., & Duan, L. (2009). Women's mammography experience and its impact on screening adherence. *Psychooncology*, 18(7), 727-734.

Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. London: SAGE.

Taylor, D., Bury, M., Campling, N., Carter, S., Garfield, S., Newbould, J., et al. (2006). A review of the use of the Health Belief Model (HBM), the Theory of Reasoned Action (TRA), the Theory of Planned Behaviour (TPB) and the Trans-Theoretical Model (TTM) to study and predict health related behaviour change. London, UK: National Institute for Health and Clinical Excellence, 1-215. Retrieved 12<sup>th</sup> Nov., 2014, from <https://www.nice.org.uk/guidance/ph6/resources/behaviour-change-taylor-et-al-models-review2>

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research : Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Thousand Oaks: Sage.

The archives of Institute of Taiwan History-Academia Sinica (2010). Taiwan archival information system. Retrieved 21<sup>st</sup> Dec., 2013, from <http://archives.ith.sinica.edu.tw/en> 【Chinese version】

The Lesbian and Gay Foundation. (2013). Beyond babies and breast cancer: Expanding our understanding of women's health needs. Retrieved 12<sup>th</sup> Nov., 2014, from [file:///C:/Users/joan/Downloads/FENT\\_1390566066\\_Health\\_care\\_needs\\_of\\_LB\\_women\\_%20\(1\).pdf](file:///C:/Users/joan/Downloads/FENT_1390566066_Health_care_needs_of_LB_women_%20(1).pdf)

Thomas, E., & Magilvy, J. K. (2011). Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing*, 16(2), 151-155.

Thompson, W. D. (1994). Genetic epidemiology of breast cancer. *Cancer*, 74(Suppl.1), 279-287.

Thorne, S. (2000). Data analysis in qualitative research. *Evidence Based Nursing*, 3(3), 68-70.

Thornton, H., & Pillarisetti, R. R. (2008). 'Breast awareness' and 'breast self-examination' are not the same. What do these terms mean? Why are they confused? What can we do? *European Journal of Cancer*, 44(15), 2118-2121.

Tilley, S. A. (2003). Challenging research practices: Turning a critical lens on the work of transcription. *Qualitative Inquiry*, 9(5), 750-773.

Tod, A. (2007). Interviewing In K. L. Gerrish & A. Lacey. (Eds.), *The research process in nursing* (pp. 337-352). London: Blackwell.

Trautmann, J., Worthy, S. L., & Lokken, K. L. (2007). Body dissatisfaction, bulimic symptoms, and clothing practices among college women. *The Journal of Psychology*, 141, 485-489.

Trochim, W. (2006). Research methods. Retrieved 22<sup>nd</sup> June, 2014, from <http://www.socialresearchmethods.net/kb/index.php>

Trost, S. G., Saunders, R., & Ward, D. S. (2002). Determinants of physical activity in middle school children. *American Journal of Health Behavior*, 26(2), 95-102.

Tsai, H. W., Twu, N. F., Ko, C. C., Yen, M. S., Yang, M. J., Chao, K. C., et al. (2011). Compliance with screening mammography and breast sonography of young Asian women. *Eur J Obstet Gynecol Reprod Biol*, 157(1), 89-93.

Tsai, Y. S. (2006). *The division of household labor in Taiwan lesbian family* (Master's thesis, Soochow University, Taipei, Taiwan). 【Chinese version】

Tseng, H. Y., Shieh, W. Y., & Hsiao, Y. L. (2008). Looking at power structure of same -sex couples from their conflict resolution styles. *Soochow Journal of Sociology*, 23, 71-106. 【Chinese version】

Tsou, P. I. (2013). *Exploration of factors affecting acceptance of mammography of female residents in Tucheng District, New Taipei City* (Master's thesis, Chang Gung University, Taoyuan, Taiwan). 【Chinese version】

US Preventive Services Task Force (USPSTF). (2009). Screening for Breast Cancer. Retrieved 13<sup>th</sup> Jan., 2014, from <http://www.uspreventiveservicestaskforce.org/uspstf/uspsbrca.htm>

Valanis, B. G., Bowen, D. J., Bassford, T., Whitlock, E., Charney, P., & Carter, R. A. (2000). Sexual orientation and health: comparisons in the women's health initiative sample. *Arch Fam Med*, 9(9), 843-853.

Van Dam, M. A. A., Koh, A. S., & Dibble, S. L. (2001). Original Research: Lesbian disclosure to health care providers and delay of care. *Journal of the Gay and Lesbian Medical Association*, 5(1), 11-19.

Vickers, A. J. (2005). Parametric versus non-parametric statistics in the analysis of randomized trials with non-normally distributed data. *BMC Medical Research Methodology*, 5(1), 35.

Wainwright, M., & Russell, A. (2010). Using NVivo audio-coding: Practical, sensorial and epistemological considerations. *Social Research Update* (60), 1-4. Retrieved 12<sup>th</sup> Nov., 2014, from <http://sru.soc.surrey.ac.uk/SRU60.pdf>

- Walker, J. N. J., Golub, S. A., Bimbi, D. S., & Parsons, J. T. (2012). Butch bottom-femme top? An exploration of lesbian stereotypes. *Journal of Lesbian Studies*, 16(1), 90-107.
- Wang, C. J. (2010). *Invisible identities: A narrative inquiry on the process of lesbian identity of people with visual impairment* (Master's thesis, Taipei Physical Education College, Taipei, Taiwan). 【Chinese version】
- Wang, T. H. (2013). *The medical experiences of lesbian women* (Master's thesis, Kaohsiung Medical University, Kaohsiung, Taiwan). 【Chinese version】
- Wasserman, J., & Jeffrey, C. (2007). *Assessing distrustful populations: Lesson from ethnographic research with street homeless*. Paper presented at the annual meeting of the American Sociological Association.
- Weinstein, N. D., & Sandman, P. M. (1992). A model of the precaution adoption process: Evidence from home radon testing. *Health Psychology*, 11, 170-180.
- Weinstein, N. D., Sandman, P. M., & Blalock, S. J. (2008). Chapter 6: The precaution adoption process model. In [K. Glanz](#), [B. K. Rimer](#), [K. Viswanath](#) (Eds.), *Health behavior and health education* (pp. 123-148). San Francisco, CA: John Wiley & Sons, Inc.
- White, J. C., & Dull, V. T. (1997). Health risk factors and health-seeking behavior in lesbians. *J Women's Health*, 6(1), 103-112.
- Whitley, E., & Ball, J. (2002). Statistics review 4: sample size calculations. *Crit Care*, 6(4), 335-341.
- World Health Organization (WHO). (2013). What do we mean by "sex" and "gender"? Retrieved 21<sup>st</sup> Dec., 2013, from <http://www.who.int/gender/whatisgender/en/>
- World Health Organization (WHO). (2014). Breast cancer burden. Retrieved 10<sup>th</sup> Nov., 2014, from <http://www.who.int/cancer/detection/breastcancer/en/index1.html>
- Worthington, R. L., & Whittaker, T. A. (2006). Scale development research a content analysis and recommendations for best practices. *The Counseling Psychologist*, 34(6), 806-838.
- Wright, K. B. (2005). Researching internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *Journal of Computer-Mediated Communication*, 10(3). Retrieved 12<sup>th</sup> Nov., 2014, from [http://onlinelibrary.wiley.com/doi/10.1111/j.1083-6101.2005.tb00259.x/full?utm\\_source](http://onlinelibrary.wiley.com/doi/10.1111/j.1083-6101.2005.tb00259.x/full?utm_source)
- Wu, T. Y., Chung, S., Yeh, M. C., Chang, S. C., Hsieh, H. F., & Ha, S. J. (2012). Understanding breast cancer screening practices in Taiwan: A country with universal health care. *Asian Pac J Cancer Prev*, 13(9), 4289-4294.
- Yalom, M. (1998). *A history of the breast*. London: Pandora.

- Yang, R. J., Huang, L. H., Hsieh, Y. S., Chung, U. L., Huang, C. S., & Bih, H. D. (2010). Motivations and reasons for women attending a breast self-examination training program: A qualitative study. *BMC Women's Health*, 10, 23.
- Yeh, H. Y. (2012). *The social protection of another intimacy--A study on the lesbian family life* (Master's thesis, Nanhua University, Chiayi, Taiwan). 【Chinese version】
- Yen, C. F., Pan, S. M., Hou, S. Y., Liu, H. C., Wu, S. J., Yang, W. C., et al. (2007). Attitudes toward gay men and lesbians and related factors among nurses in Southern Taiwan. *Public Health*, 121(1), 73-79.
- Young, I. (2005). *On female body experience: "Throwing like a girl" and other essays*. Oxford: Oxford University Press.
- Yu, D. S., Lee, D. T., & Woo, J. (2004). Issues and challenges of instrument translation. *West J Nurs Res*, 26(3), 307-320.
- Zaritsky, E., & Dibble, S. L. (2010). Risk factors for reproductive and breast cancers among older lesbians. *Journal of Women's Health*, 19(1), 125-131.
- Zeitoun, E., & Yu, C. H. (2005). The Formosan language archive: Linguistic analysis and language processing. *International Journal of Computational Linguistics & Chinese Language Processing*, 10(2), 167-200.
- Zeng, C. (2004). Lesbian's health problems and its countermeasures. *Zhongguo Xing Kexue*, 3, 39-41. 【Chinese version】
- Zhang, A. (2011). Women's breasts and beyond-A gender analysis of the appeals for breasts-unbinding: 1910s-1920s. *Postscript: A Journal of Graduate Criticism and Theory*. Retrieved 12<sup>th</sup> Nov., 2014, from <file:///C:/Users/joan/Downloads/286-881-1-PB.pdf>
- Zhang, F. J. (2011). *Unlimited love*. Taipei: China Times. 【Chinese version】



## Appendices

### Appendix 1: A protocol of Hawker et al's (2002) score system

1. Abstract and title: Did they provide a clear description of the study?
  - Good        Structured abstract with full information and clear title.
  - Fair         Abstract with most of the information.
  - Poor         Inadequate abstract.
  - Very Poor    No abstract.
2. Introduction and aims: Was there a good background and clear statement of the aims of the research?
  - Good         Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge.  
Clear statement of aim AND objectives including research questions.
  - Fair         Some background and literature review.  
Research questions outlined.
  - Poor         Some background but no aim/objectives/questions, OR  
Aims/objectives but inadequate background.
  - Very Poor    No mention of aims/objectives.  
No background or literature review.
3. Method and data: Is the method appropriate and clearly explained?
  - Good         Method is appropriate and described clearly (e.g., questionnaires included).  
Clear details of the data collection and recording.
  - Fair         Method appropriate, description could be better.  
Data described.
  - Poor         Questionable whether method is appropriate.  
Method described inadequately.  
Little description of data.
  - Very Poor    No mention of method, AND/OR  
Method inappropriate, AND/OR  
No details of data.
4. Sampling: Was the sampling strategy appropriate to address the aims?
  - Good         Details (age/gender/race/context) of who was studied and how they were recruited.  
Why this group was targeted.  
The sample size was justified for the study.  
Response rates shown and explained.
  - Fair         Sample size justified.  
Most information given, but some missing.
  - Poor         Sampling mentioned but few descriptive details.
  - Very Poor    No details of sample.
5. Data analysis: Was the description of the data analysis sufficiently rigorous?
  - Good         Clear description of how analysis was done.  
Qualitative studies: Description of how themes derived/  
respondent validation or triangulation.  
Quantitative studies: Reasons for tests selected hypothesis driven/  
numbers add up/statistical significance discussed.
  - Fair         Qualitative: Descriptive discussion of analysis.  
Quantitative.
  - Poor         Minimal details about analysis.
  - Very Poor    No discussion of analysis.

## Appendix 1: A protocol of Hawker et al's (2002) score system (Con.)

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?
- |           |                                                                                             |
|-----------|---------------------------------------------------------------------------------------------|
| Good      | Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. |
|           | Bias: Researcher was reflexive and/or aware of own bias.                                    |
| Fair      | Lip service was paid to above (i.e., these issues were acknowledged).                       |
| Poor      | Brief mention of issues.                                                                    |
| Very Poor | No mention of issues.                                                                       |
7. Results: Is there a clear statement of the findings?
- |           |                                                                                                                                                                                                            |
|-----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Good      | Findings explicit, easy to understand, and in logical progression.<br>Tables, if present, are explained in text.<br>Results relate directly to aims.<br>Sufficient data are presented to support findings. |
| Fair      | Findings mentioned but more explanation could be given.<br>Data presented relate directly to results.                                                                                                      |
| Poor      | Findings presented haphazardly, not explained, and do not progress logically from results.                                                                                                                 |
| Very Poor | Findings not mentioned or do not relate to aims.                                                                                                                                                           |
8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?
- |           |                                                                                                                                                            |
|-----------|------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Good      | Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling). |
| Fair      | Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.                |
| Poor      | Minimal description of context/setting.                                                                                                                    |
| Very Poor | No description of context/setting.                                                                                                                         |
9. Implications and usefulness: How important are these findings to policy and practice?
- |           |                                                                                                                                                                                           |
|-----------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Good      | Contributes something new and/or different in terms of understanding/insight or perspective.<br>Suggests ideas for further research.<br>Suggests implications for policy and/or practice. |
| Fair      | Two of the above (state what is missing in comments).                                                                                                                                     |
| Poor      | Only one of the above.                                                                                                                                                                    |
| Very Poor | None of the above.                                                                                                                                                                        |

---

Resources from: Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002, pp 1296-1297). Appraising the evidence: reviewing disparate data systematically. *Qualitative Health Research*, 12(9), 1284-1299.

## Appendix 2: Summary of the Taiwanese studies – qualitative interview studies, longitudinal study and secondary data analyses

Author/language	Aim	Study design	Sampling strategies	Sample/ response rates if stated	Data resource/ measurement tool/ theoretical framework	Quality of the study
Yang et al. (2010) <i>English version</i>	To understand the experiences and decision-making processes of performing BSEs among women aged 27-50 years.	Qualitative interviews	Purposive sampling	66 women Aged 27-50	Local area: North Taipei	Fair
Ku (2004) <i>English version</i>	To explore Chinese women's cultural beliefs regarding breast cancer and BSE, and to establish the Chinese features of cultural variations for the HBM of breast cancer and BSE.	Qualitative interviews	Purposive and snowball sampling	37 women Aged 18-65	Local area: Kaohsiung/ Meleis's criteria / the HBM	Good
Tsai et al. (2011) <i>English version</i>	To evaluate compliance with mammography and breast sonography and to explore the factors related to compliance.	Longitudinal study	Did not specify	1,239 women Aged 40-49	Local area: Taipei Veterans Hospital	Fair
Huang et al. (2012) <i>Chinese version</i>	To compare the utilisation rates of mammography of women aged 50-68 years both with and without diabetes mellitus (DM), and to explore the factors relating to the DM women's mammography adherence.	Secondary data analysis	Stratified random sampling	9,254 DM women 37, 016 women without DM Aged 50-68	2005 & 2006 National insurance research database	Good
Lai et al. (2012) <i>Chinese version</i>	To investigate the factors associated with the non-utilisation of mammographic screening services by women aged 50-69 years in Taiwan.	Secondary data analysis	Stratified random sampling	2,216 women Aged 50-69 Response rate: 81%	2005 National Health Interview Survey/ Anderson's Behavioural model of health services use	Good
Lai et al. (2011) <i>Chinese version</i>	To investigate the utilisation rate of mammograms among women aged 30-44 years and the factors which influenced them, despite a lack of National Health Insurance reimbursement.	Secondary data analysis	Convenience sampling	1,853 women Aged 30-44	Li-Shin Outreaching Neighbouring Screening program in Taoyuan county	Good
Lin (2008) <i>English version</i>	To explore the important factors that influence the utilisation of breast and cervical cancer screenings among Taiwanese women who have NHI.	Secondary data analysis	Stratified random sampling	9,468 women Aged 30-75 Response rate: 93.8 %	2001 National health interview survey	Good

## Appendix 2: Summary of the Taiwanese studies – cross-sectional surveys

Author/ study setting	Aim	Study design	Sampling strategies	Sample/ response rates if stated	Data resource/ measurement tool/ theoretical framework	Quality score
Wu et al. (2012) <i>English version</i>	To assess Taiwanese women's knowledge of and attitudes towards breast cancer screening and to explore the influencing factors that may be associated with it.	Cross-sectional survey	Convenience sampling	434 women Aged 40-80	Local area: community centres, parks or temples in Chang-hua city / the Chinese Mammogram Screening Beliefs Questionnaire	Fair
Chiang et al. (2011) <i>Chinese version</i>	To explore female medical professionals' breast healthcare behaviours and the factors that influenced the participants in taking up the cancer screenings based on the Health Belief Model (HBM).	Cross-sectional survey	Random sampling	384 female healthcare providers Aged 37.4 (mean) Response rate: 51.6%	Local area: one hospital in north Taiwan/ the HBM	Good
Chang & Nien (2003) <i>Chinese version</i>	To investigate the knowledge, attitudes and behaviours regarding BSE among community women in Changhua county with Beck and Rosenstock's HBM.	Cross-sectional survey	Stratified random sampling	278 women Aged 21-70 Response rate: 93%	Local area: Changhua county / Beck and Rosenstock's HBM	Good
Luo et al. (2001) <i>Chinese version</i>	To elicit the influencing factors related to performing BSEs among high-risk women based on the HBM.	Cross-sectional survey	Convenience sampling	158 women Aged 21-80 Response rate: 64.8%	Local area: six support groups of breast cancer in Taipei/the HBM	Fair
Chang et al. (2000) <i>Chinese version</i>	To determine the factors that affect women participating in the Changhua County Breast Cancer Screening Programme and to explore the factors that influence women to perform BSEs.	Cross-sectional survey	Convenience sampling	1,450 women Aged 20-70 Response rate: 97%	Local area: Changhua county	Good

**Appendix 3: Summary of US and UK studies conducted with heterosexual women – qualitative interview study, longitudinal studies and secondary data analyses**

<b>Author/ study setting</b>	<b>Aim</b>	<b>Study design</b>	<b>Sampling strategies</b>	<b>Sample/ Response rates if stated</b>	<b>Data resource/ Measurement tool/ Theoretical framework</b>	<b>Quality score</b>
Nekhlyudov et al. (2003) <i>USA</i>	To understand the decision-making process of mammography attendance among women aged 38 to 45 years.	Qualitative interviews	Purposive sampling	16 women Aged 38-45	A large New England medical practice	Good
Norman & Copper (2011) <i>UK</i>	To apply the theory of planned behaviour (TPB) to the prediction of BSE intentions and behaviour, and to test whether the frequency of past behaviour and context stability moderates intention-behaviour and habit-behaviour relations.	Longitudinal study	Did not specify	77 undergraduate female students Age not specified One-month follow-up rate: 66%	The TPB	Fair
Tang et al. (2009) <i>USA</i>	To analyse women's mammography experiences. To determine the utilisation rates of repeat mammography. To identify the predictors of repeat mammography.	Longitudinal study	Convenience sampling	397 women Aged ≥ 40 18-month follow-up: 296 women (75%).	Local area: Michigan	Good
Makuc et al. (2007) <i>USA</i>	To investigate the differences in out-of-pocket costs for mammography according to the characteristics of women and the states in which the individuals reside.	Secondary data analysis	Random sampling	4,554 women aged 40-64 years 2,137 women aged 66 years	2000 National Health Interview Survey Cancer control module	Good
McAlearney et al. (2005) <i>USA</i>	To examine the perceptions of insurance coverage and cost as barriers to the use of mammography within an underserved, predominantly low-income population of women in need of mammography.	Secondary data analysis	Random sampling	897 women Aged 40 and over Response rate: 81%	Robeson County Outreach, Screening and Education Project	Good
Coughlin et al. (2004) <i>USA</i>	To examine the breast cancer screening practices (CBE and mammography) of white and black women in the USA and assess the factors related to the screenings.	Secondary data analysis	Probability sampling design	10,403 women Aged ≥ 40	2000 National Health Interview Survey (NHIS)	Good

### Appendix 3: Summary of US and UK studies conducted with heterosexual women – cross-sectional surveys

Author/ study setting	Aim	Study design	Sampling strategies	Sample/ response rates if stated	Data resource/ measurement tool/ theoretical framework	Quality score
Forbes et al. (2011) <i>UK</i>	To explore breast cancer awareness and barriers to symptomatic presentation among different ethnic groups (white, south Asian and black) of women aged 30 and over in East London.	Cross-sectional survey	Stratified randomised sampling	1,515 women Aged $\geq 30$ Response rate: 81%	Local area: East London	Good
Miller et al. (2011) <i>USA</i>	To investigate the interaction between breast cancer anxiety and experiential avoidance in predicting mammography rates.	Cross-sectional survey	Convenience sampling	84 women Aged 54-91 Response rate: 93%	Local areas: New Jersey, Long Island and New York / Champion's Breast Cancer Fear Scale	Fair
Kratzke et al. (2010) <i>USA</i>	To explore the factors that influence mammogram use among community health workers (CHWs).	Cross-sectional survey	Convenience sampling	109 CHWs Aged 40-73 Response rate: 54%	Two urban volunteer CHW programs / PRECEDE model	Fair
Ahmed et al. (2009) <i>USA</i>	To explore knowledge of breast cancer as a predictor for reducing the barriers of the use of mammography among low-income women.	Cross-sectional survey	Random sampling	182 women Aged $\geq 40$ Response rate: 61%	TennCare MCO (Managed Care Organization) program	Fair
Fox et al. (2009) <i>USA</i>	To examine the role of provider-patient communication in mammography and the faecal occult blood test (FOBT).	Cross-sectional survey	Convenience sampling	63 physicians 904 their patients Aged 50-80 Response rates: 44% with the physicians and 51% with the female patients	Medical care research programme	Good
Gierisch et al. (2009) <i>USA</i>	To assess the barriers to women's repeated use of mammography.	Cross-sectional survey	Random sampling	596 women Aged 43-49 Response rate: 47.1-63.7%	Personal Relevant Information about Screening Mammography (PRISM)	Good

**Appendix 3: Summary of US and UK studies conducted with heterosexual women – cross-sectional surveys (con.)**

<b>Author/ study setting</b>	<b>Aim</b>	<b>Study design</b>	<b>Sampling strategies</b>	<b>Sample/ response rates if stated</b>	<b>Data resource/ measurement tool/ theoretical framework</b>	<b>Quality score</b>
Lopez et al. (2009) <i>USA</i>	To explore the barriers and facilitating factors of participation in breast screenings among women aged 40 and over.	Cross-sectional survey	Did not specify	987 women Aged 40-79 Response rate: 59.2%	Population-based survey in Mississippi / Behavioural Model of Health Services Utilization	Fair
Linsell et al. (2008) <i>UK</i>	To investigate the level of breast cancer awareness in older women.	Cross-sectional survey	Purposive sampling	712 women Aged 67-73 Response rate: 83.8%	National survey	Good
Barter-Godfrey & Taket (2007) <i>UK</i>	To identify women's perspectives on breast health issues and their beliefs and views about breast cancer, and their reasons for using or not using breast screenings.	Cross-sectional survey	Community recruitment strategy	306 women Aged 50-64 Response rate: not specified	Local area: South-east London	Fair

**Appendix 4: Summary of US and UK studies conducted with lesbians – focus groups studies, longitudinal study and secondary data analysis**

<b>Author/ study setting</b>	<b>Aim</b>	<b>Study design</b>	<b>Sampling strategies</b>	<b>Sample/ response rates if stated</b>	<b>Data resource/ measurement tool/ theoretical framework</b>	<b>Quality score</b>
Clark et al. (2003) <i>USA</i>	To explore the factors that affect unmarried women's decisions about cancer screenings.	Focus groups	Convenience sampling	14 women who partnered with women and 14 women who partnered with men Aged 40-75	The Cancer Screening Project for Women	Fair
Hart & Bowen (2009) <i>USA</i>	To observe the differences between lesbians/bisexual women and heterosexual women in their beliefs regarding breast cancer screenings, the perceived risk of breast cancer, fear about cancer and attitudes towards their healthcare providers, and to identify the factors which influenced the women in using breast screenings.	Longitudinal study	Random sampling: heterosexual women Convenience sampling: lesbians or bisexual women	150 heterosexual women and 400 lesbians / bisexual women Aged 19-74 Response rates at the baseline time and at the six-month follow-up were 71.3% / 95% (H) and 78% / 93% (L/Bi)	Local area: Washington	Good
Kerker et al. (2006) <i>USA</i>	To examine the relationship between sexual orientation, healthcare access and healthcare utilisation.	Secondary data analysis	Convenience sampling	9,764 women in 2002 (3.8% lesbians) and 9,585 women in 2004 (4.7% lesbians) Aged 18-64	Population-based survey in New York	Good



#### Appendix 4: Summary of US and UK studies conducted with lesbians – cross-sectional surveys

Author/ study setting	Aim	Study design	Sampling strategies	Sample/ response rates if stated	Data resource/ measurement tool/ theoretical framework	Quality score
DeHart (2008) <i>USA</i>	To explore lesbians' health beliefs, perceptions of heterosexism and homophobia in healthcare, and the use of services and self-care for breast health based on the HBM.	Cross-sectional survey	Convenience sampling	173 lesbians Aged 18-74 Response rates: unknown	Local areas: three southern cities – Columbia, SC; Louisville, KY; Wilmington NC / the HBM	Fair
Grindel et al. (2006) <i>USA</i>	To explore the cancer prevention and screening behaviours of lesbians under the American Cancer Society's guidelines, and to identify the factors that affect mammography screening.	Cross-sectional survey	Convenience and snowball sampling	1,139 lesbians Aged ≥ 18	Boston Lesbian Health Project II	Good
Fish (2006) <i>UK</i>	To explore lesbians' health behaviours and perceptions regarding cervical cancer and breast cancer risks. The paper aimed to present qualitative explanations about lesbians' healthcare behaviours.	Cross-sectional survey	Convenience and snowball sampling	1,066 lesbians Aged 20-70 Response rate: 29%	The programme of the lesbians and healthcare survey, UK, 1997-1998	Good
Fish & Anthony (2005) <i>UK</i>	To examine the correlation between cancer risk perception, experience of healthcare and health-seeking behaviours. The paper aimed to map patterns in the lesbians' healthcare behaviours.					
Fish & Wilkinson (2003a) <i>UK</i>	To explore the facilitating factors of lesbians' practices of breast self-examination.			137 out of the 1,066 lesbians who reported they regularly performed BSEs were included in the data analysis.		
Fish & Wilkinson (2003b) <i>UK</i>	To discover the barriers to breast self-examination among lesbians who reported never performing breast screenings.			218 out of the 1,066 lesbians who reported they never performed BSEs were included in the data analysis.		

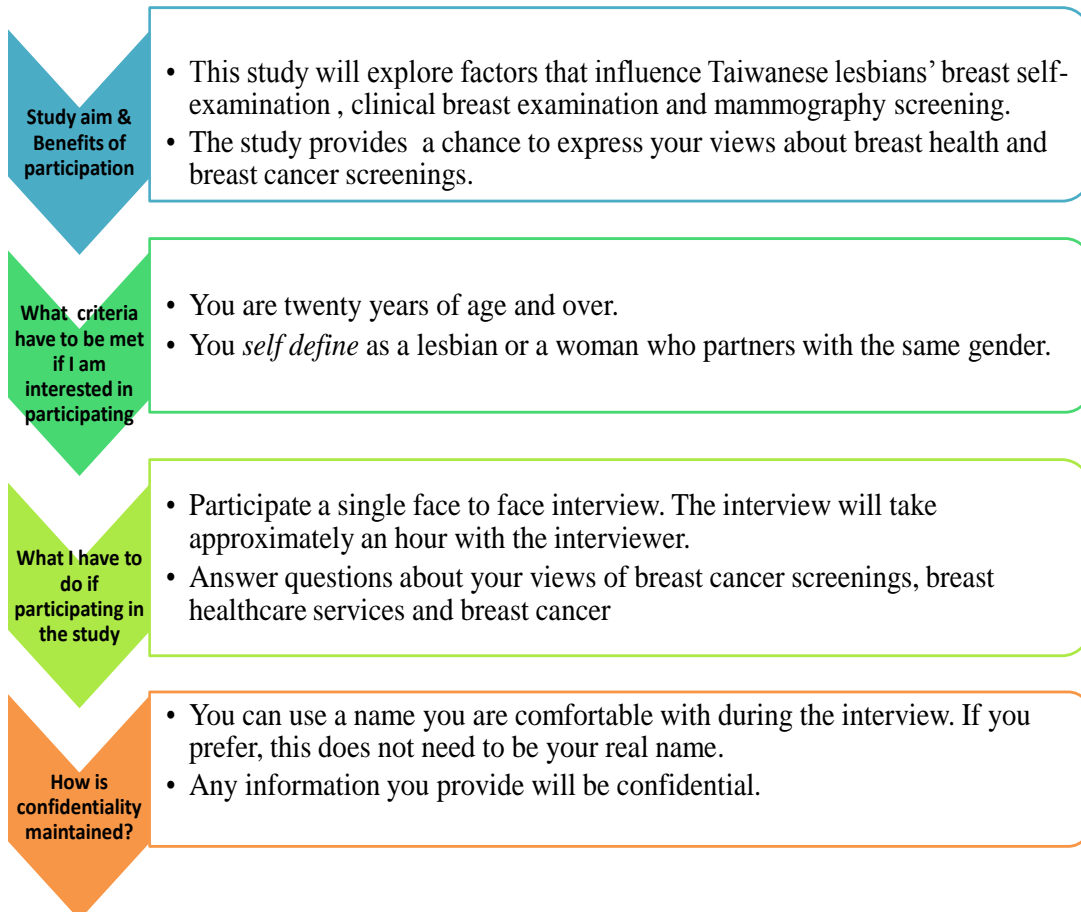
**Table Appendix 4: Summary of US and UK studies conducted with lesbians – cross-sectional surveys (con.)**

<b>Author/ study setting</b>	<b>Aim</b>	<b>Study design</b>	<b>Sampling strategies</b>	<b>Sample/ response rates if stated</b>	<b>Data resource/ measurement tool/ theoretical framework</b>	<b>Quality score</b>
Diamant et al. (2000) <i>USA</i>	To measure the utilisation of preventive health services by lesbians and to assess the influencing factors of the women's use of the services.	Cross-sectional survey	Convenience sampling	6,935 lesbians Aged 15-93 Response rates: unknown	National survey	Good
Burnett et al. (1999) <i>USA</i>	To examine the predisposing and enabling factors associated with breast screenings among lesbians who had a first degree relative with a diagnosis of breast cancer	Cross-sectional survey	Convenience sampling	139 lesbians Aged 35-75	Data was collected from local and national lesbians	Fair
Lauver et al. (1999) <i>USA</i>	To identify the barriers and facilitating factors of mammography use by lesbians.	Cross-sectional survey	Convenience and snowball sampling	107 lesbians Aged 51-80	Data was collected in the Midwest	Fair
Ranknow & Tessaro (1998) <i>USA</i>	To explore the risk factors of breast cancer and breast cancer screening adherence in a sample of self-identified lesbians and bisexual women.	Cross-sectional survey	Convenience sampling with outreach methods	570 lesbians Aged $\geq 40$ Response rates: unknown	Data was collected in North Carolina	Fair



## Looking For Voluntary Interviewees Who Are *Lesbian & Age 20+*

### *Factors Associated with Taiwanese Lesbians’ Breast Healthcare Behaviours*



*If you would like to participate in this study or require further information, please contact Ya-Ching, Wang (the principle investigator) by email at [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk) or phone at xxxx-xxxxxx.*

*This study has been approved by the Ethics Committee at the University of Manchester*

## Appendix 6: Qualitative interviews-Participant information sheet

MANCHESTER  
1824

### Factors associated with Taiwanese lesbians' breast healthcare behaviours

The University  
of Manchester

You are being invited to take part in a study which is aimed at exploring factors associated with Taiwanese lesbians' breast healthcare behaviours. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask for more information or an explanation of something you do not understand. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### Introduction

Breast cancer is the most commonly diagnosed cancer among women worldwide. In Taiwan, breast cancer incidence rates have increased sharply since 1979. Taiwan now has the highest breast cancer incidence among Eastern Asian countries. The sharply increasing trend in breast cancer in Taiwan highlights the need for breast cancer prevention and early detection.

The utilization rate of breast healthcare services in lesbians is lower than in women in general. An online survey conducted by the Taipei Association for the Promotion of Women's Rights (TAPWR) in 2008 showed significantly lower utilization rates of breast healthcare services among Taiwanese lesbians compared to heterosexual women. Although there are many studies exploring factors associated with breast healthcare behaviours within women in general in Taiwan, there is a lack of evidence on the factors related to Taiwanese lesbians' breast health behaviours. This study aims at understanding factors associated with Taiwanese lesbians' breast healthcare behaviours in order to improve uptake of breast screening and breast healthcare services for lesbians.

#### Who can take part in this study?

We are looking for women who (1) are twenty years of age and over, (2) *self define* as lesbian or women who partner with the same gender, and (3) have the ability to communicate with the interviewer in either Mandarin or Taiwanese. If you meet these criteria, you are most welcome to be recruited into the study.

#### Do I have to take part?

It is up to you to decide whether or not to take part. Participation is entirely voluntary. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without it affecting any health care or support you may be receiving.

#### What would I be asked to do if I took part?

If you are interested in participating in the study, you will be asked to take part in an interview. You can contact the researcher to arrange the interview time, date and place through emails or telephone calls privately. The place, time and date will be decided by you in order to ensure you feel comfortable and safe when talking about the topics, and to ensure the time is convenient for you.

Before the interview is conducted, an informed consent form needs to be signed. However, if you are concerned about signing the form with your real name, the consent form can be signed with the name which you would like to be called during the interview. Also, we would like to audio-record the interview with your permission.

A single face to face interview will then be conducted. The interview will take approximately an hour. During the interview, the researcher will ask questions related to your experience about breast screenings, your perceptions about breast

---

cancer and factors which influence your breast healthcare behaviour. Information about your background (such as age and occupation) will also be collected.

**How is confidentiality maintained?**

You will be given an identification number (ID) and your interview will be coded with the ID number, not with your name. In addition, any identifying details in reports will be changed in order to uphold your privacy and confidentiality. Written consent or any document which contains your personal details will be locked in a cabinet with a controlled key. Information storage on the University computer, on a laptop and/or memory sticks will be password protected and the passwords will only be held by the researcher. The digitally recorded interview and written consent form will be held for five years, and will be destroyed after that time.

**What are the benefits of taking part?**

There is no direct benefit to participants. The study will provide information about what makes it easier or more difficult for Taiwanese lesbians to protect themselves against breast cancer and will help to increase quality of care. Also, it will give ideas to policy makers about how to provide appropriate breast healthcare services to lesbians.

**What are potential harms of attending the study?**

Participants may be concerned that there could be unwanted disclosure of their sexual orientation if they take part. Therefore, in order to prevent this from happening, you can choose to be interviewed in a place where you feel safe and confident while talking. In addition, you can choose to use your real name or the name you would like to be called during the interview to sign the consent form. You will also be given an identification number and your interview will be coded with an ID, not with your name. Any identifying details in transcripts and reports will be changed in order to uphold your privacy. Some interview questions may be sensitive to you. If you feel uncomfortable answering any questions, you do not have to answer them. If you feel distressed in any way, you can decide to have a break or finish the interview at any time. After the interview, if you have concerns about the information you provide during the interview and would like to withdraw, please contact the researcher. Or, if you need support from lesbian supportive organizations, you can call Taiwan Tongzhi Hotline Association (phone number: 886-2-2392-1979 or 886-7-281-1825).

**Will the outcomes of the research be published?**

When the study is complete, it will be published. However, no personal details of participants will be revealed in any way. If you would like to receive a summary of the study results, the researcher will send it to you through either email or post.

**Who has reviewed the study?**

The study has been reviewed and approved by the Manchester University Research Ethics Committees.

**If you need further information or would like to take part in the study, please contact the researcher with following email address or telephone numbers**

Wang, Ya-Ching

The Principal Investigator and a Second Year Nursing PhD Student

School of Nursing, Midwifery and social work

University of Manchester

Tel: xxxx-xxxxxx

Email address: [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk)

*If you want to make a formal complaint about the conduct of the research you can contact the Head of the Research Office, Christie Building, University of*

***Manchester, Oxford Road, Manchester, M13 9PL.***

**The Principal Investigator**

Wang, Ya-Ching,

2<sup>nd</sup> Year Nursing PhD Student

School of Nursing, Midwifery and social worker

University of Manchester

E-mail address: [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk)

Tel: xxxx-xxxxxx

**Supervisors**

Dr Jane Griffiths PhD, BNurs, RGN, NDNCert and Professor Gunn Grande PhD MPhil

The School of Nursing, Midwifery and Social Work

The University of Manchester

Jean McFarlane Building

University Place

Oxford Road

Manchester

M13 9PL

**Appendix 7: Qualitative interviews-Consent form**



The University  
of Manchester

**CONSENT FORM**

**Study Title: Factors associated with Taiwanese lesbians' breast healthcare behaviours.**

If you are happy to participate please complete and sign the consent form below

**Please  
Initial  
Box**

1. I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.
2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to any treatment/service
3. I understand that the interviews will be audio-recorded
4. I agree to the use of anonymous quotes
5. I agree that any data collected may be passed to other researchers

I agree to take part in the above project

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature
_____	_____	_____

## Appendix 8: Structured questionnaire

Interviewee ID: (filled by the interviewer )

1. Age:
2. Family history of breast cancer: Yes \_\_\_\_\_ No
3. Occupation:
4. Educational level:  
 No education     Elementary school     High School  
 College     Graduate/Professional degree
5. Employment status  
 Employed full-time     Employed part-time  
 Unemployed     Retired
6. Relationship status:  
 Married     Partnered     Single
7. Religion:  
 Catholic     Protestant     Buddhism  
 Taoism     Yi Guan Dao     None



## Appendix 9: Topic Guide

### **Influencing Factors Associated with Taiwanese Lesbians' Breast Healthcare Behaviours**

**Objectives:** To explore factors that influence Taiwanese lesbians' breast healthcare behaviours.

**Introduction:**

1. Introduce the details of the study, including purpose, method, process of the study, confidentiality, the right to withdraw from the study at anytime, and timing.
2. Obtaining informed consent and permission to audio-record the interview.

**The interview will cover topics as following:**

**Breast cancer screenings**

- \* What do you know about breast cancer screenings?
- \* Could you please talk about your experiences with breast cancer screenings?
- \* What are factors that influence you in practicing breast self-examinations?
- \* What are factors that influence/will influence you in obtaining breast cancer screenings?

**Breast healthcare services**

- \* What do you think about breast healthcare services in Taiwan?
- \* What are factors that influence you in obtaining breast healthcare services?

**Breast cancer**

- \* In your view, what is the meaning of breast cancer?
- \* What do you think about breast cancer?

**Appendix 10: Field note format**

(Participant ID: )

Time and Date:

Location:

<b>Content part/ reflective part</b>	<b>Observation and feelings</b>
<ol style="list-style-type: none"><li>1. Describe the <i>setting</i>. Include sentences and paragraphs that are subjective. <b>These include a more personal description of what you observed.</b></li> <li>2. Describe the <i>activities</i> that took place in that setting. Reproduce the sequence of actions and behaviours. Emphasises <i>ideas, hunches, impressions</i>, etc.</li> <li>3. Describe the people <i>who took part</i> in the activities and <i>their roles</i> in the activities.</li> <li>4. Describe any <i>impact</i> you might have had on the situation when you interviewed.</li> <li>5. <i>Clarify points and correct mistakes and misunderstandings</i> in other parts of the field notes.</li> <li>6. Include <i>insights or speculation</i> about what you are observing.</li></ol>	

Reference: Observation and Field Notes. Available at: [hci.cs.siuue.edu](http://hci.cs.siuue.edu). (Accessed on 11/06/2012)

## Appendix 11: Ethical approval for the qualitative interviews



Faculty of Engineering  
and Physical Sciences  
(B42)  
The University of  
Manchester  
Sackville Street Building  
Manchester M13 9PL  
  
+44(0)161 305 3064  
Adrian.Jarvis@manchester.ac.  
uk

Ref:AJ/ethics/110612

Ms. Wang  
School of Nursing, Midwifery, and Social Work  
18<sup>th</sup> July 2012

Dear Ms. Wang

Research Ethics Committee 3

**Wang, Griffiths, Grande: Factors associated with Taiwanese lesbians' breast healthcare behaviours (ref 12122)**

I write to confirm that the Chair is now satisfied that you have addressed the concerns of the Ethics Committee of the 11<sup>th</sup> of July 2012 and has therefore given the above research project a favourable ethical opinion.

This approval is effective for a period of five years and if the project continues beyond that period it must be submitted for review. It is the Committee's practice to warn investigators that they should not depart from the agreed protocol without seeking the approval of the Committee, as any significant deviation could invalidate the insurance arrangements and constitute research misconduct. We also ask that any information sheet should carry a University logo or other indication of where it came from, and that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a university computer or kept as a hard copy in a location which is accessible only to those involved with the research.

Finally, I would be grateful if you could complete and return the attached form at the end of the project or by August 2013.

We hope the research goes well.

Yours sincerely

Adrian Jarvis  
Ethics Committee 3 Secretary

**Appendix 12: Participants' characteristics and breast healthcare behaviour (n = 37)**

<b>Age</b>	Mean	32.4	Minimum 21
	Median	30	Maximum 57
	Std. Deviation	8.5	
<b>Family history of breast cancer</b>	<b>N</b>	<b>N</b>	<b>%</b>
	No	30	81.1
	Yes	6	16.2
	Unsure	1	2.7
<b>Employment status</b>	Unemployed	3	8.1
	Retired	2	5.4
	Part-time	2	5.4
	Full-time	25	67.6
	Student	5	13.5
<b>Level of education</b>	Junior High School	1	2.7
	High School	9	24.3
	College	18	48.6
	Graduate/Professional Degree	9	24.3
<b>Religion</b>	Catholic	4	10.8
	Buddhism	6	16.2
	Taoism	9	24.3
	None	16	43.2
	Other	2	5.4
<b>Relationship status</b>	Married	1	2.7
	Partnered	22	59.5
	Single	14	37.8
<b>BSE</b>	Never	13	35.1
	Once	1	2.7
	Irregular	15	40.5
	Regular	8	21.6
<b>CBE</b>	Never	31	83.8
	Once	5	13.5
	Regular	1	2.7
<b>Mammography</b>	Never	31	83.8
	Once	4	10.8
	Irregular	1	2.7
	Regular	1	2.7

**Appendix 13: Comment sheet for the instrument**

**Factors associated with Taiwanese lesbians' breast healthcare behaviours:  
comment sheet**

1. How long did it take to complete?

\_\_\_\_\_ minutes

2. Is the survey too long?

- Yes
- No

3. Are the instructions clear?

- Yes
- No (Please specify: \_\_\_\_\_)

4. Is the wording of the questionnaire clear?

- Yes
- No

Section	Question number	Comments

5. Are any questions ambiguous?

- Yes

Section	Question	Comments

- No

6. Are any questions objectionable?

- Yes

Section	Question	Comments

- No

7. Are the answer choices compatible with your experience in the matter?

- Yes
- No

Section	Question	Answer	Comments

8. Do any of the items require you to think too long or hard before responding?

Yes

Section	Question	Answer	Comments

No

9. Are there any items that produce irritation or embarrassment? If yes, which one?

Yes (Please specify in the following table. Thank you)

Section	Question	Answer	Comments

No

10. Do the answers collected reflect your feelings or ideas with regard to the purpose of the survey?

Yes

No (Please specify in the following table. Thank you)

Section	Question	Answer	Comments

11. Do you feel comfortable answering the questions?

Yes

No (Please specify: \_\_\_\_\_)

12. Have any topics been omitted?

Yes (Please specify in the following table. Thank you)

Section	Question	Answer	Comments

No

Thank you for your responses. If you have any other comments about the questionnaire, please write them below.

--

Please send the comment sheet back to Ya-Ching before 21<sup>st</sup> July 2013.

E-mail: [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk);

[joan02082002@msn.com](mailto:joan02082002@msn.com)

Or, if you prefer to discuss by phone, Ya-Ching's phone number is 0979-014-487.

## Appendix 14: Questionnaire

### Factors associated with Taiwanese lesbians' breast healthcare behaviours

Thank you for agreeing to take part in this study. Please follow the directions below to complete the questionnaire. Thank you.

#### Section 1: Background information

Directions:

1. Answer all the questions in the order given or skip certain parts as directed.
2. Some questions have room for a written comment. Other questions have a choice of answers. Please tick **ONE** box that most closely represents your view.  
**For example: Do you regularly check the weather forecast?  Yes  No**
3. If you choose the answer "Other", please provide the information not covered by the questionnaire.

Q1. How old are you? (Please fill in the blank space)

\_\_\_ years old

Q2. What is your sexual orientation? (Please tick one box)

- Lesbian
- Not a lesbian, but a woman who has a partner of the same gender
- Bisexual
- Transsexual
- Heterosexual
- Other (Please specify:\_\_\_\_\_)

Q3. How do you identify yourself? (Please tick one box)

- T (butch lesbian)
- Bufen pian T (a slightly T-tinged bufen)
- Bufen (undifferentiated lesbian)
- Bufen pian po (a slightly po-tinged bufen)
- Po (feminine lesbian)
- Other (Please specify:\_\_\_\_\_)

Q4. Have you ever been diagnosed with breast cancer? (Please tick one box)

- Yes
- No

Q5. Have you ever been diagnosed with nonmalignant breast disease (for example, nonmalignant breast lumps, breast cysts, etc)? (Please tick one box)

- Yes
- No

Q6. Do you have a family history of breast cancer? (Please tick one box)

- Yes
- No
- Unsure

Q7. What is your religion? (Please tick one box)

- |                                       |                                                       |
|---------------------------------------|-------------------------------------------------------|
| <input type="checkbox"/> None         | <input type="checkbox"/> Buddhism                     |
| <input type="checkbox"/> Catholicism  | <input type="checkbox"/> Taoism                       |
| <input type="checkbox"/> Christianity | <input type="checkbox"/> Other (Please specify:_____) |
| <input type="checkbox"/> Yi Guan Dao  |                                                       |

Q8. What is your employment status? (Please tick one box)

- |                                                       |                                                                              |
|-------------------------------------------------------|------------------------------------------------------------------------------|
| <input type="checkbox"/> Student (Please skip to Q10) | <input type="checkbox"/> Unemployed (Please skip to Q10)                     |
| <input type="checkbox"/> Employed full-time           | <input type="checkbox"/> Retired (Please skip to Q10)                        |
| <input type="checkbox"/> Employed part-time           | <input type="checkbox"/> Other (Please specify:____)<br>(Please skip to Q10) |

Q9. What is your occupation? (Please fill in the blank space)

Q10. What is the highest-grade level you completed in school? (Please tick one box)

- |                                                             |                                                       |
|-------------------------------------------------------------|-------------------------------------------------------|
| <input type="checkbox"/> Elementary                         | <input type="checkbox"/> College degree               |
| <input type="checkbox"/> Junior high                        | <input type="checkbox"/> Graduate degree              |
| <input type="checkbox"/> High school/vocational high school | <input type="checkbox"/> Doctoral degree              |
| <input type="checkbox"/> Associate degree                   | <input type="checkbox"/> Other (Please specify:_____) |

Q11. Do you have any children? (Please tick one box)

- Yes  
 No (Please skip to Q13)

Q12. How many children do you have? (Please fill in the blank space)

Q13. Do you smoke? (Please tick one box)

- Yes, currently (Please specify:\_\_\_\_\_cigarette(s)/a day)  
 Ex-smoker  
 Never

Q14. Do you drink alcohol? (Please tick one box)

- Yes, currently (Please specify:\_\_\_\_\_drink(s)\*//a week)  
\*One drink = 350 ml of beer, 150 ml of wine or 45 ml of hard liquor  
 Ex-drinker  
 Never



## Section 2: Breast Cancer Screenings

Directions:

1. Answer all the questions in the order given, or skip certain parts as directed.
2. Please tick ONE box that most represents your view.
3. What is breast self-examination? A breast self- examination is when you check your own breasts for lumps, changes in size or shape of the breasts, or any other changes in the breasts or underarm.
4. What is Mammogram? Mammogram uses X-rays to look for breast cancers when they are too small to be seen or felt. It is an X-ray of the breast that is taken with a device that compresses and flattens the breasts.

Q1. What is your intention about performing breast self-examination?

(Please tick one box)

- I have never heard of breast self-examination (Please skip to Q3)
- I have never thought about performing breast self-examination (Please skip to Q3)
- I am undecided about performing breast self-examination (Please skip to Q3)
- I have decided I do not want to perform breast self-examination (Please skip to Q3)
- I have decided I want to perform breast self-examination (Please skip to Q3)
- I have already done it

Q2. Have you performed breast self-examination on a regular basis within the last year?

(Please tick one box)

- Yes, every month
- Yes, frequently, but not every month
- No, I only performed it infrequently
- No, I did not do it at all in the last year

Q3. What is your intention about having mammogram? (Please tick one box)

- I have never heard of mammograms (Please skip to Section 3)
- I have never thought about having a mammogram (Please skip to Section 3)
- I am undecided about having a mammogram (Please skip to Section 3)
- I have decided I do not want to have a mammogram (Please skip to Section 3)
- I have decided I want to have a mammogram (Please skip to Section 3)
- I have already had it

Q4. Did you have mammogram on a regular basis? (Please tick one box)

- Yes, every two years
- Yes, frequently, but not every two years
- No, I only had it infrequently
- No, I only had it once

### Section 3: Your views on Breasts, Breast Cancer and Breast Cancer Screenings

Directions:

- The following questions in this survey mainly ask you to answer according to a rating scale.

Rating	Description (Abbreviation)
1	STRONGLY DISAGREE (SD)
2	DISAGREE (D)
3	NEITHER AGREE NOR DISAGREE (N)
4	AGREE (A)
5	STRONGLY AGREE (SA)

- Please choose the number that most closely reflects your feelings or ideas about the following statements and tick the box under the number.

**For example:** If you were ask to rate the statement of “Checking weather forecast on the internet is much more convenient than on TV.” on such a scale, it would look like as below. You could tick the box under the number which most closely reflects your feelings or ideas.

	SD	D	N	A	SA
Checking weather forecast on the internet is much more convenient than on TV	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input checked="" type="checkbox"/>	5 <input type="checkbox"/>

#### Q1. Physician-Patient Interaction:

Please indicate how much you agree or disagree with the following statements.

	SD	D	N	A	SA
Q1.1 I would be more likely to have a mammogram if the healthcare provider was a female	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q1.2 I would be more likely to have a mammogram if the healthcare provider was a male	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q1.3 Concerns that a healthcare provider would assume that I was a heterosexual would make me less likely to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q1.4 Concerns that a healthcare provider would lack knowledge of lesbian, gay, bisexual and transgender (LGBT) issues would make me less likely to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q1.5 Concerns that a healthcare provider would feel uncomfortable with lesbians would make me less likely to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q1.6 Concerns that a healthcare provider would discriminate against me would make me less likely to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q1.7 My breasts needing to be seen by a healthcare provider puts me off having mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q1.8 My breasts needing to be touched by a healthcare provider puts me off having mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

## Q2. Partner Support:

Please answer the following questions in the order given, or skip certain parts as directed.

Q2.1 What is your relationship status? (Please tick one box)

- Partnered (with a same-sex partner)
- Married (with a same-sex partner)
- Single (Please skip to Q2.7)
- Other (Please specify: \_\_\_\_\_) (Please skip to Q2.7)

Q2.2 How long have you and your current partner been in a relationship?

(Please fill in the blank space)

\_\_\_ Year(s) \_\_\_ Month(s)

Q2.3 Does your partner think that you should perform breast self-examinations? (Please tick one box)

- Yes
- No
- I do not know

Q 2.4 Does your partner perform breast examinations for you?

(Please tick one box)

- Yes
- No

Q 2.5 Does your partner think that you should have a mammogram?

(Please tick one box)

- Yes
- No
- I do not know

Q 2.6 The following questions aim to know how much “your current partner” influences your behaviour and intention in performing/having breast cancer screenings. Please indicate how much you agree or disagree with the following statements.

	SD	D	N	A	SA
Q2.6.1 I am more likely to perform a breast self-examination if my partner thinks I should do so	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q2.6.2 I am more likely to have a mammogram if my partner thinks I should have one	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q2.6.3 I am more likely to have a mammogram if my partner accompanies me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

If you have answered Q2.6, please go to Q3.

Q2.7 Although you may not be in a current relationship, we would like to know how much you think a partner would influence your behaviour and intention in performing/having breast cancer screenings. Please indicate how much you agree or disagree with the following statements, with the assumption being ‘if I had a partner’.

	SD	D	N	A	SA
Q2.7.1 I would be more likely to perform a breast self-examination if a partner thought I should do so	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q2.7.2 I would be more likely to have a mammogram if a partner thought I should have one	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q2.7.3 I would be more likely to have a mammogram if a partner accompanied me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

### Q3. Views on Your Own Breasts:

Please indicate how much you agree or disagree with the following statements.

	SD	D	N	A	SA
Q3.1 My breasts have an important sexual function	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q3.2 I do not want my breasts	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q3.3 I feel embarrassed about my own breasts	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q3.4 I feel uncomfortable when I think of my own breasts	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q3.5 I usually bind my breasts during daily life	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q3.6 I do not like my partner to touch my breasts	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q3.7 I do not like my partner to look at my breasts	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

### Q4. Perceived Benefits and Barriers to Breast Cancer Screenings:

Please indicate how much you agree or disagree with the following statements. If you have no experience of doing a breast self-examination or having a mammogram, please choose the number that most closely reflects your “feelings or ideas” about the following statements and tick the box under the number.

	SD	D	N	A	SA
Q4.1 Breast self-examination will help protect me against breast cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.2 Performing a breast self-examination would be embarrassing for me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.3 Performing a breast self-examination would be unpleasant	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.4 Performing breast self-examinations is not a high priority for me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.5 Performing breast self-examinations would make me worry about having breast cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Q4.6 Mammograms will help protect me against breast cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.7 Having a mammogram would be embarrassing	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.8 Having a mammogram would take too much time	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.9 Having a mammogram would be painful	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.10 Having mammograms is not a high priority for me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.11 Having a mammogram would make me worry about having breast cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q4.12 Worry about my appearance being judged by other women in the waiting room would make me less likely to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

**Q5. Susceptibility to and Seriousness of Breast Cancer:**

Please choose the number that most closely reflects your “feelings or ideas” about the following questions and tick the box under the number.

	SD	D	N	A	SA
Q5.1 My chances of getting breast cancer are great	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q5.2 I worry about having breast cancer in the future	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q5.3 I am more likely than the average woman to get breast cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q5.4 Breast cancer is a life-threatening disease	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q5.5 I feel anxious when I think about breast cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q5.6 Having breast cancer would endanger the relationship between my partner and me.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

**Q6. Your Ability to Perform/Have Breast Cancer Screenings:**

Please choose the number that most closely reflects your “feelings or ideas” about the following questions and tick the box under the number.

	SD	D	N	A	SA
Q6.1 I know how to perform a breast self-examination	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q6.2 I feel confident that if I were to perform breast self-examinations, I could feel any abnormalities in my breasts	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q6.3 I know how to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q6.4 I feel confident that if I have a mammogram, any abnormalities in my breasts would be detected	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

**Q7. Facilitators to Your Breast Healthcare Behavior:**

Please indicate how much you agree or disagree with the following statements.

	SD	D	N	A	SA
Q7.1 Campaigns (TV, radio or magazines, etc) would encourage me to perform breast self-examinations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q7.2 Symptoms (such as a lump in either breast, pain or a change in the size of one or both breast) would encourage me to perform breast self-examinations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q7.3 If other people I knew (family, friends, etc) had breast cancer, this would encourage me to perform breast self-examinations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q7.4 Campaigns (TV, radio or magazines, etc) would encourage me to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q7.5 Symptoms (such as a lump in either breast, pain or a change in the size of one or both breast) would encourage me to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q7.6 If other people I knew (family, friends, etc) had breast cancer, this would encourage me to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Q7.7 A physician's recommendations would encourage me to have a mammogram	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

**This is the end of the questionnaire. Thank you for your responses. If you have any comments about this survey or the questionnaire, please write them below.**

*Thank you.*

## Appendix 15: Comment sheet for the online questionnaire performance

### Factors associated with Taiwanese lesbians' breast healthcare behaviours: piloting the online questionnaire performance Comment sheet

Thank you for agreeing to test the online questionnaire. Please follow the directions below to complete this comment sheet.

Directions:

1. Please click this link: <https://www.surveymonkey.com/s/6L95KKL> to test the online questionnaire.
2. Please answer the following questions. Thank you.

Q1: Can the online questionnaire be accessed? (Please tick one box)

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

Q2: Is the study's purpose clear? (Please tick one box)

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No Comments:

Q3: Are the directions clear? (Please tick one box)

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No Comments:

Q4: Is the question/answer piping logical? (Please tick one box)

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No Comments:

Q5: Does the appearance of the online questionnaire remain consistent? (Please tick one box)

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No Comments:

Q6: Is the online questionnaire readable? (Please tick one box)

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No Comments:

Q7: Is the font size suitable? (Please tick one box)

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No Comments:

Q8: Are there any typing errors? (Please tick one box)

<input type="checkbox"/>	Yes Comments:
<input type="checkbox"/>	No

Q9: Is the questionnaire layout design suitable? (Please tick one box)

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No Comments:

Q10: If you have any other comments about the online questionnaire (layout, font, colour or website performance), please write them below.

------------------------------------------

*Thank you for your responses and comments.*



## Appendix 16: Online survey-Invitation

**MANCHESTER**  
1824

The University of Manchester

### FACTORS ASSOCIATED WITH TAIWANESE LESBIANS' BREAST HEALTHCARE BEHAVIOURS: AN ON-LINE SURVEY

[http: https://www.surveymonkey.com/s/7J8QP2Z](https://www.surveymonkey.com/s/7J8QP2Z)

**Taiwanese lesbians age 20 years and over are being invited to take part in this study**

<b>Purpose of the study</b>	<ul style="list-style-type: none"><li>♣ By taking part in this online survey, you will be <b>contributing to knowledge about what makes it easier or more difficult for Taiwanese lesbians to protect themselves against breast cancer.</b></li></ul>
<b>Inclusion criteria</b>	<p>We are looking for women who</p> <ul style="list-style-type: none"><li>♣ <b>are 20 years of age and over,</b></li><li>♣ <b>are <i>self-defined</i> as lesbian or women who have partners of the same gender</b></li><li>♣ <b>have never been diagnosed with breast cancer</b></li></ul> <p><i>If you meet all these criteria, you are most welcome to be recruited into the study.</i></p>
<b>Study methods</b>	<ul style="list-style-type: none"><li>♣ You will complete a survey via the Internet, which will take about <b>15 to 20 minutes.</b></li><li>♣ Questions related to your <b>breast healthcare behaviours and the influencing factors</b> will be asked.</li></ul>
<b>Benefits of taking part</b>	<ul style="list-style-type: none"><li>♣ <b>You will receive a short summary of the study and will be entered in a free gift draw .</b> An email address is needed to be provided for sending the summary and informing the gift winner.</li></ul>
<b>confidentiality</b>	<ul style="list-style-type: none"><li>♣ <b>Your responses and personal information will remain confidential.</b> Only the research team (the researcher and her supervisors can view the data.</li></ul>

**For further study information or if you are interested in taking part in the study, please click the link: <https://www.surveymonkey.com/s/7J8QP2Z>**

- ♣ if you have any questions related to the study, please do not hesitate to contact the researcher (Ya-Ching, Wang) by email: [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk) or phone at 0979-014-487
- ♣ This study has been approved by the Ethics Committee at the University of Manchester

## Appendix 17: Online survey-Participant information sheet

MANCHESTER  
1824

The University  
of Manchester

### Factors associated with Taiwanese lesbians' breast healthcare behaviours: an on-line survey

You are being invited to take part in an on-line survey. Before you decide it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and feel free to ask for more information or an explanation of something you do not understand. The researcher's contact details can be found at the end of this page. Thank you for reading this.

#### Purpose of the study

This on-line survey is being conducted by Ya-Ching, Wang, a nursing PhD student at the University of Manchester, UK. The purpose of this survey is to understand more about Taiwanese lesbians' breast healthcare behaviours and factors influencing these. By taking part in the study, you will be contributing to knowledge about what makes it easier or more difficult for Taiwanese lesbians to protect themselves against breast cancer. The information will provide policy makers with ideas about how to provide appropriate breast healthcare services to Taiwanese lesbians.

#### Who can take part in this study?

We are looking for women who (1) are 20 years of age and over, (2) are *self-defined* as lesbian or women who have partners of the same gender and (3) have never been diagnosed with breast cancer. If you meet these criteria, you are most welcome to be recruited into the study.

#### Do I have to take part?

Your participation is voluntary and you are free to withdraw your participation from this study at any time. If you do not want to continue, you can leave this website or click the "Exit this survey" button which appears on every page. You may also choose to skip any questions that you do not wish to answer. At the end of the survey, if you do not click on the "Done" button, your answers and the fact you participated will not be recorded.

#### What would I be asked to do if I took part?

You will complete a survey via the Internet. It will take around 15 to 20 minutes. The survey includes questions about your future intentions and past experiences of breast screenings. Other survey questions will address factors that facilitate or inhibit you having breast cancer screenings. Demographic information will also be sought (for example, age, relationship status and gender identity) so that the researcher can accurately describe the general traits of the group of Taiwanese lesbians who take part in the study.

#### What are the benefits of taking part?

When you click on the 'Done' button at the end of the survey, if you agree to leave your email address, you will receive a short summary of the study and will be entered into a free gift draw. The number of questions you answer will not affect your

---

chances of winning the gift or receiving the summary. After we have finished collecting the data, we will conduct the draw. Winners will receive a notification of their gifts via email. We will also provide you with more detailed information about the study and its results via email after the study is completed.

#### **How is confidentiality maintained?**

Your responses will be kept completely confidential. The researcher will not track your IP address when you respond to the Internet survey. If you would like to enter the free prize draw and/or receive a short summary of the study's results, it is necessary to provide an email address. However, your personal information will not be stored with the data from your survey. Instead, you will be assigned a participant number, and only the participant number will appear with your survey responses. Your personal information will be stored electronically in a password protected folder. Only the research team (the researcher and the supervisors) can view the data. After we have finished the data collection and have sent you a copy of the results of the study, we will destroy the personal information provided (the email address).

#### **What are the potential harmful effects of taking part in the study?**

No discomfort or risks are anticipated from participating in this study. If you feel uncomfortable with a question, you can skip this question or withdraw from the survey by clicking the "Exit this survey" button. Your responses and participation will not be recorded. After the survey, if you have any concerns about the study, please contact the researcher. Or, if you need support from lesbian supportive organizations, you can call Taiwan Tongzhi Hotline Association (phone number: 886-2-2392-1979 or 886-7-281-1825).

#### **Will the outcome of the research be published?**

When the study is complete, it will be published. However, no personal details of the respondents will be revealed in any way. If you would like to receive a summary of the study's results, the researcher will send it to you through email.

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

The study has been reviewed and approved by the Manchester University Research Ethics Committee.

#### **If you need further information or would like to take part in the study, please contact the researcher with following email address or telephone numbers**

Wang, Ya-Ching

The Principal Investigator and a Second Year Nursing PhD Student

School of Nursing, Midwifery and social work

University of Manchester

Tel: 0979-014-487

Email address: [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk)

*If you want to make a formal complaint about the conduct of the research you can contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.*

**The Principal Investigator**

Wang, Ya-Ching,

2<sup>nd</sup> Year Nursing PhD Student

School of Nursing, Midwifery and social worker

University of Manchester

E-mail address: [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk)

Tel: 0979-014-487

**Supervisors**

Dr Jane Griffiths PhD, BNurs, RGN, NDNCert and Professor Gunn Grande PhD MPhil

The School of Nursing, Midwifery and Social Work

The University of Manchester

Jean McFarlane Building

University Place

Oxford Road

Manchester

M13 9PL

## Appendix 18: Online survey- Welcome page and consent

Exit this survey

### Factors associated with Taiwanese lesbians' breast healthcare behaviours: an on-line survey



You are being invited to take part in an on-line survey.

The purpose of this survey is to understand more about Taiwanese lesbians' breast healthcare behaviours and factors influencing these. By taking part in this study, you will be contributing to knowledge about what makes it easier or more difficult for Taiwanese lesbians to protect themselves against breast cancer. If you (1) are 20 years of age and over, (2) are self-defined as a lesbian or a woman who have a partner of the same gender and (3) have never been diagnosed with breast cancer, you are most welcome to be recruited into the study.

Before you decide to take part in the survey, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the information about the study carefully before deciding to take part and feel free to ask for more information or an explanation of something you do not understand. [Please click here](#) to read the information about the study. Thank you for reading this.

Your participation is voluntary and you are free to withdraw your participation from this study at any time. If you do not want to continue, you can leave this website or click the "Exit this survey" button which appears on every page.

If you agree to take part in this online survey, please click the "Next" button.


Next

Powered by [SurveyMonkey](#)  
Check out our [sample surveys](#) and create your own now!

## Appendix 19: Online survey- Business card with a QR code

(Side 1)

The University of Manchester




**Factors associated with Taiwanese lesbian's breast healthcare Behaviour: an on-line survey**

You are being invited to take part in an on-line survey which aims to understand more about Taiwanese lesbians' breast healthcare behaviours and factors influencing these. If you (1) are 20 years of age and over, (2) are self-defined as a lesbian or a woman who have a partner of the same gender and (3) have never been diagnosed with breast cancer, you are most welcome to be recruited into the study.

For further study information or if you are interested in taking part in the study, please connect the link: <https://www.surveymonkey.com/s/6L95KKL> or scan the QR code. By taking part in this study, you will receive a short summary of the study and will be entered in a free gift draw.

Thank you.



(Side 2)



王雅青  
研究主持人暨護理學博士生  
護理、助產士與社會工作學院  
英國 曼徹斯特大學  
電話: 0979-014-487  
電子信箱: [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk)  
[joan02082002@msn.com](mailto:joan02082002@msn.com)

Ya-Ching, Wang  
PI & Nursing PhD student  
School of Nursing, Midwifery and Social Worker  
University of Manchester, UK  
Phone number: +886-979-014-487  
Email: [ya-ching.wang@postgrad.manchester.ac.uk](mailto:ya-ching.wang@postgrad.manchester.ac.uk)  
[joan02082002@msn.com](mailto:joan02082002@msn.com)

## Appendix 20: Missing data

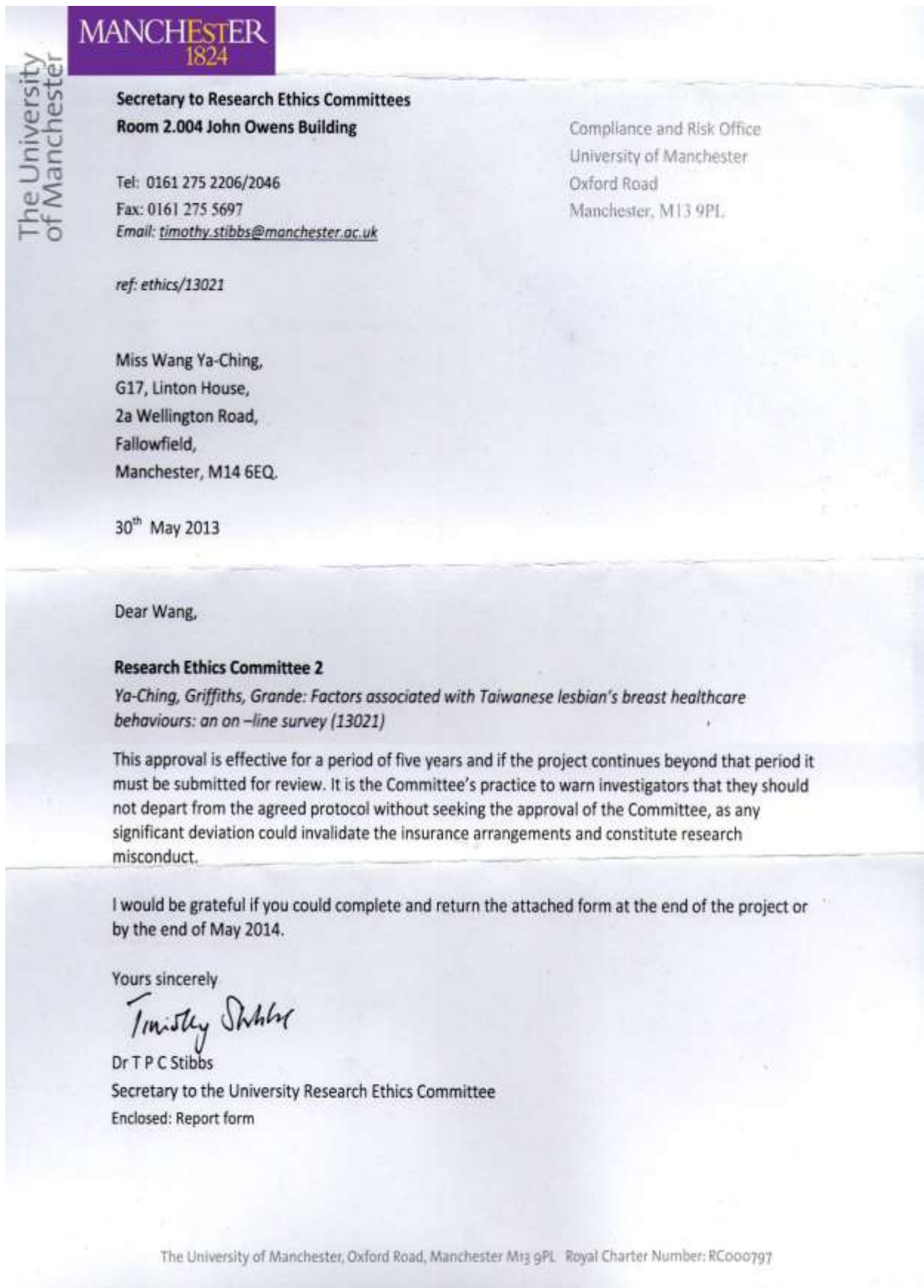
	N		Std. Deviation	Minimum	Maximum
	Valid	Missing			
<b>Section one: Background information</b>					
Age	284	0	7.329	20	58
Sexual orientation	284	0	.87001	1.00	5.00
Gender identity	283	1	1.47508	1.00	6.00
Personal history of breast cancer	284	0	0.00000	2.00	2.00
Personal history of non-malignant breast disease	282	2	.35666	1.00	2.00
Family history of breast cancer	283	1	.56151	1.00	3.00
Religion	283	1	1.64497	1.00	7.00
Employment status	284	0	.98434	1.00	6.00
Occupation?	284	0			
Educational level	283	1	.80434	3.00	8.00
Having children	284	0	.18464	1.00	2.00
Smoking	284	0	.84210	1.00	3.00
Drinking	283	1	.83528	1.00	3.00
<b>Section two: Breast cancer screenings</b>					
Intentions to BSE	284	0	1.66434	1.00	6.00
Frequencies of performing BSEs	116	0	.64530	1.00	4.00
Intentions to mammogram	284	0	1.49227	1.00	6.00
Frequencies of having mammograms	36	0	1.16972	1.00	4.00
<b>Section three: Views on breasts, breast cancer and breast cancer screenings</b>					
Female HP	278	6	.84571	1.00	5.00
Male HP	278	6	.90493	1.00	5.00
Heterosexual assumption	278	6	.99773	1.00	5.00
Lack knowledge of LGBT issues	278	6	1.18195	1.00	5.00
HP would feel uncomfortable with lesbians	278	6	1.13091	1.00	5.00
HP would discriminate against lesbians	278	6	1.22766	1.00	5.00
Breasts be seen by a HP	278	6	1.17856	1.00	5.00
Be touched by a HP	277	7	1.20169	1.00	5.00
Relationship status	278	6	.97958	1.00	4.00
Period of in the relationship	284	0			
Period of in the relationship	168	6	1.22176	1.00	4.00
Partner think that you should perform BSE	172	2	.93359	1.00	3.00
Partner perform BEs for you	173	1	.45728	1.00	2.00
Partner think that you should have a mammogram	173	1	.80957	1.00	3.00
More likely to perform BSE if partner thinks I should do so	277	7	.78637	1.00	5.00
More likely to have a mammogram if partner thinks I should have one	277	7	.74662	1.00	5.00
More likely to have a mammogram if my partner accompanies me	277	7	.86538	1.00	5.00
My breasts have an important sexual function	276	8	1.02079	1.00	5.00
I do not want my breasts	275	9	1.27180	1.00	5.00
I feel embarrassed about my own breasts	276	8	1.16806	1.00	5.00
I feel uncomfortable when I think of my own breasts	274	10	1.09565	1.00	5.00
I usually bind my breasts during daily life	274	10	1.41274	1.00	5.00
I do not like my partner to touch my breasts	276	8	1.02922	1.00	5.00
I do not like my partner to look at my breasts	276	8	1.08840	1.00	5.00
BSE will help protect me against breast cancer	273	11	.77997	1.00	5.00
Performing a BSE would be embarrassing for me	272	12	1.04744	1.00	5.00
Performing a BSE would be unpleasant	273	11	.94521	1.00	5.00
Performing BSEs is not a high priority for me	273	11	.88165	1.00	5.00
Performing BSEs would make me worry about having breast cancer	273	11	1.09356	1.00	5.00
Mammograms will help protect me against breast cancer	271	13	.90375	1.00	5.00
Having a mammogram would be embarrassing	272	12	1.20087	1.00	5.00
Having a mammogram would take too much time	271	13	1.05183	1.00	5.00
Having a mammogram would be painful	271	13	1.17298	1.00	5.00
Having mammograms is not a high priority for me	272	12	.88860	1.00	5.00
Having a mammogram would make me worry about having breast cancer	272	12	1.09260	1.00	5.00
Worry about my appearance being judged by other women	273	11	1.22501	1.00	5.00

## Appendix 20: Missing data (Con.)

My chances of getting breast cancer are great	270	14	.87514	1.00	5.00
I worry about having breast cancer in the future	268	16	.94279	1.00	5.00
I am more likely than the average woman to get breast cancer	268	16	.97096	1.00	5.00
Breast cancer is a life-threatening disease	270	14	.91645	1.00	5.00
I feel anxious when I think about breast cancer	269	15	1.05474	1.00	5.00
Having breast cancer would endanger the relationship between my partner and me	269	15	1.10202	1.00	5.00
I know how to perform a BSE	270	14	1.10449	1.00	5.00
I feel confident that if I were to perform BSEs	269	15	.99946	1.00	5.00
I know how to have a mammogram	268	16	1.12832	1.00	5.00
I feel confident that if I have a mammogram	268	16	.98186	1.00	5.00
Campaigns would encourage me to perform BSEs	269	15	.91087	1.00	5.00
Symptoms would encourage me to perform BSEs	269	15	.75009	1.00	5.00
If other people I knew had breast cancer, this would encourage me to perform BSEs	266	18	.81031	1.00	5.00
Campaigns would encourage me to perform a Mammogram	267	17	.89484	1.00	5.00
Symptoms would encourage me to perform a Mammogram	266	18	.70934	1.00	5.00
If other people I knew had breast cancer, this would encourage me to have a Mammogram	268	16	.84479	1.00	5.00
A physician's recommendations would encourage me to have a mammogram	268	16	.85561	1.00	5.00



## Appendix 21: Ethical approval for the online survey



## Appendix 22: Ethical approval for amendments in the online survey

### Ethics application 13021

---

✦ Timothy Stibbs

收件人



2013年9月9日 上午 08:31

Dear Ya-Ching,

I am pleased to say that the Chair has agreed that your proposed amendment is ethically acceptable and that you may go ahead on the basis of your email. We note, in particular, that you are giving participants adequate time to consider their participation.

Best wishes

Timothy

Dr Timothy Stibbs,  
Secretary to the Research Ethics Committees,  
Room 2.004 John Owens Building,  
University of Manchester,  
Oxford Road  
Manchester M13 9PL  
Tel 0161 275 2046