Improving Participation in Breast Screening Programmes: A mixed methods study to increase breast screening uptake in Malta

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January 2019

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Thesis submitted in partial fulfilment for the degree of Doctor of Philosophy

DECLARATION

I, Danika Maria Marmarà, declare that the work in this dissertation is my own work, except where otherwise stated by reference in the text.

Danika Maria Marmarà
January 2019

DEDICATION

'To Vince and Sam'

I dedicate this thesis to my husband, *Vincent*. Thank you for your limitless encouragement and guidance that have helped me through the duration of this project. Your incredible character and belief in my capabilities have motivated me to complete this work and for this I thank you endlessly.

I also dedicate this thesis to my son, *Samuel*, born 8th July 2018. Amidst the sleepless nights, you have lightened up my days and filled my heart with infinite love. I shall remember these days with pride and joy. I trust you shall look up to me in the future and be proud of my achievements.

ACKNOWLEDGEMENTS

This research would have not been completed without the contribution of a number of people. First, I sincerely thank my supervisors who have supported me to complete this journey. Dr. Gill Hubbard, my primary supervisor, thank you for your continuous support and availability amidst the distance between Malta and Scotland. To my clinical supervisor, Dr. Christine Campbell, thank you for sharing your clinical expertise.

I would like to acknowledge the members of the Scottish and Maltese expert committees for their contribution in this study. It has been truly valuable.

I gratefully acknowledge the Government of Malta for providing financial support with my tuition fees through the Malta Government Scholarship Scheme (MGSS).

I would also like to express my gratitude to the women and men who volunteered their time to participate in this study. To friends and colleagues, thank you for being there when I needed a break. To Dr. Ruth Jepson, your time and expertise in the field of systematic reviews have been worthwhile.

I would also like to thank my parents, in-laws and all family members, for having believed in me and have supported me throughout these years. Thank you for making this journey lighter and for providing me with your words of encouragement and positivity.

Finally, I would like to thank my husband, *Vincent*. Thank you for your unwavering support, understanding and patience. You have been my inspiration and pillar of strength. Thank you for also guiding me with statistical analyses and for encouraging me to stick at it.

ABSTRACT

Background: Breast cancer is the most common cancer among Maltese women. No studies have explored factors related to mammography underutilisation in Malta. This thesis aimed to explore barriers and facilitators to mammography screening among Maltese women to inform future screening interventions.

Methods: Seven studies were conducted through mixed methods research. First, a survey instrument to assess associations between health beliefs, illness perceptions and mammography was piloted-tested among Maltese women (Study 1). Four quantitative studies explored associations and predictors to mammography use: study 2 investigated factors associated with a first screening invitation; study 3 investigated reattendance; studies 4 and 5 examined lifetime mammography practices and timely adherence respectively. A systematic review of interventions, which employed the Health Belief Model and/or Common-Sense Model to improve mammography uptake, was conducted (Study 6). Experts helped to construct a logic model of the problem and change objectives, while members of the public interpreted the quantitative findings through the World Café method. Study 7 consisted of face-to-face interviews with non-attendees. Intervention Mapping was used to synthesise the findings and propose recommendations to increase uptake.

Findings: The survey instrument was valid and reliable for use with Maltese women (Study 1). Health beliefs were strong predictors of mammography underutilisation and illness perceptions improved non-attendance predictions (Studies 2-5). First attendance is associated with reattendance (Study 3). Illness perceptions however are rarely included in mammography interventions (Study 6). Experts supported multiple interventions, including physician recommendations, education and counselling, while members of the public identified the involvement of partners and daughters in health decision-making. Qualitative findings found that health-related knowledge was low, and that socio-cultural factors impeded attendance, particularly support networks, household dynamics, traumatic histories and mental health approaches (Study 7).

Conclusion: Multiple, theoretical strategies are considered more effective. Interventions, implemented within the community setting, should target women's barriers, particularly fear, when first invited. Family members and practitioners can help to address screening barriers.

BRIEF BACKGROUND ABOUT THE AUTHOR

I obtained a B.Sc. with First Class Honours in Radiography (Health Sciences) from the University of Malta in 2007 and a M.Sc. in Mammography from Kingston University London in 2012. I was awarded the UK Wardray Premise Prize for outstanding performance in the Masters Programme and won two national scholarships, one for the Masters program and one for my doctoral studies. Prior to embarking on my PhD studies at the University of Stirling in October 2012, I worked as a Senior Radiographer at Mater Dei Hospital and as a specialist mammographer at the Breast Screening Programme in Malta. I later worked at Sir Paul Boffa Hospital (Oncology and Haematology) as a cancer care coordinator and a year later, I took on the post of Director within the Ministry for Health. As a Director, I established the Cancer Care Pathways Directorate in Malta in October 2014 with the aim to help improve access to care, continuity and care coordination for cancer patients. I am also a reviewer for several journals. I am a speaker at National and European conferences on breast cancer and cancer care and I am involved in various surveys, research projects and strategic committees on a national and international level. I am also a pianoforte performer since the age of 4 and won several national pianoforte competitions.

The year 2009 marked the introduction of the national breast screening programme for Maltese women. During my time as a mammographer at the national Breast Screening unit, I became aware of the increasing issues around breast cancer care and other cancers, and that a number of women were invited to breast screening but did not attend. This created an opportunity and instilled a great interest in me to explore women's behaviours in a society with limited resources for cancer research. This is how I embarked on this project which took me on a six year journey in the field of breast screening and breast cancer research and widened my horizons in cancer care as a Director for Cancer Care Pathways. My special interest is to work for and with people affected by cancer to help shape the future of cancer services by addressing gaps, inequalities and disparities in cancer care.

PUBLICATIONS

Marmarà, D., Marmarà, V. and Hubbard G. (2017a) Maltese translation and adaptation of Champion's Health Belief Model Scale and the Revised Illness Perception Questionnaire for breast screening among Maltese women. *Journal of Nursing Measurement*, 25 (3), pp. 486-503.

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LIST OF ABBREVIATIONS

BC	Breast Cancer
BS	Breast Screening
BSE	Breast Self Examination
CBE	Clinical Breast Examination
CI	Confidence Interval
CHBMS	Champion's Health Belief Model Scale
DoH	Department of Health
HBM	Health Belief Model
IM	Intervention Mapping
IPQ	Illness Perception Questionnaire
IPQ-R	Revised Illness Perception Questionnaire
MBSP	Maltese Breast Screening Programme
NHS	National Health Service
NHSBSP	National Health Service Breast Screening Programme
NICE	National Institute for Health and Care Excellence

OR	Odds Ratio
PPI	Patient and Public Involvement
RCT	Randomised Controlled Trial
SPSS	Statistical Package for the Social Sciences
UK	United Kingdom
US	United States of America
WHO	World Health Organisation

DEFINITIONS

For the purpose of this study, the definitions of the key concepts used are listed below. Some of these definitions were sought from books and journals while others were drawn up for the purpose of this study.

Barriers:	*Perceived negative aspects of undertaking health behaviours (Gözüm and Aydin 2004). These may also be physical or structural concerns or perceived emotions related to behaviours that might interfere with breast screening uptake.*
Benefits:	*Positive results of steps taken to avoid contracting the condition (Gözüm and Aydin 2004).*
Breast cancer:	*Cancer that originates from breast tissue, usually from the milk-producing glands (lobules) and the tubules that carry milk from the lobules to the nipple during breastfeeding (ducts) (Sharma et al, 2010).*
Compliance:	*The proportion who present for screening amongst those invited who remain eligible and are resident in the catchment population (Marshall 1995, p.112).*
Coverage:	*The proportion of women resident and eligible for screening within a population invited for mammography screening in a specified time period (Jepson et al. 2000).*
Cues to action:	*Exposure to factors that prompt action i.e. anything that prompts an individual to think or act upon a specific health issue (i.e. TV commercials prompting to take a specific action or having a family member suffering from a specific condition) (Orji et al. 2012).*
Determinants:	*Factors significantly influencing the screening uptake (e.g., individual's characteristics, type of screening and methods involved, other) (Jepson et al. 2000).*

Incidence: *'The number of newly diagnosed cases of disease in a defined population within a defined time period. It is usual to present incidence as rates per 100 000 women' (Marshall 1995, p.112).*

Internal consistency: *The degree to which all of the items on a test measure the same construct (Bowling 2009).*

Internal validity: *The extent to which the instrument is really measuring what it purports to measure (Bowling 2009).*

Mammography: *'It consists of two mammographic views of each breast (Cranio-Caudal and Medio Lateral Oblique projections). The CC view provides sagittal orientation of breast tissue and includes most of the breast with the exception of the far lateral portion', while 'the MLO view is a view of virtually all the breast' (Eklund and Cardenosa 1992, p.22).*

Mammography screening: *'A suitable screening test that detects the great majority of breast cancers from those screened (high sensitivity) giving very few false negative results, while the majority of those not having breast cancer are eliminated from further diagnostic tests (high specificity) giving very few false positive results' (Forrest 1990, p.13).*

Morbidity: *'The relative incidence of disability/disease, i.e. non-fatal illness' (Marshall 1995, p.112).*

Mortality: *'The number of people within a defined population who die within a defined period. As for incidence, it is usual to present mortality as rates per 100 000 women' (Marshall 1995, p.112).*

Motivation: *The beliefs and behaviours related to the state of general concern about health (Gözüm and Aydin 2004).*

Opportunistic screening: *An individual seeks screening or is referred by a doctor or health care professional to non-dedicated mammography screening centers without active invitation neither control system (Anagnostopoulos et al. 2012).*

Perception:	*'The process which determines the way we appraise the world around us and forms the basis of the actions we take to remain in control of what is going on in our lives' (Payne and Walker 1996, pp.79-80). With respect to breast screening, perceptions may include: 'value of health, risk factors and early warning signs of breast cancer, importance of and confidence in the test, confidence in own capabilities in breast cancer prevention, and expectations of pain in mammography' (Aro et al. 1996, p.83).*
Perceived seriousness:	*Perceived severity of the consequences of contracting a disease (Gözüm and Aydin 2004).*
Perceived susceptibility:	*Perceived vulnerability to a disease or the risks of contracting it (Gözüm and Aydin 2004).*
Quality assurance:	*'The total overall management of actions taken to consistently provide high image quality, the primary objective being to enhance patient care. In general, quality assurance must be planned and systematic series of actions with key components being quality control' (Peart 2005, p.2).*
Reliability:	*'The extent to which the measure is consistent and minimizes random error (its repeatability) (Bowling 2009, p.468).*
Self efficacy:	*Confidence in one's ability to perform the new health behaviour (Orji et al. 2012).*
Social inequalities:	*'Health disparities, within and between countries, that are judged to be unfair, unjust, avoidable, and unnecessary (meaning: are neither inevitable nor irremediable) and that systematically burden populations rendered vulnerable by underlying social structures and political, economic, and legal institutions' (Krieger 2001, p.698).*
Test-retest reliability:	*The degree to which the results are consistent over time (Bowling 2009).*
Uptake:	*The proportion of women invited for screening for whom a screening test result is recorded (NHSBSP 2012).*

Chapter 1

Introduction

1.1 Introduction

Chronic health diseases are a global public health concern (McKenzie et al. 2008) with cancer being among the most common and expensive health issues (Centers for Disease Control (CDC) 2015). In particular, the burden of breast cancer (BC) on society, measured by incidence, mortality and economic cost (Legler et al. 2002), is estimated to increase substantially as people live longer and care and treatments become more complex and expensive (Knox 2009). Specifically, BC originates from breast tissue, usually from the milk-producing glands (lobules) and the tubules that carry milk from the lobules to the nipple during breastfeeding (ducts) (Sharma et al. 2010). BC is highly preventable and treatable if detected at the precancerous or local stage of development. Early BC detection through screening is associated with earlier-stage disease and effective treatment (Dang et al. 2010). It has been shown to be effective in decreasing BC mortality by 25-35% in women over 50 (Tabár et al, 2011; Smith et al., 2004), thereby improving women's survival (Galit et al. 2007). To achieve this goal, it is essential to have high participation rates in breast screening (BS) by mammography.

This research has been informed by my previous work entitled 'A study to evaluate women's satisfaction of the Maltese Breast Screening Programme' (Marmarà et al. 2015), which examined programme satisfaction among BS attendees. Apart from women's high satisfaction with the programme, the findings showed a low attendance rate of 55.9% at the time of study (Marmarà et al. 2015). This gap in Malta needed to be urgently addressed. In Malta, there have been no evidence-based studies on BS barriers and facilitators, and no feasible and acceptable screening interventions for the Maltese population. Hence, Maltese women were selected as the target population in this research.

This research lays the foundations to address barriers and facilitators associated with BS by exploring health beliefs and illness perceptions about BC and BS practices. Hence, the findings shall aid the design and development of a future intervention in Malta. This work is novel in Malta and may have a pivotal role in shedding light on the gap between practical strategies and any system level changes required to develop efficient and effective BS programmes in Malta. It is also hoped that this study will further contribute towards health services research knowledge and inform theoretical intervention development.

This chapter describes BC epidemiology, screening history and BS uptake in Europe and in Malta. It also introduces the Maltese context and justifies the focus of the thesis. The last section in this chapter contains a brief overview of each chapter. The terms BS and mammography screening are used interchangeably throughout this thesis.

1.2 Background

1.2.1 Malta and its healthcare system

Malta is an archipelago in the centre of the Mediterranean Sea between Sicily and the North African coast (Chapman and Cassar 2004) with a total population of around 460,000 inhabitants, making it one of the smallest and most densely populated countries in the world (NSO 2018). Malta is known for its sunny weather and attractive beaches, but most of all for its historic sites (Rudolf and Berg 2010). Malta has two official languages - Maltese and English, though Maltese is regarded as the national language.

Malta has had a reputable, long-standing medical history of healthcare provision, with its first hospital already functioning by 1372 (Savona-Ventura 2007), earning worldwide reputation for the nursing care offered to inpatients during World War 1. Malta ranked fifth in the World Health Organization's (WHO) ranking of global health systems in 2000 (Coustsoukis 2016), superseding the United States, Sweden, United Kingdom and Spain. To date, the Maltese government provides comprehensive, publicly funded health care to all Maltese residents (through taxation and national insurance), covering a wide array of treatments, such as specialist treatment, hospitalisation, prescriptions, pregnancy, childbirth and rehabilitation. The public health care system operates through public hospitals and health care centres, and is overseen by the Ministry for Health with the Chief Medical Officer, Director General (Health Care Services) and Superintendent Public Health at the helm. Eight health centres provide primary care, offering preventive, curative and rehabilitative services, while secondary and tertiary care are provided through three public hospitals. Inaugurated in 2007, the largest public hospital in Malta, 'Mater Dei', is one of the largest medical buildings in Europe, receiving a number of awards for medical excellence and research. For those who opt for private health care insurance or out-of-pocket payments, the island offers a strong private health system (Ministry for Health

2017a). Pharmacies offer services by General Practitioners, specialized physicians and allied health care professionals.

1.3 Breast cancer epidemiology

BC is the most prevalent form of cancer among women (Ferlay et al. 2013); approximately 1.7 million new cases were diagnosed worldwide in 2012 making it the second most common cancer overall (WHO 2013). BC is also the leading cause of female mortality worldwide (Stewart and Wild 2014). Despite substantial gains in mortality reductions over the past decade as well as the increase in public knowledge and the momentum gained for BS awareness, BC continues to pose a global health problem, representing a continuous threat to women's health and well-being.

In Europe, BC accounted for around 29% of female cancer incidence in 2012 (an estimated incidence of 494,100 women) and around 17% of female cancer deaths, which translates into around 129,000 deaths caused by BC yearly (Ferlay et al. 2013). The estimated lifetime risk of developing BC before the age of 85 has risen from one in nine to one in eight women living in the European Union (EU-28) (Wise 2011). The annual European BC incidence is expected to rise to 466,000 cases by 2020 (OECD 2012). The exact cause of BC is still unclear (NHS Cancer Screening Programmes 2010). However, changes in lifestyle habits, increase in sedentary lifestyle, weight gain and obesity, as well as social changes, are known to contribute to the increasing number of BC cases, such as increasing age at first birth and decreasing number of children born to women (Stewart and Wild 2014).

In Malta, BC is also the commonest type of female cancer (DHIR 2010); incident rates of 116 per 100,000 females are among the highest rates in Europe (Ferlay et al. 2013). In 2012, the mortality rate for Malta was estimated to be 26 deaths per 100,000 females, compared to 23 deaths in all Europe (**Figure 1.1**). Together with other southern European countries, the latter reflects a high mortality to incidence ratio, a proxy of unfavourable survival (Ferlay et al. 2013).

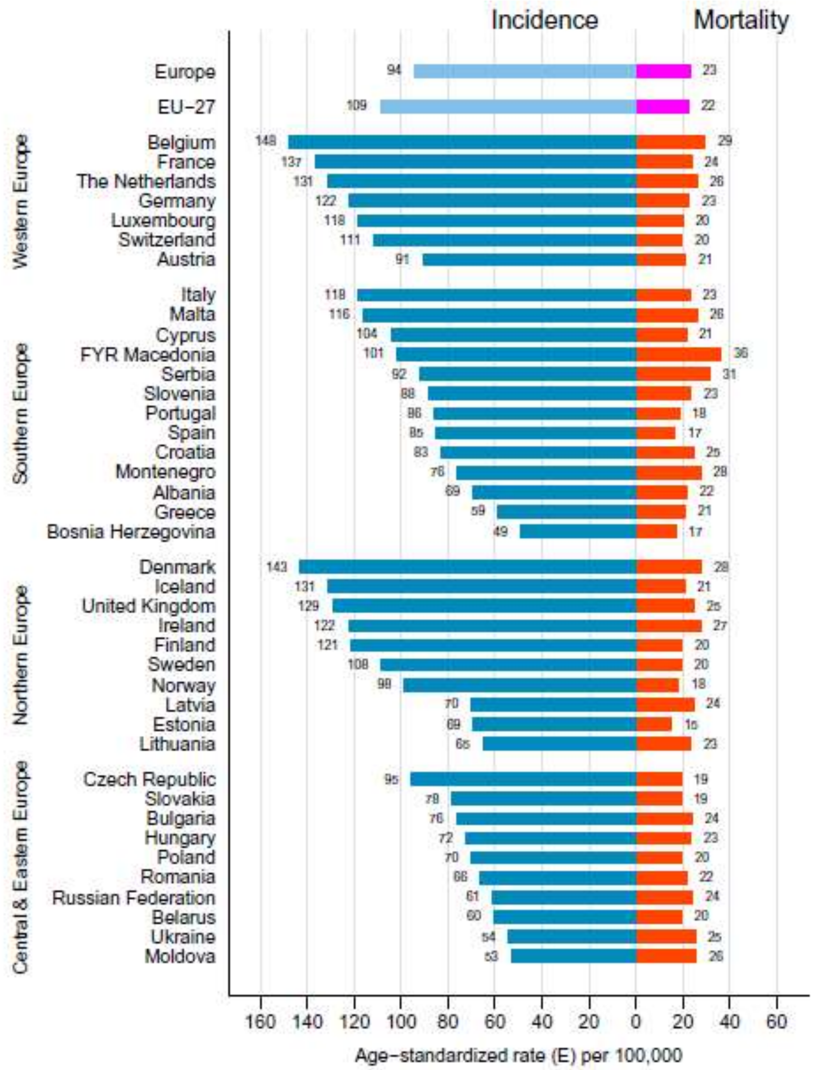

Figure 1.1 - Age-standardised incidence and mortality rates by area and country in Europe for breast cancer in 2012 (Ferlay et al. 2013, p.1397)

1.4 Approaches to breast screening

Breast self-examination (BSE), clinical breast examination (CBE) and mammography are the three major approaches to early BC detection (Perry et al. 2006; Kösters and Gøtzsche 2003). BSE and CBE involve feeling the breast for lumps or other abnormalities through physical breast examination. In BSE, women themselves systematically feel their breasts for changes, such as lumps. BSE is the preferred screening method for pre-menopausal women since mammography has a lower sensitivity to dense breast tissues (Vahabi 2003). Additionally, BSE plays an important role in interval cancer detection i.e. cancer appearing in between two successive mammograms (Lechner et al. 2004). However, medical evidence does not support the sole use of BSE (Kösters and Gøtzsche 2003). A large number of studies have indicated that BSE was not effective in improving BC mortality rates and even increased the number of women having a biopsy (Kösters and Gøtzsche 2003; Thomas et al. 2002), resulting in increased anxiety and fear among women.

On the other hand, CBE is a visual and manual breast examination conducted by health professionals to identify breast abnormalities. Other tests, such as mammography and ultrasound, are required alongside CBE when there are suspicious findings, or in women with increased risk for BC (Kösters and Gøtzsche 2003). The reason for the inclusion of other tests may be due to the limited evidence on the effectiveness of CBE in reducing BC mortality (Pisani et al. 2006). Hence, the following breast awareness advice increases the chances of early BC detection: being familiar with one's own breasts, knowing what is normal for one's breasts, informing the GP once changes in the breasts are noticeable, and attending the BS programme at 50 years of age (NHS Cancer Screening Programmes 2010).

1.4.1 Mammography screening

Mammography screening examines asymptomatic women for BC through the use of an X-ray technique in an attempt to detect tumours before they are clinically palpable (Kimberly et al. 2003), thereby minimising the probability of diagnosing advanced disease. The European Union (EU) Council recognises mammography screening as the sole screening method for women aged 50–69 on a two-year basis (Perry et al. 2006; Advisory Committee on Cancer Prevention 2000), and supports its use as one of the most effective ways to detect cancer for women with an average risk (Kimberly et al. 2003).

The efficacy of mammography screening was assessed through eight randomized control trials (RCTs) (Gøtzsche and Olsen 2000), the first being initiated in 1963 in New York (Shapiro 1997). These RCTs compared BC mortality rates in women who had been screened (intervention) to those who had not (control). The combined results of these studies showed that mammography screening reduced BC mortality by 25-30% in women over 50 after 7-12 years from entry in the trials (Tabár et al. 2011; Smith et al. 2004). The RCTs also found that mammography screening did not significantly reduce BC mortality in younger women. However, concerns have been raised about the validity of these RCTs because of supposed ‘flaws’ in randomisation and ascertainment of cause of death (Olsen and Gotzsche 2001), insufficient power to show an effect and most sample populations included women below 50 years (Sickles and Kopans 1993). More recent observational studies, reporting on the impact of population-based screening programmes have also been questioned due to similar inconsistencies (Jørgensen et al. 2011; Corder 2010).

Mammography screening has thus been associated with controversy (Gøtzsche and Jørgensen 2013) due to issues of overdiagnosis and its potential to cause harm to women through unnecessary treatments and medical procedures. These issues are related to the sensitivity of mammography in detecting slow-growing or non-aggressive lesions. These issues have provoked adverse criticism from many who believe that BS saves lives (Thornton 2001; Dilhuydy and Barreau 1997). However, since it is not possible to know which screen-detected cancers are potentially fatal, all screen-detected lesions are usually treated with the negative impact of overdiagnosis and associated treatment.

Researchers from Norway also set out to evaluate the effectiveness of mammography screening by comparing the effects on BC mortality among screened and unscreened women. The study analysed data from all women in Norway aged 50 to 79 between 1986-2009, the period in which the BS programme was rolled out across the country. The researchers found that women invited to screening in the Norwegian mammography screening programme were at a 28% lower risk of death from BC than women who had not (yet) been invited (Weedon-Fekjær et al. 2014). The authors concluded that for every 368 women aged 50-69 invited to biennial mammography screening (95% confidence interval (CI) 266 to 508), one death from BC was prevented. According to another review of the European literature examining the impact of mammographic screening on BC mortality, a reduction of 38–48% was found among those who were actually screened (Broeders et al. 2012). Amidst controversies associated with mammography screening, these two studies add to prior evidence confirming that BS saves lives (Hendrick and Helvie 2012; Mandelblatt et al. 2009).

1.5 Breast screening in Europe

The eigth RCTs encouraged the implementation of free mammography screening services worldwide. Following the 2003 recommendations by the EU Council, 22 member states began to organise BS programmes (Altobelli and Lattanzi 2014) (**Table 1.1**).

Table 1.1 - Timeliness of breast screening programmes with age covered in studied countries (Eurostat 2013)

Country	Implementation of screening programmes	Age covered
Austria	**1974**	**40+**
Belgium	**2001**	**50-69**
Bulgaria	**2012**	**45-69**
Czech Republic	**2002**	**45-69**
Cyprus	**2007**	**50-69**
Denmark	**2007**	**50-69**
Estonia	**2002**	**50-69**
France	**2003**	**50-74**
Germany	**2005**	**50-69**
Greece	**-**	**40+**
Hungary	**2001-2002**	**45-64**
Italy	**2005**	**50-69**
Latvia	**2009**	**50-69**
Malta	**2009**	**50-60**
Poland	**2006**	**50-69**
Slovenia	**2008**	**50-69**
Spain	**1990**	**45-69**
Slovak Republic	**-**	**40+**
Romania	**-**	**50-69**
Sweden	**1986**	**50-69**
Turkey	**1999**	**50-69**
United Kingdom	**1988**	**50-64**

EU countries implemented these recommendations as they deemed fit (Labrie et al. 2017). The first EU Member State to have ever implemented a BS programme was Austria in 1974. Mammography is offered to all women over 40 years old but screening remains opportunistic in most of the country (Vutuc et al. 2006). Opportunistic screening is also widespread across Belgium, with its organized screening programme offering mammograms at two-year intervals for women aged 50-69 (Altobelli and Lattanzi 2014). Norway adheres to the EU Council recommendations, while a biennial nationwide screening programme for women aged 50-75 is offered in the Netherlands (National Institute for Health and the Environment 2015). Regionally organized screening programmes are offered in Switzerland for women over 50, with the age limit varying between 69-74 years (Swiss Cancer Screening 2015). Notable exception for the screening interval is by United Kingdom (UK) and Malta who opted for the introduction of a three-yearly screening frequency (Benson et al. 2013).

Each country in the UK has a different BS programme. Following recommendations by the Forrest Committee in 1986, which sought to implement a BS Programme (NHSBSP) across England, the first national BS programme in the world was rolled out in 1988; it provided free mammograms to women aged 50-64 (Kinnear et al., 2010; Forrest, 1986). From 2010, a trial in England started phasing in an extension of the age range of invited women to those aged 47 – 49 and 71 – 73 (Moser et al., 2011). Scotland's first screening centre became operational in 1988 with the target population aged 50-70. Wales activated its programme in 1989 for women aged 50–70. In Northern Ireland the screening programme, introduced in 1990, was initially aimed at 50–64-year-olds but was extended to women aged 70 in 2004. By the end of 2004, around 40% of NHSBSP units in the UK were inviting older women; full national coverage was accomplished by 2006.

1.5.1 Breast screening in Malta

By 2012, several high income countries had screening programmes that had been in place for 20 years or more (Autier and Boniol 2012). However, it was only in October 2009 that a Maltese Breast Screening programme (MBSP) was launched in Malta for women aged 50 – 60 (**Table 1.1**). The difficulties were due to the lack of acceptability and feasibility of pilot start-ups (Ministry for Health 2017b). The MBSP has been greatly influenced by the success of the NHSBSP in the UK. The MBSP calls eligible women for mammography screening by direct invitation and is free of charge (Government Portal 2008). The MBSP was the start of Malta's cancer control strategy as recommended in Malta's first National Cancer Plan 2011-2015 which covered prevention, screening and quality of care. Following the MBSP, a colorectal screening programme was implemented in 2012 and cervical screening in 2015.

BS invitations commenced with the older client spectrum with each age group invited and completed over four-to-five monthly periods rather than through random invitations as in the

UK (European Commission 2014; Government Portal 2008). In 2015, this age cohort was in its second BS round and simultaneously expanded to include women up to 66 years (Ministry for Health 2017b) with the aim of gradually expanding the age range to 69 years over a five-year period. A woman receives a standard invitation letter from the MBSP to attend the sole static screening unit located in the heart of Valletta, Malta's capital city, which is well-served by public transport; no mobile units exist. Unlike standard practice in the UK, the Maltese citizens are not registered with a GP or GP practices (Threlfall and Fazil 2009). The invitation letter describes the location and time of the screening appointment and provides contact details of the unit for women to change their appointment, if necessary. Initially, an information booklet accompanied the invitation letter, but the content was under review together with its cost effectiveness since the beginning of 2011 and has not been issued and mailed since. As is the current practice at the MBSP, two views (medio-lateral and cranio-caudal) are carried out by trained radiographers (mammographers) and the mammograms are reported by trained breast radiologists. Adjunct ultrasound is carried out at a subsequent (recall) appointment when deemed necessary, for cases such as dense breasts or for further evaluation of suspected mammographic abnormalities.

1.6 Breast screening compliance

1.6.1 Breast screening uptake in Europe

The need to reduce BC mortality through early detection has become an increased recognized national priority worldwide (Ka'opua et al. 2011; Malta Breast Screening Programme 2011). Nonetheless, screening rates remain suboptimal across the EU with participation varying considerably across Europe (Schopper and de Wolf 2009). EU guidelines promote a recommended acceptable target rate of >70% (Perry et al. 2006) and a desirable benchmark of at least 75% of eligible women in EU countries (European Commission 2014). Nevertheless, in 2010, only four countries had reached this target, with rates ranging from as low as 8% in Romania to over 80% in Finland, Slovenia and the Netherlands (**Figure 1.2**). Low screening rates may represent a system-level failure in care in some countries (Lester et al. 2009). However, the variation in participation may also, in part, be explained by programme longevity, with some countries having well-established programmes and others commencing programmes more recently, including Malta (OECD 2012).

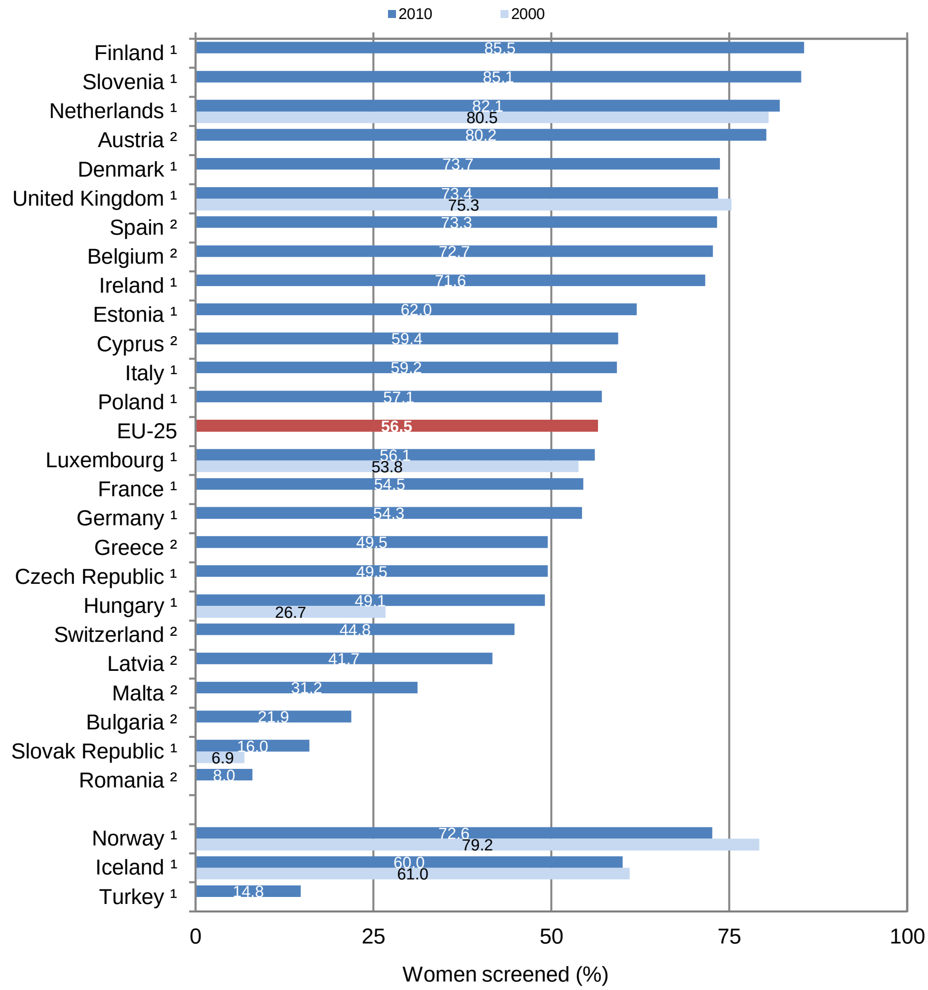

Figure 1.2 - Mammography screening, percentage of women aged 50-69 screened, for the years 2000 to 2010 (or nearest year) (OECD 2012)

One of the countries that reached the EU benchmark was the UK, achieving an attendance rate of 73.4% for women aged 45-74 in 2010/11, or almost three-quarters of women (NHSBSP 2012). This percentage resulted in the detection of more than 17,258 cancers in the UK – an increase of over 700 when compared to the previous year.

1.6.2 Breast screening uptake in Malta

By the end of the national roll-out of the MBSP's first cycle, 193 women were diagnosed with BC (iNews Malta 2013). However, only 58.7% of those invited had accepted their invitation (iNews Malta 2013). This possibly reflects variations in the perceived costs, perceived benefits to screening, as well as facilitators and barriers to screening (Carney et al. 2013). Hence, identifying and addressing the barriers, facilitators and misconceptions affecting uptake and maximising coverage is crucial for a cancer screening programme's success (Weller and Campbell 2009; Shen et al. 2005), as the percentage of non-attenders could well result in missed cancer detection (NHSBSP 2009). This further highlights the need for effective interventions to increase uptake and reduce any inequalities among the population (Weller and Campbell 2009).

1.7 Aims and research questions

The overall aim of this thesis is to explore the barriers and facilitators to mammography screening, to inform future development of an intervention to improve BS uptake in Malta. To fulfil this aim, this thesis aimed to address the following research questions (RQs) (**Table 1.2**).

Table 1.2 – Research questions

RQ number	Research Questions	Chapter	Study
RQ 1.	Is the Maltese Breast Screening Questionnaire (MBSQ) valid and reliable?	Chapter 4	*Study 1*
RQ 2a-d.	Which significant factors i.e. health beliefs, illness perceptions, knowledge, socio-demographic factors and health status of women are associated with: (2a) BS uptake to a first invitation at the MBSP, (2b) re-attendance, (2c) lifetime mammography use, and (2d) adherence to timely mammography practices in Malta?	Chapter 4	*Studies 2- 5 respectively*
RQ 3.	What types of interventions (which have employed the Health Belief Model and/or Common-Sense Model of illness self-regulation) are effective at increasing mammography uptake?	Chapter 5	*Study 6*
RQ 4.	Which factors influence non-attendance among lifetime non-attendees and which interventions are considered appropriate to increase mammography screening uptake in Malta?	Chapter 8	*Study 7*

Each study had associated objectives as follows:

Study 1:

1. To pilot test the reliability and validity of Champion's Health Belief Model Scale for Mammography Screening (CHBMS-MS) and the Revised Illness Perception Questionnaire (IPQ-R) and their Maltese translated version (MBSQ).

Study 2:

1. To describe Maltese women's knowledge, health beliefs and illness perceptions about BC and screening;
2. To identify the main reasons related to non-attendance at the MBSP;
3. To determine if health beliefs, illness perceptions, knowledge, socio-demographic factors and health status of women are associated with uptake to a first MBSP invitation;
4. To determine significant predictors to a first BS invitation.

Study 3:

1. To explore whether sociodemographic factors, health status, knowledge, health beliefs and illness perceptions are significant predictors of uptake to a second MBSP invitation;
2. To determine if uptake of first MBSP invitation is a significant predictor of uptake to the second invitation.

Study 4:

1. To determine the socio-demographics, health status, knowledge, health beliefs and illness perceptions of women who attend or do not attend for mammography screening during their lifetime;
2. To examine the most significant predictors of lifetime mammography utilization and its non-use.

Study 5:

1. To determine mammography screening use within or exceeding the recommended three-year frequency in Malta;
2. To explore associations between socio-demographic factors, health status, knowledge, health beliefs and illness perception variables of adherent and non-adherent women.

Study 6:

1. To describe study design and methods, report intervention effectiveness on BS behaviour, and to describe theories, procedures, functions and content of the interventions.

Study 7:

1. To gain a better understanding of beliefs, perceptions, attitudes, barriers and knowledge regarding BS among lifetime non-attendees;
2. To determine which interventions and channels are appropriate for communicating with women about BC and BS.

1.8 Thesis Overview

To address the above aims and RQs, this project was divided into nine chapters. This thesis comprised 7 studies in total, which were conducted to gather and analyse new data. Two expert steering groups and members of the public provided feedback on the quantitative findings from these studies and to deepen my understanding of what future intervention(s) could improve BS uptake in Malta. These studies are listed in **Table 1.2**.

Chapter 1 provided an introduction to this thesis and laid the policy contextual background about the Maltese healthcare system, BC and BS history, including the aims, objectives and RQs addressed in this thesis.

Chapter 2 reviews the existing literature and empirical evidence regarding factors related to mammography screening behaviours and the application of relevant theoretical models to explain women's behaviours. Chapter 2 therefore provides an in-depth description of key factors that influence BS behaviours and presents two main theoretical frameworks – the Health Belief Model (HBM) and the Common-Sense Model (CSM) of illness self-regulation.

Chapter 3 describes the over-arching methodological approach and methods used in this research. Here, the Intervention Mapping (IM) approach is described, and how each study influenced subsequent studies in a mixed methods approach to fulfil the RQs is also described in the context of using the IM approach.

Chapter 4 presents a detailed overview of the quantitative findings of this thesis and is divided into five studies:

- Study 1 describes the tool development used for the succeeding cross-sectional survey, and how it was translated and adapted for BS among Maltese women. Specifically, Study 1 aimed to translate, adapt and pilot the adapted English version of CHBMS-MS and IPQ-R among Maltese women and the Maltese version of the latter scales (MBSQ).
- Study 2 utilized the HBM and CSM to investigate factors associated with BS uptake in Malta and to identify the most important predictors to first BS uptake in a quantitative national study.
- Study 3 investigated reattendance to the second MBSP round through a prospective study. Study 3 explored predictors and behaviour to re-attendance, and to determine if uptake of first invitation at the MBSP is a significant predictor of second BS uptake.
- Studies 4 and 5 examine the predictors and/or associations for lifetime mammography practices and adherence to timely mammography use in Malta respectively.

Each piece of quantitative analysis was labelled as a study for ease of reference, even though studies 2-5 all form part of one large national survey.

Following the findings of the previous quantitative studies based on HBM and CSM, a systematic review of the literature was carried out in relation to effective interventions aimed at increasing mammography screening and which utilised the latter theoretical models (Chapter 5, Study 6).

All the previous information was collated, presented and discussed with two expert steering groups (Chapter 6). These groups were set up to provide expert advice on the core elements of a future intervention. These groups reviewed the evidence from the quantitative data, literature review findings on BS determinants and the systematic review on interventions. The objectives were to develop a logic model of the problem and a logic model of change, and to judge basic fit of potential future intervention(s).

Chapter 7 presents findings gathered from a Patient and Public Involvement (PPI) event through the World Café method to engage members of the public to enhance the understanding of the quantitative and systematic review findings, and to inform the design of future interventions.

In order to understand the perceptions of the previous findings in more depth, 20 face-to-face interviews were carried with Maltese women who never attended for mammography i.e. ‘lifetime’ non-attendees (Chapter 8, Study 7).

The above information and findings provided a wealth of knowledge and the opportunity to converge this insight into more tangible recommendations for health care providers and policy makers. Such recommendations, presented in Chapter 9, have the potential to be used as a guide for the development of future BS interventions in Malta through the use of a more targeted approach for Maltese women.

Chapter 2

Literature Review

2.1 Introduction

Chapter 1 provided an introduction to the thesis including breast cancer (BC) epidemiology, Malta and its healthcare system, and the history of breast screening (BS) services in Europe and in Malta. Chapter 1 therefore set the policy context for this thesis. Chapter 2 provides an in-depth literature review of the factors influencing BS behaviour, namely psychosocial, knowledge, socio-demographic, medical and logistical factors. This is relevant to the overall aim of this thesis, which is to explore the barriers and facilitators of BS attendance in Malta. Health behaviour theories/models that may be used to explain BS behaviour are also described here. The two key models are the Health Belief Model (HBM) and the Common-Sense Model (CSM). A critique of the literature, and in particular, key gaps in evidence is also presented.

2.2 Factors related to mammography screening

Despite the known benefits of BS by mammography, a wide range of key screening determinants may influence a woman's decision not to attend for screening (Vedel et al. 2011). Reasons for BS attendance include peace of mind, risk perception, positive prior screening experiences, anxiety, beliefs, intention to attend, socio-demographic factors and personal or family experiences of BC (Zackrisson et al. 2004; Isaacs et al. 2002; Lagerlund et al. 2002).

Reasons for non-attendance are well documented and multifactorial (Whelehan et al. 2013; Anagnostopoulos et al. 2012). Substantial research has focused on identifying women's, physicians', and system-level barriers to mammography screening (Anagnostopoulos et al. 2012; Arnold et al. 2009; Audrey et al. 2008). These factors are categorized into key groups:

- Psychosocial factors (Petrak et al. 2015; Anagnostopoulos et al. 2012; Huaman et al. 2011; Champion et al. 2008);
- Knowledge (Liu et al. 2014; Dundar et al. 2006);
- Socio-demographic factors (Liu et al. 2014; Walsh et al. 2011; Meissner et al. 2004);
- Health status (medical factors) (Anagnostopoulos et al. 2012; Cohen and Azaiza 2010; Meissner et al. 2007);
- Logistical factors (Elias et al. 2017; Carney et al. 2013).

These factors are discussed in the following sections.

2.2.1 Psychosocial factors

2.2.1.1 Understanding beliefs and perceptions

Health behaviours can be shaped by our beliefs. Beliefs are influenced by perceptions (or cognitive characteristics) that can be acquired by:

- internalising the beliefs of the people close to us during childhood (primary socialisation);
- adopting beliefs of significant others in the individual's surroundings (i.e. peers and leaders);
- exposure to repetitive messages, such as informative campaigns and association of beliefs with strong positive or negative emotions such as images of love;
- physical trauma (Day et al. 2010).

There is an assumption that beliefs can be modified since they can differ among individuals from the same background (Parsa et al. 2006). However, modifying beliefs can be difficult as people often cling to beliefs and act on them, even against their own self-interest (Day et al. 2010). In a study by Yarbrough and Braden (2001), residents of a community with an increased cancer incidence were very resistant to health education interventions despite knowing about their increased risk. Yarbrough and Braden (2001) argued that health promotion activities might not be effective for reducing cancer risk because the cause of cancer is unclear. Numerous beliefs, perceptions and attitudinal factors have been linked with variance in the uptake of BS (Parsa et al. 2006) and these shall be discussed in the following sections.

2.2.1.2 Beliefs and perceptions of Breast Cancer and Breast Screening

Health beliefs and perceptions have long been reported to act as key facilitators or barriers to attending screening (Jahanlou et al. 2013; Champion 1999). Women may not perceive the importance of BS and this may result in low screening rates or late cancer detection, which may lead to less effective treatment. Studies have found that some women do not perceive the importance of detecting BC early as they lack adequate information (Im et al. 2004; Hisham and Yip 2003; Chong et al. 2002; Jarvandi et al. 2002). The findings revealed that women feared both cancer and death, and directly connected cancer to dying from the disease (Juon et al., 2004; Nissan et al., 2004). In a Korean qualitative study (Im et al., 2004), women did not perceive the need for BS if they did not experience any recognizable symptoms, if they had no family history of BC or because they had breastfed their children. This calls for educational interventions providing women with accurate information about BC risk factors and screening.

2.2.1.3 Socio-cultural influences

Individual BS behaviour is directly influenced by women's wider social and cultural context (Moudatsou et al. 2014; Pasick et al. 2009). Socio-cultural influences include knowing someone with the disease or condition; having support of family, friends or significant others, such as a physician or other healthcare providers; being a member of a club, church or other organization; or knowing someone who has been screened (Jepson et al. 2000). The following are all associated with higher mammography attendance (Cabeza et al. 2007; Zackrisson et al. 2004; Lagerlund et al. 2002): being married or cohabitating and having social support from significant others (Farmer et al. 2007; Lechner et al. 1997), having a close friend (Calnan 1984), social participation and being a member of volunteer groups (Maxwell et al. 2001). Conversely, social isolation is associated with lower attendance (Lagerlund et al. 2014; Pasick and Burke 2008). It has been suggested that if socially isolated women are underscreened, they may have greater risks of undetected BC and dying from the disease (Lagerlund et al. 2014).

A variety of barriers to BC awareness may include fatalism, inability to act without a husband's permission, fear of casting stigma on one's daughters, fear of being disliked or not accepted, fear of contagion, language barriers, and preference for traditional healers (Smith et al. 2006). For example, cancer fatalism stems from the belief that there is little an individual can do to alter one's fate (Austin et al. 2002) and hence, death is inevitable when cancer is diagnosed (Powe and Finnie 2003). Fatalism is a prominent barrier to seek screening and is negatively associated with BS uptake (Schueler et al. 2008). Such socio-cultural barriers can be addressed with education or tailored approaches that take into account culture, religion and other factors. Tailored approaches will need to be directed towards women, health care workers, and relevant others in the community.

Social support and network

Social support is an interactive process in which particular behaviours or actions can have a positive effect on one's physical or psychosocial well-being (O'Reilly 1988). Studies have found that the presence of social support increased BS attendance (Jensen et al. 2016; Documet et al. 2015; Farmer et al. 2007; Courtney-Long et al. 2011; Lagerlund et al. 2014; McFall and Davila 2008). A few studies, however, did not find this association (Price et al. 2010; Aro et al. 1999). These differences may be attributed to variances in the methods these studies used, e.g. measuring different attributes of social support or using different target populations (Jensen et al. 2016). Additionally, identified associations may be confounded by socioeconomic factors (Jensen et al. 2016).

Social norms act as subjectivity norms in shaping an attitude such as a health behaviour (Tolma et al. 2003). There is evidence that participation in social networks influence social norms through a perceived sense of responsibility towards one's social group by taking care of oneself and each other e.g., through social pressures to follow prevailing social norms around screening (Bankston and Zhou 2002). Social and family networks enable screening utilisation by providing the necessary structural, appraisal and emotional support (Moudatsou et al. 2014). The evidence for this is that being part of a social group/network brings about a sense of security, trust, belonging and reciprocity (Magai et al. 2007). In turn, these factors have been associated with increased BS rates (Burke et al. 2009; Pasick et al. 2009; Bankston and Zhou 2002).

Moreover, women have the intention to adhere to screening guidelines when people who are important to them think that they should do so (Griva et al. 2009). Evidence suggests that recommendations and support from family and friends are associated with greater mammography intentions and compliance (Molina et al. 2013; Tejeda et al. 2009; Fowler 2007; Luquis and Cruz 2006). In particular, family recommendations may be potentially relevant due to particular cultural emphasis on maintaining family harmony (Molina et al. 2014). More specifically, the relationship between mother and daughter has an enabling role on mothers' decisions to adhere to screening guidelines (Pasick et al. 2009). Another factor in close relations that could influence BS attendance is previous cancer or specifically BC (Manjer et al. 2015). If the social support network, including employers, colleagues, family and friends can be improved through appropriate health education campaigns, then it is likely that a more positive attitude towards preventive health care will prevail (Juon et al. 2004).

The role of physicians and other healthcare professionals in primary care

Physicians, nurses and social workers can provide effective preventive interventions on cancer (Trigoni et al. 2008; Magai et al. 2007). Largely, there is strong evidence that recommedations by physicians predict mammography use among diverse populations (Roman et al. 2014; Sunil et al. 2014; Villani and Mortensen 2013; González and Borrayo 2011; Nuno et al. 2011; Meissner et al. 2007). An exploratory study by Molina et al. (2014) found that physicians are effective in educating and promoting early detection behaviours among women with low levels of perceived seriousness regarding BC. Doctors may therefore be effective in disseminating information concerning mammography benefits and the perceived seriousness of BC (Juckett, 2013).

2.2.1.4 Fear of Breast Cancer and Breast Screening

Fear of results, fear of treatment and fear of mammography itself are substantial deterrents to screening attendance and re-attendance (Brain et al. 2008). The word 'cancer' brings with it risk perceptions due to its associated potential mortality, disfigurement due to surgical treatment, sexuality threats, an impact on employment and the family, and late treatment effects (de Boer et al. 2009; Montazeri et al. 2008). Hence, a cancer diagnosis and fear of its associated treatment may take away one's sense of security and control among multiple wellbeing domains (Coumans and Lee 2008), resulting in a negative psychological, physical and social impact on women and their way of life (Brett et al. 2005; Marshall 1995). It follows that the meaning of cancer will alter the meaning and perception of life, resulting in implications towards family life, social life and the *'self'*. Women's fear of finding something wrong and the feeling that it is better not to know have been reported as barriers to BS among Iranian women (Lamyian et al. 2007). Such fears and anxieties often arise before, during or after screening (Brain et al. 2008; Van Dooren et al. 2005) and are consistent findings across countries, such as Malaysia (Hisham and Yip 2003), United Arab Emirates (Bener et al. 2002), Iran (Jarvandi et al. 2002) and Jordan (Petro-Nustus and Mikhail 2002).

Besides the risks of BC, the general public's perception of mammography has been reported as a painful experience (Myklebust et al. 2009; Davey 2007; Poulos and Llewellyn 2005; Asghari and Nicholas 2004). Women's fears are associated with breast compression that is perceived to ‘damage the breasts’ (Poulos and Llewellyn 2005, p.20). Women continue to experience this fear during compression itself and after the test (Yilmaz and Kiymaz 2010; Myklebust et al. 2009; Asghari and Nicholas 2004). Although perceptions of pain and discomfort in mammography have been extensively studied, both are still not easily quantified. The pain experience has shown great variability ranging from minimal to intense pain (Myklebust et al. 2009; Asghari and Nicholas 2004). The reported prevalence of pain or discomfort ranges significantly from 1.3% to 92.3% in various studies (Asghari and Nicholas 2004; Bennett et al. 1994); and specifically between 41% and 76% for discomfort (Papas and Klassen 2005; Dullum et al. 2000; Bruyninckx et al. 1999; Aro et al. 1996). Possibly, this reflects the methodological diversity of the publications on this subject, such as age-related anatomic breast differences between younger and older women (Almog et al. 2008). Much of that variability may also be due to the measures used to rate mammography pain.

Poulos and Llewellyn (2005) confirmed that women’s experiences may be intertwined with prior experiences of mammography discomfort and pain. This supports the outcome of earlier studies which found that a significant proportion of women who experienced pain at a prior mammogram did not re-attend (Hamilton et al. 2003; Drossaert et al. 2002; Drossaert et al. 2001). Nonetheless, pain experience is subjective and may be related to physiological and situational factors, for e.g. tense or worried women may experience greater pain than calmer women (Davey 2007; Aro et al. 1996). In fact, anxiety is perceived to influence pain experiences during screening (Poulos and Llewellyn 2005). Hafslund (2000) surveyed 170 women aged 40-69 and found that there was a correlation between anxiety and pain ($p<0.01$).

Given that mammography can be a painful experience, and that this pain should be amenable to minimisation, it was important to establish its related causes. Women often relate this bad experience to radiographers’ technique, incompetence and ineffective listening (Poulos and Llewellyn 2005; Van Goethem et al. 2003). The latter are among reasons cited by women for not adhering to recommended guidelines for screening (Mainiero et al. 2001). In a qualitative study of 12 women, Poulos and Llewellyn (2005) showed that beliefs about mammography influence women’s experiences on the day, which in turn influences their perceptions of the procedure. Therefore, it is possible that a change in any one of these three concepts will alter the perception of mammography discomfort, possibly resulting in mammography service dissatisfaction and refusing re-attendance (**Figure 2.1**).

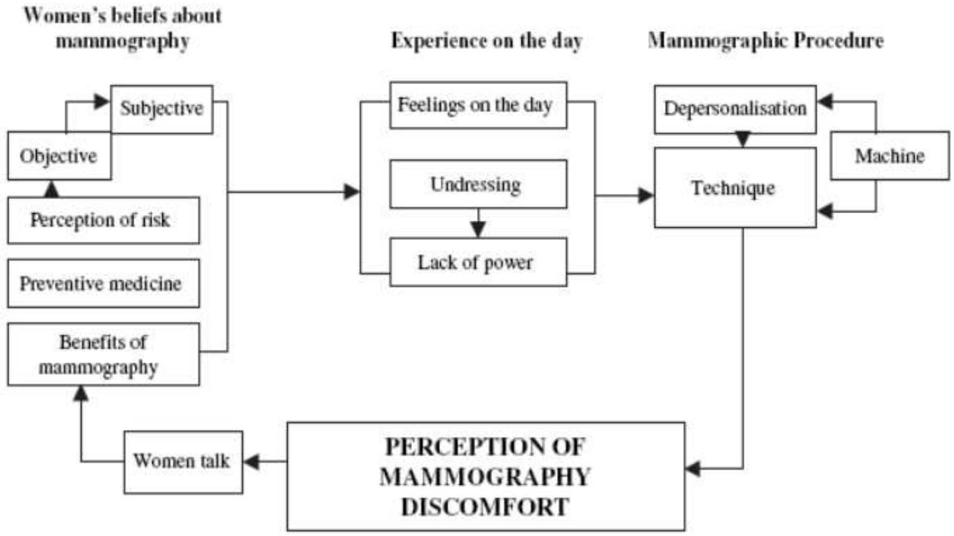

Figure 2.1 - The conceptual framework of perception of mammography discomfort (Poulos and Llewellyn 2005, p.19)

Currently, there are few interventions that have proven to reduce pain and discomfort in mammography (Miller et al. 2008). Effective communication is one recommendation to minimize discomfort (McNichol and Hamer 2006). Moreover, teaching the realistic risks of developing BC and the importance of BS can reduce these fears and would enable women to overcome barriers.

2.2.1.5 Embarrassment

Researchers have identified embarrassment as an emotional obstacle which could prevent women from attending screening (Schueler et al. 2008; Magai et al. 2007). BC is a very sensitive topic in various communities, not only because it is a private subject, but also because women feel embarrassed when talking about their breasts and may feel ashamed or embarrassed to expose them infront of others (Collins et al. 2010; Gany et al. 2006). It appears that besides pain, embarrassment is frequently reported and associated with mammography. The literature demonstrates that women of different nationalities, such as Chinese women (Gany et al. 2006), Korean American women (Lee 2015) as well as Maltese women (Marmarà et al. 2015), are reluctant to expose their breasts infront of others. However, some studies reported that there was no significant association between embarrassment and breast screening (Lee et al. 2011; Lee et al. 2009). However, Zhang (2014) found that women did not view embarrassment as a major problem because they believed it was worth enduring due to detecting BC early. When female professionals carry out mammograms, embarrassment can be overcome (Kwok et al., 2005). It is therefore essential for BS educational materials and programmes to emphasise the fact that mammography is conducted by female professionals at national BS programmes to encourage BS participation.

2.2.1.6 Stress and distress

Stress has mostly been studied in association with mammography or in relation to waiting for or dealing with screening results (Brown and Pakenham 2004). Researchers agree that women often experience emotional and psychological distress, feelings of depression or anxiety before, during and/or after screening (Brown and Pakenham 2004; Gurevich et al., 2004).

From a different perspective, Lagerlund and colleagues (2014) examined stress as a reflection of women's general life situation and its impact on screening attendance. They found that women who experience higher levels of stress have less time or energy for attending screening tests. However, this result contradicts findings from other studies. For e.g. a Finnish study found that stress was unrelated to mammography attendance (Aro et al. 1999), and an American study found that women who experienced high stress in the past year were more likely to have had a mammogram compared with women who experienced low stress (Rakowski et al. 1993). Van Dooren et al. (2005) studied the association between psychological distress and BC in 351 women and their relatives, and found that the impact of a BC diagnosis in a sister, particularly a recent diagnosis, increased screening participants' psychological distress and may increase pain during mammography (Poulos and Llewellyn 2005; Drossaert et al. 2002). Differences across studies may result from differing definitions of stress and cultural experiences of stress.

2.2.2 Knowledge factors

2.2.2.1 Knowledge and attitudes toward breast cancer and mammography screening

Knowledge of BS has been shown to be an important facilitator of mammography use (Secginli and Nahcivan 2006; Jarvandi et al. 2002). Unfortunately, the literature has consistently identified that women have limited knowledge of BC and BS practices (Liu et al. 2014; Charkazi et al. 2013; Guvenc et al. 2012). For instance, Grunfeld et al. (2002) showed that only 38% of women were aware that nipple retraction was a sign of BC, and awareness of risk factors was even lower. Notably, several misconceptions of BC, BS and preventive behaviour such as hitting or bumping the breast, or that having one mammogram is sufficient, have been found consistently with women's beliefs in diverse cultures, such as the Philippines, Korea, Saudi Arabia, Singapore and Australia (Dandash and Al-Mohaimeed 2007; Han et al. 2007; Im et al. 2004; Goel et al. 2003; Chong et al. 2002; Grunfeld et al. 2002).

Among women of Asian descent, lower screening rates were associated with their limited knowledge and misperceptions of preventive health measures (Chua 2005; Juon et al. 2004; Nissan 2004). Knowledge of BS guidelines was a major predictor of regular screening for women in studies carried out in Korea (Joun et al. 2004) and Turkey (Secginli and Nahcivan 2006). Adequate knowledge about the recommended screening interval and higher values for BC worry were associated with an increased number of repeat lifetime mammograms in a study by Aro et al. (2001). Another study also found that women with knowledge of mammography guidelines were 10 times more likely to have regular mammography (Secginli and Nahcivan 2006). These findings support the positive effects of screening knowledge on undertaking regular mammography.

A number of demographic factors can affect level of BC/BS knowledge. Examples of these demographic factors include income status, age and educational attainment status. Dandash and Al-Mohaimeed (2007) found that higher income status was the strongest significant predictor of higher knowledge levels of BS/BC among female teachers in Buraidah, Saudi Arabia. On the other hand, many studies found a negative association of knowledge scores with age (Dandash and Al-Mohaimeed 2007; Chamot and Perneger 2002; Dolan et al. 1997), while data among Hispanic women revealed poor knowledge among the poorest and least educated women (Ramirez et al. 2000). Older women tend to lack knowledge of BC signs and symptoms (Grunfeld et al. 2002); 20% of older women never look at or feel their breasts (Linsell et al. 2009) and present with more advanced disease resulting in poorer survival than younger women

(Moller et al. 2010). This may possibly be a result of lack of BC awareness, apathy, lack of concern, or low perceived need (Lagerlund 2002).

To make an informed decision about BS, women need accurate and sufficient information about their risk and screening benefits. Women do receive a plethora of information from screening invitations, such as the benefits and risks of BS; the examination; waiting times; what should be avoided to avoid artefacts, e.g. deodorants or anti-perspirants (Young et al. 2002); parking facilities; who can accompany clients; further tests and professional teams involved (Perry et al. 2008; Goldsmith et al. 2007; Lee et al. 2003). Thus, this information, as per screening guidelines, should be presented in suitable format prior to attending screening through ‘written materials’, ‘web-site’ or ‘phone lines’ (Giordano et al. 2006, p.383). The use of media has been documented as an important source of BC and screening information for women that could improve their knowledge about BC risks and causes, and the mammography procedure (Secginli and Nahcivan 2006; Juon et al. 2004; Jarvandi et al. 2002).

2.2.2.2 Previous mammography experience

Women who are knowledgeable of the procedure and satisfied with the experience of the first screening episode often return for another mammogram (Almog et al. 2008; BreastScreen Australia 2008). In contrast, bad experiences may deter women from re-attendance, resulting in a reluctancy to recommend the examination to others (Yilmaz and Kiymaz 2010; Myklebust et al. 2009; Miller et al. 2008). There is some evidence that procedural pain may diminish feelings of self-efficacy and thus act as an indirect factor to non-reattendance (Drossaert et al. 2001). In a systematic review of three studies by Whelehan et al. (2013), the proportion of non-reattendance accounted for by prior mammography pain ranged from 25% to 46% (Elwood et al. 1998; Rutter et al. 1997; Marshall 1994). However, the sample sizes were small in all three studies, with a combined sample size of 261. When transposing the two UK studies’ figures of 25% and 41% (Rutter et al. 1997 and Marshall 1994 respectively) onto the English NHSBSP 2010/11 figure for non-attendance, this would mean that between 47,000 and 77,000 clients had chosen not to re-attend in that year due to prior mammography pain (The Health and Social Care Information Centre 2012). This finding is further confirmed in prior literature showing the lack of compliance with follow-up appointments (Chiarelli et al. 2010; Myklebust et al. 2009). In the context of cumulative participation rates, this is an important finding being increasingly recognised as an important performance indicator in screening (Jacobsen and Euler-Chelpin 2012).

2.2.3 Socio-demographic factors

Population characteristics may influence the effectiveness and uptake of screening programmes (Damiani et al. 2012). Sociodemographic and economic characteristics such as age, gender, education, income, marital status and cohabitation, employment status, rural versus urban setting, health insurance coverage, ethnicity and religion, may be important variables associated with mammography use (Threlfall and Fazil 2009; Zackrisson et al. 2004; Jepson et al. 2000). For example, factors such as older age (>50), lower education, lower economic status (including higher level of deprivation), belonging to ethnic minority or living in a rural location, being single or divorced, have been widely discussed as having a positive association with lower BS uptake (Lofters et al. 2011; Thomas et al., 2005).

2.2.3.1 Age

Variances among different age groups have been noted in previous research about BS uptake. Some studies have demonstrated that increasing age is positively associated with mammography screening (Feldstein et al. 2011; Walsh et al. 2011) while others demonstrate that increasing age is associated with lower mammography uptake (Edwards and Jones 2000). For example, among ethnic groups residing in the US, younger Hispanic American women (<50 years) are more likely to have received a recent mammogram than older women (aged 50 and over) (Gorin and Heck 2005). Older Turkish women were more likely to have a mammogram in a study by Sadikoglu et al. (2010), while younger age was related to mammography adherence for South Korean women (Suh and Park 2009). In summary, younger age is generally associated with higher uptake while older age is mostly related to poorer adherence to cancer control measures in most studies (Petrak 2013).

2.2.3.2 Education and occupation

A positive association of education and occupation with BS uptake has been confirmed in many studies (Damiani et al. 2012; Duport et al. 2008; Hewitt et al. 2004). In the study by Damiani et al. (2012) on socioeconomic disparities in cancer screening uptake in Italy, higher levels of educational attainment and being in employment were related to higher likelihood to undergo a mammogram than being less educated or unemployed (OR=1.77; 95% CI=1.55-2.03, OR=1.63; 95% CI=1.40-1.91 respectively). A significant difference was found between women in the highest occupational class versus those in the lowest class (OR=1.81; 95% CI=1.63-2.01). The researchers also found that screening invitees with lower education or lower occupational levels were more likely to attend organised screening programmes than the more advantaged women who also attended those services from their own initiative (Damiani et al. 2012). Those having low educational attainment and manual occupation are associated with higher nonattendance rates (Aarts et al. 2011; Lagerlund et al. 2002; Abdullah and Leung 2001; Madan et al. 2000). However, Madan et al. (2000) and Abdullah and Leung (2001) studies have limitations such as women's self reports of the screening test which may lead to an overestimation of BS. While cancer screening is critical to improving health outcomes, findings clearly indicate that those less educated and minority groups are among the most vulnerable (Zapka et al. 2011; Greiner et al. 2005), particularly since minority populations have been under-represented in national and community studies (Bazargan et al. 2009). Therefore, the reasons for disparities in screening behaviour are less clear among these populations than others and require particular attention.

2.2.3.3 Income

A powerful driver of BS uptake is known to be a woman's socioeconomic status (Moser et al. 2009). In a study by Maheswarab et al. (2006) on the association between BS uptake and socio-economic deprivation, travel distance, urban-rural status, location and type of screening unit, the strongest association was socioeconomic deprivation with BS uptake especially with significantly lower uptake from deprived areas. In the UK, Blanks et al. (2002) found that women who attended BS were more likely to live in less deprived areas than those who did not attend it. In another study, Moser et al. (2009) investigated the inequalities in screening among 3,185 women aged 40-74, and found a strong link between wealth and BS uptake, with car ownership and housing status as indicators of household wealth. This study showed no association between BS and other factors such as education and ethnicity. There is consistent evidence that lower household income demonstrates lower BS utilization (Paul 2012; Lagerlund et al. 2002; Jepson et al. 2000), which seems to be associated with late stage BC presentation among Londoners (Cuthbertson et al. 2009).

2.2.3.4 Marital status

A husband's social support has a positive influence on his wife's health behaviours (Harley and Eskenazi 2006). In relation to mammography use, while some studies have not found an association between mammography attendance and being married (Aldridge et al. 2006; Coughlin et al. 2004), other studies have found that being married and having a partner's support may act as a screening facilitator. Soni (2007) found that 62.8% of single women and 64.1% of separated women were less likely than married women (75.6%) to have mammography. Damiani et al. (2012) further confirmed these findings, reporting that married women were 1.83 times more likely than single women to undertake regular BS practices (95% CI=1.56-2.15).

2.2.3.5 Rural versus urban setting

The evidence on the prevalence of BS uptake in rural regions is very limited in certain countries (Amelio 2013). However, it appears that there are lower levels of BS uptake in rural regions compared to urban ones (Day et al. 2010; Spaczynski et al. 2010). Prażmowska et al. (2010) found that in a sample of Polish women who attended free mammography, only 10% lived in a rural region. It is likely that women from rural areas will have limited access to health services, subsequently limiting BS access (Coughlin et al. 2002).

2.2.3.6 Health Insurance

Health insurance is a significant predictor of BS adherence (Vedel et al. 2011; Young et al. 2011; Meissner et al. 2004). Women with health insurance are more likely than those without health insurance to undergo mammography (Secginli and Nahcivan 2006; Juon et al. 2004), and uninsured women are more likely to be overdue screeners (Elkin et al. 2010) or never screeners than insured women (Lopez et al. 2009). In seven out of twelve reviewed studies in the systematic review by Jepson et al. (2000), mammography rates were significantly higher amongst insured women. Women with private insurance are more likely to be those with higher educational levels and higher income (Esteva et al. 2008). However, recommendations and guidelines for mammography as a public health practice may vary between countries. For instance, insurance coverage in Poland has been resolved since the last health care reform in 2003, and currently every individual has the right to state funded health care (Golinowska and Kozierkiewicz 2008). Similarly, in Malta, healthcare is state funded. Nonetheless, a number of Maltese and foreign residents consider private healthcare on a regular basis due to a range of services offered and shorter waiting times.

2.2.4 Health status

Health status (medical factors) that influence uptake include having a family history of BC, experiencing BC symptoms, number of previous visits to a doctor and physician recommendation of BS, self-reported health status, able to perform activities of daily living and access to a regular source of health care (Cohen and Azaiza 2010; Meissner et al. 2007; Meissner et al. 2004). Women with poor health status are significantly less likely to undergo mammography than those having good health (Day et al. 2010; Sadler et al. 2007). These findings contrast those by Jepson et al. (2000), where the majority of reviewed studies did not find an association between health status and the uptake of mammograms. Personal or family experiences of BC (Isaacs et al. 2002; Meiser et al. 2000) are known motivators to attendance. Moreover, several studies suggest that a physician referral and having a gynaecologist as a regular physician are important predictors of BS uptake (Secginli and Nahcivan 2006; Juon et al. 2004; Im et al. 2004). The rate of referral by a physician was substantially higher among women who reported having mammography in the latter studies. In a cross-sectional study among Arab women in Qatar, only one quarter of the women interviewed said their doctors had discussed BC with them (Donnelly et al. 2013). Moreover, conflicting expert recommendations on BS may result in non-compliance over time (Han et al. 2007). Efforts to educate health care providers, particularly physicians, should emphasize the importance of recommending BS and informing women about screening guidelines.

2.2.5 Logistical and health system factors

2.2.5.1 Forgetfulness and competing priorities

Having competing priorities, such as having concerns that are more important than screening may contribute to forgetfulness and lacking time to receive screening. The latter are reported as two of the most common barriers for BS among women in Asia (Hisham and Yip 2003; Jarvandi et al. 2002) and other countries (Watson-Johnson et al. 2011; Tejeda et al. 2009; Clark and Natipagon-Shah 2008) and are known to be significant predictors of nonadherence (Carney et al. 2013; Gierisch et al. 2009; Lopez et al. 2009). These barriers could be due to the multiple responsibilities held by women at the workplace and at home, and time restrictions that urge working women to postpone their own health appointments or personal concerns for the sake of the family. Women may perceive cancer screening as less important than other health or personal concerns (Makuc et al. 2007; Ahmed et al. 2004) or as a low priority relative to other obligations they have, including work and childcare (Tejeda et al. 2009; Peek et al. 2008). Taking time off from work (Gany et al. 2006; Moy et al. 2006) and lacking a source of childcare during the appointment (Watson-Johnson et al. 2011), have been cited as screening barriers. In addition, amidst their busy schedules, women report forgetting to get a mammogram (Lee-Lin et al. 2007; Champion and Skinner 2003).

2.2.5.2 Appointment barriers

The BS pathway can be time consuming for some women. Six studies cited issues in navigating the healthcare system to make and attend screening appointments as screening barriers (Watson-Johnson et al. 2011; Clark and Natipagon-Shah 2008; Documet et al. 2008; Davis et al. 2005; Fernandez et al. 2005; Ahmed et al. 2001). These issues included barriers at the point of making an appointment, barriers between making the appointment and attending it, and barriers when attending the appointment. Women complain of being unable to arrange an appointment in an efficient manner (Sarma 2015; Watson-Johnson et al. 2011; Ahmed et al. 2001). In a study of African-American women who had not had a mammogram in the previous year, 22% of interviewed women said that they were unable to get an appointment (Davis et al. 2005). Delays between making the appointment and the appointment date is also a perceived barrier to mammography use (Watson-Johnson et al. 2011). Women who reported long waiting times at the screening facility (Young et al. 2011; Wu et al. 2006; Liang et al. 2004) and long waits for receiving test results (Sarma 2015; Watson-Johnson et al. 2011) were less likely to be adherent to other screening appointments.

2.2.5.3 Lack of accessibility

Lack of access to screening services, including lack of transportation and a lack of a nearby facility, can be a barrier to screening attendance (Carney et al. 2013) and a significant predictor of non-adherence (Young et al. 2011; Elkin et al. 2010; Documet et al. 2008; Levy-Storms et al. 2004). Furthermore, inconvenience in taking public transport, having to pay for parking or having to navigate to an inconvenient location may also be a screening barrier (Watson-Johnson et al. 2011; Liang et al. 2004). Depite the location of the screening service, women will often opt for that service that provides easy and free access and parking facilities (Hamilton et al. 2003), which in turn have shown to enhance client satisfaction, attendance and re-attendance (Peipins et al. 2006; Hamilton et al. 2003).

2.2.5.4 Medical mistrust

Understanding why women do not make it through the clinic door is critical to having an effective health care system. Individuals often avoid seeking medical care when they suspect it may be necessary (Yousaf et al. 2013; Scott and Walter 2010) or when experiencing symptoms (Barbour et al. 2012; Ristvedt and Trinkaus 2005). A literature review by Sarma (2015) identified distrust of the medical system as a screening barrier in various studies (Documet et al. 2008; Peek et al. 2008; Fowler 2006; Moy et al. 2006). Most research among minority groups investigating trust in the medical system has focused on African Americans (Born et al. 2009; Corbie-Smith et al. 2002). In a study by Davis et al. (2012) based in New York, Maryland, and Puerto Rico, Hispanics lacked trust in medical professionals and feared being a "guinea pig". It may be that individuals do not believe that medical personnel will act in their best interests. Fowler (2006) explored African-American women's perceived barriers to mammography, and found that some women aged 60 and older indicated that the past discrimination and abuse of African-Americans by the healthcare system resulted in a distrust of health professionals. This resulted in less frequent attendance to medical appointments (Fowler 2006). In another study, African-American participants reported discriminatory treatment, including being patronised by staff, receiving insufficient medical explanations, being treated like experimental subjects and as second-class citizens because of their public health insurance, while Latina women complained about rude treatment and anti-immigrant attitudes in the same study (Documet et al. 2008). Hence, discriminatory experiences in healthcare settings can act as BS barriers.

2.3 Applications of health psychology models to early breast cancer detection and prevention

Health psychology aims at understanding how psychological, behavioural and cultural factors contribute to physical health and illness in an attempt to explain health behaviours (Parsa et al. 2006). A theory is defined as "a set of interrelated constructs (concepts), definitions, and propositions that present a systematic view of phenomena by specifying relations among variables, with the purpose of explaining and predicting phenomena" (Kerlinger 1986, p.9). The use of health behaviour theory has been widely instrumental and used within research on health psychology in an attempt to predict behavioural outcomes including cancer screening (Glanz et al. 2008). Since many behaviour theories were developed for different settings and purposes, only few theories are relevant to BC and BS, particularly due to their construct validity (Glanz et al. 2008; Lauver et al. 2003). Moreover, there is little consensus regarding which theory is superior in explaining a health behaviour. Hence, understanding the relative merits and limitations of these theories might help to inform future research design on mammography participation, and facilitate the improvement of women's compliance in mammography screening through the application of strategies supported by these theories. Mainly, there are two categories of theoretical models: social cognition models and stage-based models (Sutton 2002).

2.3.1 Social cognition models

Social cognition models assume that behaviour change is determined by key cognitive variables, beliefs and attitudes, and socio-demographic variables (Sutton 2002; Stroebe 2000). Commonly used social cognition models on the prediction of women's understanding of BC and BS compliance are evaluated and described in detail in the following sections. These models include the Health Belief Model (HBM) (Becker 1974), the Protection Motivation Theory (PMT) (Rogers 1983), the Theory of Planned Behaviour (TPB) (Ajzen 1991), and the Common-Sense Model of illness self-regulation or the Self-Regulation Model of Illness Behaviour (CSM or SRMI) (Leventhal et al. 1984).

2.3.1.1 The Health Belief Model

The HBM was initially developed in the 1950s by social psychologists Hochbaum, Leventhal, Kegeles, and Rosenstock in the U.S. Public Health Service in response to the failure of a free tuberculosis health screening program (Rosenstock et al. 1988; Janz and Becker 1984). The HBM considers one's overall perceived risk of an illness as a precursor to positive, preventive health behaviour (Wendt 2005). The fundamental premise of the HBM is that an individual's desire to evade illness, coupled with a belief that a particular health action would avert onset of the illness, can be interpreted and explained in relation to a number of diseases.

Prior to 1984, the HBM was not regularly used to explain screening behaviours. The year1984 proved to be a major turning point for the HBM, where Victoria Champion conducted an array of research and developed an innovative research instrument i.e. Champion's Health Belief Model Scale (CHBMS) and subsequent others, to measure HBM concepts in relation to Breast Self Examination (BSE) (Champion and Miller 1992) and later mammography (Champion 1999). The HBM is now considered the most frequently used social cognition model for predicting BS behaviour (Orji et al. 2012).

2.3.1.2 The main components of HBM

The HBM's core components are perceived susceptibility, perceived severity, perceived benefits and perceived barriers, which account for people's 'readiness to act'. The constructs 'cues to action' and 'self-efficacy' were later added to the model by Becker and Maiman (1975) and Rosenstock et al. (1988) respectively. The major HBM constructs are presented in **Table 2.1** for definition of each term, their widespread applications and examples as they relate to this study.

Table 2.1 - The Health Belief Model Constructs, their application to Breast Screening and HBM Construct Examples (adapted from Guilford 2011; Hayden 2009; Austin et al. 2002, p.124)

CONSTRUCT	DEFINITION	Application	Example as related to this study
Perceived Susceptibility	An individual's assessment of his or her chances of getting the disease	Define population(s) at risk, risk levels; personalize risk based on a person's features or behaviour; heighten perceived susceptibility if too low	How likely am I to get BC?
Perceived Severity	Belief about the seriousness of the condition, or leaving it untreated and its consequences	Specify consequences of the risk and the condition	How serious will BC be?
Perceived Benefits	Belief as to whether the new behavior is better than what one is already doing	Define action to take; how, where, when; clarify the positive effects to be expected	What will I gain from participating in BS?
Perceived Barriers	Belief about the potential negative aspects of a particular health action	Identify and reduce barriers through reassurance, incentives, assistance	What is hindering me from participating in BS?
Cues to Action	Strategies/factors which activate "readiness", triggering action	Provide how-to information, promote awareness, reminders	What will remind/cause me to perform screening?
Self-Efficacy	Personal belief (confidence) in one's own ability to take action	Provide training, guidance in performing action	Have I the skills/confidence to perform screening?

Perceived Susceptibility

The HBM predicts that in order for an individual to engage in a specific behaviour, he or she needs to believe that it is likely, or at least possible, that the behaviour is intended to prevent contracting that particular illness (Champion and Skinner 2008). However, perception of increased susceptibility does not always lead to behaviour change. In the context of BS behaviour, Hispanic women, for instance, have a very low perceived susceptibility to BC that leads to poor compliance with screening (Fulton et al. 1995). This may lead to an increased risk for cancer because of their curative rather than preventive practices.

Perceived Severity

If an individual perceives that the condition would have a large impact on his or her life, including physical, practical, emotional and psychological issues (Harmer and Cruickshank 2014), for example, whether it is life-threatening or may cause disability or pain, or reduced functioning at work or in social roles, that individual is more likely to engage in preventive behaviour (Carpenter 2010).

The combination of perceived susceptibility and perceived severity is referred to as perceived threat (Glanz et al. 2008) and depend on knowledge about the condition (Rosenstock 1974). If the perception of threat is specific to a serious disease for which there is a real risk or is seen as fatal, this provides reason to combat the condition, and consequently, behaviour often changes. According to the HBM, women who believe that they are susceptible to BC and that BC is a serious condition are more likely to undergo mammography (Parsa et al. 2006). While perceived threat concentrates more on the perceptions of the disease, the remaining constructs emphasize the individual's perceptions of the preventative behaviour (Champion and Skinner 2008).

Perceived Benefits

If an individual believes that engaging in a particular behaviour will result in positive outcomes such as reduced susceptibility or severity to a health problem and the prevention of negative outcomes of the disease, then he or she is more likely to adopt the healthier behaviour to experience these positive outcomes (Carpenter 2010; Champion and Skinner 2008). Hatefnia et al. (2010) and Eskandari-Torbagha et al. (2014) found a significant difference in women's perceived benefits after receiving an intervention involving BS training, compared to women who had not received the intervention.

Perceived Barriers

Of all the constructs, the final core construct of the HBM, perceived barriers, is the most significant to determine behaviour change (Janz and Becker 1984). This construct relates to the perceived negative aspects of an action and the beliefs that would deter an individual from eliciting the behaviour. For example, barriers to mammography such as fear, pain or discomfort, embarrassment, inconvenience or competing priorities (Trigoni et al. 2008; Dandash et al. 2007; Jepson et al. 2000), exert a greater influence over the behaviour than does the threat of BC itself (Champion and Menon 1997). Hence, the perception of mammography pain, for instance, may act as a barrier to undergoing mammography (Myklebust et al. 2009). Women who perceive more benefits and fewer barriers from mammography are more likely to use BS behaviours (Jahanlou et al. 2013).

Cues to action

In addition to the four main constructs, cues to action is also included as a modifying factor to perceived threat. The HBM suggests that a cue, or trigger, is necessary for prompting engagement in health behaviours (Janz and Becker 1984). Cues to action suggests that internal (e.g. pain, symptoms) and/or external events (e.g. mass media campaigns, the media, advice from friends or health care providers, or reminders) would trigger a readiness to act and stimulate behaviour change (Carpenter 2010; Graham 2002; Rosenstock 1974). The cues to action for mammography adherence, especially physician support, have long been shown to be significant factors in various studies (Hartman 2002; Champion and Miller 1996; Aiken et al. 1994). Individuals who believe they are at low risk for contracting a disease, and who do not have reliable health care access may require more external cues to get screened for BC.

Self-efficacy

The constructs of perceived benefits, barriers, and susceptibility have explained only around 40% of the variance in mammography behaviour (Rosenstock et al. 1988). It is important to consider, evaluate and accurately measure additional constructs such as self-efficacy in an attempt to better explain individual differences in health behaviours (Champion and Miller 1996). Regarding mammography behaviours, women who are more confident in their ability to detect abnormal lumps, more motivated to promote their health by overcoming potential barriers, for example, finding a mammography unit that provides the service, obtaining a referral, and paying for mammography (Champion and Skinner, 2008) are more likely to undergo mammography (Champion 1999). In several studies, perceived self-efficacy for mammography has been predictive of mammography screening (Aymoori et al. 2015; Moodi et al. 2012). For example, it has been shown that women with a moderate level of fear from BC, in combination with a higher level of self-efficacy for mammography are more likely to adhere to mammography than women with a high level of BC fear in combination with lower self-efficacy (Champion et al. 2008) and fewer perceived benefits of mammography (Fair et al. 2012). Some women experiencing a low level of BC fear, regardless of self-efficacy and perceived benefits of mammography may not feel motivated to take action. This may be partly due to the lack of verbal persuasion and social influence (Hashemian et al. 2015). A persuasive caregiver, such as a doctor's recommendations (Moshki et al. 2017), may be able to influence women's decisions to attend for mammography.

Figure 2.2 illustrates the most common conceptualization of the HBM and how behaviour change is a function of the perceived threat and behavioural evaluation, where external cues to action activate or moderate the perceived threat. Additionally, sociodemographic variables can influence an individual's perceptions of the HBM's four main constructs.

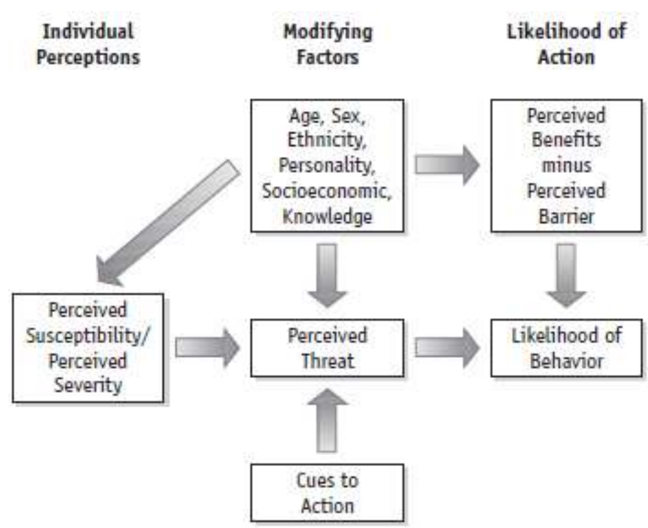

Figure 2.2 - The Health Belief Model (Glanz et al. 2002, p. 52; Strecher et al. 1997)

According to HBM, behaviour change is directly influenced by perceived threat and the net difference of benefits minus barriers. Perceived susceptibility to and perceived severity of the disease affect an individual's perception of threat from that specific disease. Perceived benefits and barriers of adopting a health action also influence an individual's evaluation of the recommended action (Becker 1974). Research performed in Turkey (Secginli and Nahcivan 2006), Korea (Han et al. 2000) and the US (Champion 1999) showed that perceived susceptibility, seriousness, benefits, and self-efficacy are positively associated with screening behaviours, while perceived barriers are negatively associated with them. Additionally, individual characteristics such as demographic variables (e.g. age, sex, education, ethnicity), psychological characteristics (e.g. personality, social class) and structural variables (e.g. knowledge about a given disease and prior contact with the disease) can affect perceptions on health behaviour (Rosenstock 1974). This is due to their effect on each of the HBM components (i.e. perceived seriousness, susceptibility, benefits and barriers) with the exception of cues to action (Glanz et al. 2008; Abraham and Sheeran 2005).

2.3.1.3 Utility of the Health Belief Model

A number of uses have been outlined for the HBM. Prior to the early 1970s, HBM was used to provide a useful framework for understanding individual differences in health behaviour, and for designing interventions to behavioural change (Abraham and Sheeran 2005). In later years, it has gained recognition in various health settings to address public health concerns and to evaluate health behaviours beyond prevention across diverse populations (Orji et al. 2012; Glanz et al. 2002). It has been applied to increase mammography screening (Michielutte et al. 2005), breast self-examination (Umeh and Rogan-Gibson 2001), to evaluate responses to symptoms and diagnoses as well as medical adherence (Champion and Skinner 2008) and in designing effective health interventions (Kharrazi et al. 2009).

The HBM has been criticised for its limitations which make the different operationalisations of the theoretical constructs not strictly comparable across studies (Glanz et al. 2008). First, HBM does not provide a clear explanation of how its model components interact with each other or combine to affect behaviour (Morrison and Bennett 2006). Second, HBM does not account for sociocultural and economic factors, behavioural intentions and previous experiences (Soliday and Hoeksel 2000), resulting in its weak predictive validity of its core psychological components (Armitage and Conner 2000). Although self-efficacy has been added by Rosenstock et al. (1988), its mode of operation in relation to the other component variables has not been defined and its use in HBM studies has been limited (Carpenter 2010). The models PMT and TPB, however, address this construct, and are discussed in **sections 2.4.1.4** and **2.4.1.5**. Since this construct has been recognised as a significant component of health behaviour change (Glanz et al. 2008; Seydel et al. 1990), self-efficacy has been included in the HBM model used for this study.

Third, the six HBM components have been generally examined independently on the prediction of health behaviour in many studies (Abraham et al. 1996). Hence, there is a lack of consistency in the measurement of each HBM component (Abraham and Sheeran 2005); most attention has focused on the four factors contained in the threat and behavioural evaluation. Since cues are diverse and changeable, cues to action have not been examined in many studies on the HBM (Sheeran and Abraham 1996; Harrison et al. 1992) and is rarely included in HBM theoretical testing and meta-analyses (Kiviniemi et al. 2011; Carpenter 2010). For example, two meta-analyses (Harrison et al. 1992; Janz and Becker 1984) have calculated significance ratios and effect sizes for behavioural impact for the four main HBM constructs, but there does not appear to have been any such analysis for the other constructs (such as cues to action). In my research, cues to action was included in the evaluated model of HBM due to its potential importance.

Fourth, the HBM does not provide detailed description on how the social/environmental factors such as social norms, family and friends may prevent engagement in desired behaviours (Janz and Becker 1984). Moreover, fear may be a key factor in predicting health-related behaviour (Glanz et al. 2008) but the HBM does not consider the impact of emotions on health-related behaviour. Based on the above methodological shortcomings of the model, the HBM has limited power to predict behaviours consistently (Yarbrough and Braden 2001) and can therefore only explain some variation in BS behaviour (Orji et al. 2012). This is why the Common-Sense Model (CSM) of self-regulation, has been used to consider the cognitive and emotional representations of an illness (Anagnostopoulos et al. 2012).

2.3.1.4 Protection Motivation Theory

Protection Motivation Theory (PMT) (Rogers 1975) differs from the HBM in that it specifically aims to predict intentions from cognitive responses of individuals to health interventions (Fry and Prentice-Dunn 2006). Originally, PMT was proposed to provide conceptual clarity to the understanding of fear appeals and coping mechanisms to protect an individual from a health threat (Rogers 1975). A later revision of PMT (Rogers 1983) extended the theory to a more general theory of persuasive communication, such as health warning messages, with an emphasis on the cognitive processes mediating behavioural change (Morrison and Bennett 2006).

Several components are common between PMT and HBM. However, PMT emphasises the impact of fear on behaviour change, which HBM does not. Fear messages stimulate two parallel appraisal processes: threat appraisal, i.e. perceived sensitivity, perceived severity, and perceived rewards; and coping appraisal, i.e. perceived self-efficacy, perceived response efficacy, and perceived costs (Rogers 1983). Thus, the outcomes of these two stages i.e. fear, will direct protection motivation i.e. people's intention to adopt adaptive responses and behaviour (Norman et al. 2005). Furthermore, according to PMT, protection motivation or maladaptive coping, i.e. avoidance, denial and the absence of behaviours, are functions of an individual's threat appraisal, and the appraisal of coping responses (Prentice-Dunn and Rogers 1986). Individuals are considered likely to intend to adopt the recommended health behaviour when they perceive that the threat is high, i.e. high 'perceived susceptibility,' 'perceived severity' and 'fear'; and if they believe that the recommended behaviour will be effective, i.e. high 'response efficacy'; with little cost, i.e. low 'response cost'; and easy to adopt, i.e. high 'self-efficacy' (Fry and Prentice-Dunn 2006).

PMT has been a useful theoretical framework to predict cancer prevention and early detection behaviours (Inukai and Ninomiya 2010; Fry and Prentice-Dunn 2006). However, participation in mammography screening has not been specifically investigated using PMT, and therefore, few studies have applied this model to mammography screening (Naito et al. 2009). Inukai and Ninomiya (2010) have reported that self-efficacy and perceived consequences of behavioural responses, i.e. response costs, predict mammography screening attendance. However, evidence provides indirect support for the suggested relationships between PMT variables and intention and participation in mammography screening (Rutter 2000; Pearlman et al. 1999). In addition, popular health interventions include providing information and using persuasion (Hardeman et al. 2002), where the PMT partially explains the mediating cognitive processes that link informational interventions to cognitive and behavioural changes (Fry and Prentice-Dunn 2006). Informational interventions based on the PMT framework have been shown to increase intentions for health behaviours in various studies (Fry and Prentice-Dunn 2006; Kaljee et al. 2005; Milne et al. 2002). However, while findings support the anticipated relationships between BC information and mammography screening, screening knowledge and risk factors, PMT variables, and mammography intentions, the effects of PMT-based informational interventions on women's mammography intentions have not been explicitly investigated.

PMT has been criticised since the adoption of health behaviour is also influenced by other variables other than the threat appraisal and coping appraisal. For example, normative beliefs, which refer to an individual's beliefs about the level of other people's approval of their behaviour (Stroebe 2000), have been found to be an important variable influencing women's BS participation. In a study examining the relationships between social network characteristics and BS practices, Allen et al. (2008) found that social norms significantly affected women's regular screening attendance. Additionly, the normative beliefs in relation to the physician, family members and close friends have an important influence on women's intention to attend the initial mammography screening (Tolma et al. 2003). Within social cognition models, only TPB explicitly addresses the subjective norm variable, a component of normative beliefs (Conner and Norman 2005).

2.3.1.5 The Theory of Planned Behaviour / Reasoned Action

In 1975, Fishbein and Ajzen developed the Theory of Reasoned Action (TRA) and proposed that a person's intention to adopt a particular behaviour was influenced by a person's attitudes (evaluation of taking the action), and subjective norms about the behaviour (the influence of others on the individual's behaviour (social pressure) (Fishbein and Ajzen 1975). Because TRA was criticised for limitations in dealing with behaviour over which people do not have complete voluntary control, the model was revised by Ajzen (1991) with the addition of a third component i.e. perceived behavioural control (**Figure 2.3**) and renamed the Theory of Planned Behaviour (TPB) (Godin and Kok 1996; Ajzen 1991) to predict deliberate behaviours (Ajzen 2011). The

TPB and PMT theories overlap in predicting intentions, each model providing unique contribution amounting only to 5% (Boer and Mashamba 2005).

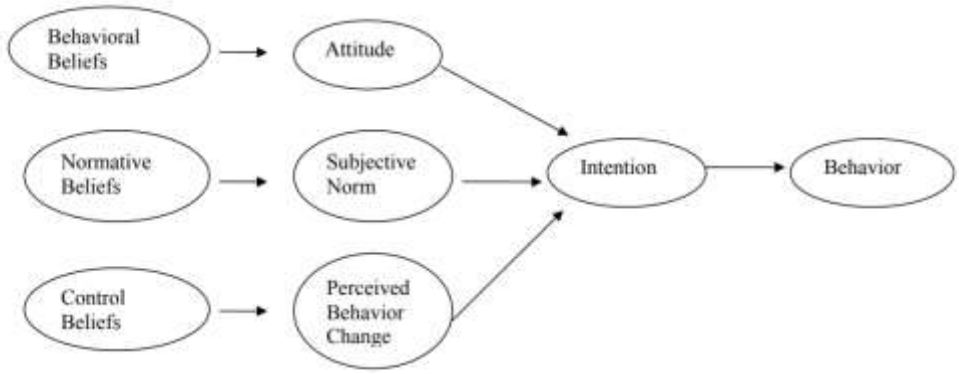

Figure 2.3 - Schematic representation of TPB (adapted from Amelio 2013, p.109; Armitage and Conner 2001, p.472; Ajzen 1991)

Considerable support exists for TPB in the prediction of a range of intentions and health behaviours (Brickell et al. 2006; Myers and Horswill 2006; Boer and Mashamba 2005). Intention is the key predictor of actual behaviour in the TPB theory, and intentions are in turn predicted by attitudes (positive or negative beliefs about the consequences of the behaviour), perceived behavioural control (i.e. beliefs about the ease or difficulty to perform a given behaviour and is assumed to reflect past experience and anticipated barriers), and subjective norms (perceived social pressure to performing the behaviour (Ajzen 1998). Povey and colleagues concluded that perceived behavioural control is different from self-efficacy and it could be a better predictor of intentions (Povey et al. 2000).

Women’s actual participation in mammography screening is determined by their intention to undergo mammography (intention leads to behaviour). The strong predictor of mammography screening was found to be intention in studies reporting actual attendance (Steadman and Rutter 2004; Drossaert et al. 2003; Steadman et al. 2002; Rutter 2000) or self-reported attendance (Steele and Porche 2005), while the subjective norm is generally considered as the weakest predictor of intention (Godin and Kok 1996). As in PMT, although these two theories suggest that an individual’s intention can directly lead to the performance of behaviour, it has been found that woman’s intention to participate in mammography screening does not always lead to participation (Walker et al. 2012). This is because patients’ behaviours may be influenced by attitudes, perception of screening barriers and benefits, fear of cancer, illness perceptions, and socio-demographic factors (Hay et al. 2005). The lack of provision of an explanation of the intention-behaviour gap is therefore a clear weakness of TPB.

Since TPB focuses on individuals' existing beliefs and attitudes (Ajzen 1998), behaviour is often predicted through the measurement of TPB variables and intentions at baseline or in studies that do not involve interventions (Hardeman et al. 2002). One area of weakness relates to inconsistencies in the predictive abilities of component variables. In their study to predict condom use through TPB, Bennett and Bozionelos (2000) found that the proportion of variance in behaviour explained by intentions reached significant levels in only just over a third (35%) of the studies they reviewed. TPB can account for moderate variance in intentions and behaviours in general but attitudes, subjective norms, and perceived behavioural control do not always allow the prediction of various health behaviours (Taylor et al. 2006). TPB does not explicitly include threat appraisal when compared with HBM and PMT and hence, TPB does not include affective variables in explaining health-related intention or behaviour (Oliver and Berger 1979).

2.3.1.6 The Common-Sense Model (CSM) of Illness Self-Regulation or the Self-Regulation Model of Illness Behaviour (SRMI)

Developed by Leventhal and colleagues in 1980s (Leventhal et al. 1980), the Common-Sense Model (CSM) of illness self-regulation (Leventhal et al. 1984) is also known by various terms, such as the Self-regulatory Model of illness behaviour (SRMI), the Illness Perception Model, the Illness Representations Model, the Parallel Process Model or Leventhal's model (Hale et al. 2007). This model provides a theoretical framework to understand the self-regulation process of illness and health (McAndrew et al. 2008), where individuals deal with the illness or symptoms through three hierarchical stages: representations, coping and appraisal (Leventhal et al. 1992). Representations refer to how one makes sense of his or her disease (Leventhal et al. 1992) which then informs a coping response. This response is thought to be appropriate on the basis of an individual's cognitive and emotional representations to cope with the illness (Rees et al. 2004). Two broad coping actions (approach coping and avoidance coping) are defined in this stage (Leventhal et al. 1992). When individuals suffer from an illness, coping strategies are developed to regain their healthy state. The success of a coping strategy is assessed which then leads individuals to adjust their coping plan and/or representation of the illness or health threat according to their appraisal (Morrison and Bennett 2006). Hence, the model is conceptualized as a 'parallel-processing' model in that individuals actively produce both illness cognitions and emotional representations to a health threat when they receive an internal stimulus such as pain or external stimulus such as cancer diagnosis (Leventhal et al. 1980) (**Figure 2.4**). Such individual subjectivity and constructions, based on common sense about the health threat and personal experiences of a symptom or diagnosis, guides the understanding of the current situation and subsequently guides coping behaviour (de Castro et al. 2015).

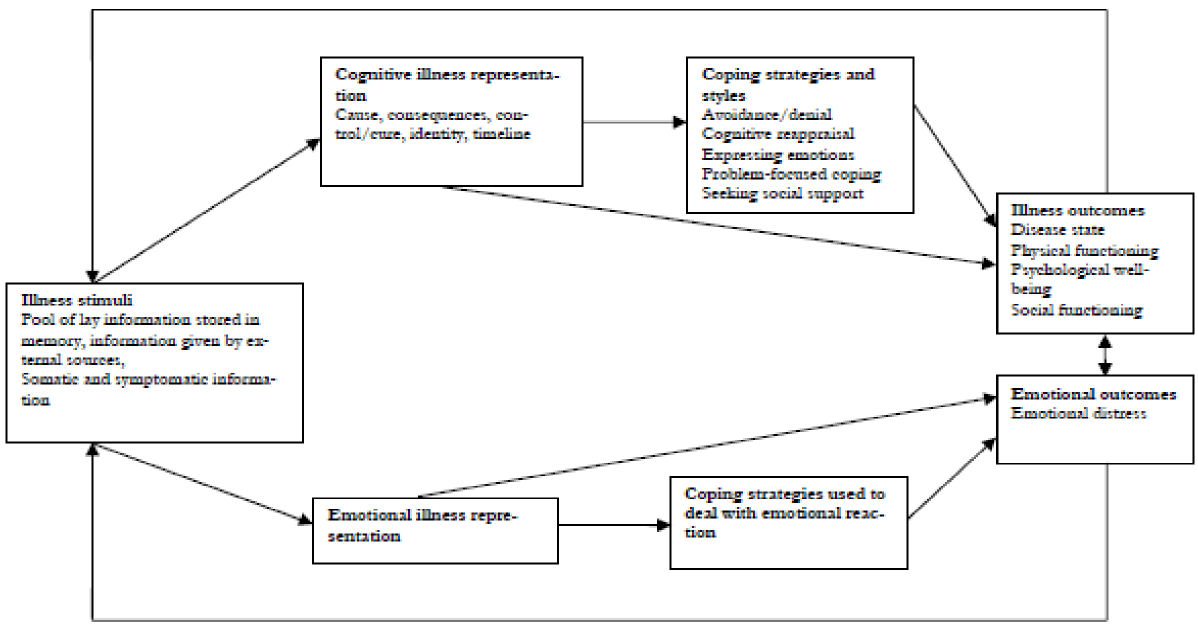

Figure 2.4 - Schematic representation of the Common-Sense Model of Illness Representations (adapted from Brandes and Mullan 2014, p.131; Hagger and Orbell 2003)

Originally, illness representations comprised five domains: *identity* (possible related symptoms), *causes* (factors that give rise to the illness), *timeline* (course of the disease over time; e.g., acute/chronic – beliefs about the relative chronicity of the illness), *consequences* (severity of the disease and its anticipated impact on the physical, psychological and social functioning), and *cure/control* (perception of if and how an illness can be cured or controlled) (Baines and Wittkowski 2013). A logical relationship exists between these five components (Morrison and Bennett 2006). A meta-analysis of the model reported consistent strong negative relationships between cure/control and identity, timeline and consequences while there is positive relationships between identity, consequences and timeline (Hagger and Orbell 2003). Moreover, evidence indicates that when individuals considered that the illness outcomes can be influenced by coping strategies, illness perceptions had a more direct effect on the illness outcomes such as utilisation of medical treatment (Leventhal et al. 1992), treatment adherence (Horne and Weinman, 2002), and engagement in self-care activities (Hampson et al. 1990). The original five dimensions were further differentiated to include another four domains: timeline cyclical (beliefs about the fluctuation in symptoms and temporal illness changeability); personal and treatment control (perception of how an individual can control or cure the illness and treatment effectiveness); illness coherence (perception of how an individual understands the disease) and emotional representations (emotions involving the illness experience) (Moss-Morris et al. 2002).

The utility of the CSM

The utility of the CSM has been extensively investigated quantitatively following the development of the Illness Perception Questionnaire (IPQ) (Weinman et al. 1996), which addresses the first five key dimensions. This was later revised and renamed as the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al. 2002) with the inclusion of the new dimensions. The CSM has generally been employed in disease-affected populations to assess the cognitive (i.e. beliefs, thoughts, ideas) and emotional (i.e. feelings) representations of a health threat (Anagnostopoulos et al. 2012; Cameron 2008), derived from one's own unique experience of an illness or illness-related symptoms (Leventhal et al. 1980). Healthy individuals can similarly develop illness perceptions to those affected by a disease through these cues. An individual's behaviour can be affected by the assessment of symptoms and knowledge, beliefs and risk perceptions (de Castro et al. 2013) derived from various sources, including internal cues (e.g., existing understanding of an illness) (Cameron and Moss-Morris 2004) and external cues (e.g., information obtained from family, friends and/or media) (Morrison and Bennett 2006). In fact, healthy individuals who have lived with a relative with cancer hold stronger negative emotional representations (e.g., depressed, upset, fear) about cancer than healthy people without an affected relative (Del Castillo et al. 2011). Hence, CSM has also been used in a small number of studies to examine the illness perceptions of asymptomatic individuals (Anagnostopoulos et al. 2012; Adams 2010; Moore 2008) including skin cancer (Cameron 2008; Figueiras and Alves 2007), AIDS and tuberculosis (Figueiras and Alves 2007). In the study by Figuerias and Alves (2007), the cognitive dimensions (illness coherence, psychological attributions, chronic timeline and the perception of disease consequences) explained some variance in attitudes towards preventive behaviours and intention to adopt them. The evidence showed that those who endorse more acute/chronic timelines, fewer psychological causes (causal attributions), more severe consequences of the disease and its treatment, and have a better understanding of the illnesses (illness coherence), exhibit more positive attitudes towards health behaviours (Figuerias and Alves 2007). This suggests that illness representations may influence health-related behaviours in healthy individuals, independent of the illness experience. In relation to BC, healthy women have stronger beliefs about BC consequences (Buick and Petrie 2002), perceived susceptibility and treatment side-effects and duration (Buick 1997) than BC patients. One study found that older asymptomatic women perceived more negative consequences (physical disfigurement due to BC) and identified fewer risk factors (causal attributions) and symptoms (identity) of BC (Grunfeld et al. 2002). Moreover, the capacity to identify BC symptoms has been linked to one's seeking intent (Hunter et al. 2003) and postponement of medical assistance (Grunfeld et al. 2003).

Illness perceptions also appear to be precursors of screening behaviour (de Castro et al. 2013), including mammography screening (Adachi et al. 2015; Petrak 2013; Anagnostopoulos et al. 2012). In an effort to determine the factors that are associated with asymptomatic women's mammography behaviours among 408 Greek women, aged 40 or older, Anagnostopoulos and colleagues (Anagnostopoulos et al. 2012) employed the validated IPQ-R to rate women's perceptions of BC. The findings showed that women who participate in mammography screening are significantly more likely to perceive greater benefits and fewer barriers to BS, similar to previous findings (Lagerlund et al. 2000; Holm et al. 1999). Moreover, the higher level of negative emotional representations on BC (e.g. feeling afraid, getting depressed when thinking about BC) were associated with an increased likelihood of never having a mammogram. This is consistent with previous research on mammography utilization, which suggests that emotional responses and distress can influence mammography behaviour in a reverse fashion (Decruyenaere et al. 2000). Regarding repeat mammography screening, BC worry was a significant predictor of repeat mammography use. This positive association has been previously reported in other studies (Adachi et al. 2013; Diefenbach et al. 1999), in a meta-analysis (McCaul et al. 1996) and with a significant, albeit weak, positive association between these two variables in another study (Hay et al. 2006). Moreover, knowledge about recommended frequency of mammography screening also emerged as a significant predictor of repeat mammography screening. The latter result confers with the findings from Russell et al. (2006) who found that knowledge about recommended mammography screening interval was predictive of more repeat mammography use. However, the other illness representation dimensions (consequences, cyclical timeline, treatment control, personal control, and illness coherence) did not significantly predict mammography use in the Greek study (Anagnostopoulos et al. 2012). Key limitations of this study are that the causal (obtained low reliability) and identity subscales and the components of coping behaviours representations were excluded (Hagger and Orbell 2003). In a meta-analysis of 45 empirical studies to examine the intercorrelations between illness representations dimensions, coping strategies and health outcomes, Hagger and Orbell (2003) revealed that the correlations between illness representation dimensions and the coping behaviours are of low-to-moderate magnitude. Explanations for these findings may be that coping behaviours may only mediate the impact of illness representations on health outcomes or that illness representations focus on the beliefs of the illness rather than coping with the behaviour, which may, in turn, consist of a different set of dimensions (e.g. beliefs on the efficacy of mammography) (Hagger and Orbell 2003).

Limitations of CSM

Some criticisms about the use of this model in this context have been raised. Firstly, in terms of mammography use, CSM does not include perceived barriers and benefits to the performance of health-related behaviours (Zhang 2014) even though it is known that barriers and benefits significantly determine BS participation (Secginli and Nahcivan 2006; Han et al. 2000; Champion 1999). Secondly, the CSM excludes the role of significant others such as family, friends and healthcare providers (Hale et al. 2007). As mentioned in the literature review above, the support of family and recommendations by a physician are known facilitators to BS uptake (Trigoni et al. 2008; Magai et al. 2007; Jepson et al. 2000). In contrast to CSM, HBM addresses perceived benefits, perceived barriers and cues to action.

2.3.2 Stage models

As discussed previously, social cognition models are a group of similar theories, each of which identifies various components (such as cognitive and affective factors, i.e. beliefs and attitudes) (Sutton 2002) which are combined to predict a continuum of behaviour likelihood (Weinstein et al. 1998). While stage models use similar concepts to social cognition models, they are fundamentally different in structure as they organize concepts in a different way (Weinstein et al. 1998). Stage models relevant to health behaviours include the Transtheoretical Model (TTM) (Prochaska and DiClemente 1984), the Precaution Adoption Process Model (PAPM) (Weinstein and Sandman 1992), and the Health Action Process Approach (HAPA) (Schwarzer and Fuchs 1996). Since TTM is the dominant model in the field and has relatively more evidence in its application to health behaviours compared with the PAPM and HAPA (Schuz et al. 2009; Conner and Norman 2005), this section focuses on the TTM.

2.3.2.1 The Transtheoretical Model

Often referred to simply as the stages of change model, the TTM was initially developed by James Prochaska in 1977 to understand the processes of change in psychotherapy and smoking cessation (Prochaska 2013), but has been applied to a wide range of other health behaviours (Prochaska and Velicer 1997) including BS (Partin and Slater 2003; Chamot et al. 2001; Rakowski et al. 1996). The name ‘transtheoretical’ emerges from the fact that TTM attempts to integrate fifteen different constructs in a single comprehensive framework (Sutton 2002), which are drawn from different theories of behaviour change. These 15 constructs include the stages of change (the basic organizing principle of TTM), the 10 processes of change (i.e. the things that people think and do to help them move through the stages), the perceived pros and cons of changing (i.e. the perceived advantages and disadvantages of changing), self-efficacy (borrowed from Bandura's social cognitive theory) and temptation (the degree to which a person expects to feel tempted to lapse in different situations) (**Figure 2.5**). The pros and cons in the TTM are conceptually the same as HBM’s perceived benefits and barriers. For example, women are more likely to be in the later stage of mammography use if they perceive more pros than cons towards mammography. Moreover, the transitions between the successive stages are influenced by self-efficacy and temptation in the TTM (Prochaska et al. 2002). Hence, stage models and social cognition models share some concepts, though the former suggest the stages of behaviour change and the latter emphasize that behaviour change is a continuous process (Zhang 2014).

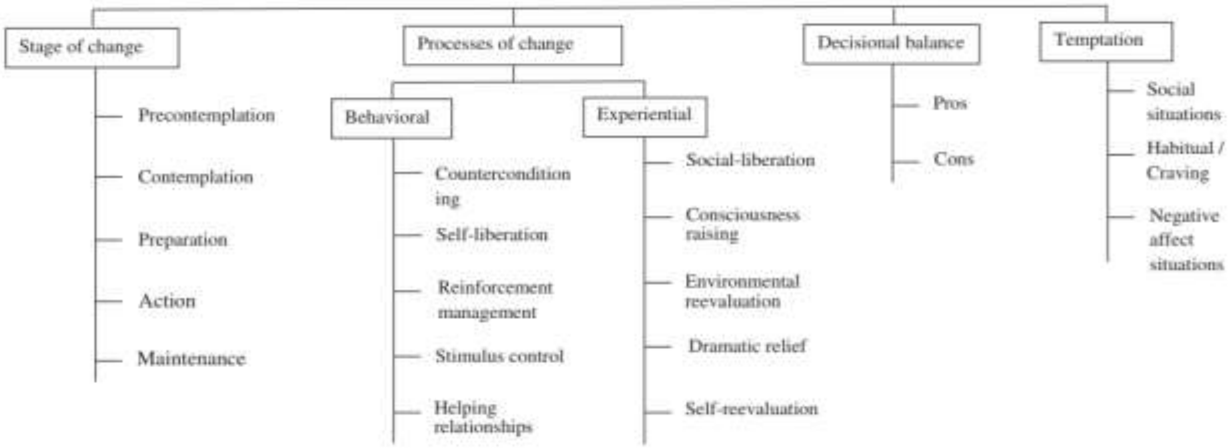

Figure 2.5 - Schematic representation of the TTM constructs (Sarbandi et al. 2013, p.2)

The version of the TTM used most widely in recent years includes five stages of behaviour change: precontemplation, contemplation, preparation, action and maintenance (DiClemente et al. 1991). The first three stages are defined in terms of current intentions and past behaviour: (1) precontemplation (where individuals lack awareness of health problems with no intention for behavioural change), (2) contemplation (where individuals begin to consider behaviour change possibly caused by the unhealthy behaviour and increased perceived susceptibility), and (3) preparation (where individuals plan to change behaviour). In spite of having a strong intention to change their behaviour in this stage, individuals may vary in their confidence in implementing behaviour change. Stages 4 and 5 of the TTM are purely defined in terms of behaviour: (4) action (individuals engage in behaviour change) and (5) maintenance (individuals enter into the stage of maintenance when they keep up the change over time, e.g. for more than 6 months). Although TTM assumes that individuals go through the five stages in order, it also assumes that individuals relapse to an earlier stage and can cycle and recycle from one stage to another before achieving successfully long-term behaviour change (Sutton 2002).

The TTM was applied by researchers to explore mammography screening practices. Studies were reviewed by Spencer et al. (2005) who reported that findings support the construct validity of the TTM in mammography screening. Among immigrant Muslim women living in the US, the use of TTM yielded relevant information on how to improve this group of women's attendance (Hasnain et al. 2014). However, the HBM supported the theoretical framework to guide the latter study, since it was useful to explore the effectiveness of introducing an intervention rather than to directly explore Muslim women's mammography screening behaviour (Lawal et al. 2017).

Limitations of the Transtheoretical Model

While there is a large body of evidence to support the model (Spencer et al. 2005), limitations of the TTM include: lack of standardization of measures, particularly of the central construct of stages of change; logical flaws in current staging algorithms; inadequate specification of the causal relationships among the different constructs; misinterpretation of cross-sectional data on stages of change; and confusion concerning the nature of stage models and their measurement (Sutton 2002; Sutton 2000). Further consideration should be given to the notion that behaviour change involves progression through a series of qualitative, sequential stages.

2.4 Justification for using the Health Belief Model and the Common-Sense Model as the main theoretical framework

The reviewed theories have similarities and differences on a theoretical level. As discussed earlier, social cognition models have been adopted to understand the determinants of mammography behaviour and behaviour change. Such models assume that personal choices and behaviour result from the analyses of benefits and costs of the possible consequences of courses of action (Conner and Norman 2005). Individuals generally prefer to choose the ideal behaviour with the combination of the highest probable outcome and the best expected value (Zhang 2014).

Perceived benefits and barriers have been demonstrated to be significant predictors of mammography screening. Hence, understanding different beliefs and attitudes related to BS as well as the benefits and barriers related to the behaviour will partially explain why some women engage in positive behaviours and why others opt not to, particularly to target the barriers that inhibit individuals' engagement in positive behaviours. Moreover, as mentioned in the literature review above, the support from family and physician's recommendations predict mammography use among diverse populations (Sunil et al. 2014; Roman et al. 2014; Villani and Mortensen

2013). Such cues to action are included in the HBM but not in the other models, such as the CSM (Hale et al. 2007). In contrast to TPB and TTM, both the HBM and PMT explicitly emphasise the perceived health threat in terms of perceived susceptibility and perceived severity. However, Sheeran (2002) found that among those with positive intentions to perform cancer screening, 47% of participants did not implement the behaviour. It has been suggested that having the intention to go for BS may not be sufficient to initiate the behaviour due to a psychological 'intention-behaviour gap' (Sutton 2002), but rather forming a plan of action may bridge the gap between intention and behaviour, which can significantly improve mammography screening uptake (Zhang 2014). Therefore, it is essential for this study to explore the cues that would facilitate Maltese women converting intentions to attend mammography screening into tangible utilisation. Compared with TPB and PMT, HBM has ignored the link between intention and behaviour.

The HBM, PMT and CSM are considered as content-specific models as they provide detailed information about factors that are related to health behaviour or illness perceptions. In contrast, the HBM, PMT and CSM provide a stricter guideline towards the understanding of health behaviours, compared with the TPB (a content-free model that has only three constructs) which does not define any specific content and the content of the included constructs is filled during the process of using this theory to understand a specific behaviour (Ajzen 1998). There is also evidence that TPB is infrequently used directly to inform behavioural change interventions, and when this has been the case, there has been relatively limited, additional health benefits gained (Hardeman et al. 2002). Moreover, systematic reviews and randomised controlled studies have not provided sufficient evidence for TTM's effectiveness in interventions on health behaviour change or promoting the progression through the 'stages of change' mechanisms (Callaghan and Herzog 2006; Sutton 2005; West 2005).

The application of HBM has received strong support by researchers to understand BS behaviours (Aflakseir and Abbasi 2012; Anagnostopoulos et al. 2012; Champion et al. 2008). It has been suggested that HBM is the best framework to understand infrequent health-related behaviour (e.g., mammography screening) while other models (e.g. PMT, TPB and TTM) are considered to be more predictive in frequent behaviour (e.g., smoking cessation) (Sanderson

2004). Because of its long record of use in several studies exploring health and cancer screening behaviours, the HBM was employed as one of two theoretical frameworks for this study to explore BC-related knowledge, beliefs, perceptions, and screening behaviours among Maltese women - a population not previously targeted. However, HBM only explains some variation in BS behaviour (Orji et al. 2012), and although the HBM may be used to derive information that may then prompt interventions designed to change health beliefs and behaviours, using the model alone cannot inform decision-making as to how such interventions might best be structured. HBM does not take into account the role of emotions in decision-making as well as the value of the 'perceived threat' element (Henshaw and Freedman-Doan 2009). Related to this is the increasing interest in models of self-regulation, whereby conscious personal management involves the process of guiding individual thoughts, behaviours and feelings to enact the behaviour. The CSM has made a great contribution to explain the effect of cognitive and emotional representations (such as fear) on behaviour change (Anagnostopoulos et al. 2012; Norman and Brain 2005). On the other hand, the CSM does not describe the perceived barriers and benefits to the performance of health-related behaviours (Zhang 2014) such as mammography use, and excludes the role of significant others such as family, friends and healthcare providers (Hale et al. 2007), nor does it accommodate social and environmental influences of past behaviour (Lunt et al. 2005). By contrast, the HBM addresses all of these, incorporating the components of perceived benefits, perceived barriers and cues to action. Therefore, both HBM and CSM have been chosen as the theoretical frameworks to guide the prediction of mammography screening uptake in Malta.

2.5 Chapter summary

There has been substantial interest worldwide in exploring BS determinants and how to address the factors influencing screening compliance, many of which are inter-related. In summary, this literature review related to mammography screening uptake has shown that risk perception, peace of mind, positive screening experiences, anxiety, beliefs in early detection, socio-demographic factors, and personal or family experiences of BC are among the main reasons for BS attendance. On the other hand, psychosocial factors including fears and social influences, as well as the physical, socio-demographic, health status, logistical and knowledge variables may contribute to BS non-attendance. An understanding of these factors might contribute to the development of BS interventions. This chapter also provides a context for Chapter 4 as it reviews the literature that forms the basis of the questionnaire and topic guides used in a study of women's beliefs and perceptions about BS in Malta.

The review of previous literature on the utility of behavioural theories highlights how models appear to have been widely used in attempting to understand behaviours in many different settings or more specifically, women's BS behaviour. The theories discussed above could be used to inform studies on BS and underpin interventions to improve uptake. Although it was not possible to cover all theory combinations and applications, studies have acknowledged the strengths of individual theories by adding more or innovative constructs or embedding theoretical approaches within other broader frameworks. However, it is important to understand the limitations surrounding theories, for example, abstraction from context, focus on cognition rather than the progression by which behaviour might change or through which interventions can effect change. This is particularly important as the effect of such limitations and those factors not accounted for, could be significant to the understanding of women's participation in mammography screening. While the HBM focuses on the individual, including one's perceived barriers and benefits to health behaviours, and does not incorporate the role of emotions in decision-making behaviours, the CSM explains the effect of cognitive and emotional representations of a health threat on behaviour change. Due to the strengths of the HBM and CSM, both models were adopted in this thesis to explore the factors affecting women's use of mammography in Malta. The following chapter provides the methodology, which guided the research questions in this thesis.

Chapter 3

Methodology

3.1 Introduction

This chapter discusses the overarching approach to this research by illustrating the application of Intervention Mapping (IM) to explore breast screening (BS) determinants, and plan a future tailored intervention that would have the potential to increase BS uptake among Maltese women. Subsequently, the mixed methods approach used throughout this research is explained in relation to each step of the IM framework. Since there are a number of studies, the entire thesis will be referred to as 'the research'. While each study is briefly introduced, the detailed methods used for each study are presented in subsequent chapters. The purpose of this chapter is to describe the overarching framework to the entire research.

3.2 Intervention mapping

Interventions designed to address the needs of women attending BS may be complex and involve multi-level strategies to produce system and individual changes to improve attendance. Planning, developing and implementing such complex interventions may be guided by IM (Bartholomew et al. 2006). IM is a systematic approach that has been successfully used to adapt health promotion programmes (Leerlooijer et al. 2011) and to plan, implement and evaluate interventions that showed significant increase in uptake of disease prevention programmes (Garba and Gadanya 2017). Examples of these include colorectal cancer screening (Besharati et al. 2017), cervical cancer screening (Fernandez et al. 2005) and BS (Highfield et al. 2015; Zhang 2014; Fernandez et al. 2005). Therefore, IM was employed as the overarching framework to guide the mixed methods approach to fulfil the aim and research questions (RQs) of this research.

IM is an iterative process rather than a linear one (Bartholomew et al. 2006). It encompasses six steps (Bartholomew et al. 2016):

- Step 1 is to conduct a needs assessment or problem analysis, identifying what needs to be changed and for whom;
- Step 2 aims to create matrices of change objectives (COs) by combining (sub-) behaviours or performance objectives (POs) with behavioural determinants, and identifying which beliefs should be targeted by the intervention;

- Step 3 aims to select theory-based intervention methods that match the determinants with what the identified beliefs aggregate into, and translate these into practical applications that satisfy the parameters for effectiveness of the selected methods;
- Step 4 aims to integrate methods and the practical applications into an organised intervention;
- Step 5 considers and plans the adoption, implementation and sustainability of the intervention in real-life contexts;
- Step 6 aims to formulate an evaluation plan, which not only assesses intervention effectiveness, but also examines the process and delivery of the intervention.

The completion of the tasks within an IM step creates a product that guides the subsequent step, each of which link theory and evidence to practice to provide a systematic framework for planning, developing and implementating interventions (Kok et al. 2016) rather than providing another theoretical model (Kok et al. 2004). Effective decision-making at each step of the intervention development process is guided by the input from priority population members (Drum et al. 2009) and by operationalising the theoretical components to link POs with intervention methods and implementation strategies (Bartholomew et al. 2006). Therefore, IM is suitable for this research as the diverse component studies within this research adequately fit within IM's various steps.

IM steps 1-3 were adapted and utilized as the overarching framework for the purpose of this research, and were conducted with specific tasks (**Table 3.1**). Steps 4 – 6 were beyond the scope of the current research. In the future, the researcher may seek further funding to conduct a research study to carry out IM's final steps through testing the feasibility of a potential intervention, and evaluating the potential effect of the proposed intervention on particular behaviours of screening non-attendees.

Table 3.1 - Steps of Intervention Mapping (IM) for this research

Step	Key Stages	Research Questions (RQs)	Tasks	Method	Chapter / Study
1	***Logic Model of the problem***				
	Needs assessment		(1). To identify key factors that influence BS behaviours and relevant theoretical models that explain why these factors influence behaviours.	(1). A literature review	(1). Chapter 2
		(1). Is the Maltese Breast Screening Questionnaire (MBSQ) valid and reliable?	(2). To translate, adapt and pilot-test Champion's Health Belief Model Scale for Mammography Screening (CHBMS-MS) and Revised Illness Perception Questionnaire (IPQ-R) and their Maltese translated version (MBSQ) among Maltese women.	(2). Translation pathway (n=4); expert panel (n=12); focus group with asymptomatic women (n=6); face-to-face interviews (n=15).	(2). Chapter 4, Study 1
		(2). Which significant factors are associated with: (a) BS uptake to a first invitation at the MBSP, (b) re-attendance, (c) lifetime mammography use and (d) adherence to timely mammography practices in Malta?	(3). To measure barriers, facilitators, associations and predictors to BS uptake in Malta.	(3). (a) National cross-sectional survey on first invitation to the MBSP; (b) Prospective study on re-attendance; (c) Retrospective study on lifetime mammography use; (d) Retrospective study on timely screening adherence	(3). Chapter 4, (a) Study 2 (b) Study 3 (c) Study 4 (d) Study 5

2	***Logic Model of Change***				
	(a) Search for evidence-based interventions to address BS behaviour	(3). What types of interventions are effective at increasing mammography uptake?	(4). To determine the effectiveness of interventions to improve mammography uptake, which have employed the HBM and/or CSM as the theoretical basis.	(4). A systematic review of interventions	(4). Chapter 5, Study 6.
	(b) Identify intervention outcomes and change objectives		5(i). To specify performance objectives (POs) (i.e. preparatory behaviour); 5(ii). To specify important, changeable determinants; 5(iii). To differentiate the target population; 5(iv). To construct matrices of change objectives; 5(v). To identify essential elements of a potential intervention; 5(vi). To discuss delivery, design, cultural fit, implementation fit and plan adaptations with field experts.	(5). Two expert steering groups	(5). Chapter 6
3	***Intervention Design***				
	Select theory-based intervention methodologies, practical strategies and suggestions from targeted users.	(4). Which factors influence non-attendance among lifetime non-attendees and which interventions are considered appropriate to increase mammography screening uptake in Malta?	(6). To brainstorm methods to achieve intervention objectives and to translate methods into strategies.	(6). World café *type* focus groups with women and men – PPI event (7). Face-to-face in-depth interviews with non-attendees	(6). Chapter 7 (7). Chapter 8, Study 7

3.3 Materials and Methods

3.3.1 Mixed methods for Intervention Mapping

Steps 1-3 of IM address all 4 RQs through a mixed methods approach (**Table 3.1**). A mixed methods approach was used in the design of this research to provide a basis for triangulation as the source of conceptualising a problem in different ways (Spratt et al. 2004). A mixed methods design was chosen to strengthen the reliability of data, validity of the findings and recommendations, and to deepen the understanding of the processes through which outcomes and impacts are achieved, and how these are affected by the context within which the intervention is implemented (Bamberger 2012). Mixed methodology goes beyond the limitations of a single approach as it can capitalise on the strengths of both quantitative and qualitative methods and offset their different weaknesses (Creswell and Garrett 2008).

Distinct differences between qualitative and quantitative research approaches exist. Their primary differences are related to their research orientation and data analysis. Quantitative research is generally used to quantify a problem and seeks to test hypotheses by generating numerical values or data that can be analysed through statistical techniques (Carson et al. 2001). While quantitative data is more efficient to test hypotheses, it may miss contextual detail. On the other hand, qualitative research is exploratory in nature as it is provides deeper insights into research gaps and rich descriptive data on participants' lives and social experiences (Smith 2003) by uncovering trends in thoughts and perspectives through individual or group investigation (Smith 2006). Qualitative research occurs in participants' natural settings, where conditions continuously develop and interact with each other to produce a process of ongoing change (Zhang 2014). This allows qualitative researchers to understand why and how people make decisions rather than just what, where and when. Naturalistic verbal reports are collated, such as from written accounts or interview transcripts, and data are analysed within textural contexts (Stuckey 2014). Therefore, quantitative research tends to focus on exploring what is measurable, while qualitative research tends to focus on the interpretation of the problem.

Flexibility is another key difference between the two methods (Haq 2014). In comparison, qualitative research is more flexible than quantitative research. Quantitative methods use highly structured methods (e.g., survey questionnaires or experimental designs) to investigate numerical data and to test the strength and significance of the relationships between variables (Bowling 2009). Responses do not affect or determine subsequent questions as scales are used to rate particular questions. In contrast, qualitative researchers utilise relatively unstructured methods, such as focus groups and in-depth interviews to capture individual's perspective, their views and individuality (Smith 2006). In turn, questions can be adjusted according to participants' responses and open-ended questions are used, thereby creating more spontaneity, interaction and a closer social relationship between the researcher and the participant/s when compared with the response of fixed answers in quantitative studies (Howitt 2010). Hence, researchers are considered to be insiders in qualitative research rather than outsiders as in quantitative research (Denzin and Lincoln 2000).

Qualitative research is often criticised for lacking scientific rigour in terms of reliability, validity and generalizability (Noble and Smith 2015) with poor justification of the methods used, lack of transparency in the analytical procedures and the findings being merely a collection of personal opinions subject to researcher bias (Rolfe 2006). Nonetheless, the criteria of reliability and validity that apply to quantitative research are not suitable for qualitative methods (Yardley 2008). On the other hand, qualitative methods explore individuals' opinions, attitudes and experiences in different contexts and individuals' differences (Yardley 2008). For example, women may give different descriptions of the severity of mammography pain when questioned by different people, such as family members or health professionals. This suggests that people may produce diverse replies to the same subject in different contexts. Hence, the criteria of reliability do not fit most of the qualitative studies.

Some researchers argue that it is the pragmatic nature of mixed methods that enables this method to achieve multiple goals, such as explanation, confirmation and triangulation in explaining complex social constructs (Caruth 2013; Teddlie and Tashakkori 2012). Hence, a mixed methods design was employed in this research to obtain both breadth and depth about the topic under investigation, and to identify relationships between variables and the meanings of specific social phenomena, as these will be determined and explored for the first time. Therefore, a mixed methods approach would increase this research's strength by enabling investigation of the problem from various perspectives (Driscoll et al. 2007), thereby providing more comprehensive answers to the RQs.

3.3.3.1 Step 1 of IM

Primarily, the scoping review of the literature (Chapter 2) and the results of Studies 1-5 (Chapter 4) in this thesis fulfilled the needs assessment (**Step 1**) of IM, and then fed into steps two and three (Chapters 5-8) of the IM process. These methods were considered sufficiently flexible to answer the RQs of each study in this research. The starting point for needs assessment was to review the literature to recognise BS determinants (Chapter 2). This literature review was used to design a quantitative instrument and qualitative topic guides that provided information to appraise factors that have an impact on BS behaviour in Malta. The quantitative instrument, a survey questionnaire, was translated by four expert translators and adapted by a panel of twelve experts to ascertain content validity and clinically meaningful content. The questionnaire was pilot-tested with six Maltese asymptomatic women and then tested for reliability through face-to-face interviews with fifteen bilingual women, thus meeting RQ 1 (Study 1).

Study 1 was followed by quantitative studies 2-5 (Chapter 4). The latter studies included a national, retrospective, cross-sectional survey among Maltese women to investigate first screening uptake at the MBSP (Study 2), a prospective study on re-attendance at the MBSP (Study 3), and retrospective studies on lifetime mammography use (Study 4) and timely screening adherence (Study 5), thus meeting RQ 2.

A cross-sectional study is particularly suitable for estimating the prevalence of a behaviour or disease in a population (Sedgwick 2014) and can be used to capture information based on data obtained at a single point in time (Levin 2006). However, cross-sectional surveys cannot be used to analyse behaviour over a period of time. The data gathered are from a sample of participants with varied characteristics and demographics. Cross-sectional studies are generally quick, easy, and cheap to perform and are often based on a questionnaire survey. Participants are not lost to follow-up because they are interviewed only once. Therefore, a cross-sectional survey was considered as the most appropriate method to: 1) identify the main reasons for non-attendance to mammography; 2) gather data on women's sociodemographic factors, health status, knowledge, health beliefs and illness perceptions about BC and BS, and 3) to determine the associations and significant predictors to mammography practices.

3.3.3.2 Step 2 of IM

Step 2 aimed to address RQ 3 by determining the key components, techniques and the basic fit of a future intervention and its mechanisms. This step was supported by a systematic review (Chapter 5, Study 6) and two expert steering groups - one carried out in Scotland and one in Malta (Chapter 6).

Systematic review

The systematic review was conducted to gain an understanding of effective interventions to increase BS attendance. A systematic review involves a detailed and comprehensive plan and search strategy derived a priori to identify relevant research to specific RQs, and appraise and synthesize all relevant studies through systematic and explicit, accountable methods (Gough et al. 2012). This provides reliable research evidence for decision-makers (Centre for Reviews and Dissemination 2009). The data gathered from the systematic review informed this research on which interventions could be replicated for the Maltese population.

Expert steering groups

All intervention development should be based on broad participation of community members and through development of a working group, best composed of stakeholders who have an interest in the health problem, the intervention or its outcome (Bartholomew et al. 2006; Yoo et al. 2004). The development of this linkage system should begin early, optimally in project-funding development and needs assessment (Bartholomew et al., 2006). The aim of the Scottish steering group (SSG) was to identify factors associated with BS behaviour, and formulate Performance Objectives (POs) i.e. statements of what a woman will do (preparatory behaviour) (Dalum et al. 2012) or how the BS behaviour will be modified, including who will create the change. Another aim was to formulate Change Objectives (COs) (i.e. specific intervention objectives or the specifications of what needs to change in the determinants of BS behaviour in order to accomplish the POs) (Bartholomew et al. 2006).

On the other hand, the purpose of the Maltese steering group (MSG) was to suggest practical and suitable strategies for the intervention population and its context. Basic fit is an initial assessment of how well an intervention tested in a specific setting might fit the needs and resources in another context (Highfield et al. 2015). The MSG helped to link COs to practical strategies i.e. specific techniques derived from theoretical methods for behaviour change to fit the intervention population and context in which the intervention will be conducted (Bartholomew et al. 2006). Ultimately, this helped to reveal the specific knowledge and actions that BS non-attendees need to learn and perform to change their screening behaviour.

3.3.3.3 Step 3 of IM

The third IM step was to identify suitable strategies in changing BS determinants and to translate these into practical applications (Suzuki et al. 2012), considering whether each strategy was appropriate in the Maltese context. In IM, it is advisable to involve the target group, as this is perceived as effective in increasing BS uptake and in developing interventions. Hence, **Step 3** of IM included patient and public involvement (PPI) through the World Café method (Chapter 7) and face-to-face interviews with non-attendees (Chapter 8, Study 7). Qualitative research conducted in people's natural social setting helped to provide a holistic picture of potential effective interventions and detailed participant views and enabled 'deeper understanding of people, their perception and events' (Bowling 2009, p.433), thus meeting RQ 4. A semi-structured topic guide that was reviewed by other researchers and pilot-tested with two women, was used during face-to-face interviews (Chapter 8, Study 7).

3.4 Chapter summary

The aim of Chapter 3 was to describe and evaluate the methodology of this thesis. A description and outline of the IM approach was provided to identify and measure the determinants to BS uptake with the aim of developing a future intervention that has potential to increase BS uptake among Maltese women. A mixed methods approach was chosen for data collection, analysis and synthesis of results in this thesis. This involved a scoping review of the literature on barriers and facilitators to BS, tool translation, adaptation and pilot-testing, a national retrospective cross-sectional survey, a prospective quantitative study and retrospective studies on lifetime mammography use and timely screening adherence respectively. The quantitative studies were followed by a systematic review of interventions, the involvement of expert steering groups and members of the public, and qualitative face-to-face interviews. All of these were based on the stepwise IM framework that describes an iterative path from the identification of gaps to problem solving. The following chapter presents the findings of the five quantitative studies.

Chapter 4

Study 1: Maltese Translation and Adaptation of Champion's Health Belief Model Scale and the Revised Illness Perception Questionnaire for Breast Screening among Maltese women[1]

[1] A version of this chapter has been published in the *Journal of Nursing Measurement* (**Appendix 4.1.1**) (Marmarà et al. 2017a).

4.1 Introduction

As outlined in Chapter 2, breast screening (BS) uptake is influenced by a multitude of factors (Mamdouh et al. 2014). In particular, studies have demonstrated that beliefs about breast cancer (BC) and BS (Huaman et al. 2011) as well as illness perceptions (Anagnostopoulos et al. 2012) are important predictors of mammography compliance. However, little is known why Maltese women are less likely to have a screening mammogram than their European counterparts. This is because a gap exists in the understanding of factors impacting Maltese women's decisions to undergo BS, partly due to the lack of instruments locally validated for this aim. The instruments chosen for translation and adaptation were selected from the extant literature, which shows that health beliefs and illness perceptions are key determinants of BS behaviour (Anagnostopoulos et al. 2012; Champion et al. 2008; Moss-Morris et al. 2002).

4.1.1 Conceptual framework

4.1.1.1 History and development of the Champion's Health Belief Model Scale (CHBMS)

The Health Belief Model (HBM), developed in the early 1950s, comprises its six fundamental constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Jahanlou et al. 2013). Champion developed and validated a scale in 1984 (Champion's Health Belief Model Scale - CHBMS), consisting of 36 items to measure perceived susceptibility to BC, perceived benefits and barriers to BS (Champion 1984). In 1999, Champion revised CHBMS for mammography screening (CHBMS-MS), excluding the breast self-examination used in the original studies, showing significant correlation between mammography compliance and high scores in the susceptibility and benefit subscales, whereas perceived barriers were associated with lower screening compliance (Huaman et al. 2011). This scale was originally validated in Indiana, US by Champion (Champion 1999) in a cohort of 804 women aged 50 and over in a population of Caucasians (68%) and African-Americans (30%), accounting for 54% of the variance and showing adequate construct validity and reliability. Since then, Champion's HBM scale has been tested for reliability and validity around the globe and translated for Iranian (Hashemian et al. 2013; Taymoori and Berry 2009), Lithuanian (Zelviene and Bogusevicius 2007), Malaysian (Parsa et al. 2008), Arabic (Mikhail and Petro-Nustas 2001), Korean (Lee et al. 2002), Chinese-Australian (Kwok et al. 2010), Turkish

(Norman and Brain 2005; Lunt et al. 2005), African-American (Champion et al. 2008), and Spanish-speaking American women (Medina-Shepherd and Kleier 2010). Findings of these studies have provided support for the validity and reliability of these HBM-based scales.

Since HBM is widely cited (Noar and Zimmerman 2005), I used Champion's revised HBM scale for mammography screening (CHBMS-MS) (Champion 1999) to translate, adapt and test among Maltese women. HBM, however, only explains some of the variation in BS behaviour, such that it does not consider the impact of emotions (such as fear) (Norman and Brain 2005), nor does it accommodate social and environmental influences of past behaviour (Lunt et al. 2005). This is why other models have been incorporated in studies to understand BS uptake (Cameron 2008). In response to HBM's limitations, an instrument associated with the Common-Sense Model (CSM) of self-regulation was also translated, adapted and tested.

4.1.1.2 History and development of the Revised Illness Perception Questionnaire (IPQ-R)

Leventhal and colleagues in the 1980s developed the CSM, which provides a framework for understanding how individual symptoms and emotions experienced during the health threat or diagnosis influence illness perceptions and guide subsequent coping behaviour (Diefenebach and Leventhal 1996). This model was later used to understand illness prevention and preventive behaviour intentions (Figueiras and Alves 2007).

The Illness Perception Questionnaire (IPQ) (Weinman et al. 1996) was developed in light of self-regulation theory to provide a quantitative assessment of the five components of illness representations - *identity, cause, timeline, consequences,* and *control/cure* in Leventhal's self-regulation model (Moss-Morris et al. 2002). These five dimensions have been studied in BS (Anagnostopoulos et al. 2012) and colorectal screening (Orbell et al. 2008). Subsequent measures include the <u>Brief</u> Illness Perception Questionnaire (**B**-IPQ) (Broadbent et al. 2015), the <u>Revised</u> Illness Perception Questionnaire (IPQ-**R**) (Moss-Morris et al. 2002) which examines illness beliefs and behaviours within specific groups of patients, or groups at risk from an illness, and an adapted version of the Revised Illness Perception Questionnaire (IPQ-R) for "<u>healthy</u>" individuals (IPQ-R**H**) in recognition of the unique characteristics of asymptomatic populations (Figueiras and Alves 2007).

In order to remedy shortcomings in the original IPQ scale, the IPQ-R was developed by Moss-Morris et al. (2002) as a more comprehensive, psychometrically acceptable, quantitative measure to include measures of perceptions of illness duration ('acute/chronic timeline'), fluctuation in illness over time ('cyclical timeline'), perceptions of 'treatment control' and 'personal control' over illness, 'illness coherence' (how clear and comprehensive an individual feels her illness to be) and 'emotional representations' (feelings of depression, upset, anger, worry, and anxiety). The IPQ-R has been validated for use in diverse diseases or healthy populations (Chen et al. 2008) with language-specific validated measures, such as Italian (Giardini et al. 2007), Swedish (Brink et al. 2011), Greek (Giannousi et al. 2010), Croatian and Lebanese (Petrak et al. 2015) and Portuguese (Figueiras and Alves 2007) versions. However, it has not yet been adapted and validated for Maltese asymptomatic and/or symptomatic women. Hence, I adapted the IPQ-R in this study to make it appropriate for both healthy women and those with cancer.

4.1.2 Aims and Objectives

The aim of Study 1 was to translate and adapt existing scales i.e. Champion's Health Belief Model Scale for mammography screening (CHBMS-MS) and the Illness Perception Questionnaire (IPQ-R) from English to Maltese (CHBMS-MS-M + IPQ-R-M = Maltese Breast Screening Questionnaire [MBSQ]) so that these could subsequently be used to examine why women in Malta attend/do not attend BS when invited. In reaching this aim and to address RQ 1, *Is the adapted tool i.e. MBSQ valid and reliable?*, the analysis has targeted the following objective:

(i) To pilot test the reliability and validity of the English version of CHBMS-MS and IPQ-R and their Maltese translated version (MBSQ).

Since the English language is an official language for the Maltese but not the national and sole mother-tongue language, I aimed to pre-test not only the Maltese version but also the English version, since some Maltese women may opt to respond in the language they prefer.

4.1.3 Methods

4.1.3.1 Data sources and study design

The study was conducted during June 2015, as part of a larger cross-sectional study about BS in Malta. The parent study was approved by the School Research Ethics Committee at the School of Health Sciences, University of Stirling (SREC14/15-Paper No.18v4) (**Appendix 4.1.2**) and by the Maltese Health Ethics Committee (HEC 02/2015) (**Appendix 4.1.3**). Permission to use the scales (CHBMS-MS and IPQ-R) was sought from the respective authors (**Appendix 4.1.4, 4.1.5** respectively).

4.1.3.2 Sample and procedures

Four translators were recruited for the translation pathway as follows: two translators (i.e. an EU translator working in Brussels who was also a bilingual native speaker of both Maltese and English languages, and a Maltese expert translator) translated the instrument from English to Maltese (steps 2-3) and two different bilingual translators (i.e. a bilingual expert from the Health Ministry and an expert interpreter at the University of Malta) back-translated the instrument from Maltese to English (step 4). An expert panel (*n=12*) was set up to ascertain content validity and to verify that the content is clinically meaningful to experts in the clinical area (Anagnostopoulos et al. 2012). The twelve members comprised the lead researcher for this study, the four expert translators/interpreters, a statistician with ten years experience in statistical analysis, two mammographers (Maltese and Scottish radiographers), a BS client, a BC survivor, a Consultant, and a Clinician.

A focus group was conducted with a convenience sample of asymptomatic women (*n=6*) to pilot test the adapted Maltese version of the instrument. Three of the women were housewives (53, 55, 58 years respectively) who had attended BS, two were public employees (59, 60 years respectively) who had not attended BS and the other was a retired 62-year old midwife who had also not attended BS when invited.

A convenience sample of fifteen women (*n=15*) participated in structured face-to-face interviews in order to assess comprehensibility and suitability of the research instrument and to ensure understanding of all scale items in both languages. Women were recruited from the MBSP and were BS attendees, aged 50-60. The convenience sample was recruited because it was felt that such women would be interested in engaging in such a topic (Creswell and Plano Clark 2011), thereby giving access to a range of women with different backgrounds (Kalsta et al. 2013). Women with prior history of BC or breast surgery, those who sought BC treatment as well as non-bilingual women were excluded. Participants were assured that they had no obligation to participate, that their participation was voluntary and that they could withdraw from the study at any time without the need to give any reason. The cover letter provided information to the women on how the researcher would protect their anonymity and confidentiality through coding (**Appendix 4.1.6a, b**). Following explanation on the nature of the research, informed consent was obtained from the participants (**Appendix 4.1.7a, b**).

4.1.3.3 Translation and adaptation

Figure 4.1 illustrates the pathway in which the translation and adaptation of the above scales was undertaken, based on published methods (Yilmaz and Sayin 2014; Champion 1999, 1984).

- **Steps 1-2: Identification of scales and forward translation**

Following the identification of validated scales by the researcher, initial translation of the questionnaire from English (original) to Maltese (target) languages was performed by two translators. This bilingual team first prepared their own translated versions; they then exchanged versions and finally came up with collaborative decisions about the translation.

- **Step 3: Reconciliation session**

The two experts met up with the researcher in a 'reconciliation session' in Malta and reviewed the translation together for inconsistencies with the original English scale and to ensure that the language was kept simple to be understood by Maltese women.

- **Step 4: Back translation into English**

The adequacy of the Maltese translated instrument was evaluated using the back-translation technique. The Maltese version was back-translated into English (original language) by another team of experts (i.e. not the original translators in Steps 2-3).

- **Step 5: Adaptation process**

Both language versions were examined for conceptual equivalence by the expert panel (*n=12*) (**Section 4.1.3.2**). The back-translation and original English instrument version were compared with attention given to grammar and the meaning conveyed by the words. In this ‘adaptation’ process, cultural and social characteristics of the translation are protected as much as possible (Kulis et al. 2011).

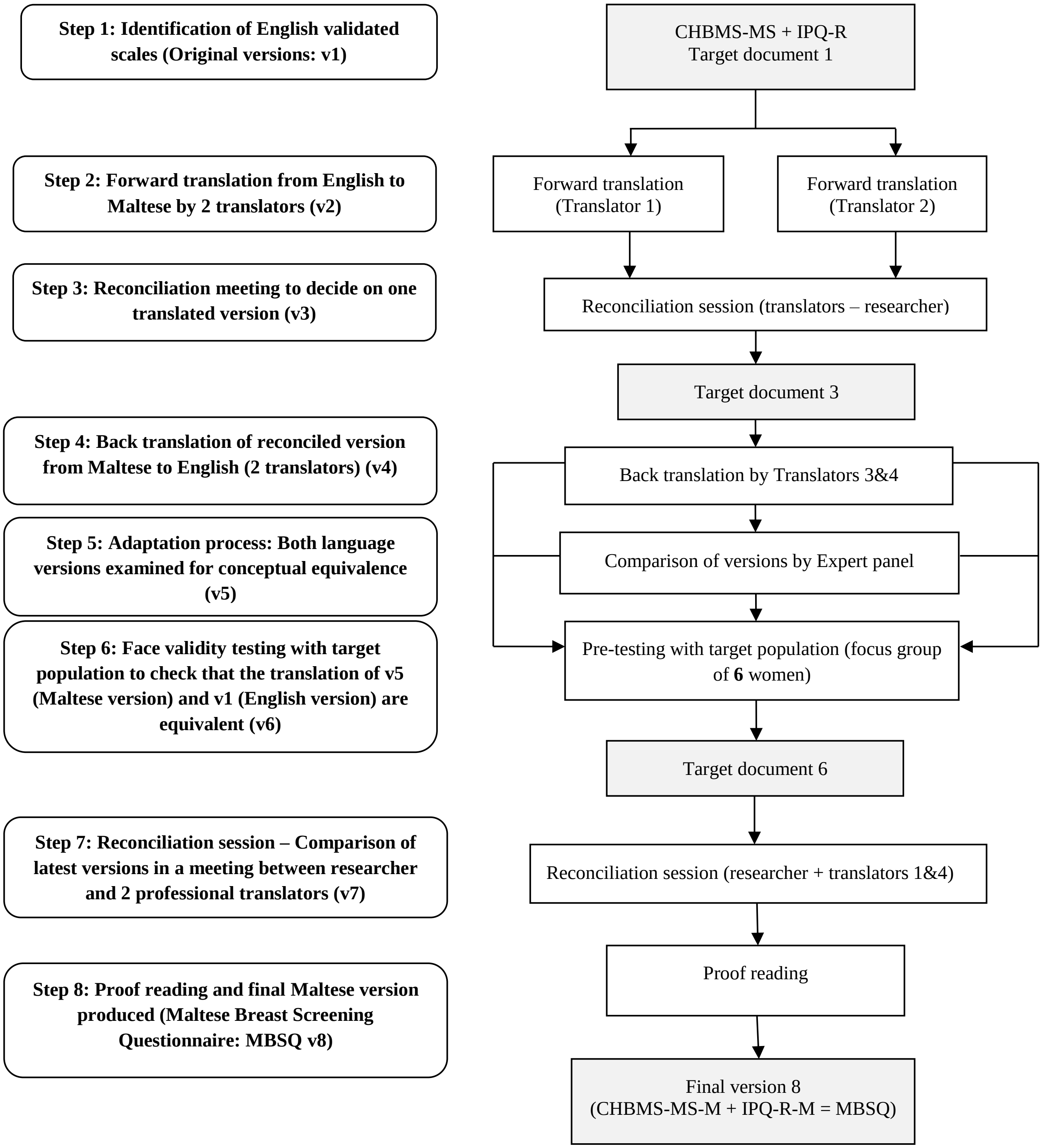

Figure 4.1 - Translation, adaptation, face and content validity (MBSQ pathway)

- **Step 6: Face validity testing**

A focus group was conducted with a convenience sample of asymptomatic women (*n=6*) to pilot test the adapted Maltese instrument version. This cognitive debriefing procedure (Wild et al. 2005) was followed to ascertain face validity of the instrument, to ensure clarity and comprehensibility of the items, to highlight inappropriate items or response options, and to identify and test translation modifications. This ensures that conceptual equivalence and cultural appropriateness are achieved (Anagnostopoulos et al. 2012). This group of screened/non-screened women tested the instrument's face validity and determined its cultural appropriateness and the accuracy of the translation, similar to the undertaken Turkish process (Yilmaz and Sayin 2014). The researcher read the translated text aloud to the participants, following which each item was scored on a five-point scale.

- **Step 7: Reconciliation session**

The scales were modified in a 'reconciliation session', where two translators met up with the researcher in Malta to review the final version so that it could be administered by an interviewer.

- **Step 8: Proof reading**

Following proof reading, the final Maltese version was produced (MBSQ). The following procedures were used to test the MBSQ.

4.1.3.4 Test-retest reliability

The final version (MBSQ) from step 8 was then tested for reliability (step 9). An estimation of *stability* is commonly assessed by a *test-retest reliability analysis,* where the questionnaire is given to the same person or set of respondents, in the same way, on two different occasions, usually with an interval of two to six weeks (Yilmaz and Sayin, 2014). In this study, a convenience sample of 15 bilingual women, aged 50-60, were recruited by the researcher from the MBSP to assess test-retest reliability of the Maltese and English subscales respectively. Participants responded to the questionnaire through face-to-face interviews on two occasions separated by a two-week interval, a test-retest period considered appropriate (Streiner et al. 2008). These women were contacted by a research assistant and two convenient times were arranged with each participant. The interviews were conducted in the participants' homes. Participants were informed that they were free to choose only one language. However, all participants were willing to complete the survey in both languages and opted to respond to the questionnaire first in Maltese followed by the English language at both time points (Day 1, Day 14) to test and re-test for stability and reliability of responses in the same language. The scores were then correlated.

4.1.3.5 Instrument scoring

Items were answered on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), similarly used in other studies (Yilmaz and Sayin 2014; Anagnostopoulos et al. 2012; Huaman et al. 2011). Possible score ranges included: 3-15 for susceptibility, personal control, treatment control and emotional representations respectively; 6-30 for benefits; 13-65 for barriers; 7-35 for cues to action and self-efficacy; 8-40 for BC identity and consequences; 18-90 for the causal scale, 2-10 for acute/chronic timeline and illness coherence, and 1-5 for cyclical timeline. Higher scores indicated stronger agreement.

4.1.3.6 Approaches to reliability and validity assessments

Reliability was evaluated by *Cronbach's alpha* (α) for internal consistency (reliability) and *test-retest correlation*. In terms of reliability, lower values indicate no internal consistency of the tool ($0.00 \leq \alpha < 0.40$ not reliable, $0.40 \leq \alpha < 0.60$ low reliability, $0.60 \leq \alpha < 0.80$ high reliability, $0.80 \leq \alpha < 1$ very high reliability) (Yilmaz and Sayin 2014; Buyukozturk 2012; Tekindal 2009). If Cronbach's alpha score is low, then the corrected item-total correlations for values of <0.30 are considered (minimum acceptable item-total correlation is 0.30) (Yilmaz and Sayin 2014). Such low values might be considered satisfactory if item deletion does not improve the overall alpha value (Buyukozturk 2012). Test-retest scores for each dimension were computed for the Maltese and English measures respectively using *Pearson's correlations* at both time points (T1, T2) for an estimation of reliability over time. Test-retest reliability refers to the correlation coefficient which should be at least 0.6 (Buyukozturk 2012; Huaman et al. 2011). Construct validity, a measure that confirms the extent to which inferences can be made from scale scores in relation to the theoretical construct of interest (Pruitt et al. 2010), was supported through Pearson's correlations to test the associations between subscales for each measure. Quantitative data analysis was performed using the Statistical Package for Social Sciences (SPSS® software) Version 21.0.

4.1.4 Results

4.1.4.1 Translation and adaptation

Four queries of subcultural word comprehension were raised by the bilingual translators, which required consensus. The term ‘breast lumps’ in the original instrument was translated to ‘boċoċ f’sidrek’. The second controversial term was ‘mammogram’, for which two panel members argued that some women in the target population may not be aware of early diagnostic breast examinations. Although ‘mammografija’ in the translated instrument was acceptable, the general known term was ‘mammogram’. Following this debate, the panel decided that both words were suitable and could be used interchangeably (i.e. mammogram, mammografija). A third controversial term was ‘thickening of the breast’. Following discussion, the panel decided on the phrase ‘ħxuna tat-tessuti tas-sider’. Another word discussed by all group members was ‘nipple’. Several controversaries arose on whether to use the word ‘nipple’ as is, ‘nippla’ or the pure technical phrase ‘ras il-biżla’. Most members argued that some women in the target population are not aware of the technical phrase but are familiar with the English term. This was then literally translated to ‘nipil’.

Since most women perceive BC as a serious threat (Lagerlund et al. 2000), it was decided that the construct ‘perceived severity’ would not be measured using HBM, similarly in Anagnostopoulos et al. (2012). Further removal of this item in the HBM scale would also avoid duplication since BC severity was addressed in the IPQ-R scale. Moreover, since the use of both HBM and CSM often fail to address contextual constraints such as low income and education level that may influence women’s screening behaviour, socio-demographic and socio-economic factors, as well as lifetime mammography use were added because of the acknowledgement of their contributions as BS determinants (Anagnostopoulos et al. 2012; Jepson et al. 2000). The panel further added cues to action (such as physician recommendations and family history) which are often omitted from empirical studies through HBM use (Anagnostopoulos et al. 2012). Finally, based on these conclusions, the original instrument version consisted of 124 items and was presented to the focus group (*n=6*) for testing.

4.1.4.2 Face Validity

From the original 50-item IPQ-R, two-items were removed from the cancer timeline domain

(‘BC will last for a long time’; ‘I expect to have BC for the rest of my life’) as they were found to confuse women and cause consistent heightened anxiety in responders, resulting in a 48-item Maltese (M) version (entitled IPQ-R-M). Participants were asked to report their personal views about BC rather than their perceptions of an illness personally affecting them. For example: ‘My illness has serious economic and financial consequences’ was replaced with ‘BC has serious economic and financial consequences’. The IPQ-R risk factors domain title were also amended to read ‘risk/lifestyle factors’, while the sections ‘personal’ and ‘treatment’ control were categorized under the heading ‘Curability/Controllability’. For the lifetime mammography use domain, 1 item was deleted to avoid overlap (‘a mammogram prior to BS invitation’ yes/no). Hence, the final Maltese instrument (MBSQ), comprising the Maltese (M) scales CHBMS-MS-M and IPQ-R-M, consisted of 121-items that were clustered into:

1) 11 subscales for socio-demographic and health status (20 items) related to age, residing district, education, employment, marital status, family income, car ownership/driving, illness/disability, having a GP, breast condition, family history of BC or other cancer. Response options were "yes", "no" or a series of tick boxes. Open questions were asked when it was believed to be important that women could provide further detail, e.g., type of illness, breast condition or cancer site.
2) 4 subscales for lifetime BS practices (17 items), that were clustered into: lifetime mammography use (4 items), attendance/non-attendance to first round screening (8 items), re-attendance/intention (4 items), knowledge about recommended screening frequency (1 item). Most of the response options were mostly designed to elicit "yes", "no" or "unsure" answers. Closed questions allowed women to respond to a series of tick boxes.
3) 5 subscales (psychosocial constructs) for health beliefs (36 items) that were clustered into: perceived susceptibility (3 items), perceived benefits (6 items), perceived barriers (13 items), cues to action (7 items) and self-efficacy (7 items). All items had 5 response options ranging from: 1 = ‘strongly disagree’ to 5 = ‘strongly agree’. Reverse scoring (r) was performed for only one item, ‘There is no possibility of getting BC’, so that higher values would indicate greater possibility.
4) 7 subscales (psychosocial constructs) for illness perceptions (48 items) that were clustered into: BC identity (8 items), causal scale (18 items), cancer timeline: acute/chronic (2 items), cyclical (1 item), consequences (8 items), curability/controllability (personal control - 3

items; treatment control - 3 items), illness coherence (2 items), and emotional representations (3 items). All items had 5 response options ranging from: 1 = ‘strongly disagree’ to 5 = ‘strongly agree’.

The above method found the instrument to be acceptable and ready for use in psychometric testing among the target population. Of the convenience sample of fifteen women (*n=15*), the mean age was 54.5 years ± 3.2 years (SD); 6 women were from below average income families (lower than €16,113), 11 women were housewives and 12 women had a secondary education level.

4.1.4.3 Instrument Scoring

For the scope of preliminary mean instrument scoring, the mean values at Time point 1 in Maltese were analysed (**refer to mean Maltese T1, Table 4.1.2**). Subscale scores were retrieved as the mean of items (following reverse scoring (r) for only one item ‘There is no possibility of getting BC’ in the perceived susceptibility subscale). Higher scores for health belief subscales, for instance, indicate more susceptibility, benefits, barriers, cues to action and self-efficacy (Champion 1999). Maltese women scored highest for perceived benefits and cyclical timeline, and lowest for perceived barriers and acute/chronic timeline.

4.1.4.4 Internal consistency and correlation analysis: psychometric estimates of reliability

Table 4.1.1 presents measures of central tendency (mean), variability (standard deviation) and alpha coefficients for the scales. In terms of reliability, Cronbach’s alpha value was 0.93 for CHBMS-MS and 0.92 for IPQ-R. Such a result in excess of 0.80 shows high internal consistency (reliability) (Huaman et al. 2011). Cronbach’s alpha estimations of each subscale were as follows: health beliefs - susceptibility (α=0.91), benefits (α=0.75), barriers (α = 0.88), cues to action (α=0.86), self-efficacy (α=0.90), while for illness perceptions - BC identity (α=0.92), BC causes (α=0.90), timeline acute/chronic (α=0.88), timeline cyclical (α=0.86), consequences (α=0.93), personal control (α=0.90), treatment control (α=0.90), illness coherence (α=0.86), and emotional representations (α=0.96). These values showed that the scale items measured similar features with high reliability since each dimension was expected to have an alpha of at least 0.7 (Huaman et al. 2011). Hence, preliminary high Cronbach’s alpha values indicated internal consistency for the Maltese instrument.

Table 4.1.1 - Internal consistency of the subscales for the CHBMS-MS and IPQ-R scales

	Mean (Maltese)	SD	Mean (English)	SD	Cronbach's alpha (Maltese vs English)	Inter-item correlation (Pearson)
Health Beliefs	**3.15**	**1.33**	**3.16**	**1.29**	**0.93**	**0.87**
Perceived Susceptibility	3.04	1.24	2.88	1.22	0.91	0.83
Perceived benefits	4.03	0.71	4.03	0.57	0.75	0.69
Perceived barriers	1.99	1.01	2.06	1.02	0.88	0.78
Cues to action	3.72	0.92	3.37	0.85	0.86	0.75
Self-efficacy	4.00	1.02	4.00	1.02	0.90	0.81
Illness Perceptions	**3.20**	**1.19**	**3.20**	**1.19**	**0.92**	**0.85**
BC Identity	3.72	0.82	3.70	0.84	0.92	0.85
BC Causes	2.78	1.18	2.76	1.20	0.90	0.82
Timeline (Acute/Chronic)	2.58	1.09	2.70	1.12	0.88	0.79
Timeline (Cyclical)	3.90	0.76	4.07	0.74	0.86	0.75
Consequences	3.56	1.17	3.60	1.15	0.93	0.87
Personal Control	3.68	0.91	3.66	0.95	0.90	0.82
Treatment Control	3.31	1.29	3.19	1.18	0.90	0.81
Illness Coherence	2.98	1.19	3.03	1.19	0.86	0.88
Emotional Representations	3.09	1.28	3.08	1.21	0.96	0.93

**The Pearson correlation test was tested against a p-value of 0.001. All Pearson correlation values were found to be statistically significant with a p-value <0.001.*

4.1.4.5 Reliability over time

The CHBMS-MS and IPQ-R subscales demonstrated acceptable stability over a 2-week period for all measures. Responses were compared between time 1 (T1) and time 2 (T2) after two weeks for both Maltese and English versions respectively. Test-retest scores for all dimensions showed Pearson correlation coefficients higher than 0.6 for both languages. For test-retest reliability (Maltese) (**Table 4.1.2**), Pearson’s correlation coefficients for CHBMS-MS-M and IPQ-R-M were 0.79 and 0.75 respectively. For test-retest reliability (English), Pearson's correlation coefficients for CHBMS-MS and IPQ-R were 0.83 and 0.74 respectively (**Table 4.1.3**). Hence, all of the subscale items met the criteria of reliability and were retained.

Table 4.1.2 - Test-retest correlations of the theoretical variables (Maltese)

	Mean (Maltese T1)	SD (T1)	Mean (Maltese T2)	SD (T2)	Cronbach's alpha	Test-retest correlation (Pearson)
Health Beliefs	**3.17**	**1.27**	**3.13**	**1.38**	**0.88**	**0.79**
Perceived Susceptibility	3.07	1.18	3.02	1.32	0.86	0.76
Perceived benefits	4.06	0.73	4.00	0.70	0.71	0.62
Perceived barriers	2.13	1.04	1.86	0.95	0.80	0.67
Cues to action	3.69	0.96	3.76	0.87	0.77	0.63
Self-efficacy	3.85	0.98	4.15	1.04	0.79	0.65
Illness Perceptions	**3.18**	**1.19**	**3.21**	**1.19**	**0.86**	**0.75**
BC Identity	3.74	0.92	3.70	0.71	0.76	0.63
BC Causes	2.80	1.17	2.76	1.20	0.84	0.72
Timeline (Acute/Chronic)	2.63	1.13	2.53	1.07	0.81	0.68
Timeline (Cyclical)	3.93	0.70	3.87	0.83	0.83	0.71
Consequences	3.45	1.17	3.66	1.17	0.88	0.78
Personal Control	3.49	1.04	3.87	0.73	0.72	0.68
Treatment Control	3.42	1.23	3.20	1.34	0.90	0.81
Illness Coherence	2.87	1.25	3.10	1.13	0.80	0.67
Emotional Representations	3.11	1.25	3.07	1.32	0.90	0.82

**The Pearson correlation test was tested against a p-value of 0.001. All Pearson correlation values were found to be statistically significant with a p-value <0.001.*

Table 4.1.3 - Test-retest correlations of the theoretical variables (English)

	Mean (English T1)	SD (T1)	Mean (English T2)	SD (T2)	Cronbach's alpha	Test-retest correlation (Pearson)
Health Beliefs	**3.19**	**1.23**	**3.126**	**1.341**	**0.905**	**0.83**
Perceived Susceptibility	2.84	1.09	2.91	1.35	0.85	0.75
Perceived benefits	4.06	0.53	4.00	0.62	0.78	0.71
Perceived barriers	2.21	1.03	1.91	0.98	0.82	0.70
Cues to action	3.71	0.93	3.75	0.77	0.71	0.61
Self-efficacy	3.92	0.99	4.09	1.05	0.91	0.84
Illness Perceptions	**3.21**	**1.16**	**3.18**	**1.22**	**0.85**	**0.74**
BC Identity	3.73	0.90	3.68	0.78	0.87	0.78
BC Causes	2.83	1.20	2.70	1.21	0.76	0.61
Timeline (Acute/Chronic)	2.73	1.08	2.67	1.18	0.85	0.74
Timeline (Cyclical)	4.00	0.76	4.13	0.74	0.78	0.64
Consequences	3.58	1.06	3.62	1.23	0.83	0.72
Personal Control	3.49	0.97	3.82	0.91	0.80	0.67
Treatment Control	3.18	1.17	3.20	1.20	0.95	0.91
Illness Coherence	2.97	1.13	3.10	1.27	0.90	0.82
Emotional Representations	3.09	1.15	3.07	1.29	0.92	0.86

**The Pearson correlation test was tested against a p-value of 0.001. All Pearson correlation values were found to be statistically significant with a p-value <0.001.*

4.1.4.6 Construct validity

When applying Correlation analysis between the English and the Maltese versions (**Table 4.1.1**), the Pearson correlation values for CHBMS-MS and IPQ-R were 0.87 and 0.85 respectively. All correlation values exceeded 0.6, and showed a significant correlation between the items of both versions ($p<0.001$). The Pearson correlation values were tested at the 0.05 level of significance.

When applying a Pearson Correlation between the two time points, the Pearson Correlation value was 0.778, showing a strong positive correlation between both time points. Such an association was found to be significantly different ($p<0.001$).

4.1.5 Discussion

The current study focused on translating, adapting and pilot-testing the validity and reliability of two existing scales for use among Maltese women. It was feasible to translate and adapt these scales, and the translated instrument showed promise of acceptable validity and reliability. The high correlation values obtained are suggestive of strong validity of scale items (Heale and Twycross 2015). Moreover, completeness was high (100% of participants answered all questions), thereby indicating that the instrument was easy and simple to administer.

Results of the translation and adaptation pathway and focus group analysis provided useful information on the understanding of items. Evidence suggests that although measures may be valid and reliable across diverse cultures, researchers are encouraged to modify and reword subscale items, taking into account cultural settings and any linguistic origins of their populations under exploration (Abubakari et al. 2012). This led to some items being omitted from the original scales because they either duplicated other items or failed to convey a clear expression of the intended objectives.

Overall positive and high correlation of the total inter-item correlation (Pearson) was obtained in this study for health beliefs (0.87) and illness perceptions (0.85), and high Cronbach's alpha (CHBMS-MS: 0.93, IPQ-R: 0.92) denoting overall acceptable internal consistency. Moreover, internal consistency ranged from 0.69 to 0.83 for health beliefs. Similarly, internal consistency reliability ranged from 0.69 to 0.83 in Gozum and Aydin’s study (Gozum and Aydin 2004), from 0.64 to 0.79 in Hashemian and colleagues’ study (Hashemian et al. 2013), and was above 0.73 for all scales in Champion’s study (Champion et al. 2008) among African-American women. A high consistency was observed in my study between the three perceived susceptibility scale items. Champion similarly reported high internal consistency of items for this subscale and observed a proper fit (0.82) using confirmatory factor analysis (Champion 1999). However, I could not confirm the subscales through confirmatory factor analysis as my reported findings were limited to a small sample in comparison, though the aim of Study 1 was not to elicit the most important factors that explain health beliefs and illness perceptions. Therefore, the findings can only be considered as preliminary values for the instrument’s internal consistency.

In this study, test-retest reliability correlations were from 0.62 to 0.76 for CHBMS-MS-M (Maltese) and ranged from 0.61 to 0.84 for CHBMS-MS (English). In Hashemian and colleagues' study, test-retest reliability correlation ranged from 0.67 to 0.92 for health belief subscales, and ranged from 0.67 to 0.92 for the Persian scale version among Iranian women (Hashemian et al. 2013). The test-retest data for the health beliefs dimensions shows that perceived susceptibility and perceived benefits appear to remain the most consistent over the two-week period. This may suggest that women will take action to screen for, or control illness if they believe they are susceptible to it, especially if the illness is viewed to potentially have serious personal consequences, and if they believe that screening benefits outweigh the barriers for doing so.

In Medina-Shepherd and Kleier's study (Medina-Shepherd and Kleier 2010), test–retest correlations for control group women (*n=20*) were perceived susceptibility (Spearman's rho: r=0.57), perceived benefits (r=0.63) and perceived barriers (r=0.83). In Champion's original validation study in an American city (Champion 1999), test–retest scores were 0.62 (susceptibility), 0.61 (benefits) and 0.71 (barriers). The findings of Study 1 were similarly significant for test-retest correlation (0.76, 0.62, 0.67 respectively for Maltese version; 0.75, 0.71, 0.70 respectively for English version), while all five CHBMS-MS subscales showed similar psychometric properties to more recent findings (Yilmaz and Sayin 2014; Medina-Shepherd and Kleier 2010). A test-retest score <0.80 indicates that women did not reply in the same way at the second time point (Yilmaz and Sayin 2014), which could mean that women did not read the scale items in the same way at both time points. However, according to the test-retest results, women answered scale items similarly in both sessions, indicating that the scale has strong stability over time. The test-retest results in Study 1 were generally higher than those reported in the Medina-Shepherd and Kleier's study (Medina-Shepherd and Kleier 2010) and Champion's study (Champion 1999). This difference may be attributed to the small sample in this study.

My preliminary findings for Cronbach's alpha coefficients were 0.91 (susceptibility), 0.88 (barriers), 0.75 (benefits), 0.86 (cues to action) and 0.90 (self-efficacy). Similarly, Cronbach's alpha coefficient for Champion's subscales were also reported between 0.77 to 0.90 among

Chinese American women (Wu and Yu 2003), and were found to be equal to 0.88 (barriers) and 0.93 (benefits) in a Malaysian study (Parsa et al. 2008), 0.89 and 0.73 respectively among African-American women (Champion et al. 2008) but lower (0.63 for benefits) in Medina-Shepherd and Kleier's study (Medina-Shepherd and Kleier 2010). Among Iranian women with family history of BC, Cronbach's alpha coefficients were 0.72 (susceptibility), 0.75 (seriousness), 0.82 (benefits) and 0.76 (barriers), though a limitation in the Iranian study is that all participants had a family history of BC which can be considered to guide further prevention and increase women's susceptibility for this disease (Hashemian et al. 2013). A controversial HBM subscale is perceived barriers (ibid) because of the diverse individual and environmental barriers present in different communities (Park et al. 2011). However, none of the items of this subscale in the original version of the questionnaire were omitted because women considered all items to be equally important.

The original IPQ-R demonstrates higher internal consistency (Cronbach's alpha range from 0.75 to 0.89) than the original IPQ and good test-retest reliability ranging from 0.46 to 0.88 over three weeks (Moss-Morris et al. 2002). In this study, the IPQ-R scale similarly demonstrated a relatively high degree of internal consistency (Cronbach's alpha = 0.75–0.93), with overall Cronbach's alpha >0.70 (α = 0.86 {Maltese} and 0.85 {English}). My test–retest data of the IPQ-R dimensions is homogeneous with the original IPQ and IPQ-R versions (Moss-Morris et al. 2002; Weinman et al. 1996) and show that the IPQ-R has acceptable stability levels over two weeks. Test-retest reliability (Pearson's) correlations were computed between the IPQ-R completed at the two time points with correlations above 0.6 i.e. 0.63-0.82 (Maltese) and 0.61-0.91 (English). 'BC identity', 'causes' and 'emotional representations' appear to remain the most consistent over this time period for the Maltese language. This suggests that patients possibly attribute a relatively high or low number of symptoms to their illness and experience a wide range of emotional issues. As for the English version, treatment control and emotional representations remain most consistent. These findings provide evidence towards the validity and reliability of the IPQ-R as a suitable measure of illness perceptions in the BS context. IPQ-R dimensions prove to be useful measures on how illness 'makes sense' holistically to symptomatic or asymptomatic women and may play an important role in longer term adjustment and symptom response. The IPQ-R also allows researchers to investigate how emotional representations affect coping behaviours and illness outcomes (Moss-Morris et al. 2002). Moreover, cognitive beliefs that the illness has severe consequences, is cyclical in nature and out of one's personal control, seem to strongly affect women's emotional responses.

4.1.6 Implications

The Maltese and English versions of the CHBMS-MS and IPQ-R can be used by nurses and other health care professionals as measures to assess Maltese women's health beliefs and illness perceptions concerning BC and BS. Nurses have frequent patient contact in a variety of health care settings and are known to be valuable change agents and patient advocates (Arabi et al. 2014). An important breast health promotion opportunity for public health nurses as well as physicians is raising public awareness on BC by educating women about the importance of screening. Likewise, health professionals can structure patient education and counselling sessions guided by the conceptual theoretical framework proposed in this study to ensure comprehensiveness of approach and content. For instance, information on BC risks, BC susceptibility, signs and symptoms and its consequences, as operationalised by different HBM and CSM constructs, can increase patients' knowledge to improve screening use (Noar and Zimmerman 2005). Moreover, health providers can use the HBM and CSM to understand patients' needs, employing constructs of the models to guide patient interviewing. For instance, a BS invitation may be based on factors that influence BS behaviour such as existing perceptions of benefits and barriers and on psychological and social factors (Kalsta et al. 2013). Health care providers can therefore assess women's level of perceived risk and target their teaching about health-promoting behaviours to reduce risk perception by educating women about BC risk factors. If women are aware they may be at risk of developing BC, they may perceive themselves at risk and participate in screening. Counseling may be required to increase the likelihood that a woman attends for screening by increasing women's confidence. Particular focus on the BS appointment could provide an opportunity for targeted interventions to increase uptake, such as assisting women with scheduling an appointment, ensuring that guidelines and information is provided about the recommended intervals between mammograms and addressing the importance of regular screening. This will ultimately affect the quality of an individual's life and reduce the allocation of resources needed to treat those who develop BC.

Since individuals possess multifaceted cognitive representations of various diseases (Lykins et al. 2008), nurses can support patients across their care pathway to explore beliefs and perceptions by helping them to relate personal accounts about their families, culture and their illness perceptions, including causal attributions for the disease (Richer and Ezer 2000). Achieving this may be more attainable if health care providers are knowledgeable, competent and feel supported in providing education and counselling in the clinical setting. This presents a challenge for all health care disciplines considering that health implications span the entire health care continuum. Furthermore, the gap in competency among health professionals includes lack of recognition of screening relevancy which may impact the uptake of continuing education in this area.

To overcome these challenges, robust interventions are needed with reliable measures that can adequately assess the outcomes of these strategies. Validated instruments for health care professionals and patient assessment should be made available in clinical settings as a priority. With reliable measures to inform the required interventions and outcomes associated with their implementation, nurse-led and physician-led interventions make it possible to design cost-effective strategies focused upon reducing disparities across diverse populations and increasing quality within health care systems.

4.1.7 Limitations

Although our preliminary internal consistency and test-retest reliability correlation scores were relatively similar or higher to those reported in prior validation studies of the CHBMS and IPQ-R research, this study has its limitations. Firstly, the findings cannot be generalized as these are limited to a convenience sample. The aim was not to obtain a representative sample, but rather to obtain an indication of the instrument's reliability and validity among women with varied backgrounds and diverse perspectives. For greater applicability, it is recommended that this instrument be tested among a larger sample. Secondly, recruitment of these women may have led to a biased sample of women with no socio-economic inequalities. It is acknowledged that those who participated may have been more interested in and knowledgeable about screening as compared with those who do not attend for screening. Thirdly, for those who participated in this study, the formal consent to participate sets them apart from those who would refuse such an invitation. Moreover, although women were asked to express their true feelings, they may have responded in a way that is considered socially acceptable. Despite these limitations, the rigorous approach undertaken to translating and adapting the instrument provides confidence in the instrument's acceptability and readiness for use to collect data from the target population.

4.1.8 Conclusion

The novel part of this study is the translation and adaptation of two scales as one instrument. Preliminary evidence of the psychometric properties assessment of the MBSQ shows promise of being a valid and reliable instrument that can be used among Maltese women to assess their health beliefs and illness perceptions towards BC and screening practices, and provides insights for the planning of effective interventions. Hence, these translated instruments were used for studies 2 to 5 that are described throughout chapter 4. Nonetheless, these are preliminary findings; further psychometric testing of these scales is recommended to include diverse socioeconomic strata, educational levels and geographic location. Future studies should include factor analyses on the current scale items using a larger sample size. Further research to measure women's health beliefs and illness perceptions on BC and BS is also warranted.

Chapter 4

Study 2: Health Beliefs, Illness Perceptions and Determinants of Breast Screening Uptake in Malta: *A Cross-Sectional Survey*[2]

[2]A version of this chapter has been published in the *BMC Public Health Journal* (**Appendix 4.2.1**) (Marmarà et al. 2017b).

4.2 Introduction

Study 1 found preliminary evidence that the Maltese questionnaire (MBSQ) is a valid and reliable tool that can be utilised among Maltese women. It did not, however, explore women's health beliefs and illness perceptions towards BC and BS from a national perspective. Understanding women's beliefs and perceptions of BC and BS in Malta may help highlight the salient predictor for BS practices among Maltese women and provide potential opportunities for interventions to help women increase their attendance to screening. For the first time, this cross-sectional study utilized the HBM and CSM to explore factors associated with BS uptake in Malta and subsequently, to identify the most important predictors to first BS uptake.

4.2.1 Aims and Objectives

The aim of Study 2 was to gain an understanding of determinants associated with uptake to first invitation at the MBSP, thus meeting RQ 2a:

RQ 2a. Which significant factors (i.e. health beliefs, illness perceptions, knowledge, socio-demographic factors and health status) are associated with BS uptake to a first invitation at the MBSP?

In reaching this RQ, this analysis has targeted the following objectives:

1. To describe Maltese women's knowledge, health beliefs and illness perceptions about BC and screening;
2. To identify the main reasons related to non-attendance at the MBSP;
3. To determine if health beliefs, illness perceptions, knowledge, socio-demographic factors and health status are associated with uptake to a first MBSP invitation;
4. To determine significant predictors to a first BS invitation.

'Strengthening the Reporting of Observational Studies in Epidemiology' (STROBE) guidelines (von Elm et al. 2007) (**Appendix 4.2.2**), have been used to present the findings in this study. It was hypothesized that there would be significant associations between health beliefs and illness perceptions, knowledge, socio-demographic factors, health status, and BS uptake.

4.2.2 Methods

4.2.2.1 Study design

A cross-sectional survey of women's uptake of first MBSP invitation was undertaken by telephone through the use of validated tools (Study 1) to measure women's health beliefs, illness perceptions, knowledge of BC and BS, socio-demographic factors and health status.

4.2.2.2 Setting

The study was carried out in Malta between June 2015 and September 2015. Since there is only one public screening centre (no mobile units), located in Malta's capital city, Valletta, all data was generated from one computerized screening database and women were contacted from the centre.

4.2.2.3 Participants

The inclusion criteria were: women aged 50-60 at the time of their first screening invitation, residents in Malta or Gozo with a valid identity card number, able to communicate in English or Maltese, and with no severe co-morbidities. Women were excluded if they had been diagnosed with BC (n=200), if they were invited to the second screening cycle (n=12,210), if registered as deceased at the time of the sample selection (n=71) and if incorrect information existed at the MBSP (n=209) (**Figure 4.2**).

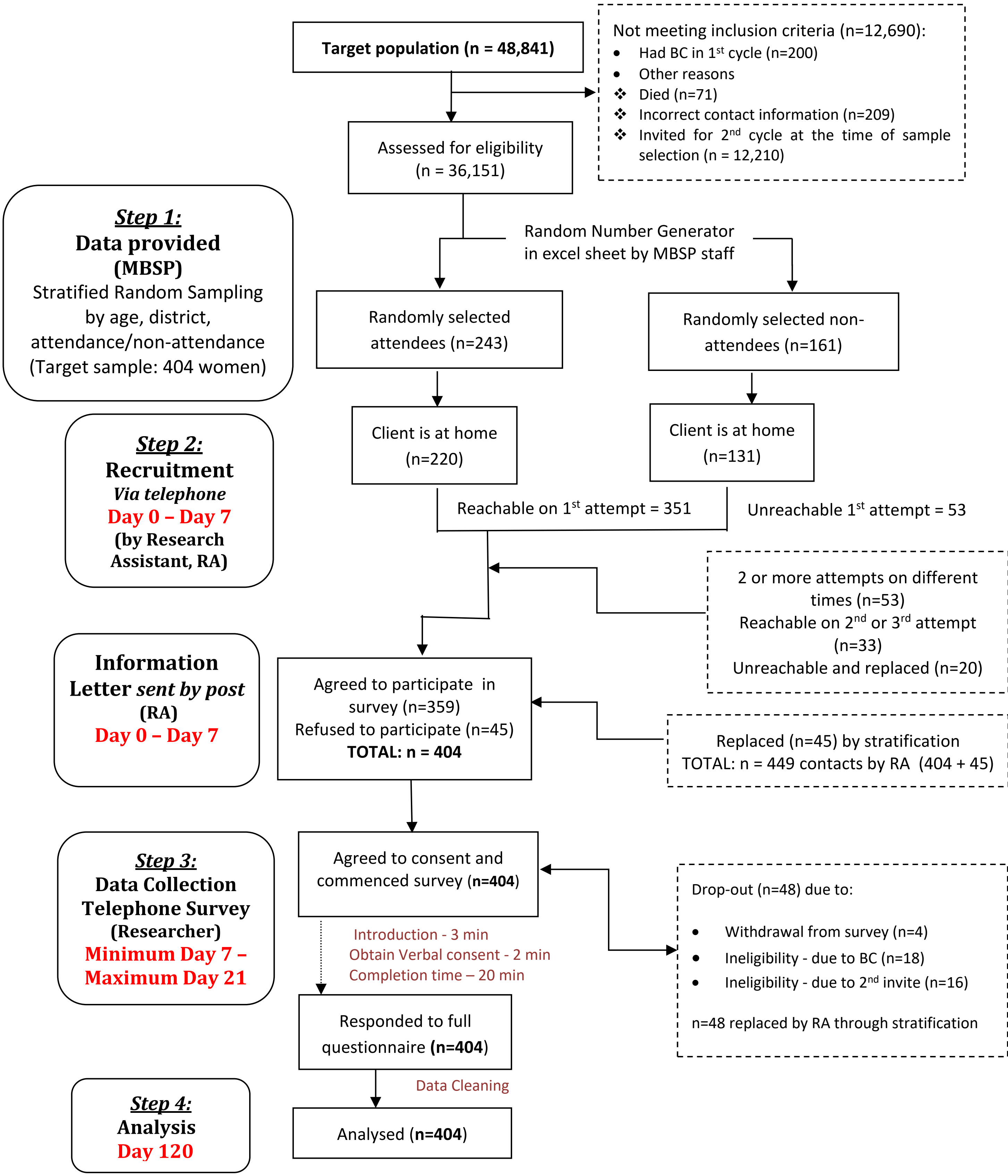

Figure 4.2 - Participant pathway and sampling flowchart (based on STROBE guidelines)

4.2.2.4 Sample size and sampling technique

According to the MBSP, the target population was estimated to be 48,841 women who were invited during the first screening cycle (Maltatoday 2013). Following the exclusion of subjects (numbers in parentheses) in the sampling flowchart (**Figure 4.2**), the eligible population was calculated to be equal to 36,151 women. A sample size of 404 women was determined using a 95% confidence level and a 5% confidence interval through the sample size equations. This level of confidence is the typical estimation of the level of precision used in similar surveys (Taherdoost 2017). In order to ensure that the sample was nationally representative of the screening population and to decrease the margin of error in the estimation, women were selected by a stratified random sampling technique, employed by strata i.e. district (geographical distribution), age and attendance/non-attendance to the first BS invitation (**Step 1**). In order to obtain the target sample size (n=404), the following number of attendees and non-attendees were randomly selected through a random number generator as follows: n = 243 attendees (women's reasons for attendance may provide a better insight to why people do not turn up for BS), and n = 161 non-attendees (this is representative of the actual population as 58.7% of those invited accepted their first invitation) (Marmarà et al. 2015). Three hundred and fifty one women from the target sample of 404 women were reached by the research assistant (RA) on her first telephone contact attempt (**Step 2**). Those who were unreachable were recontacted for two or more attempts on different times. If they remained unreachable, women were replaced by the RA, based on the random sampling technique adopted for this study via stratification. Three hundred and fifty nine women agreed to participate in the survey, while forty five women refused participation in this study. These 45 women were free to provide their own reason for non-participation in the study, following which content analysis of their open-ended comments on reasons for refusal was employed and later categorised and classified as being one of two reported reasons (i.e. lack of time due to work and family; fearful to speak about the topic under investigation). Women's comments were typical reasons for refusals in similar studies (Menold and Zuell 2010). Hence, all 45 women were replaced by RA, once again based on the random sampling technique adopted through stratification so that all replacements were carried out in a way so as not to lose any of the sample representativeness of the population. Due to women's refused participation, 449 women were eventually contacted by RA in order to reach the necessary quota for each strata (404/449 = 90% response rate). Hence, the required total sample of 404 women was collected and passed on to the researcher to commence data collection (**Step 3**). Upon contact by the researcher, 48 women from the target sample of 404 women dropped out since they either withdrew from the study or were found to be ineligible during the telephone survey. These 48 women were therefore replaced by RA by resorting to the original sample to be stratified with the same demographics of the non-respondent (i.e. according to age, district and attendance/non-attendance to the MBSP). **Step 4** included an analysis of the replies of the 404 women.

4.2.2.5 Data collection

The participant recruitment pathway is presented in **Figure 4.2**. Participants were recruited by telephone, by a trained research assistant who requested initial verbal consent. If the client agreed to participate, a brief explanation of the study was provided by telephone. Thereafter, a written information letter was posted to women on that same day. Hence, women received pre-notification letters to further inform the participant about the study's aims and objectives, thus allowing participants adequate time to read the information letter before further contact (**Appendix 4.1.6a, b**). Those who refused participation were deemed to have refused consent and were not contacted further. Scheduled appointments were set at women's most convenient date and time (in around 7 days from first call) so that participants would not to be caught 'off-guard' when contacted, and also so that the researcher could conduct a telephone survey which was the chosen, feasible method for this study. Telephone surveys have also been utilised successfully in the extant literature (Chambers et al. 2014; Hersch et al. 2014). In cases of non-response, three call-backs were performed on different occasions, following which the researcher moved on to contact other women.

Respondents were assured that all the collected information would be processed anonymously and confidentially. They were also informed that they could refuse to answer any question or decline participation at any point. For those participants who affirmed they were willing to respond, verbal informed consent was obtained by telephone through the use of standard procedures and guidelines (Sturges and Hanrahan 2004). Verbal consent is common practice when conducting survey interviews or interventions by telephone (Chambers et al. 2014; Hersch et al. 2014; Fair et al. 2012) and was chosen because it facilitates comprehension of study objectives and questionnaire items, and reduces the unnecessary burden entailed in a written consent form (Hersch et al. 2014). Participant recruitment by the research assistant was done manually, using paper format to record verbal consent by ticking Yes/No and to schedule appointments for the participants and the primary investigator (DM) (**Appendix 4.2.3a, b**). The telephone survey was carried out by a single researcher (DM) and data entry was carried out (DM) through the use of computer-assisted technology through an online tool (the SurveyMonkey program). Subsequently, the data were downloaded by the primary investigator (DM) from the same program. Minor formatting adjustments were made to the raw aggregate data in Microsoft Excel, and then the data were exported into SPSS®. This method of handling data significantly decreased human error in the data entry process. This procedure of data storage and handling was secure, ensuring confidentiality of information provided by participants.

4.2.2.6 Measures

The MBSQ was used in this cross-sectional study. Further details on the 121-item questionnaire can be found in **section 4.1.4.2.**

4.2.2.7 Ethical considerations

As discussed in Study 1, ethics approval was obtained from SREC (**Appendix 4.1.2**) and HEC (**Appendix 4.1.3**). Following approvals, data were obtained from the MBSP and was computer generated from the screening register.

4.2.2.8 Variable definitions

A first invitation was defined as the first (initial) time a woman is invited to the MBSP and either attends or does not attend for the screening mammogram. Modifying factors include socio-demographic and health status variables (some of which were confirmed from women's health records from the screening database), and structural variables such as knowledge of screening frequency and of the disease. These variables were collected from the survey administered retrospectively from the time of the first screening invitation.

4.2.2.9 Data analysis

Data entry and statistical analysis were performed using SPSS® version 21.0 under direct guidance of an expert statistician. Descriptive and inferential statistics, such as percentages, frequencies, means, standard deviations and confidence intervals, were used to present basic statistics in relation to socio-demographics, knowledge, health beliefs and illness perception variables. Tests for associations (Chi-square test: to determine significant associations between one categorical variable and another) were applied to investigate the associations of health beliefs, illness representations, knowledge, socio-demographic factors and health status with uptake to MBSP. Binary logistic regression modelling, using the "Backward-elimination" method, was performed to identify the significant predictors for BS uptake. The unstandardized coefficients, standard error, the Wald value, p-values, Odds Ratios (ORs) and 95% confidence intervals (95% CIs) were calculated for each logistic regression model. The level of accuracy was included in the final outcome of the model. Missing data was minimal and reported in **Table 4.2.1**. Statistical significance was established at $p < 0.05$ for all analyses.

4.2.2.10 Piloting the data collection method

A pilot study was conducted with a random sample of 15 women of different age groups to assess the practicalities of conducting the tool by telephone. In order to reduce bias, a random selection of participants was computer generated from the computerized MBSP database; hence, attendance for first round screening was ascertained from programme records. A similar approach to the larger study for 'selection' and 'recruitment' was undertaken as in the participant pathway (**Figure 4.2**). These women were contacted by a research assistant and those who agreed to participate were introduced to the researcher. A convenient time was arranged with each participant in order for the researcher to conduct the pilot survey by telephone. Verbal informed consent was sought from all 15 participants. The results from the pilot study showed that the tool was practical and feasible to conduct by telephone and that no methodological changes were required. Women participating in the pilot study were not included in the larger study. The time for scale completion had a median of 25 minutes (range, 15 – 45 minutes).

4.2.3 Results

4.2.3.1 Sample characteristics

The sample characteristics (n=404) are presented in **Table 4.2.1**. Women were aged between 50 to 60 years at the time of the programme's first screening round, with a mean age of 54.6 years ± 2.8 years (SD). The majority were married (86.9%, n=351), housewives (77%, n=311), had up to a secondary education level (75.7%, n=306) and more than half (60.3%, n=244) were from below average income families (lower than €16,113). Although the majority owned a family car (83.7%, n=338), only 43.8% (n=177) could drive. An illness, disability or condition was reported by 45.8% of women (n=185) and 2.5% (n=10) had cancer (other than BC).

Furthermore, 81.7% (n=330) had relatives or close friends with cancer (6.7% (mother with BC) and 21.3% (close friend with BC)). The majority (93.3%, n=377) reported having a named family physician (GP); however, 88.6% (n=358) of the total sample visited a GP only when they had a problem. Furthermore, nearly 70% of women in this study reported that they were not encouraged by their GP to attend to BS.

Table 4.2.1 - Sample Characteristics (n = 404)

Characteristics	Mean	SD	N	%
Age (year)				
50			20	5.0
51			45	11.1
52			42	10.4
53			48	11.9
54			56	13.9
55			44	10.9
56			29	7.2
57			44	10.9
58			27	6.7
59			37	9.2
60			12	3.0
	54.62	2.79		
Education level				
No schooling			1	0.3
Primary level			67	16.6
Secondary level			306	75.7
Tertiary level			30	7.4
Occupation				

Pensioner	5	1.2
Housewife	311	77.0
Employee	88	21.8
Status		
Single	16	4.0
Married	351	86.9
Separated/Divorced	13	3.2
Widowed	24	5.9
Family income		
Less than €10,737	102	25.3
€10,737 – €16,113	142	35.2
€16,114 – €23,563	20	5.0
€23,564 – €33,966	14	3.5
Greater than €33,966	1	0.3
Prefer not to say	125	30.9
Own a car		
Yes	338	83.7
No	66	16.3
Drive		
Yes	177	43.8
No	227	56.2
Any illness, disability or condition		
Yes	185	45.8
No	219	54.2
Family physician (GP)		
Yes	377	93.3
No	27	6.7
Frequency of GP visit		
Only when I have a problem	358	88.6
Once a month	6	1.5
More than once a year	16	4.0
Once a year	1	0.2
Missing	23	5.7
Lumpy breasts		
Yes	30	7.4
No	374	92.6
Relatives or close friends had cancer		
Yes	330	81.7
No	68	16.8
Prefer not to say	6	1.5

4.2.3.2 Knowledge of breast screening frequency and breast cancer

The majority of women were knowledgeable of the recommended screening frequency to varying degrees (**Table 4.2.2**): 46.3% (n=187) indicated yearly mammograms; 3.7% (n=15):

every 1.5 years; 43.3% (n=175): every 2-3 years; 6.2% (n=25) were unsure. BC identity scores were reported by above 80% of women for the majority of the sub-scale items (7 out of 8 items) (**Table 4.2.3**). However, there was wide variation for knowledge of BC causes and risk factors among Maltese women (**Table 4.2.3**). Hereditary predisposition to the disease was the most commonly reported risk factor, followed by smoking, altered immunity and pollution. Misconceptions concerning risk factors of BC were found (e.g. a germ or virus (38.6% ‘agree’, 30.7% ‘disagree’; accident or injury (47.5% ‘agree’; 39.1% ‘disagree’)).

Table 4.2.2 - Women’s Knowledge of breast screening frequency (n = 404)

	n	%
Knowledge about recommended BS frequency		
Every year	187	46.3
Every year and a half	15	3.7
Every 2-3 years	175	43.3
Every 4-5 years	2	0.5
Unsure	25	6.2

Table 4.2.3 - Women’s Knowledge on breast cancer identity and causes (n = 404)

Breast cancer identity scores, n (%)			
	Disagree/Strongly Disagree	**Undecided**	**Agree/Strongly Agree**
The presence of a lump or thickening in the breast	5 (1.2)	26 (6.4)	373 (92.3)
Nipple discharge	3 (0.7)	54 (13.4)	347 (85.9)
Sudden nipple retraction	2 (0.5)	64 (15.8)	338 (83.7)
Change in shape or appearance of the nipple	2 (0.5)	29 (7.2)	373 (92.3)
Breast swelling, dimpling, redness or soreness of the skin	3 (0.7)	66 (16.3)	335 (82.9)
Skin changes of the breast	3 (0.7)	67 (16.6)	334 (82.7)
A sudden change in breast size	5 (1.2)	52 (12.9)	347 (85.9)
Aching breasts	40 (9.9)	114 (28.2)	250 (61.9)
Causes of breast cancer scores, n (%)			
	Disagree/Strongly Disagree	**Undecided**	**Agree/Strongly Agree**
Stress or worry	152 (37.6)	95 (23.5)	157 (38.9)
Your mental attitude	262 (64.9)	94 (23.3)	48 (11.8)
Family problems or worries	171 (42.3)	82 (20.3)	151 (37.4)

Overwork	281 (69.6)	59 (14.6)	64 (15.8)
Your emotional state	257 (63.6)	76 (18.8)	71 (17.6)
Your personality	262 (64.9)	94 (23.3)	48 (11.8)
Hereditary - it runs in the family	5 (1.2)	10 (2.5)	389 (96.3)
Diet or eating habits	121 (30.0)	61 (15.1)	222 (55.0)
Poor medical care in the past	98 (24.3)	90 (22.3)	216 (53.4)
Your own behaviour	174 (43.1)	172 (42.6)	58 (14.3)
Ageing	142 (35.1)	63 (15.6)	199 (49.3)
Smoking	47 (11.6)	39 (9.7)	318 (78.7)
Alcohol	80 (19.8)	60 (14.9)	264 (65.3)
A germ or virus	124 (30.7)	124 (30.7)	156 (38.6)
Pollution in the environment	65 (16.1)	49 (12.1)	290 (71.8)
Altered immunity	43 (10.6)	69 (17.1)	292 (72.3)
Chance or bad luck	205 (50.7)	37 (9.2)	162 (40.1)
Accident or injury	158 (39.1)	54 (13.4)	192 (47.5)

4.2.3.3 Health beliefs and Illness perceptions

Women's health beliefs and illness perceptions are presented in **Table 4.2.4**. Subscale scores were retrieved as the mean of items (i.e. those items with which respondents are most in agreement, though a disagreement answer for barrier items represents a more positive result). In general, higher percentage scores indicate higher agreement among participants for perceived mammography benefits (79.7%), self-efficacy (77.7%) and cues to action (76.6%), while lower scores indicate lower agreement among women for perceived barriers (45.1%). There was also higher agreement with emotional representations (82.0%), personal control items (78.7%), BC identity (76.5%) and cyclical cancer timeline (72.0%), while lower agreement for BC causes (62.4%) and cancer timeline (acute/chronic) (61.0%).

Table 4.2.4 - Instrument scoring: the percentage and mean scores for Health Beliefs and Illness Perceptions

		Health Beliefs		
***Subscale**	**Minimum**	**Maximum**	**Mean Score**	**Percentage Score**
Perceived Susceptibility	3	15	9.6	64.0%
Perceived Benefits	6	30	23.9	79.7%
Perceived Barriers	13	65	29.3	45.1%
Cues to action	7	35	26.8	76.6%
Self-Efficacy	7	35	27.2	77.7%

Illness Perceptions				
*Subscale	Minimum	Maximum	Mean Score	Percentage Score
BC Identity	8	40	30.6	76.5%
BC Causes	18	90	56.2	62.4%
Cancer Timeline: Acute/Chronic	2	10	6.1	61.0%
Cancer Timeline: Cyclical	1	5	3.6	72.0%
Consequences	8	40	28.3	70.8%
Personal Control	3	15	11.8	78.7%
Treatment Control	3	15	9.9	66.0%
Illness Coherence	2	10	7	70.0%
Emotional Representations	5	15	12.3	82.0%

*All subscale items were grouped according to their respective subscale. Each subscale item had 5 response options ranging from 1 = 'strongly disagree' to 5 = 'strongly agree'.

When comparing health beliefs and illness perceptions among attendees and non-attendees (**Tables 4.2.5 - 4.2.6**), the majority agree that the possibility of developing BC in their lifetime is high (M=4.0, SD=0.3) and believe in early detection through screening (M=4.2, SD=0.5). Each item in the 'perceived barrier' subscale was scored by respondents with the highest level of uncertainty, such that 6 out of 13 items had a mean score of 2.5 - 3.5 (**Table 4.2.5**).

This study found that a large number of participants had higher emotional representations when they think about BC, such that they get anxious (M=3.6, SD=1.1), feel afraid (M=4.3, SD=0.7) and worried (M=4.4, SD=0.7), they believe that BC has major consequences on a patient's life (M=4.3, SD=0.6), and more specifically, their whole life would change (M=4.2, SD=0.6). The course of the BC pathway is believed to be dependent on their actions (M=3.9, SD=0.4).

Table 4.2.5 - Comparison of Health Beliefs between attendees and non-attendees

When you received your invite to the MBSP, did you attend?	Yes		No		Total		Chi-Square test[a]	
Health Beliefs	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**χ2**	**p-value**
There is no possibility of getting BC *(r)*	1.9	0.7	2.0	0.7	2.0	0.7	4.3	0.367
Your chances of getting BC are high	3.7	0.7	3.6	0.8	3.6	0.8	7.1	0.130
There may be the possibility of developing BC in your lifetime	4.0	0.3	4.0	0.4	4.0	0.3	1.7	0.645
When you get a mammogram, you feel good about yourself	4.0	0.4	3.9	0.5	4.0	0.5	16.7	0.001*

When you get a mammogram, you do not worry as much about BC	3.8	0.8	3.6	0.8	3.7	0.8	2.8	0.423
Having a mammogram will help you find lumps early in your breasts	4.2	0.4	4.1	0.5	4.2	0.5	7.8	0.051
If you find a lump through a mammogram, the treatment for BC may not be as bad	4.0	0.4	4.0	0.3	4.0	0.4	3.3	0.349
Having a mammogram will decrease your chances of dying from BC	4.0	0.4	4.0	0.3	4.0	0.3	6.2	0.103
Having a mammogram will help you find a lump before it can be felt by yourself or a health professional	4.0	0.5	4.0	0.4	4.0	0.5	0.6	0.899
Having a routine mammogram would make you anxious about BC	2.7	1.0	2.9	1.0	2.8	1.0	7.1	0.070
Having a routine mammogram would make you worry	2.7	1.0	2.9	1.0	2.8	1.0	3.9	0.416
You fear having a mammogram because you might find out that something is wrong	2.9	1.0	3.2	1.0	3.0	1.1	12.0	0.017*
You fear having a mammogram because you do not know the procedure or what to expect	2.2	0.6	2.5	0.9	2.3	0.8	31.9	0.000*
You fear having a mammogram because you know someone (family or friend) with BC	2.6	1.1	2.9	1.1	2.7	1.1	7.1	0.132
It is embarrassing for you to have a mammogram	2.4	0.8	2.7	1.0	2.5	0.9	13.6	0.009*
Undergoing mammography will be painful or uncomfortable	3.4	1.0	3.3	0.9	3.3	1.0	39.0	0.000*
Having a mammogram is time consuming	1.2	0.4	1.3	0.6	1.3	0.5	7.2	0.067
You are discontent with BS personnel as they have been rude to you	1.2	0.5	n/a	n/a	1.2	0.5	n/a	n/a
You have fear or distrust in the medical team	1.7	0.7	2.2	0.9	1.9	0.8	38.3	0.000*
Having a mammogram would expose you to unnecessary radiation	2.2	0.6	2.5	0.8	2.3	0.7	16.6	0.001*
You have too many other problems in your life than to get a mammogram done	1.6	0.6	2.0	0.8	1.7	0.7	38.8	0.000*
You are not old enough to have a mammogram periodically	1.7	0.5	1.9	0.4	1.8	0.5	22.6	0.000*
If your GP advises you to attend for a mammogram, you will attend	4.3	0.6	4.0	0.7	4.2	0.7	13.6	0.004*
If your relatives or friends advise you to attend for a mammogram, you will attend	3.4	1.0	3.4	1.0	3.4	1.0	2.0	0.576
If someone close to you has been diagnosed with BC, you will attend for a mammogram	4.2	1.0	3.9	1.0	4.1	1.0	13.8	0.008*

Hearing about BC and BS in the media or news makes you think about getting a mammogram	3.8	0.7	3.5	0.9	3.6	0.8	15.7	0.000*
Reminder letters would help you to get a mammogram	4.0	0.4	3.8	0.7	3.9	0.5	15.4	0.001*
Reminder phone calls or text messages would help you to get a mammogram	4.0	0.4	3.8	0.7	3.9	0.5	15.4	0.001*
Routine educational talks regarding BC awareness would help you to get a mammogram	3.8	0.7	3.5	0.9	3.6	0.8	16.9	0.001*
You feel confident that if you had a mammogram done, any abnormalities in your breasts will be detected	3.7	0.6	3.6	0.7	3.7	0.6	2.2	0.697
You can arrange other things in your life to get a mammogram	4.2	0.6	4.0	0.7	4.1	0.7	13.1	0.011*
In case you need a mammogram, you will find a place to get it done	4.2	0.5	4.1	0.5	4.2	0.5	10.9	0.028*
You can make an appointment for a mammogram	4.2	0.5	4.1	0.6	4.2	0.5	12.1	0.016*
You can arrange transportation to get a mammogram	4.2	0.5	4.1	0.6	4.2	0.6	13.1	0.011*
You can talk to people at the BS centre about your concerns	4.1	0.7	n/a	n/a	4.1	0.7	n/a	n/a
You can find a way to pay for a mammogram if you need to	4.2	0.5	4.1	0.5	4.2	0.5	10.3	0.036*

*Significant at α=0.05; *(r) = reverse scored*

[a]Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree.

Table 4.2.6 - Comparison of Illness Perceptions between attendees and non-attendees

When you received your invite to the MBSP, did you attend?	Yes		No		Total		Chi-Square test[a]	
Illness Perception	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**χ2**	**p-value**
The presence of a lump of thickening in the breast	3.9	0.4	3.9	0.3	3.9	0.3	5.5	0.141
Nipple discharge	3.9	0.4	3.8	0.4	3.9	0.4	3.8	0.286
Sudden nipple retraction	3.9	0.4	3.8	0.4	3.8	0.4	5.8	0.121
Change in shape or appearance of the nipple	3.9	0.3	3.9	0.3	3.9	0.3	1.7	0.630
Breast swelling, dimpling, redness or soreness of the skin	3.8	0.4	3.8	0.4	3.8	0.4	2.6	0.463
Skin changes of the breast	3.8	0.4	3.8	0.4	3.8	0.4	2.1	0.555
A sudden change in breast size	3.8	0.4	3.9	0.4	3.9	0.4	0.4	0.950
Aching breasts	3.5	0.7	3.5	0.7	3.5	0.7	2.9	0.578
Stress or worry	3.0	0.9	3.0	0.8	3.0	0.9	3.9	0.140
Your mental attitude (e.g. thinking about life negatively)	2.5	0.7	2.5	0.7	2.5	0.7	6.0	0.111
Family problems or worries	3.0	0.9	2.9	0.9	3.0	0.9	3.5	0.178
Overwork	2.5	0.8	2.4	0.7	2.5	0.8	4.1	0.249

Your emotional state (e.g. feeling down, lonely, anxious, empty)	2.5	0.8	2.6	0.8	2.5	0.8	19.0	0.000*
Your personality	2.4	0.7	2.5	0.7	2.5	0.7	6.6	0.087
Hereditary - it runs in the family	4.6	0.6	4.4	0.6	4.5	0.6	13.4	0.004*
Diet or eating habits	3.3	0.9	3.2	0.9	3.3	0.9	5.6	0.131
Poor medical care in the past	3.3	0.8	3.3	0.8	3.3	0.8	2.4	0.489
Your own behaviour	2.7	0.7	2.8	0.7	2.7	0.7	10.0	0.018*
Ageing	3.1	0.9	3.1	0.9	3.1	0.9	4.9	0.087
Smoking	3.7	0.7	3.6	0.7	3.7	0.7	3.0	0.399
Alcohol	3.5	0.8	3.4	0.8	3.5	0.8	0.1	0.948
A germ or virus	3.0	0.8	3.1	0.8	3.1	0.8	3.7	0.160
Pollution in the environment	3.7	0.8	3.5	0.8	3.6	0.8	6.1	0.108
Altered immunity	3.6	0.7	3.6	0.7	3.6	0.7	1.5	0.683
Chance or bad luck	3.0	1.0	2.8	0.9	2.9	1.0	5.8	0.214
Accident or injury	3.1	0.9	3.1	0.9	3.1	0.9	1.7	0.782
BC will last a short time	2.8	0.7	2.9	0.7	2.8	0.7	4.2	0.241
BC is likely to be permanent rather than temporary	3.3	0.8	3.2	0.8	3.3	0.8	1.5	0.481
A patient with BC goes through cycles in which her illness gets better and worse	3.7	0.7	3.4	0.7	3.6	0.7	11.1	0.026*
BC has major consequences on a patient's life	4.3	0.6	4.2	0.5	4.3	0.6	14.2	0.003*
BC will not have much effect on your life	1.5	0.7	1.6	0.7	1.5	0.7	11.8	0.019*
BC would strongly affect the way others see you	3.3	1.0	3.3	0.9	3.3	0.9	14.9	0.005*
BC has serious economic and financial consequences	3.9	0.6	3.7	0.7	3.8	0.6	13.3	0.004*
BC would strongly affect the way you see yourself as a person	4.1	0.5	4.0	0.6	4.1	0.6	0.7	0.875
BC would threaten a relationship with your husband or partner	3.1	0.9	3.0	0.9	3.1	0.9	2.2	0.699
If you had BC, your whole life would change	4.3	0.7	4.1	0.6	4.2	0.6	18.0	0.000*
If you developed BC, the chances of living a long life would decrease	4.0	0.5	4.0	0.3	4.0	0.4	9.4	0.024*
There is a lot which you can do to control the symptoms if BC occurs	3.9	0.4	3.9	0.4	3.9	0.4	2.6	0.629
The course of BC will depend on your actions	4.0	0.4	3.9	0.3	3.9	0.4	5.9	0.118
Your actions will have an effect on the outcome of BC	4.0	0.3	4.0	0.2	4.0	0.3	5.9	0.118
There is no treatment that will help to improve BC	2.0	0.6	2.0	0.5	2.0	0.5	5.8	0.211
The treatment provided will be effective in controlling or curing BC	4.0	0.3	3.9	0.3	4.0	0.3	1.8	0.615
The negative effects of BC can be prevented or avoided by the treatment given	4.0	0.3	3.9	0.3	3.9	0.3	5.5	0.241
You have a clear picture and understanding of BC	3.8	0.6	3.8	0.6	3.8	0.6	0.7	0.873
BC is a mystery to you	3.2	1.0	3.2	1.0	3.2	1.0	3.7	0.455

You get anxious when you think about BC	3.6	1.1	3.7	1.1	3.6	1.1	2.6	0.464
BC makes you feel afraid	4.3	0.7	4.3	0.6	4.3	0.7	1.7	0.645
You get worried when you think about BC	4.4	0.7	4.4	0.6	4.4	0.7	1.4	0.502

*Significant at α=0.05

[a]Chi-square test was applied for all illness perceptions; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree.

4.2.3.4 Reasons for non-attendance to first screening invitation

When non-attendees were asked to further identify reasons for non-attendance to first MBSP invitation (i.e. respondents were allowed to mention more than one reason), the main reported reason was fear (41.0%, n=66), of which sub-categories included 'fear of result' (20.5%; n=33), 'fear of pain' (10.6%; n=17), 'fear of an unknown procedure' (depicting knowledge gap) (6.2%; n=10), 'fear of radiation' (3.7%, n=6) and 'embarrassment' (8.1%; n=13). Some women had also opted for the service elsewhere (38.5%, n=62) or had never received an invitation (13.7%; n=22). Practical reasons were mentioned by 8.7% (n=14) of non-attendees, which included 'busy at work' or 'home', 'transport issues', 'on vacation' and 'being ill'.

4.2.3.5 Associations between health beliefs and uptake to first screening invitation

The variables related to HBM constructs were compared with attendance and non-attendance to the first MBSP invitation (**Table 4.2.5**). In general, the majority of the HBM constructs showed statistical significance as follows:

Perceived Benefits

Women who feel good about themselves when getting a mammogram ($\chi2 = 16.7$, $p = 0.001$) were more likely to attend their first screening invitation. On the other hand, non-attendees believe less than attendees that BS will help to detect a lump early before it can be felt ($\chi2 = 7.8$, $p = 0.051$).

Perceived Barriers

Although there was no significant association between anxiety and initial screening uptake, fear was found to be statistically significant across all subscale items ($p<0.05$). Non-attendees expressed fear of a cancer diagnosis ($\chi2 = 12.0$, $p = 0.017$), fear of the unknown procedure ($\chi2$

= 31.9, p = 0.000), fear of radiation ($\chi2$ = 16.6, p = 0.001), consider mammography to be embarrassing ($\chi2$ = 13.6, p = 0.009), other problems in life are considered greater than getting a mammogram ($\chi2$ = 38.8, p = 0.000), and women were more undecided on whether mammography is painful ($\chi2$ = 39.0, p = 0.000). On the other hand, attendees are more in disagreement with the statement: 'they are not old enough to have a mammogram periodically' ($\chi2$ = 22.6, p = 0.000) and have less fear or distrust in the medical team ($\chi2$ = 38.3, p = 0.000).

Cues to action

Women attend more if advised by their GP ($\chi2$ = 13.6, p = 0.004) and if someone close to them had BC ($\chi2$ = 13.8, p = 0.008), but do not attend more if advised by their relatives or friends ($\chi2$ = 2.0, p = 0.576). Attendees are more in agreement that hearing about BC and BS in the media or news makes them think about getting a mammogram ($\chi2$ = 15.7, p = 0.000), and similarly reminder letters ($\chi2$ = 15.4), phone calls or text messages ($\chi2$ = 15.4), and educational talks ($\chi2$ = 16.9) help them to get a mammogram done (p = 0.001 respectively).

Self-Efficacy

Attendees also tend to agree more that they can arrange other things in life to get a mammogram ($\chi2$ = 13.1, p = 0.011), such as finding a place to get it done ($\chi2$ = 10.9, p = 0.028), arranging an appointment ($\chi2$ = 12.1, p = 0.016) and transportation ($\chi2$ = 13.1, p = 0.011), and also paying for it if they need to ($\chi2$ = 10.3, p = 0.036).

4.2.3.6 Associations between illness perceptions and uptake to first screening invitation

Illness perception constructs were compared with attendance and non-attendance to the first MBSP invitation (**Table 4.2.6**). In general, Chi-square tests showed no statistical significance for BC identity, acute/chronic cancer timeline, personal and treatment control, illness coherence and emotional representation items with first screening uptake.

Causes of Breast Cancer

In general, no significant association was found for most causal variables. However, attendees were more in agreement that BC could be hereditary ($\chi2$ = 13.4, p = 0.004) and considered one's own behaviour to cause BC ($\chi2 = 10.0$, $p = 0.018$), while non-attendees were more undecided whether one's emotional state or personality cause BC ($\chi2 = 19.0$, $p = 0.000$).

Cancer Timeline (Cyclical)

Attendees agree more than non-attendees that a BC patient gets better and worse along the treatment pathway ($\chi2 = 11.1$, $p = 0.026$).

Consequences

Attendees consider more that BC has major consequences on a patient's life ($\chi2 = 14.2$, $p = 0.003$), has serious economic and financial consequences ($\chi2 = 13.3$, $p = 0.004$) and is life-changing ($\chi2 = 18.0$, $p = 0.000$). On the other hand, non-attendees are more undecided whether BC would strongly affect the way others see them ($\chi2 = 14.9$, $p = 0.005$) and consider the chances of living a long life to decrease ($\chi2 = 9.4$, $p = 0.024$).

4.2.3.7 Associations between sociodemographic and health status, knowledge of breast screening frequency and uptake to first screening invitation

There were no significant associations for demographic factors or health status variables with first screening uptake, except for family income ($\chi2 = 9.7$, $p = 0.047$). Non-attendees were the most unsure of the recommended screening frequency ($\chi2 = 13.9$, $p = 0.003$).

4.2.3.8 Predictors of uptake to first screening invitation

Different groups of variables and constructs were incorporated into seven logistic regression models and 'backward-elimination' method was applied to every model to identify significant BS predictors (**Table 4.2.7**).

- **Model 1 (Demographics) and Model 2 (Health Status)**

All items related to demographic variables were incorporated in a logistic regression model (Model 1) and health status items were incorporated into Model 2. Both demographics and health status variables were found to be non-important BS predictors, such that for both models, non-attendance was not predicted and none of the variables were significantly different.

- **Model 3 (Health Belief items)**

All HBM items were incorporated in a logistic regression model (Model 3). Five variables were found to be good BS predictors: 'distrust in medical team', 'fear of unknown procedure', 'other life problems', 'relatives and friends' advice' and 'reminder letters' (**Table 7**). For this model, attendance was predicted with an accuracy of 88.5% and non-attendance with 38.8%.

- **Model 4 (Illness Perception items)**

All IPQ-R variables were incorporated into one logistic regression model (Model 4). Seven variables were found to be good BS predictors: 'hereditary', 'pollution', 'a patient with BC goes through cycles in which her illness gets better and worse', 'BC has major consequences on a patient's life', 'if you had BC, your whole life would change', 'if you developed BC, the chances of living a long life would decrease' and 'BC makes you feel afraid' (**Table 4.2.7**). The accuracy for this model was found to be 83.5% for attendance and 37.3% for non-attendance.

- **Model 5 (Significant predictors from Models 3 and 4)**

The above significant predictors from both models 3 and 4 were incorporated into a new single model (Model 5) and backward-elimination was applied on these 12 variables (five Health Beliefs and seven Illness Perception variables). The final model retained nine significant predictors, without excluding any of the Health Belief variables, hence showing that Health Beliefs are more significant predictors than Illness Perceptions. When combining both scores, the model accuracy improved to 53.8% for non-attendance and 84.8% for attendance.

- **Model 6 (All individual Health Belief and Illness Perception items)**

When all items related to Health Beliefs and Illness Perceptions were incorporated into one model (Model 6), 21 variables were found to be significantly different. The model accuracy improved again to 85.2% for attendees and 65% for non-attendees.

- **Model 7 (All 14 constructs)**

When the 14 constructs (not individual items) related to Health Beliefs and Illness Perceptions were used to construct a logistic regression model (Model 7), 'perceived barriers', 'cancer timeline (cyclical)' and 'illness coherence' were found to be significant predictors, of which the 'perceived barriers' construct was the strongest predictor. However, the accuracy for predicting the non-attendees was found to be 42.2%, which is inferior when compared to Model 5. Moreover, when removing the 'perceived barriers' variable from the latter model, the accuracy to predict non-attendance decreased sharply from 42.2% to 14.9%.

Our findings reveal that 'perceived barriers' is the most important construct to describe the variance between attendees and non-attendees. This result is further echoed in Model 5, where three predictors (from all the other predictors) are all related to perceived barriers. The above logistic regression analyses show that, although Health Beliefs are the most important BS predictors, the inclusion of Illness Perception items into one logistic regression model is important to improve model accuracy (Model 5 vs Model 3).

Table 4.2.7 - Logistic Regression Models on breast screening uptake against different variables and different constructs

	B	SE	Wald	*P*-value	OR	95% CI	Model Accuracy YES	Model Accuracy NO
Model 1: Demographics							100%	0%
Drive	-0.361	0.207	3.047	0.081	0.697	0.465, 1.045		
Constant	0.979	0.342	8.172	0.004	2.661			
Model 2: Health Status							100%	0%
Breast condition	0.174	0.265	0.430	0.512	1.190	0.708, 1.998		
Constant	0.081	0.492	0.027	0.869	1.085			
Model 3: Health Beliefs							88.5%	38.8%
Distrust in medical team	-0.573	0.153	14.051	0.000	0.564	0.418, 0.761		
Fear of unknown procedure	-0.409	0.153	7.120	0.008	0.664	0.492, 0.897		
Other life problems	-0.693	0.195	12.630	0.000	0.500	0.341, 0.733		
Relatives or friends' advice	-0.363	0.130	7.745	0.005	0.696	0.539, 0.898		
Reminder letters	0.660	0.238	7.678	0.006	1.934	1.213, 3.083		
Constant	2.336	1.091	4.585	0.032	10.335			
Model 4: Illness Perceptions							83.5%	37.3%
Hereditary	0.456	0.185	6.072	0.014	1.578	1.098, 2.268		
Pollution	0.290	0.134	4.682	0.030	1.336	1.028, 1.738		
Illness gets better and worse	0.312	0.153	4.154	0.042	1.366	1.012, 1.844		
Major consequences in life	0.420	0.195	4.640	0.031	1.522	1.039, 2.231		
Whole life would change	0.509	0.201	6.442	0.011	1.664	1.123, 2.466		
Living long decreases	-0.685	0.298	5.290	0.021	0.504	0.281, 0.904		
Fear of BC	-0.363	0.176	4.264	0.039	0.695	0.492, 0.983		
Constant	-3.375	1.494	5.106	0.024	0.034			

Model 5: Health Beliefs and Illness Perceptions							84.8%	53.8%
Distrust in medical team	-0.676	0.162	17.468	0.000	0.509	0.371, 0.699		
Fear of unknown procedure	-0.612	0.166	13.629	0.000	0.542	0.392, 0.751		
Other life problems	-0.669	0.206	10.544	0.001	0.512	0.342, 0.767		
Relatives or friends' advice	-0.476	0.140	11.610	0.001	0.621	0.473, 0.817		
Reminder letters	0.687	0.251	7.470	0.006	1.987	1.214, 3.251		
Pollution	0.479	0.151	10.060	0.002	1.615	1.201, 2.172		
Illness gets better and worse	0.396	0.167	5.656	0.017	1.486	1.072, 2.061		
Whole life would change	0.855	0.221	14.924	0.000	2.351	1.524, 3.626		
Living long decreases	-0.890	0.336	7.016	0.008	0.411	0.212, 0.793		
Constant	0.113	1.742	0.004	0.948	1.120			
Model 6: Health Beliefs and Illness Perceptions							85.2%	65.0%
Fear of unknown procedure	-0.742	0.194	14.633	0.000	0.476	0.325, 0.696		
Embarrassing	-0.320	0.149	4.600	0.032	0.726	0.542, 0.973		
Distrust in medical team	-0.808	0.176	21.149	0.000	0.446	0.316, 0.629		
Other life problems	-0.735	0.234	9.843	0.002	0.479	0.303, 0.759		
Relatives or friends' advice	-0.529	0.153	11.965	0.001	0.589	0.437, 0.795		
Reminder letters	0.795	0.290	7.536	0.006	2.215	1.255, 3.907		
Arrange appointment	1.133	0.506	5.020	0.025	3.106	1.153, 8.372		
Pay for mammography	-1.669	0.580	8.286	0.004	0.188	0.06, 0.587		
Stress or worry	-0.940	0.419	5.044	0.025	0.39	0.172, 0.887		
Family problems	0.839	0.405	4.292	0.038	2.314	1.046, 5.118		
Overwork	0.539	0.216	6.262	0.012	1.715	1.124, 2.616		
Personality	-0.548	0.240	5.235	0.022	0.578	0.361, 0.924		
Hereditary	0.533	0.231	5.342	0.021	1.704	1.084, 2.677		
Pollution	0.500	0.170	8.698	0.003	1.649	1.183, 2.299		
Change or bad luck	0.432	0.140	9.568	0.002	1.54	1.171, 2.024		
Illness gets better and worse	0.398	0.185	4.629	0.031	1.489	1.036, 2.141		
Economic consequences	0.647	0.223	8.438	0.004	1.91	1.234, 2.955		
Whole life would change	0.755	0.245	9.493	0.002	2.128	1.316, 3.441		
Living long decreases	-1.177	0.373	9.956	0.002	0.308	0.148, 0.64		

Depends on your actions	0.856	0.409	4.381	0.036	2.354	1.056, 5.246		
Your actions effects outcome	-1.094	0.552	3.933	0.047	0.335	0.114, 0.987		
Constant	0.384	3.083	0.016	0.901	1.468			
Model 7: The 14 constructs							84.4%	42.2%
Perceived barriers	-0.121	0.022	31.731	0.000	0.886	0.849, 0.924		
Cancer timeline cyclical	0.432	0.154	7.893	0.005	1.54	1.139, 2.081		
Illness coherence	0.249	0.100	6.179	0.013	1.283	1.054, 1.561		
Constant	0.623	0.895	0.484	0.487	1.864			

B unstandardized coefficients; *SE* standard error; *OR* odds ratio; *CI* confidence interval

4.2.4 Discussion

For the first time, this study aimed to explore factors related to Maltese women's BS behaviours, their knowledge, health beliefs and illness perceptions related to BC and BS, providing answers as to why more than 40% of eligible women did not attend their first MBSP invitation.

4.2.4.1 Knowledge

Study findings confirm the wide variation in knowledge level of Maltese women about BC causes and its related risk factors, though good awareness of BC signs and symptoms were reported, such as nipple discharge and sudden nipple retraction. Women's limited knowledge about BC and BS practices has been identified in a consistent body of literature (Liu et al. 2014; Charkazi et al. 2013; Guvenc et al. 2012; Dandash and Al-Mohaimeed 2007). For instance, Grunfeld et al. (2007) showed that only 38% of people were aware that nipple retraction was a sign of BC, and awareness of risk factors was even lower. Notably, local misconceptions (e.g., one's own behaviour, personality, emotional state, germ or virus, accident or injury could cause BC) also corroborate findings in older studies (e.g., hitting or bumping the breast), which is consistent with women's beliefs in other societies with different cultures such as the Philippines, Korea, Saudi Arabia and Australia (Dandash and Al-Mohaimeed 2007; Han et al. 2007; Grunfeld et al. 2002).

Since relevant knowledge has been emphasized as a screening compliance predictor (Ritvo et al. 2012; Lagerlund 2002) or a screening barrier (Guilford 2011), it was hypothesized that there would be significant association between knowledge and BS uptake in Malta. The findings support this hypothesis since Maltese women who have a lack of awareness regarding screening recommendations, guidelines and BC risk factors are more likely not to attend and this may prove difficult for women to perceive their risk (Liu et al. 2014). Communicating risk information to the general public makes knowledge an essential element of health promotion, disease prevention and screening interventions (Vahabi 2005). Despite the vast array of worldwide initiatives, an overlap exists between knowledge, health beliefs and illness perceptions; the knowledge construct operationalized in BS studies does not often include identifications of specific beliefs (Ritvo et al. 2012). Hence, in order for a woman to attend for her BS appointment, she must perceive the actual BC threat, believe that cancer can be avoided by BS, and that she is capable of accessing the unit, which may include remembering her appointment, driving to or be driven to the unit, and not be afraid of the test (Gozum et al. 2010).

4.2.4.2 Reasons to non-attendance

Fears, negative expectation of the screening experience, and embarrassment were among the main BS barriers in this study, similarly reported as barriers to attendance and re-attendance worldwide (Whelehan et al. 2013; Paul 2012; Esteva et al. 2008). Minor practical barriers to non-attendance reported in this study (such as lack of time, transportation issues) are also reiterated in previous studies (Carney et al. 2013; Trigoni et al. 2008; Aro et al. 2001), justifying local transportation accessibility improvements and reduction of logistical barriers (Charkazi et al. 2013).

4.2.4.3 Health beliefs and illness perceptions

Significant associations were mainly found for health beliefs about BS and BC i.e. the perceptions of the behaviour (barriers, self-efficacy, cues to action), while weaker associations were found for the perceptions of the illness i.e. significant associations for certain illness perception items (causes, cyclical cancer timeline, consequences) with uptake. BS non-attendance was related to more perceived barriers, less perceived benefits, lower self-efficacy and cues to action, and to the representations of the causes, consequences and timeline of BC. In contrast to HBM, perceived susceptibility was not significantly associated with first screening attendance in this study; a finding which corroborates results in previous studies (Moodi et al.

2012; Hatefnia et al. 2010; Farmer et al. 2007) and contrasts others (Champion et al. 2008; Dundar et al. 2006; Secginli and Nahcivan 2006). One explanation for this finding may be due to women's lack of knowledge about BC and BS (Moodi et al. 2012), such that improving women's risk assessment of developing BC may increase uptake rates. Our findings are in agreement with previous studies where positive association with perceived self-efficacy and having BS was found (Farmer et al. 2007; Secginli and Nahcivan 2006). This implies that attendees feel confident that they can arrange other things in their life to get a mammogram. However, self-efficacy was not the most important predictor for the decision to undergo screening in Malta. This result complies with a study in Cyprus (Tolma et al. 2006) and contrasts the findings by others (Orji et al. 2012).

It has also been reported that if a woman perceives mammography benefits to be higher than perceived barriers, she is more likely to attend (Carney et al. 2013; Avci and Kurt, 2008; Dundar et al. 2006). However, the benefits subscale was not the most significant component associated with BS in Malta unlike in other studies (Dundar et al. 2012; Soskolne et al. 2007). It was the strong negative association between perceived barriers and screening uptake which was mainly identified in this study, similar to findings among American asymptomatic women (Aiken et al. 1994), Israeli women (Cohen 2006) and other populations (Hatefnia et al. 2010; Farmer et al. 2007; Parsa et al. 2006; Secginli and Nahcivan 2006). It was predominantly fear that was found to be statistically significant across all subscale items. This is evidenced by women who do not attend for mammography in other countries because they perceive greater fear of BC (Fayanju et al. 2014; Baron-Epel et al. 2009; Consedine et al. 2004). A cancer diagnosis seems to be associated with a negative physical, psychological and social impact on Maltese women's ability to cope with BC outcomes, which can have a profound effect on their way of life: an economical and financial impact, altered perception of others and oneself, altered relationship with their husband/partner, and that diagnosis may lead to mortality. This is noticeable in other findings (Baron-Epel et al. 2009; Consedine et al. 2004; Austin et al. 2002). It is also likely that the fear of knowing someone with cancer is related to the cultural impact it would have on a woman's life or social local networks (Baron-Epel et al. 2009). This consistent fear across populations stems from the belief that there is little an individual can do to alter fate (fatalism) or prevent cancer (Austin et al. 2002). Therefore, non-attendees may be more pessimistic of early BC detection and the effectiveness of subsequent treatment, and may perceive BC as being uncontrollable, chronic and highly symptomatic with avoidance and denial coping strategies (Hagger and Orbell 2003).

Helping to manage barriers associated with cancer and screening could be one of the main tasks addressed by interventions to increase uptake, for example through the use of patient navigators alongside access to care (Pascal et al. 2011) and the identified recommendations from a physician, health care providers, family members and personal communication with other women which have been proven to be of greater importance than external cues (Cohen and Azaiza 2010; Trigoni et al. 2008; Meissner et al. 2007; Sohl and Moyer 2007). However, our findings show that many women are not encouraged by their GP to attend to BS and would attend more if advised. This is in agreement with a previous study where screening tests are advised at suboptimal rates (Trigoni et al. 2008). Similarly, in a cross-sectional study among Arab women in Qatar, only one quarter of the women interviewed said their doctors had discussed BC with them (Donnelly et al. 2013). It is important to provide a local context for the lack of GP recommendation and to take into account unique aspects of the Maltese health care service. Although the state health system and private GPs provide primary health care in Malta, patients are not affiliated with a regular primary care general practitioner or group practice (Parliamentary Secretariat for Health 2014). Besides, there exists an extent of private purchase of screening outside public health services (Parliamentary Secretariat for Health 2014). However, little is known in Malta regarding the true supporting network of women’s care pathway to date (Government of Malta 2016). These issues, coupled with negative women’s representations of BC and perceived BS barriers may have resulted in non-attendance to the first MBSP invitation.

4.2.4.4 Sociodemographic factors and health status

The findings also demonstrate that women with a lower family income tend to attend less to screening. There is consistent evidence that lower household income demonstrates lower utilization of BS in various countries (Paul 2012; Cuthbertson et al. 2009; Lagerlund et al. 2002). However, in regression analyses, the results revealed that the demographic and health status variables were poor and insignificant predictors of screening uptake and hence, do not provide strong prediction of non-attendees. Similarly, sociodemographic factors do not appear to constitute strong predictions of non-attendance in various studies (Lagerlund et al. 2000), which is why other determinants, such as health beliefs and illness perceptions, need to be explored within populations because of their importance in stimulating positive health behaviours (Dundar et al. 2012).

4.2.4.5 Predictors to first breast screening uptake

Previous studies have demonstrated that beliefs about BC and BS are important predictors of uptake (Anagnostopoulos et al. 2012; Huaman et al. 2011; Dundar et al. 2012). In regression analysis, health belief constructs emerged as the strongest and most significant predictors of attendance and non-attendance, and that perceived barriers were the strongest predictors to describe the variance between attendees and non-attendees ($p<0.05$). This fits well with previous literature, where interventions tailored after the HBM were more effective in increasing BS uptake than those that were not (6 studies OR = 2.51, OR = 1.27, $p<0.001$) (Sohl and Moyer 2007). Limited evidence for the effectiveness of interventions based on other models was found (Bridle et al. 2005).

Only one Greek study similarly incorporated both HBM and CSM to explore health beliefs and illness perceptions (Anagnostopoulos et al. 2012), though this theoretical framework was related to lifetime mammography use as opposed to this study regarding BS uptake in an organised programme. However, their results similarly showed that illness perception dimensions did not prove to be significant predictors of mammography lifetime use. There may be a number of alternative explanations for the non-significant associations and the less significant predictions exhibited by illness representation dimensions and screening uptake in Study 2. Hagger and Orbell (2003) hypothesized that coping may just mediate the effect of illness cognitions on the outcomes of an illness (e.g., psychological well-being, social, and role functioning). This may be due to women’s focus on illness perceptions ('mental representation') as such, rather than on coping strategies (such as obtaining a screening mammogram or visiting a doctor) which, in turn, may possess a different set of diverse and multiple characteristics which IPQ-R does not tackle (e.g., specific beliefs about mammography risks). Therefore, it seems that it is the HBM constructs related to response efficacy (expecting that a particular health action will result in an outcome, such as undertaking mammography screening), self-efficacy, and utility beliefs (believing that taking a certain action would be worthwhile to reduce BC susceptibility or severity, if the disease did occur, while perceived benefits would outweigh perceived barriers to undertaking health actions) that are significant BS predictors, rather than the IPQ-R dimensions. However, the CSM is the only model which seriously considers the role of emotions in response to illness (Lunt et al. 2005), although even here 'emotions' are often inadequately operationalised as 'anxiety', worry about, or 'fear' of symptoms. On the other hand, the HBM is considered a weak predictor of behaviour change as it does not include the formation of an intention to change behaviour as a precursor to behavioural change, does not accommodate social and environmental influences or past behaviour, and assumes that human decision-making are rational (Lunt et al. 2005). In response to each model's limitations, a combination of the two may determine behaviour likelihood (Kalsta et al. 2013; Lunt et al. 2005) and as shown in this study, their combination provided improved prediction of non-attendance (i.e. from 38.8% to 65.0% when combining all significant predictors). This suggests that interventions could be aimed to incorporate various dimensions of both models.

4.2.5 Limitations

Although these data can be generalizable to other screening programmes with a similar population, such as Mediterranean populations, this study has some limitations. First, a temporal relationship between exposure and outcome cannot be established because the study was cross-sectional thus excluding causal associations. Second, the study's retrospective design may have had an impact on the recall of events. Third, it was not possible to capture data of repeat mammograms at another facility as this was not recorded on the screening database at the time of study. Such data would show more accurately women's adherence to screening guidelines (Rutter et al. 1997) by using multiple points of service. Hence, future research should take into account the type of screening programme and a clear distinction of the type of mammography (screening or diagnostic mammography), since women's accuracy and consistency in reporting mammography experiences sharply declines with an increased number of lifetime mammograms (Rauscher et al. 2002). Fourth, data collected might be affected by recall or social-desirability response bias i.e. having performed mammography, whether in the organized screening programme or as opportunistic screening due to its well-publicized recommendation by media and clinicians (Anagnostopoulos et al. 2012), thus amplifying the recall bias effects. Additional research is required to test the interactions of HBM and CSM components in multivariate models to test threat representations and coping mechanisms. Further research to measure health beliefs and illness perceptions before and after screening could help to clarify the HBM and CSM's value in explaining the beliefs and perceptions of BC risks. Additionally, a longitudinal study design could provide better understanding of the psychological and emotional pathways and processes involved in how individuals form beliefs and risk perceptions of a particular health threat to better understand the factors underpinning health behaviours and reduce BC risk. Further research is warranted to determine whether uptake to first screening invitation is a significant predictor of subsequent screening in Malta.

4.2.6 Conclusions

Study 2 showed that there is high awareness of BC signs and symptoms among Maltese women, but wide variation in knowledge about causes of BC and its related risk factors. Non-attendees were the most unsure of BS recommended practices and had higher emotional barriers. Interventions to increase BC screening uptake in Malta should address health beliefs, in particular perceived barriers such as fear, since these emerged as the strongest predictors of uptake throughout the analyses. However, those interventions that also address illness representations, such as causes, consequences and cyclical timeline of BC, may increase their effectiveness since these were also associated with BS uptake. The CHBMS-MS and IPQ-R variables that contributed most to the regression model were perceived barriers, cues to action and self-efficacy, BC causes, cancer cyclical timeline, consequences and personal control. The findings of Study 2 indicate that it was the combination of HBM and CSM constructs which provides improved prediction of non-attendance. To the best of my knowledge, this is an innovative finding in BS research which can aid researchers, screening leads and public health educators to design culturally sensitive interventions to improve BS behaviours.

Chapter 4

Study 3: Predicting reattendance to the second round of the Maltese National Breast Screening Programme[3]

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[3]A version of this chapter has been submitted for publication in the *BMC Public Health Journal (Marmarà et al. 2019).*

4.3 Introduction

Detecting BC early is not ensured by a one-off BS attendance (Marshall 1994), but on the consistency of attendance (*'adherence'*) in line with recommended time intervals (Coyle et al. 2014) i.e. biennial screening mammography in average-risk women aged 50-69 as recommended by the EU Council (Perry et al. 2006). Thus, an important factor that merits exploration includes screening adherence in Malta, because of its significant impact on morbidity and mortality reductions (Anagnostopoulos et al. 2012; Ritvo et al. 2012). In 2009, the MBSP was set up similar to the UK, to screen women aged 50-60 through mammography every three years (Marmarà et al. 2017b), aiming gradual expansion to reach women until the age of 69 years while reducing the screening time interval as in other countries. In 2015, this age cohort (50-60 years) was in its second BS round.

The literature suggests that previous mammography use is highly associated with future use (Allen et al. 2008) because when women believe in the effectiveness of screening, it in turn, increases their intentions to go for screening, resulting in their adherence to subsequent screens (Abbaszadeh et al. 2007). An earlier study by Cockburn et al. (1997) found that those having weakest intentions to attend for their first screening are less likely to attend for their second screening (OR = 0.44, CI 0.23, 0.85). Therefore, it has been suggested that programs should focus on reaching those who have underutilized mammography in their past (Allen et al. 2008) as this would feed into attendance in subsequent BS rounds. Nonetheless, many studies have focused on the reasons for one-time screening rather than subsequent use (Ritvo et al. 2012; Halabi et al. 2000) and limited studies have sought to specifically explore predictors of uptake for *second* round BS invitations (O'Byrne et al. 2000; Cockburn et al. 1997; Rutter et al. 1997). In a comparative study of 200 re-attenders and 200 non-reattenders for second triennial National BS appointments in Nottingham (Marshall 1994), the 200 women who failed to accept their invitation implicated their negative initial screening experience in their decision, with 41% implicating pain, 6% stress and 3% embarrassment.

Study 2 found that a number of barriers influence women's uptake to a first BS invitation. Health beliefs, in particular perceived barriers, were the strongest predictors of uptake of first MBSP invitation, though the inclusion of illness representation dimensions improved the predictive accuracy for non-attendance. Prior to this research, no studies had explored women's reattendance at the MBSP or screening predictors to the second BS cycle. This analytical descriptive study follows Maltese women to explore predictors and behaviour to re-attendance, and to determine if uptake of first MBSP invitation is a significant predictor of second screening uptake, thus meeting research question 2b:

RQ 2b. Which significant factors (i.e. health beliefs, illness perceptions, knowledge, socio-demographic factors and health status) are associated with re-attendance at the MBSP?

4.3.1 Aims and Objectives

The aim of Study 3 was to gain an understanding of women's re-attendance at the second BS invitation round. In reaching this aim, the analysis has targeted the following objectives:

(1) To explore whether sociodemographic factors, health status, knowledge, health beliefs and illness perceptions are significant predictors of uptake to a second MBSP invitation; and

(2) To determine if uptake of first invitation to attend the MBSP is a significant predictor of uptake to the second invitation.

4.3.2 Methods

4.3.2.1 Design and setting

Full details of the methods are described in Study 2 (**Section 4.2.2**). This prospective study was conducted in Malta in January 2016 to determine factors associated with the second BS cycle.

4.3.2.2 Participants

The MBSP database was used to identify the 404 women who participated in the previous study on the first MBSP invitation (Marmarà et al. 2017b) for their attendance and non-attendance to the second invitation. Characteristics of the larger sample (n = 404) are found in Study 2. Of the 404 women surveyed between June and September 2015 about their first MBSP attendance, 100 women were identified in January 2016 to have subsequently been invited to the second round. These 100 women were a sub-sample of the larger study who had received an invitation to attend both the first and second MBSP rounds.

4.3.2.3 Measures

To predict reattendance, the previously constructed 121-item questionnaire was used. Refer to **section 4.1.3** for its translation, adaptation and pilot-testing and **section 4.1.4.2** for full details on its composition.

4.3.2.4 Ethical considerations

As discussed in Study 1, ethics approval was obtained from SREC (**Appendix 4.1.2**) and HEC (**Appendix 4.1.3**). In Study 2, participants were informed that their data could be used for further analysis of subsequent BS cycles, if required, for which they provided verbal consent. Data was computer generated from the MBSP register.

4.3.2.5 Variable definitions

A second invitation was defined as the second (subsequent) time a woman is invited to the MBSP and either attends or does not attend for the mammogram. Women were considered eligible in this study if their scheduled appointment date had elapsed for their second BS invitation and they had not informed the unit to reschedule their mammography invitation. A screening invitation is posted to the client approximately one month before the scheduled mammography date. Hence, those women invited to the second round and awaiting their scheduled day for mammography screening were not considered in this study.

4.3.2.6 Data analysis

Primarily, the Chi-square test was used to assess the association between attendance or non-attendance to the second MBSP invitation and women's knowledge, health beliefs and illness perceptions. When one of the assumptions of the Chi-Square test was violated, Fisher's exact test was used. Secondly, the Shapiro-Wilk test was applied on all constructs to verify whether the data was normally distributed. The Independent Samples t-test was used to compare if there were significant differences between attendees versus non-attendees against all the constructs. However, the non-parametric Mann-Whitney test was used for cases where the test variable was found to be not normally distributed. Thirdly, significant predictors for re-attendance were determined through binary logistic regression. The logistic regression model produced the unstandardized coefficients, standard error, the Wald value, p-values, Odds Ratios (ORs) and

95% confidence intervals (CIs). Seven logistic regression models were developed through different groups of variables and constructs, with the ‘backward-elimination’ method applied to every model. The reason for providing these models in this format was to understand the level of accuracy in predicting the dependent variable, based on different categories of variables. Hence, it was possible to identify the most important category of variables (i.e. health beliefs and illness perceptions) to predict attendance and non-attendance to the second MBSP cycle. In order to explore if the uptake of first MBSP invitation is a significant predictor of uptake to second invitation, a logistic regression model was applied to predict second (subsequent) BS uptake using the first BS uptake as the predictor. The data was analysed using SPSS version 21 under the guidance of an expert statistician. A P-value of < 0.05 was considered statistically significant and missing data was minimal (**Table 4.3.1**).

4.3.3 Results

4.3.3.1 Sample characteristics

Table 4.3.1 presents the sample characteristics (n = 100). Women were aged between 53-63 years at the time of the second screening cycle, with a mean of 58.63 years (±2.63 standard deviation (SD)). The majority of women were housewives (n = 78), married (n = 85), had a secondary education level (n = 68) and were from below average income families (n = 60).

Table 4.3.1 - Sample Characteristics (n = 100)

Characteristics	Mean	SD	N	%
Age (year)				
	58.63	2.63		
Education level				
Primary level			26	26.0
Secondary level			68	68.0
Tertiary level			6	6.0
Occupation				
Pensioner			4	4.0
Housewife			78	78.0
Employee			18	18.0
Status				
Single			4	4.0
Married			85	85.0
Separated/Divorced			5	5.0
Widowed			6	6.0
Family income				
Less than €10,737			28	28.0

€10,737 – €16,113	32	32.0
€16,114 – €23,563	8	8.0
€23,564 – €33,966	2	2.0
Greater than €33,966	2	2.0
Prefer not to say	30	30.0
Own a car		
Yes	78	78.0
No	22	22.0
Drive		
Yes	46	46.0
No	54	54.0
Any illness, disability or condition		
Yes	58	58.0
No	42	42.0
Family physician (GP)		
Yes	92	92.0
No	8	8.0
Frequency of GP visit		
Only when I have a problem	80	80.0
Once a month	5	5.0
More than once a year	7	7.0
Missing	8	8.0
Lumpy breasts		
Yes	9	9.0
No	91	91.0
Relatives or close friends had cancer		
Yes	89	89.0
No	9	9.0
Prefer not to say	2	2.0

From the 100 women invited to the second screening round (**Figure 4.3**), nearly three-quarters of this sample (74%; n = 74) attended the second round; of these, 83.8% (n = 62) had responded to their first invitation while 16.2% (n = 12) had not attended the first round. Over a quarter of our sample (26%; n = 26) did not attend the second round; of these, 34.6% (n = 9) had attended the first screening cycle while 65.4% (n = 17) had not responded to their first invitation. Women who attended their first invitation were more likely to sustain mammography screening than non-attendees ($\chi 2$ = 22.6, p < 0.001).

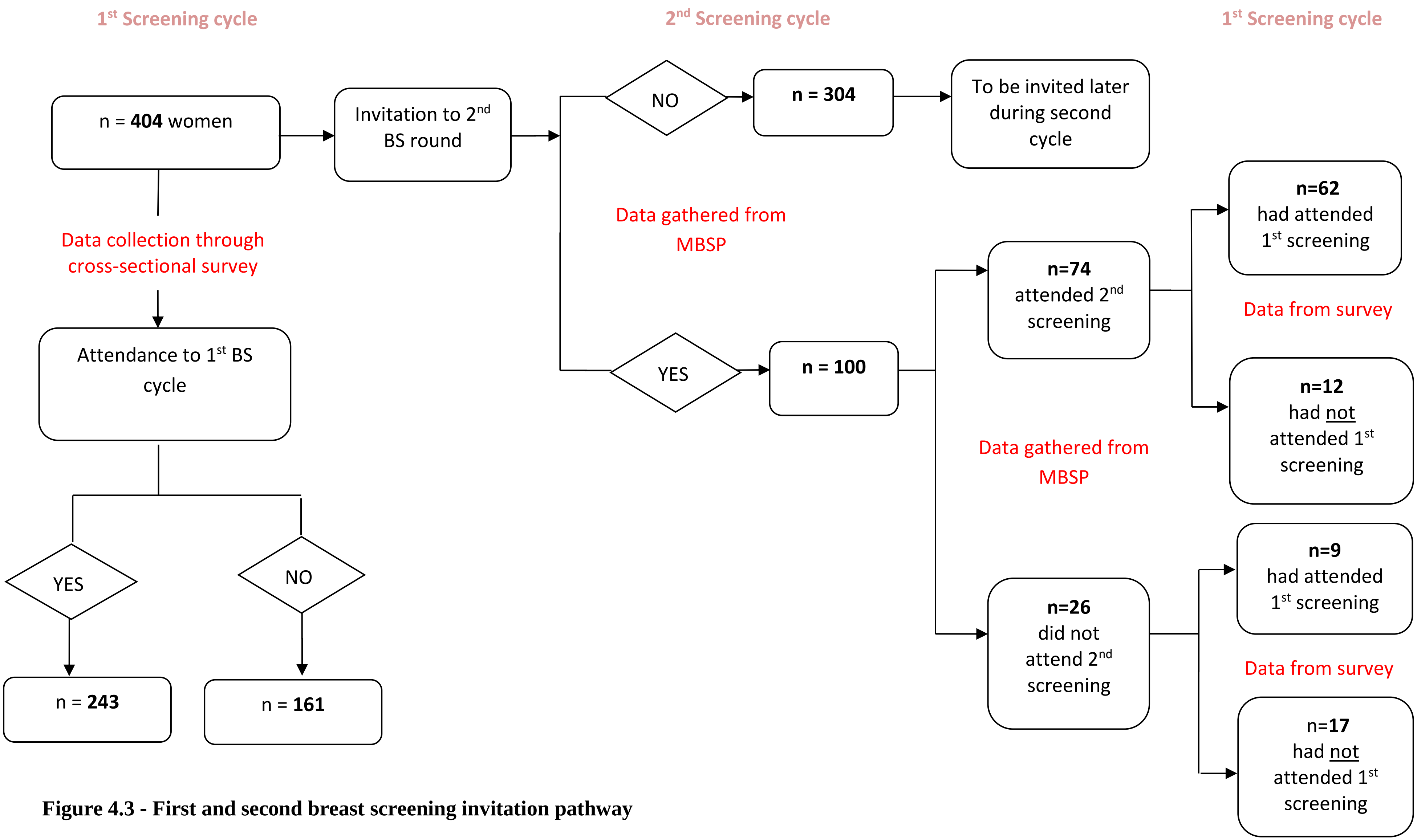

Figure 4.3 - First and second breast screening invitation pathway

4.3.3.2 Associations between psychosocial factors, and attendance and non-attendance to a second breast screening invitation

Sociodemographic factors and health status

There was a significant association between breast condition (lumps or cysts but not BC) and second screening uptake (*Fisher's exact test* applied: $p = 0.046$), whereby from those who attended their second invitation, 15.1% had a breast condition, whereas from among non-attendees, 34.6% had a breast condition. There were no significant associations for other sociodemographic or health status variables ($p > 0.05$).

Knowledge of the recommended screening frequency

There was a significant association between knowledge about recommended frequency for attend BS; women who did not attend the second invitation were most unsure of the recommended frequency ($\chi 2 = 9.580$, $p = 0.048$).

Health beliefs

In general, the majority of the HBM constructs showed no statistical significance, except for 5 items as follows (**Table 4.3.2**): 25.7% of women who attended the second round strongly disagreed with the statement: 'there is no is possibility of getting BC' as opposed to 11.5% of non-attendees ($p = 0.041$), while 23.1% of non-attendees were undecided. Attendees considered more strongly than non-attendees (41.9% vs 19.2%) that they would sustain mammography adherence if their GP advised them to attend ($p = 0.028$).

On the other hand, non-attendees were in stronger agreement than attendees (11.5% vs 0.0%) that mammography is painful or uncomfortable ($p = 0.008$). Non-attendance to the second round was more likely for women who considered reminder letters, reminder phone calls and text messages not to be helpful (15.4% non-attendees vs 1.4% attendees) ($p = 0.017$ respectively).

4.3.3.2.4 Illness perceptions

Chi-square tests showed no statistical significance for all illness perception items except for one variable (**Table 4.3.3**): those who attended the second round agreed more strongly than non-attendees (39.2% vs 7.7%) that their whole life would change if BC occurred ($p = 0.011$).

Table 4.3.2 - Comparison of Health Beliefs between attendees and non-attendees

Attendance to the second BS invitation	Yes		No		Total		Chi-Square test[a]	
Health Beliefs	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**χ2**	***p*-value**
There is no possibility of getting BC *(r)*	1.8	0.6	2.2	0.7	1.9	0.6	0.3	0.041*
Your chances of getting BC are high	3.6	0.7	3.5	0.7	3.6	0.7	1.1	0.789
There may be the possibility of developing BC in your lifetime	4.0	0.3	3.9	0.4	4.0	0.3	3.8	0.147
When you get a mammogram, you feel good about yourself	4.0	0.3	3.9	0.5	4.0	0.4	6.5	0.088
When you get a mammogram, you do not worry as much about BC	3.8	0.7	3.7	0.7	3.8	0.7	1.2	0.759
Having a mammogram will help you find lumps early in your breasts	4.2	0.5	4.1	0.5	4.2	0.5	3.3	0.355
If you find a lump through a mammogram, the treatment for BC may not be as bad	4.0	0.4	4.0	0.2	4.0	0.3	1.2	0.750
Having a mammogram will decrease your chances of dying from BC	4.0	0.4	3.9	0.4	4.0	0.4	4.3	0.227
Having a mammogram will help you find a lump before it can be felt by yourself or a health professional	4.0	0.4	3.9	0.4	4.0	0.4	3.3	0.344
Having a routine mammogram would make you anxious about BC	2.7	1.0	3.0	1.1	2.8	1.0	1.6	0.449
Having a routine mammogram would make you worry	2.7	1.0	2.9	1.1	2.7	1.0	1.5	0.685
You fear having a mammogram because you might find out that something is wrong	2.8	1.1	3.2	1.2	2.9	1.1	6.2	0.103
You fear having a mammogram because you do not know the procedure or what to expect	2.1	0.5	2.4	0.8	2.2	0.6	4.8	0.092
You fear having a mammogram because you know someone (family or friend) with BC	2.6	1.1	2.7	1.2	2.6	1.1	0.6	0.907
It is embarrassing for you to have a mammogram	2.3	0.8	2.4	0.9	2.4	0.8	0.5	0.779
Undergoing mammography will be painful or uncomfortable	3.2	1.0	3.3	1.1	3.2	1.0	11.9	0.008*
Having a mammogram is time consuming	1.3	0.5	1.3	0.7	1.3	0.5	3.8	0.153
You are discontent with BS personnel as they have been rude to you	1.1	0.4	n/a	n/a	1.1	0.4	n/a	n/a
You have fear or distrust in the medical team	1.7	0.8	2.0	0.8	1.8	0.8	4.7	0.094
Having a mammogram would expose you to unnecessary radiation	2.2	0.6	2.4	0.8	2.3	0.7	1.6	0.652
You have too many other problems in your life than to get a mammogram done	1.7	0.6	1.8	0.7	1.7	0.6	0.7	0.699
You are not old enough to have a mammogram periodically	1.8	0.4	1.8	0.4	1.8	0.4	0.9	0.344
If your GP advises you to attend for a mammogram, you will attend	4.4	0.5	4.1	0.6	4.3	0.6	9.1	0.028*

If your relatives or friends advise you to attend for a mammogram, you will attend	3.6	0.9	3.3	1.0	3.5	0.9	1.9	0.586
If someone close to you has been diagnosed with BC, you will attend for a mammogram	4.3	0.9	4.2	0.9	4.3	0.9	0.9	0.826
Hearing about BC and BS in the media or news makes you think about getting a mammogram	3.6	0.8	3.4	1.0	3.6	0.9	1.7	0.418
Reminder letters would help you to get a mammogram	4.0	0.3	3.7	0.8	3.9	0.5	8.1	0.017*
Reminder phone calls or text messages would help you to get a mammogram	4.0	0.3	3.7	0.8	3.9	0.5	8.1	0.017*
Routine educational talks regarding BC awareness would help you to get a mammogram	3.6	0.8	3.4	1.0	3.6	0.9	1.7	0.418
You feel confident that if you had a mammogram done, any abnormalities in your breasts will be detected	3.7	0.6	3.5	0.7	3.7	0.6	3.1	0.378
You can arrange other things in your life to get a mammogram	4.2	0.6	4.0	0.9	4.1	0.7	6.2	0.103
In case you need a mammogram, you will find a place to get it done	4.2	0.5	4.1	0.5	4.2	0.5	3.3	0.355
You can make an appointment for a mammogram	4.2	0.5	4.2	0.5	4.2	0.5	3.3	0.355
You can arrange transportation to get a mammogram	4.2	0.5	4.2	0.5	4.2	0.5	3.3	0.355
You can talk to people at the BS centre about your concerns	4.1	1.0	n/a	n/a	4.1	1.0	n/a	n/a
You can find a way to pay for a mammogram if you need to	4.3	0.4	4.2	0.5	4.2	0.5	2.9	0.234

*Significant at α=0.05

(r) = reverse scored

[a]Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree.

Table 4.3.3 - Comparison of Illness Perceptions between attendees and non-attendees

Attendance to the second BS invitation	**Yes**		**No**		**Total**		**Chi-Square test[a]**	
Illness Perception	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**χ2**	**p-value**
The presence of a lump or thickening in the breast	3.9	0.3	3.9	0.4	3.9	0.4	4.8	0.186
Nipple discharge	3.9	0.4	3.8	0.4	3.9	0.4	0.8	0.666
Sudden nipple retraction	3.8	0.4	3.7	0.5	3.8	0.4	1.3	0.509
Change in shape or appearance of the nipple	3.9	0.3	3.8	0.4	3.9	0.3	1.0	0.603
Breast swelling, dimpling, redness or soreness of the skin	3.9	0.3	3.7	0.5	3.9	0.4	4.2	0.124
Skin changes of the breast	3.8	0.4	3.7	0.5	3.8	0.4	1.3	0.509
A sudden change in breast size	3.9	0.4	3.8	0.4	3.9	0.4	3.4	0.180
Aching breasts	3.6	0.6	3.4	0.6	3.6	0.6	4.1	0.132
Stress or worry	2.9	0.9	2.8	0.8	2.9	0.9	0.8	0.673
Your mental attitude (e.g. thinking about life negatively)	2.4	0.6	2.2	0.5	2.4	0.6	1.9	0.379

Family problems or worries	2.9	0.9	2.7	0.8	2.8	0.9	1.5	0.477
Overwork	2.4	0.7	2.2	0.6	2.4	0.7	1.5	0.483
Your emotional state (e.g. feeling down, lonely, anxious, empty)	2.5	0.8	2.3	0.5	2.5	0.7	3.6	0.167
Your personality	2.5	0.8	2.3	0.5	2.4	0.7	1.9	0.597
Hereditary - it runs in the family	4.6	0.5	4.4	0.7	4.6	0.6	5.1	0.080
Diet or eating habits	3.3	0.9	2.8	0.9	3.2	0.9	7.1	0.069
Poor medical care in the past	3.3	0.9	3.3	0.8	3.3	0.9	0.9	0.818
Your own behaviour	2.6	0.7	2.7	0.6	2.6	0.7	3.6	0.164
Ageing	3.0	0.9	3.2	0.9	3.1	0.9	1.2	0.562
Smoking	3.7	0.6	3.5	0.8	3.7	0.7	3.5	0.174
Alcohol	3.5	0.8	3.2	0.9	3.4	0.8	2.6	0.272
A germ or virus	3.1	0.8	3.0	0.8	3.1	0.8	0.8	0.686
Pollution in the environment	3.7	0.7	3.3	1.0	3.6	0.8	6.2	0.104
Altered immunity	3.6	0.7	3.8	0.5	3.7	0.6	5.7	0.129
Chance or bad luck	2.9	1.0	3.1	1.0	2.9	1.0	4.1	0.386
Accident or injury	3.0	1.0	3.0	0.9	3.0	0.9	0.9	0.831
BC will last a short time	2.7	0.7	2.7	0.5	2.7	0.7	3.8	0.286
BC is likely to be permanent rather than temporary	3.4	0.7	3.2	0.8	3.3	0.7	3.4	0.178
A patient with BC goes through cycles in which her illness gets better and worse	3.6	0.7	3.4	0.7	3.5	0.7	3.0	0.394
BC has major consequences on a patient's life	4.4	0.6	4.1	0.6	4.3	0.6	6.3	0.096
BC will not have much effect on your life	1.5	0.7	1.5	0.8	1.5	0.7	3.7	0.297
BC would strongly affect the way others see you	3.4	0.9	3.6	0.8	3.5	0.8	1.4	0.506
BC has serious economic and financial consequences	3.9	0.5	3.8	0.5	3.9	0.5	1.9	0.587
BC would strongly affect the way you see yourself as a person	4.1	0.5	4.1	0.6	4.1	0.5	0.6	0.736
BC would threaten a relationship with your husband or partner	3.1	1.0	2.9	0.9	3.1	0.9	1.4	0.714
If you had BC, your whole life would change	4.4	0.6	4.0	0.4	4.3	0.6	11.2	0.011*
If you developed BC, the chances of living a long life would decrease	4.1	0.4	4.0	0.0	4.0	0.3	3.9	0.142
There is a lot which you can do to control the symptoms if BC occurs	3.9	0.5	4.0	0.0	3.9	0.4	1.8	0.604
The course of BC will depend on your actions	4.0	0.4	4.0	0.0	4.0	0.3	1.5	0.691
Your actions will have an effect on the outcome of BC	4.0	0.4	4.0	0.0	4.0	0.3	2.2	0.524
There is no treatment that will help to improve BC	2.1	0.6	2.0	0.6	2.0	0.6	0.5	0.930
The treatment provided will be effective in controlling or curing BC	4.0	0.2	4.0	0.2	4.0	0.2	0.4	0.804
The negative effects of BC can be prevented or avoided by the treatment given	4.0	0.2	4.0	0.2	4.0	0.2	1.0	0.621
You have a clear picture and understanding of BC	3.6	0.7	3.7	0.7	3.7	0.7	0.7	0.722
BC is a mystery to you	3.2	1.0	3.2	1.0	3.2	1.0	1.3	0.860
You get anxious when you think about BC	3.6	1.1	3.7	1.0	3.6	1.1	3.2	0.359
BC makes you feel afraid	4.2	0.7	4.3	0.5	4.2	0.7	2.2	0.523

You get worried when you think about BC	4.3	0.8	4.4	0.5	4.3	0.7	2.3	0.504

*Significant at α=0.05

[a]Chi-square test was applied for all illness perceptions; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree.

4.3.3.3 Differences between attendees and non-attendees

We further explored health beliefs and illness perceptions as 'constructs' and which of these constructs were statistically significant with BS uptake. **Table 4.3.4** shows the relationship of all 14 constructs respectively (*perceived susceptibility, perceived benefits, perceived barriers, cues to action, self-efficacy, BC identity, BC causes, cancer timeline: acute/chronic, cancer timeline: cyclical, consequences, personal control, treatment control, illness coherence, emotional representations)* when compared to attendance and non-attendance to second BS round.

Table 4.3.4 - Comparisons between health beliefs/illness perception constructs and second breast screening uptake

	Range	Attendees (n = 74)	Non-attendees (n = 26)	Test Statistic	*p*-value
Perceived Susceptibility	3 – 15	M=9.5, SD=0.8	M=9.6, SD=0.9	1019.5[b]	0.626
Perceived Benefits	6 - 30	M=24.0, SD=1.7	M=23.6, SD=1.6	864.0[b]	0.384
Perceived Barriers	13 – 65	M=27.0, SD=4.5	M=29.2, SD=6.1	-2.0[a]	0.049*
Cues to action	7 – 35	M=27.6, SD=2.8	M=25.9, SD=4.4	726.5[b]	0.061
Self-Efficacy	7 – 35	M=24.9, SD=2.7	M=24.2, SD=2.7	783.0[b]	0.129
BC Identity	8 – 40	M=30.8, SD=1.9	M=29.9, SD=2.5	776.0[b]	0.124
BC Causes	18 – 90	M=55.8, SD=7.2	M=53.9, SD=5.9	1.2[a]	0.238
Cancer Timeline: Acute/Chronic	2 – 10	M=6.1, SD=0.8	M=5.9, SD=0.8	839.0[b]	0.295
Cancer Timeline: Cyclical	1 – 5	M=3.6, SD=0.7	M=3.4, SD=0.7	829.5[b]	0.221
Consequences	8 – 40	M=28.8, SD=2.3	M=28.1, SD=1.9	744.0[b]	0.083
Personal Control	3 - 15	M=11.9, SD=0.7	M=12.0, SD=0.0	1014.0[b]	0.432
Treatment Control	3 - 15	M=10.0, SD=0.6	M=9.9, SD=0.6	865.0[b]	0.265
Illness Coherence	2 - 10	M=6.8, SD=1.2	M=6.9, SD=1.1	991.5[b]	0.802
Emotional Representations	3 - 15	M=12.1, SD=2.3	M=12.4, SD=1.8	991.5[b]	0.811

*Significant at α=0.05, [a] Independent Samples t-test, [b] Mann Whitney

The ‘perceived barrier’ construct was the only statistically significant variable that described the variance between attendees and non-attendees.

4.3.3.4 Predictors of attendance and non-attendance to the second screening round

For all logistic regression models, the most significant variables were identified and presented in **Table 4.3.5**. Logistic regression models 1 and 2 incorporated all items related to socio-demographic and health status variables respectively, though none were found to be significant predictors of second BS uptake.

Models 3 to 7 include the psychosocial variables. Model 3 focused on health belief variables only; hence, all HBM items were incorporated in logistic regression model 3, of which three variables were found to be good BS predictors: 'there is no possibility of getting BC', 'fear of the unknown procedure', and 'GP advice to attend' (**Table 4.3.5**). For this model, attendance was predicted with an accuracy of 93.2% and non-attendance with 30.8% accuracy. When removing ‘fear of the unknown procedure’ from the model, the accuracy decreased from 30.8% to 19.2% and hence was retained even though $p > 0.05$.

Model 4 focused on the illness perception variables only; hence, Model 4 included all IPQ-R variables, of which four variables were found to be good predictors: 'breast swelling, dimpling, redness or soreness of the skin', 'diet', 'altered immunity', and 'if you had BC, your whole life would change' (**Table 4.3.5**). The model accuracy was 89.2% for attendance and 69.2% for non-attendance.

Model 5 focused on the significant variables found in model 3 and 4 altogether, i.e. on 7 variables (3 Health Beliefs and 4 Illness Perception variables). The final model (Model 5) retained the same significant predictors as in Model 4, excluding the Health Belief variables, hence showing that Illness Perceptions are important predictors for second BS uptake. The model accuracy, when combining both scores, was identical to that of Model 4, predicting attendance by 89.2% and non-attendance by 69.2%.

Model 6 incorporated all individual Health Beliefs and Illness Perception items, of which 14 variables were significantly different. However, the latter variables made this model more complex due to the large number of predictors. The model accuracy improved substantially to 95.9% for attendees and 84.6% accuracy for non-attendees. The model accuracy decreased from 84.6% to 76.9% when the following variables were removed from the model: 'if you find a lump through a mammogram, BC treatment may not be as bad' and 'having a mammogram will decrease your chances of dying from BC'. Hence, the latter variables were retained even though $p > 0.05$.

When Health Beliefs and Illness Perceptions were used to construct a logistic regression model (Model 7) with all 14 constructs (not individual items), 'perceived barriers', 'BC identity', 'BC causes' and 'consequences' were found to be the most significant predictors, with 'perceived barriers' being the strongest predictor. However, non-attendance was predicted with an accuracy of 30.0%, which is inferior when compared to Models 5 and 6 (69.2%). Moreover, when removing the constructs 'BC causes' and 'consequences' from the model (p-value slightly greater than 0.05), the accuracy to predict non-attendance would decrease from 30.0% to 15.4% even though $p > 0.05$.

Although 'perceived barriers' remains the most important construct to describe the variance between attendees and non-attendees, illness perception constructs (BC identity, its causes and consequences) can also be considered as strong predictors of second BS uptake; a result further echoed in Model 5, where the predictors are all related to illness perceptions (BC identity, causes and consequences). Hence, although Health Beliefs are important BS predictors, the model accuracy improved with the inclusion of illness perception items into one logistic regression model (Model 6 vs Model 3).

Table 4.3.5 - Logistic Regression Models on second breast screening uptake against different variables and different constructs

	B	SE	Wald	*P*-value	OR	95% CI	Model Accuracy YES	Model Accuracy NO
Model 1: Demographics							100%	0%
Age	-0.154	0.084	3.329	0.068	0.858	0.727, 1.011		
Constant	7.926	4.905	2.611	0.106	2769.527			
Model 2: Health Status							100%	0%
Breast condition	-1.093	0.526	4.315	0.038	0.335	0.119, 0.940		
Constant	0.893	0.940	0.902	0.342	2.441			
Model 3: Health Beliefs							93.2%	30.8%
No possibility of getting BC	1.064	0.474	5.030	0.025	2.897	1.144, 7.338		

Fear of unknown procedure*	0.563	0.388	2.102	0.147	1.755	0.820, 3.756		
GP advice	-1.145	0.562	4.158	0.041	0.318	0.106, 0.956		
Constant	0.480	2.717	0.031	0.860	1.617			
Model 4: Illness Perceptions							89.2%	69.2%
Breast swelling, dimpling, redness or soreness of the skin	-1.796	0.720	6.215	0.013	0.166	0.040, 0.681		
Diet	-1.029	0.312	10.873	0.001	0.357	0.194, 0.659		
Altered immunity	1.462	0.568	6.610	0.010	4.313	1.415, 3.141		
Whole life would change	-1.334	0.533	6.257	0.012	0.263	0.093, 0.749		
Constant	9.082	3.931	5.337	0.021	8796.855			
Model 5: Health Beliefs and Illness Perceptions							89.2%	69.2%
Breast swelling, dimpling, redness or soreness of the skin	-1.796	0.720	6.215	0.013	0.166	0.040, 0.681		
Diet	-1.029	0.312	10.873	0.001	0.357	0.194, 0.659		
Altered immunity	1.462	0.568	6.610	0.010	4.313	1.415, 3.141		
Whole life would change	-1.334	0.533	6.257	0.012	0.263	0.093, 0.749		
Constant	9.082	3.931	5.337	0.021	8796.855			
Model 6: Health Beliefs and Illness Perceptions							95.9%	84.6%
Early detection	5.699	2.097	7.390	0.007	298.646	4.904, 18187.040		
If early detection, treatment not as bad**	12.267	7.293	2.830	0.093	2.126×10^{5}	0.132, 3.427×10^{11}		
Having mammography decreases chances of dying**	-8.890	6.724	1.748	0.186	0.000	0.000, 72.821		
Fear of unknown procedure	5.210	1.842	8.003	0.005	183.103	4.955, 6765.914		
Unnecessary radiation	4.471	1.655	7.301	0.007	87.419	3.414, 2238.732		
Breast swelling, dimpling, redness or soreness of the skin	-8.961	3.119	8.252	0.004	0.000	0.000, 0.058		
Personality	-5.566	2.295	5.885	0.015	0.004	0.000, 0.343		
Diet	-5.558	1.946	8.160	0.004	0.004	0.000, 0.175		
Germ or virus	-5.721	2.168	6.967	0.008	0.003	0.000, 0.229		
Altered immunity	8.217	2.860	8.254	0.004	3705.048	13.620, 1.008×10^{6}		

BC lasts a short time	-2.623	1.042	6.340	0.012	0.073	0.009, 0.559		
Affects the way others see you	3.105	1.286	5.831	0.016	22.305	1.795, 277.210		
Whole life would change	-9.738	3.266	8.888	0.003	0.000	0.000, 0.036		
You get worried if BC occurs	2.444	1.199	4.159	0.041	11.521	1.100, 120.694		
Constant	14.947	26.502	0.318	0.573	3.102×10^6			
Model 7: The 14 constructs							94.6%	30.0%
Perceived barriers	0.155	0.054	8.305	0.004	0.167	1.051, 1.296		
BC identity	-0.231	0.120	3.691	0.055	0.794	0.627, 1.005		
BC Causes* **	-0.070	0.040	3.022	0.082	0.932	0.861, 1.009		
Consequences* **	-0.204	0.116	3.082	0.079	0.815	0.649, 1.024		
Constant	11.286	4.983	5.129	0.024	79721.454			

B unstandardized coefficients; *SE* standard error; *OR* odds ratio; *CI* confidence interval

**'Fear of unknown procedure' was retained due to better accuracy in the logistic regression model. Without this variable, the accuracy would decrease from 30.8% to 19.2%.*
***'If early detection, treatment not bad' and 'Having mammography decreases death' were retained due to better accuracy in the logistic regression model. Without these variables, the accuracy would decrease from 84.6% to 76.9%.*
****'BC Causes' and 'Consequences' were retained due to better accuracy in the logistic regression model. Without these variables, the accuracy would decrease from 30.0% to 15.4%.*

4.3.3.5 Predicting attendance to second screening using first screening uptake

When a logistic regression model was applied to predict second BS uptake using the first BS uptake as the predictor (**Table 4.3.6,** Model 8), non-attendance was predicted with an accuracy of 65.4% and attendance with an accuracy of 83.8%.

Another model (**Table 4.3.6**, Model 9) incorporated the Health Beliefs and Illness Perception constructs as covariates, together with the first BS uptake variable as the main dependent variable. Model 9 shows that, following the inclusion of all constructs, 'perceived barriers' and 'BC identity' were found to be important covariates to improve the accuracy of predicting attendance to the second cycle i.e. 83.8% (Model 8) to 91.9% (Model 9). On the other hand, model accuracy dropped from 65.4% (Model 8) to 61.5% (Model 9) when predicting non-attendance to the second MBSP invitation.

Table 4.3.6 - Logistic regression analysis on the prediction of second breast screening uptake

	B	SE	Wald	*P*-value	OR	95% CI	Model Accuracy YES	Model Accuracy NO
Model 8: 2nd Screening Uptake				-			83.8%	65.4%
1st Screening Uptake	-2.278	0.519	19.266	0.000	0.102	0.037, 0.283		
Constant	0.348	0.377	0.853	0.356	1.417			
Model 9: 2nd Screening Uptake							91.9%	61.5%
1st Screening Uptake	2.462	0.571	18.591	0.000	11.728	3.830, 35.914		
Perceived barriers	0.129	0.057	5.102	0.024	1.138	1.017, 1.273		
BC identity	-0.272	0.123	4.917	0.027	0.762	0.599,0.969		
Constant	0.157	3.730	0.002	0.966	1.170			

B unstandardized coefficients; *SE* standard error; *OR* odds ratio; *CI* confidence interval

4.3.4 Discussion

It is not enough to getting women to initiate BS, but it is essential to encourage them to maintain use over time. Previous studies have examined re-attendance rates (Jack et al. 2014; Gierisch et al. 2010; O'Byrne et al. 2000). However, BS statistics are not available specifically for a second BS invitation. The available routine BS statistics largely provide cross-sectional estimates of coverage rather than information on women's ongoing BS attendance (Moser et al. 2009). Moreover, data has long relied on self-reports (Meissner et al. 1998), are measured by area deprivation (using either residential postcodes or general practice postcodes) rather than individual characteristics (Maheswaran et al. 2006) and can be affected by inflation based on registered general practice lists (Moser et al. 2009).

The preliminary rates for Maltese women invited to their second call seem to be lower than those in other countries (**Figure 4.3.2**: from the total data (*n* = 100), 62% of Maltese women attended the first and second round, 9% had attended the first but not the second round, 17% attended neither call). In a recent study in London among different ethnic groups (Jack et al. 2014), white British women were most likely to attend their first call (67%) and routine recall (78%). Mixed White and Asian women had the next highest uptake of routine recall invitations (75%), followed by Indian women (first call (61%) or routine recall (74%) appointments), Pakistani (52% and 67%, respectively) and Bangladeshi women (43% and

61%, respectively). The lower subsequent uptake rates in Malta could be due to the programme being relatively new. This study therefore sought to explore the associations and predictive psychosocial factors to second screening based on HBM and CSM.

All sociodemographic characteristics were not significantly associated with second screening uptake and the latter were also found to be non-significant predictors of second screening at the MBSP. These findings are substantiated by similar predictors of returning to a second screen in Australia (O'Byrne et al. 2000).

More specifically, earlier studies found that women with a breast problem were more likely to undergo clinical breast examination (CBE) and mammography than those who had none (Parsa and Kandiah 2010; Juon et al. 2002), while poor self-rated general health status was not associated with ever having had a mammogram in another study (Achat et al. 2005). This relationship is likely driven by higher knowledge levels on BS benefits (Juon et al. 2002). In contrast, significant differences were not observed between attendees and non-attendees for self-reported health status in this study, except for those who claimed they had a breast condition. The latter women were more likely not to attend for second screening when compared with those who said they had no breast problems. It is acknowledged that self-reports may not be as accurate as clinically documented mammographic reports. Nonetheless, in view of the nature and organization of the cognitive and emotional representations of such a health threat, as proposed by CSM (Anagnostopoulos et al. 2012; Baines and Wittkowski 2013), women may have opted to attend for private mammography, possibly as my earlier studies suggests, to obtain an earlier result (Marmarà et al. 2017b; Marmarà et al. 2015). Such reasons for non-attendance to second screening merit further investigation in the local context.

This study also provides evidence that women who were less knowledgeable of the recommended screening frequency were less likely to reattend at the MBSP. There is a similar widespread lack of knowledge of recommended screening guidelines for a first BS invitation in Malta (Marmarà et al. 2017b) and in other countries (Charkazi et al. 2013; Sadler et al. 2007). The impact of the physician-patient relationship may play an important role in the latter finding. In this respect, it is important to note the variation in the order of invitation from service to service as highlighted in **section 1.5.1**. For example, in the UK, women are invited to BS through GP practices (Zelenyanszki 2009) whereas in Malta, women are invited to BS according to age cohorts. Possibly, this infrequent encounter between GPs and Maltese women (**Table 4.3.1**) may be the reason for physicians' lack of opportunity to address knowledge gaps and to recommend regular BS.

Factors associated with BS behaviours in other populations (Kim et al. 2014; Secginli and Nahcivan 2006) were similar to the second MBSP round. Namely, Maltese women who believed that they were susceptible to BC, considered personal consequences of the disease, believed that mammography was not painful, and considered cues to action to motivate them to attend, were more likely than others to reattend. Similarly, items for BC consequences and cues to action as well as mammography pain were also significantly associated with first BS uptake. Evidence has shown that women's responsibilities within the family may conflict with self-care and limit screening attendance and re-attendance (Haley et al. 2011). Efforts to educate health care providers, particularly physicians, should emphasize the importance of mammography and regular physical check-ups (Secginli and Nahcivan 2006).

Of the remaining cognitive variables, perceived BC susceptibility and attitude towards BS use predicted attendance to the second round, echoing predictors of repeat use in other studies (Rauscher et al. 2005) while contrasting others (Gierisch et al. 2010). Attitudes towards BS behaviour and risk perceptions may be necessary components of why Maltese women contemplate maintaining a behaviour, but may not be prime motivators to influence the initiation of that behaviour.

Self-efficacy was not significantly associated with maintaining BS practices in Study 3 but played a key role in explaining why some women were unable to initiate BS at the MBSP (Marmarà et al. 2017b). Although previous research has shown that self-efficacy may be particularly central in moving women from contemplating about undergoing mammography to actually obtaining it (Menon et al. 2007), in the context of a second invitation, the rising challenges or barriers women experience when trying to maintain that behaviour may buffer the intentions that prompt planning for that behaviour (Gierisch et al. 2010).

Although several variables differentiated those women who returned for second screening from those who did not, the 'perceived barrier' construct was found to consistently explain the differences between attendees and non-attendees and to improve the accuracy of predicting attendance to the second screening cycle; a concurrent finding for first invitation.

A trial by Farhadifar and colleagues (Farhadifar et al. 2016) also suggests that regular BS practices are related to fewer barriers. The fact that some women did not return to their second invitation implies that based on their first contact with the screening service, they were less likely to return for routine calls. In the extant literature, this is attributable to a previous negative experience (Parkington et al. 2009), possibly due to pain or discomfort (Marmarà et al. 2015; Carney et al. 2002), embarrassment, distress, unhelpful staff and/or lower reassurance during the first screen (Myklebust et al. 2009). Study 2 also provides evidence that fear of pain was a major factor for not attending the first BS invitation (Marmarà et al. 2017b) and similarly, this study found pain to be a significant determinant to non-adherence. Preparing women through the invitation letter or in screening campaigns (Aro et al. 2001) and improving the mammography experience so that it matches women's expectations could help to increase and maintain BS uptake (Jack et al. 2014).

The inclusion of both Health Beliefs and Illness Perception items in Study 3 improved the accuracy of predicting non-attendance to the second cycle (Model 6, 84.6%). This finding coincides with findings for first invitation (Marmarà et al. 2017b). Given the importance of both theories and the higher predictive accuracy for both BS cycles, it is likely that psychosocial variables, women's BC perception and its related risk, and the enactment of cancer control measures predict regular BS behaviours (Petrak et al. 2015) in an attempt to gain control over the disease (Katapodi et al. 2004). This sense of internal control has been proven among disease-effected individuals across diverse health contexts (Cabassa et al. 2008; Hill et al. 2007; Moss-Morris et al. 2002) and healthy individuals (Petrak et al. 2015; Anagnostopoulos et al. 2012).

Finally, when considering that only one variable was utilised to predict second BS uptake, Model 8 can be considered as an extreme improvement over all the previous logistic regression models (**Table 4.3.5**). Furthermore, the fact that Model 8 utilised only one predictor to predict second uptake makes the model more efficient and easy to use. Moreover, first screening uptake is a very important and significant predictor to predict future uptake as this variable does not require any health beliefs and/or illness perception variables or any other information to predict second BS uptake. These results further support the evidence that women who obtain at least one mammogram are more likely to obtain subsequent screening (Anagnostopoulos et al. 2012; Moodi et al. 2012; Allen et al. 2008). Attendees may be more aware of the possibility for BC to occur, possibly because a BC threat (BC identity, causes and consequences found as CSM predictors for a second BS invitation in this study), coupled by BS benefits, may have helped the individual to ascertain what factors pose barriers to BS attendance and adjust these in the first place. Therefore, what matters most is the social and psychological characteristics, health behaviours and attitudes which women bring to screening the first time, such as a positive attitude towards BS, its value, health behaviours and the belief that an individual would be able to overcome any obstacles to attendance (Anagnostopoulos et al. 2012; Moodi et al. 2012). The most important implication is that if women can be recruited successfully on the first occasion, they will probably stay in the programme. Hence, efforts could be focused on identifying and encouraging attendance among women who have never participated in BS and who are reluctant or unsure to participate initially (Cockburn et al. 1997) because if women are persuaded to change their beliefs, attendance rates will increase and reattendance will become a routine (Rutter et al. 1997).

4.3.5 Strengths and limitations

Study 3 was not subject to response bias because figures for re-attendance were extracted from screening records. This study is one of a few to assess sociodemographic and attitudinal variables as predictors of adherence, but we found none that used initial predictors including HBM and CSM to explore factors to second screening. There are some limitations in our research. The limited sample size to examine women's attendance to a second BS invitation may have reduced sample representativeness. The characteristics of some women may have changed from first to second screening; this may have introduced misclassification and an underestimation of the relationships presented. Notwithstanding, the study design was necessary for the feasibility to conduct a prospective study to clarify and strengthen our findings, based on an understanding of the culture and attitudes among Maltese womenn. Additional research would help to identify barriers and reasons influencing decisions about BS adherence at the MBSP.

4.3.6 Conclusions

Researchers have focused more often on promoting behaviour change than on sustaining change. For the first time, the psychosocial associations and predictors to the second screening invitation were explored based on demographic factors, health status, knowledge, health beliefs, illness perceptions, and actual previous health behaviours. The combination of HBM and CSM variables provided improved prediction of attendance and non-attendance to the second screening call. Perceived barriers, BC identity, causes of BC, and consequences contributed most to the regression model, though perceived barriers was consistently significant across the analyses. Interventions should particularly target non-attendance to first screening. If non-attendees can be persuaded to attend once, they are likely to re-attend, unless their screening experience has been a negative one. The implications of these results are considered for theory, policy and practice to improve the limited understanding of second round screening and to aid the design of culturally sensitive interventions to improve BS uptake in Malta.

Chapter 4

Study 4: Lifetime utilization of mammography among Maltese women[4]

[4]A version of this chapter has been published in the *BMC Public Health Journal* (**Appendix 4.3.1**) (Marmarà et al. 2018a).

4.4 Introduction

Study 3 concluded that BS interventions to increase uptake should target first invitees since attending for the first time is a strong predictor of uptake to the second cycle. Furthermore, Study 2 identified that screening non-attendees consisted clearly of two distinct subgroups: (i) women, who had obtained a mammogram outside the MBSP, possibly as a self-initiated action or routine check-up (Aro et al. 2001) or as part of private breast awareness campaigns, which may have been based on their recognition of BC susceptibility and high self-efficacy in preventing BC (Jahanlou et al. 2013), and
(ii) 'lifetime non-attendees' i.e. women who have never attended anywhere for mammography during their lifetime. It is unknown which determinants are predictive of lifetime attendance 'anywhere' and lifetime non-attendance.

Most of the literature does not take into account the context of mammography provision, such as countries with dual health systems (organized and private screening). Considering the fact that the Maltese NHS comprises both the public and private sectors, and that the MBSP was introduced at the end of 2009 for women aged 50-60 at the time (European Commission 2014), some women chose to go privately for a mammogram before the year 2009 and still do so to date rather than taking up the invitation to be screened at the MBSP. It is the diversity of 'lifetime non-attendees' that needs to be better understood, in order to develop culturally sensitive interventions (Aro et al. 2001).

This study is a continuation of Study 2 such that data from that 2015 national survey were used to examine the relationship between ever-using mammography i.e. attendance 'anywhere' (*LIFETIME* attendance) or never using mammography (*LIFETIME* non-attendance) with socio-demographics, health status, knowledge, health beliefs and illness perception variables. Study 4 was guided by STROBE guidelines (**Appendix 4.3.2**).

4.4.1 Aims and Objectives

The aim of Study 4 was to gain an understanding of the determinants of lifetime mammography use among Maltese women who attend for mammography 'anywhere' and those who 'never' attend for mammography during their lifetime, thus meeting research question 2c:

RQ 2c: Which significant factors (i.e. health beliefs, illness perceptions, knowledge, socio-demographic factors and health status) are associated with lifetime mammography use?

In reaching this RQ, the analysis has targeted the following objectives:

(1) To determine the socio-demographics, health status, knowledge, health beliefs and illness perceptions of women who attend or do not attend for mammography screening during their lifetime;

(2) To examine the most significant predictors of lifetime mammography utilization and its non-use.

4.4.2 Methods

4.4.2.1 Design and setting

Since Study 4 uses the same dataset of Study 2, the full details of the methods and sample are described in **Section 4.2.3**. For those invited to the MBSP, attendance or non-attendance was verified through screening records but further mammography performed in private practices was self-reported.

4.4.2.2 Survey development

The composition of the survey questionnaire is described elsewhere (**Section 4.1.4.2**). Lifetime mammography practices and knowledge on mammography time intervals were incorporated into 4 subscales (17 items).

4.4.2.3 Classification of variables

Women were asked if they ever had a mammogram in their lifetime with a yes/no response. Women were categorized as LIFETIME ATTENDEES if they had *ever* had a mammogram in their lifetime or LIFETIME NON-ATTENDEES if they had *never* attended for a mammogram during their lifetime.

4.4.2.4 Statistical Analysis

The chi-square test was used for comparison of proportions between two categorical variables. The Shapiro Wilk test was applied on the 14 constructs in order to determine whether these variables are normally distributed. It was found that only the variable Causes of BC was normally distributed. Hence, parametric tests were used for this latter construct. All the other 13 constructs were found to be not normally distributed (p-value <0.001) and hence, non-parametric tests were used for all the 13 constructs. When comparing two independent samples, the Independent Samples t-test was used for normally distributed data (parametric test) and Mann-Whitney test was used for the non-normal distributed dataset (non-parametric test). Similarly, for analysis including two of more independent samples, ANOVA was used for normally distributed data and Kruskal-Wallis test was used for the non-normal distributed datasets. Different variables and constructs were incorporated into six logistic regression models and the 'backward-elimination' method was applied to each model to identify the significant predictors of lifetime mammography use. The results of the regression are reported with 95% confidence intervals, Beta (unstandardized) coefficients, Standard Errors (SE), Walds, Odds Ratios (OR) and p-values. All tests were analysed with an $\alpha = 0.05$ level of significance; hence, any statistical test obtaining a p-value of < 0.05 was considered as statistically significant. Missing data was minimal (n=23 for frequency of GP visit) and this missing data was reported in Study 2 (**Table 4.2.1)**. Missing data was reported as is; hence this data was not excluded. The data was analyzed using SPSS® version 21.0

4.4.3 Results

4.4.3.1 Sample characteristics

Descriptive statistics are presented in Study 2 (**Section 4.2.3.1**).

4.4.3.2 Mammography screening practices

Mammography screening practices are presented in **Figure 4.4**. BS use (LIFETIME ATTENDEES) was reported by 86.1% of women (n = 348), of which 243 women underwent a mammogram at the MBSP. From those who did not undergo a mammogram at the MBSP (n = 161), 105 women underwent mammography elsewhere. No mammography was reported by 13.9% (n = 56) (LIFETIME NON-ATTENDEES).

4.4.3.3 Lifetime attendees *versus* lifetime non-attendees subgroup analyses

Chi-square tests were performed to explore associations between lifetime attendees and non-attendees, and the following variables: sociodemographic factors, health status, knowledge, health beliefs and illness perceptions.

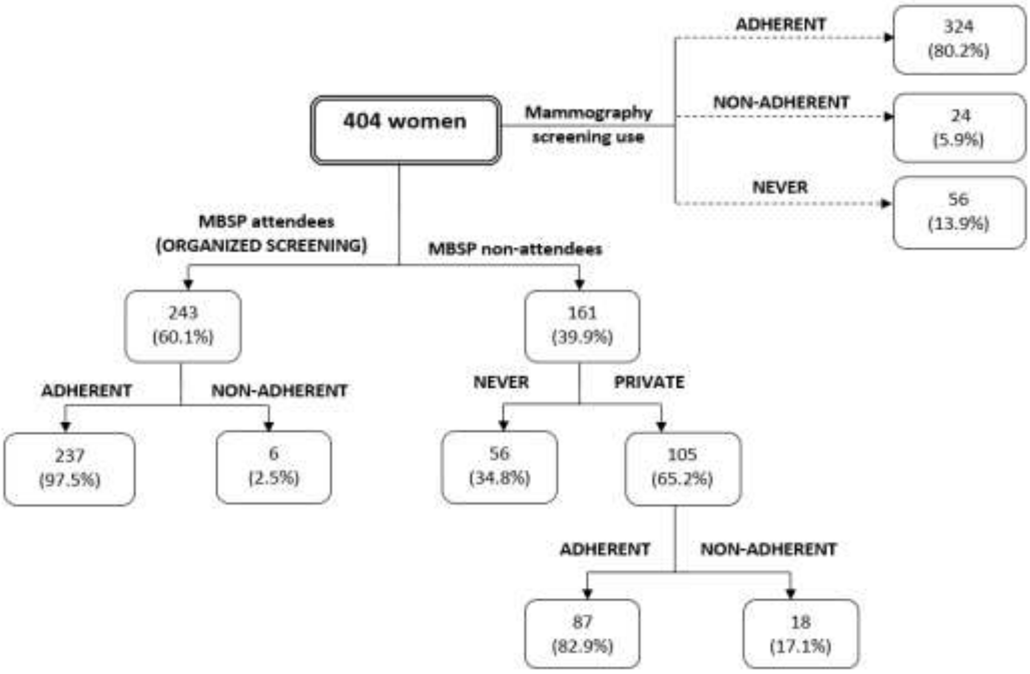

Figure 4.4 - Mammography use in Malta

4.4.3.4 Sociodemographic factors and health status

There was significant association between marital status and lifetime mammography ($\chi2$ = 9.0, p = 0.030) such that a lower number of widowers attended for mammography (66.7%) when compared to women of other statuses (single, married, separated/divorced) (≥87%). The higher their family income, the more likely it is for a woman to undergo mammography in her lifetime ($\chi2$ = 13.1, p = 0.011). In fact, all women who had a family annual income greater than €23 564 claimed that they acquired mammography during their lifetime while from those with a family annual income lower than €10 737, around one in every four women did not undergo mammography. In addition, those who do not drive are more likely not to attend for a mammogram ($\chi2$ = 7.7, p = 0.006). Our data showed that 91.5% of drivers attended for a mammogram in their lifetime as compared to 81.9% of non-drivers. All women in our sample who said they had a breast condition attended for mammography in their lifetime when compared to 82.9% of women without a breast condition ($\chi2$ = 14.2, p < 0.001). Moreover, those who had relatives or close friends with cancer were more likely to attend for mammography ($\chi2$ = 8.3, p = 0.016).

No significant association was found between lifetime mammography and age (Independent samples t-test: p = 0.133), district ($\chi2$ = 7.8, p = 0.802), owning a car ($\chi2$ = 1.2, p = 0.267) or having an illness ($\chi2$ = 0.1, p = 0.709). Although there was no significant association for education level ($\chi2 = 5.4$, $p = 0.067$) and occupation ($\chi2 = 5.7$, $p = 0.057$), women with a higher education level and who were employed were more likely to undergo mammography in their lifetime (e.g. 93.2% {employed} *versus* 83.9% {housewives}). There was no significant association between having a family physician and lifetime mammography ($\chi2 = 3.5$, $p = 0.060$). However, women who were not encouraged by their GP were more likely not to attend for a mammogram during their lifetime ($\chi2 = 4.9$, $p = 0.027$).

4.4.3.5 Knowledge of the recommended mammography frequency

Knowledge of mammography frequency was significantly associated with whether women had undergone a mammogram in their lifetime ($\chi2 = 28.5$, $p < 0.001$). The main difference arises with those who said they were 'unsure' about the recommended mammography frequency (48% of the latter group did not undergo a mammogram in their lifetime), whereas for women who mentioned other mammography frequency options (i.e. 'every year'; 'every 1.5 years'; 'every 2-3 years'), more than 86% of women from each individual latter groups had acquired a mammogram.

4.4.3.6 Health beliefs

All sub-scale items for perceived barriers and cues to action for mammography use were found to be statistically significant ($p < 0.05$) (**Table 4.4.1**). Women tend to attend less for mammography if they are in agreement with or are undecided on the following: having a mammogram *'would make you more anxious', 'more worried', 'more fearful about BC'* and '*the procedure itself*', is '*embarrassing'* and '*time-consuming'* and '*causes unnecessary radiation'*, have '*fear or distrust the medical team'*, 'consider *other problems in life to be greater'* and feel they are '*not old enough to have a mammogram periodically'* ($p < 0.001$ respectively). Significant association is mirrored for the statement '*you fear having a mammogram because you know someone (family or friend) with BC*' ($p < 0.001$). When comparing pain and discomfort with mammography use, statistical significance is mirrored ($p < 0.001$), whereby the absolute majority of the undecided group (95.8%) do not attend for a mammogram in their lifetime whereas those who are in disagreement or in agreement (≥88%) attend for mammography.

Those who underwent mammography tend to attend more for mammography if advised by their GP ($\chi2 = 54.4$, $p < 0.001$) or by relatives or friends ($\chi2 = 16.9$, $p = 0.001$). Those who are in disagreement that hearing about BC and BS in the media would trigger thoughts to get a mammogram tend to attend less. The absolute majority of those who are in disagreement that cues to action (such as ‘reminder letters’, ‘reminder phone calls’ or ‘text messages’) are effective, are more likely not to attend for mammography. There is also similar significant association for the vast majority of self-efficacy sub-scale items (p < 0.001) i.e. for attendees, the stronger is women’s confidence in arranging other things in their life to get a mammogram, while for the undecided group and those who are in disagreement with self-efficacy items are more likely not to attend for mammography screening.

Table 4.4.1 - Health Belief items

	LIFETIME SCREENERS versus NON-SCREENERS	
Health Beliefs	**χ2**	**p-value**
There is no possibility of getting BC *(r)*	8.4	0.077
Your chances of getting BC are high	8.2	0.085
There may be the possibility of developing BC in your lifetime	3.0	0.390
When you get a mammogram, you feel good about yourself	45.5	< 0.001*
When you get a mammogram, you do not worry as much about BC	6.4	0.093
Having a mammogram will help you find lumps early in your breasts	19.1	< 0.001*
If you find a lump through a mammogram, the treatment for BC may not be as bad	5.2	0.160
Having a mammogram will decrease your chances of dying from BC	7.5	0.580
Having a mammogram will help you find a lump before it can be felt by yourself or a health professional	7.2	0.065
Having a routine mammogram would make you anxious about BC	27.7	< 0.001*
Having a routine mammogram would make you worry	22.8	< 0.001*
You fear having a mammogram because you might find out that something is wrong	39.7	< 0.001*
You fear having a mammogram because you do not know the procedure or what to expect	145.8	< 0.001*
You fear having a mammogram because you know someone (family or friend) with BC	20.0	< 0.001*
It is embarrassing for you to have a mammogram	40.4	< 0.001*
Undergoing mammography will be painful or uncomfortable	147.5	< 0.001*
Having a mammogram is time consuming	31.1	< 0.001*

You are discontent with personnel at the MBSP as they have been rude to you	n/a	n/a
You have fear or distrust in the medical team	32.9	< 0.001*
Having a mammogram would expose you to unnecessary radiation	27.9	< 0.001*
You have too many other problems in your life than to get a mammogram done	83.1	< 0.001*
You are not old enough to have a mammogram periodically	35.4	< 0.001*
If your GP advises you to attend for a mammogram, you will attend	54.4	< 0.001*
If your relatives or friends advise you to attend for a mammogram, you will attend	16.9	0.001*
If someone close to you has been diagnosed with BC, you will attend for a mammogram	39.4	< 0.001*
Hearing about BC and BS in the media or news makes you think about getting a mammogram	34.2	< 0.001*
Reminder letters would help you to get a mammogram	38.9	< 0.001*
Reminder phone calls or text messages would help you to get a mammogram	38.9	< 0.001*
Routine educational talks regarding BC awareness would help you to get a mammogram	37.1	< 0.001*
You feel confident that if you had a mammogram done, any abnormalities in your breasts will be detected	0.6	0.960
You can arrange other things in your life to get a mammogram	49.2	< 0.001*
In case you need a mammogram, you will find a place to get it done	32.8	< 0.001*
You can make an appointment for a mammogram	36.0	< 0.001*
You can arrange transportation to get a mammogram	41.1	< 0.001*
You can talk to people at the BS centre about your concerns	n/a	n/a
You can find a way to pay for a mammogram if you need to	32.3	< 0.001*

*Statistically significant

(r) = reverse scored

[a]Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree. For certain items, responses were re-grouped to ensure the feasibility of the Chi-square test.

4.4.3.7 Illness perceptions

There is significant association for emotional representation subscale items ($p < 0.05$) (**Table 4.4.2**). For lifetime non-attendees, the higher is their anxiety ($\chi2 = 8.3$, $p = 0.040$) and fear ($\chi2 = 8.3$, $p = 0.039$) of BC. The undecided group attend less for mammography when taking into account that their emotional state ($\chi2 = 12.9$, $p = 0.002$) and their own behaviour ($\chi2 = 12.7$, $p = 0.002$) is perceived to possibly cause BC. Those who agree that BC can be caused by their own behaviour ($\chi2 = 12.7$, $p = 0.002$) or by a germ/virus ($\chi2 = 9.4$, $p = 0.009$) attend less for mammography, while those who consider BC to have major consequences in life ($\chi2 = 9.9$, $p = 0.019$) attend more.

Table 4.4.2 - Illness Perception items

	LIFETIME SCREENERS *versus* NON-SCREENERS	
Illness Perceptions	**χ2**	**p-value**
The presence of a lump or thickening in the breast	1.8	0.611
Nipple discharge	2.3	0.509
Sudden nipple retraction	1.1	0.769
Change in shape or appearance of the nipple	1.2	0.743
Breast swelling, dimpling, redness or soreness of the skin	0.9	0.826
Skin changes of the breast	1.7	0.641
A sudden change in breast size	1.5	0.688
Aching breasts	1.5	0.820
Stress or worry	3.0	0.223
Your mental attitude (e.g. thinking about life negatively)	2.0	0.580
Family problems or worries	2.9	0.233
Overwork	7.9	0.052
Your emotional state (e.g. feeling down, lonely, anxious, empty)	12.9	0.002*
Your personality	3.0	0.391
Hereditary - it runs in the family	9.7	0.021*
Diet or eating habits	1.5	0.679
Poor medical care in the past	0.8	0.847
Your own behaviour	12.7	0.002*
Ageing	1.9	0.395
Smoking	1.8	0.601
Alcohol	1.2	0.538
A germ or virus	9.4	0.009*
Pollution in the environment	1.4	0.709
Altered immunity	2.5	0.469
Chance or bad luck	3.0	0.562
Accident or injury	3.6	0.460
BC will last a short time	5.8	0.120
BC is likely to be permanent rather than temporary	0.9	0.650
A patient with BC goes through cycles in which her illness gets better and worse	5.8	0.215

BC has major consequences on a patient's life	9.9	0.019*
BC will not have much effect on your life	6.1	0.189
BC would strongly affect the way others see you	7.8	0.100
BC has serious economic and financial consequences	5.0	0.174
BC would strongly affect the way you see yourself as a person	0.9	0.826
BC would threaten a relationship with your husband or partner	2.5	0.641
If you had BC, your whole life would change	5.6	0.133
If you developed BC, the chances of living a long life would decrease	4.9	0.179
There is a lot which you can do to control the symptoms if BC occurs	0.7	0.948
The course of BC will depend on your actions	2.9	0.400
Your actions will have an effect on the outcome of BC	4.0	0.261
There is no treatment that will help to improve BC	4.0	0.400
The treatment provided will be effective in controlling or curing BC	3.1	0.371
The negative effects of BC can be prevented or avoided by the treatment given	1.5	0.822
You have a clear picture and understanding of BC	4.5	0.211
BC is a mystery to you	2.1	0.720
You get anxious when you think about BC	8.3	0.040*
BC makes you feel afraid	8.3	0.039*
You get worried when you think about BC	4.3	0.231

*Statistically significant

[a]Chi-square test was applied for all illness perceptions; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree. For certain items, responses were re-grouped to ensure the feasibility of the Chi-square test.

4.4.3.8 Health beliefs and illness perception constructs

The following 4 HBM and 1 CSM constructs were found to be significantly different when comparing lifetime mammography attendees and non-attendees: perceived benefits, perceived barriers, cues to action, self-efficacy ($p < 0.001$ respectively) and emotional representations ($p = 0.033$) (**Table 4.4.3**).

Table 4.4.3 - Comparisons between mammography screening use and health beliefs/illness perception constructs. For all constructs, Mann Whitney test and Independent Samples t-test were applied to compare 'LIFETIME ATTENDEES' and 'LIFETIME NON-ATTENDEES'

	LIFETIME ATTENDEES (n = 348)	LIFETIME NON-ATTENDEES (n = 56)	Test Statistic	*p*-value
Perceived Susceptibility	M=9.6, SD=1.0	M=9.6, SD=1.0	10,065.5[a]	0.669
Perceived Benefits	M=24.0, SD=1.8	M=23.1, SD=1.5	6816.5[a]	< 0.001*
Perceived Barriers	M=27.5, SD=4.9	M=34.8, SD=4.9	16569.5[a]	< 0.001*
Cues to action	M=27.3, SD=3.2	M=23.1, SD=4.8	4306.0[a]	< 0.001*
Self-Efficacy	M=24.8, SD=2.7	M=22.7, SD=2.8	6114.5[a]	< 0.001*
BC Identity	M=30.6, SD=2.3	M=30.7, SD=2.0	10,344.0[a]	0.434

BC Causes	M=56.0, SD=7.2	M=57.4, SD=6.9	-1.3[b]	0.186
Cancer Timeline: Acute/Chronic	M=6.1, SD=0.9	M=6.2, SD=0.9	10,213.5[a]	0.534
Cancer Timeline: Cyclical	M=3.6, SD=0.7	M=3.4, SD=0.7	8513.0[a]	0.069
Consequences	M=28.2, SD=2.5	M=28.5, SD=2.0	9909.0[a]	0.837
Personal Control	M=11.8, SD=0.8	M=11.9, SD=0.5	9890.0[a]	0.757
Treatment Control	M=9.9, SD=0.7	M=10.0, SD=0.5	10,592.0[a]	0.119
Illness Coherence	M=7.0, SD=1.1	M=7.0, SD=1.1	9857.5[a]	0.880
Emotional Representations	M=12.2, SD=2.1	M=12.7, SD=2.5	11,431.5[a]	0.033*

*Statistically significant, [a] Mann Whitney test, [b] Independent Samples t-test

The findings show that for women who acquire mammography during their lifetime, the higher is their agreement on perceived mammography benefits, while more cues to action and greater self-efficacy help women to undergo mammography. Higher perceived barriers to mammography screening and stronger emotional representations of BC are associated with no mammography use during a woman's lifetime.

4.4.3.9 Predictors of mammography screening practices

We further explored which variables and constructs were most significant to women's attendance (LIFETIME ATTENDEES *versus* LIFETIME NON-ATTENDEES). A number of logistic regression models were applied (**Table 4.4.4**) in order to examine the variables/constructs (independent variables) which are key to identifying differences between women who attended mammography during lifetime and non-attendees (dependent variables).

Model 1 represents the demographics against attendance/non-attendance. Although 'drive' and 'status' variables were found to be significant ($p < 0.05$), this model was not found to provide any accuracy to predict non-attendance. Hence, demographics did not provide any useful prediction for the scope of this analysis. Model 2 focused on Health Belief variables only, which served as the independent variables for this model. This model predicted attendance with an accuracy of 98.3% and non-attendance with an accuracy of 48.2%. Five variables were found to be significant ($p < 0.05$) with an Odds Ratio (OR) that varies between 0.213 (fear of unknown procedure) and 3.327 (arrange transportation) for all the five variables. Model 3 focused on Illness Perception variables only, which served as the independent variables for this model. This model predicted attendance with an accuracy of 99.4% and non-attendance with an accuracy of 5.4%. Six variables were found to be significant ($p < 0.05$) with OR varying between 0.432 (fear of BC) and 1.926 (major consequences in life). The above significant predictors from both models 2 and 3 were incorporated into a new single model (Model 4), both health beliefs and illness perception variables serving as the independent variables for this model. The model accuracy, when combining both scores, improved to 98.0% for attendance and 53.6% for non-attendance. The model retained six significant predictors ($p < 0.05$) with OR varying between 0.212 (fear of unknown procedure) and 3.202 (arrange transportation). When all individual Health Belief and Illness Perception items were incorporated into one model (Model 5), eight variables were found to be significantly different ($p < 0.05$) with OR varying between 0.149 (fear of unknown procedure) and 3.716 (arrange transportation). The accuracy of the model improved again to 97.1% for attendees and 58.9% accuracy for non-attendees. When the 14 constructs (not individual items) related to Health Beliefs and Illness Perceptions were used to construct a logistic regression model (Model 6), 'perceived barriers' (OR 0.776) and 'cues to action' (OR 1.196) were found to be the strongest and most significant predictors ($p < 0.05$) to describe the variance between the subgroups. However, the accuracy for predicting non-attendees was found to be 37.5% and 96.6% for predicting attendance, which is inferior when compared to Model 4. No health status variables were found to be significant and were therefore not included in **Table 4.4.4**.

4.4.4 Discussion

The extant research identifies multifactorial reasons why women choose not to attend for BS (Kinnear et al. 2011; McDonald and Sherman 2010; Doescher and Jackson 2009; Staniscia et al. 2003), particularly psychological, socio-economic and practical factors (Moser et al. 2009; Steadman and Rutter 2004; Aro et al. 2001). Hence, this study was carried out to provide an understanding of the determinants of lifetime mammography use among Maltese women who attend 'anywhere' and those who 'never' attend for mammography.

Table 4.4.4 - Logistic Regression Models on lifetime mammography use (LIFETIME ATTENDEES versus LIFETIME NON-ATTENDEES) against different variables and different constructs

	B	SE	Wald	*P*-value	OR	95% CI	Model Accuracy Attendance	Model Accuracy Non-attendance
Model 1: Demographics							100%	0%
Drive	0.912	0.325	7.891	0.005	2.488	1.317, 4.700		
Status	0.591	0.224	6.987	0.008	1.807	1.165, 2.801		
Constant	-4.605	0.792	33.773	0.000	0.010			
Model 2: Health Beliefs							98.3%	48.2%
Fear of unknown procedure	-1.548	0.219	50.028	0.000	0.213	0.138, 0.327		
Other life problems	-1.213	0.302	16.130	0.000	0.297	0.165, 0.537		
Relative or close friend with breast cancer	0.383	0.187	4.218	0.040	1.467	1.018, 2.114		
Reminder letters	1.099	0.307	12.826	0.000	3.001	1.645, 5.475		
Arrange Transportation	1.202	0.410	8.605	0.003	3.327	1.490, 7.427		
Constant	-1.993	2.109	0.893	0.345	0.136			
Model 3: Illness Perceptions							99.4%	5.4%
Hereditary	0.579	0.233	6.179	0.013	1.784	1.130, 2.816		
Own behaviour	-0.554	0.213	6.774	0.009	0.575	0.379, 0.872		
Major consequences in life	0.655	0.255	6.627	0.010	1.926	1.169, 3.172		
Economic consequences	0.520	0.238	4.777	0.029	1.683	1.055, 2.683		
Threatens your relationship	-0.396	0.178	4.973	0.026	0.673	0.475, 0.953		
Fear of BC	-0.840	0.280	9.038	0.003	0.432	0.250, 0.746		
Constant	1.060	1.828	0.337	0.562	2.888			
Model 4: Health Beliefs and Illness Perceptions							98.0%	53.6%
Fear of unknown procedure	-1.553	0.224	48.123	0.000	0.212	0.136, 0.328		
Other life problems	-1.239	0.310	15.973	0.000	0.290	0.158, 0.532		

Relative or close friend with breast cancer	0.407	0.189	4.618	0.032	1.502	1.036, 2.178		
Reminder letters	1.123	0.316	12.638	0.000	3.074	1.655, 5.710		
Arrange transportation	1.164	0.411	8.028	0.005	3.202	1.432, 7.163		
Own behaviour	-0.612	0.288	4.536	0.033	0.542	0.309, 0.952		
Constant	-0.240	2.306	0.011	0.917	0.787			
Model 5: Health Beliefs and Illness Perceptions							97.1%	58.9%
Poor medical care	0.878	0.360	5.970	0.015	2.407	1.190, 4.870		
Own behaviour	-1.195	0.380	9.893	0.002	0.303	0.144, 0.637		
Pollution	0.603	0.283	4.543	0.033	1.829	1.050, 3.185		
Possibility of developing breast cancer	-1.295	0.658	3.876	0.049	0.274	0.075, 0.994		
Fear of unknown procedure	-1.907	0.268	50.587	0.000	0.149	0.088, 0.251		
Other life problems	-1.478	0.331	19.976	0.000	0.228	0.119, 0.436		
Reminder letters	1.256	0.321	15.352	0.000	3.512	1.874, 6.584		
Arrange transportation	1.313	0.442	8.832	0.003	3.716	1.564, 8.831		
Constant	3.476	3.406	1.041	0.308	32.328			
Model 6: The 14 constructs							96.6%	37.5%
Perceived barriers	-0.253	0.039	43.157	0.000	0.776	0.720, 0.837		
Cues to action	0.179	0.041	19.169	0.000	1.196	1.104, 1.295		
Constant	5.192	1.688	9.460	0.002	179.859			

B unstandardized coefficients; *SE* standard error; *OR* odds ratio; *CI* confidence interval

Study 4 found that four health belief constructs (perceived benefits, perceived barriers, cues to action, self-efficacy) and one illness perception construct (emotional representations) influence lifetime BS practices among Maltese women. In particular, the findings show that women who perceive more barriers to mammography attendance (e.g. fear of pain, fear of the result), fewer benefits (e.g. lower belief in early detection), lower cues to action (e.g. no advice by a GP) and lower self-efficacy (e.g. lower confidence in one's ability to arrange other things in life), and who have higher emotional representations of BC (e.g. greater fear, worry, anxiety and who consider other problems in life to be greater) were less likely to attend for mammography during their lifetime. This is consistent with Champion's HBM and Leventhal's CSM. This also implies that women who have previously experienced BS may already have established health-related behaviours (Moodi et al. 2012) and have therefore already recognized the benefits of undergoing regular mammography, have already overcome personal barriers to undergo mammography, have increased their self-confidence in getting screened throughout their lifetime and have higher levels of health motivation (Anagnostopoulos et al. 2012; Moodi et al. 2012; Allen et al. 2008). Therefore, efforts should be focused on identifying and encouraging attendance among women who have never participated in screening (Jepson et al. 2000).

The findings emphasize the importance of adapting interventions for women with lower socio-economic backgrounds. This is so since widowers, those having lower family incomes and non-drivers were found to be significantly associated with lifetime non-attendance in this study. These women are less likely to attend for screening anywhere. Women with socio-economic disadvantages in life are less likely to take part in BS. This relationship has been shown in previous literature (Lagerlund 2002). This socioeconomic difference is re-emphasized in Study 2 whereby household income has solely emerged as significantly associated with attendance to first MBSP invitation (Marmarà et al. 2017b). Although not statistically significant in Study 4, women with a higher level of education and in employment were found to be more likely to attend than non-employed women and those with a lower education level. These socio-economic characteristics may serve as a proxy for interaction with other people, and in the degree of social integration during women's lifetime. These findings may indirectly reflect social differences and the degree of equality regarding BC detection and treatment received, and may help to identify prognostic factors amenable to intervention.

There were significant associations in this study between lifetime attendees and non-attendees regarding having a breast condition or having BC in the family and the close relations, such that women with a breast condition or who had relatives or close friends with cancer were more likely to attend for mammography during their lifetime. Similarly, having a family member or close friends with BC was associated with mammography attendance in other studies (Tejeda et al. 2009; Willis 2008) but contrast others (Manjer et al. 2015; Dundar et al. 2012; Luengo et al. 1999). Women most often play key roles as health managers and family caregivers (Marton and Choo 2012; Yoo and Robbins 2008; Young 1996) and this is not only reflected in that women more regularly than men are searching for health-related information on the internet (Bidmon and Terlutter 2015) but in women seeking a preventive action when faced with a prior personal or close relation experience that subsequently triggers them to engage in health-related behaviours (Fleming et al. 2013; Zackrisson et al. 2004; Luengo et al. 1999). This corresponds with other research in other fields, particularly on mothers and children (Jansen et al. 2012).

It has been acknowledged that lifetime non-attendees are an extremely difficult group to target and are a real challenge for screening management and public health officials (Australian Government 2014). For instance, structural and socio-economic factors such as age, income and marital status cannot be directly or easily modified (Consedine et al. 2004). Hence, although the exploration of such variables can help identify those at risk for a poor screening profile, such research offers little direction in terms of viable interventions. Therefore, in order to better understand which constructs are most significant to lifetime mammography non-attendees in Malta, logistic regression analyses confirmed that *health beliefs* were the strongest and most important predictors to lifetime non-attendance and this result has been consistent across my studies on first MBSP invitation (Marmarà et al. 2017b) and re-attendance (Marmarà et al. 2018a). This implies that lifetime non-attendees are women who were not motivated in health behaviour, have strong emotional representations of BS and BC, who highlight more screening barriers, lower benefits and less cues to action because this is a new skill for them. This is evidenced by women who do not attend for mammography in other countries (Fayanju et al. 2014; Consedine et al. 2004) because they perceive greater BS barriers.

The data shows evidence that lifetime non-attendees were less encouraged by their GP to attend for a mammogram during their lifetime. However, it is also true that Maltese women tend to visit their GPs when they have a problem rather than routinely (Marmarà et al. 2017b). While it is known that GPs are significantly more influential than relatives or friends at supporting mammography uptake (Fleming et al. 2013), women obtain information more often from friends and relatives than from official sources (Kee et al. 1992). This reinforces the influence of word of mouth from friends and relatives as a means of screening promotion (Fleming et al. 2013), supporting related promotional schemes worldwide (Passanisi et al. 2001; Bencivenga et al. 2008; Kiger 2003). However, while word of mouth is important, such initiatives are aimed at ensuring that information passed through word of mouth is based on factual information, rather than emotional reasons (Fleming et al. 2013). Although physician recommendation is critical for the provision of factual information about BS, BC and adherence recommendations, many women still do not screen frequently enough (Consedine et al. 2004). Hence, it seems increasingly clear that interventions should be developed to target variables that are both amenable to change and for which there is scope for improvement, if BS rates are to be improved.

The undecided group of women in this study tend to attend less for BS, particularly those who are unsure about: (i) self-efficacy items such as whether they can arrange other things in life to get a mammogram, (ii) screening barriers such as whether mammography is painful or uncomfortable, (iii) illness perception items such as whether one's emotional state or own behaviour causes BC, and (iv) mammography frequency recommendations. In all of my findings, limited knowledge was found to be significantly associated with attendance to the first screening invitation, re-attendance and lifetime mammography use. This calls for urgent renewed health education and tailored information on the importance of screening while addressing misunderstandings, debunking screening myths and improving knowledge gaps. All of the findings in Study 4, and when considered in the light of previous results, can be used to lead the development of current non-existent, evidence-based interventions in Malta.

4.4.5 Strengths and limitations

The group of lifetime non-attendees came from the same target screening group, which further strengthens the value of this data. Additionally, the rich dataset allowed for diverse subgroup analyses, which facilitated an overview of lifetime screening practices. An additional strength is that the 121-item tool (MBSQ) contains information that makes it possible to adjust the analyses for potential confounders. Some aspects of study limitations should be considered. One limitation of this study is its cross-sectional design, which does not allow for the associations of non-attendance with socio-demographic factors such as age to be studied over time. Future research is needed to evaluate a potential cause effect relation. A problem in some of the analyses is the low number of lifetime non-attendees, hence a lower level of confidence in the results for this particular group. This may have led to a type I and/or type II error in relation to some of the analysed factors. Another limitation of this study is that self-reports for private mammography was used to measure lifetime mammography rather than objective data from private mammographic screening clinics. However, no national data records from private practices are currently available to date in Malta. Hence, self-reports for lifetime mammography use was the only possible method of data collection. The findings are likely to be generalizable and broadly applicable to other populations.

4.4.6 Conclusions

In general, the results are in line with differences reported in the literature between screening attendees and non-attendees, such that non-attendees were less knowledgeable of the recommended mammography frequency, had attitudinal, emotional and motivational barriers, less socio-economic support and were less confident in themselves. Additionally, Study 4 showed that health beliefs were the most significant predictors to lifetime mammography screening behaviour. Hence, screening organisers and public health officials should target women's perceived barriers, particularly fear, and enhance cues to action when reaching out to non-attendees. Further qualitative research is required to clarify the determinants and consequences of emotional barriers, particularly fear among lifetime non-attendees, and also to evaluate the need for a more targeted approach among this hardest-to-reach group in order to understand the complexity of their behavioural barriers.

Chapter 4

Study 5: Adherence to Timely Mammography Use in Malta[5]

[5]A version of this chapter has been published in the *BMC Cancer Journal* (**Appendix 4.4.1**) (Marmarà et al. 2018b).

4.5 Introduction

To improve chances of survival from breast cancer (BC), women must attend breast screening (BS) regularly at recommended time intervals (Greif 2010). Maltese women are routinely invited to undergo mammography at three-year intervals at an organized screening programme (MBSP) or can opt to attend a private clinic. Prior to the MBSP, women in Malta could only use private mammography for routine screening (there are currently seven private practices offering mammography in Malta). Despite the current availability of the MBSP, a number of women still do not attend for mammography or may not attend at the recommended frequency. This is evidenced by data from Study 2 showing that the uptake rate for the first MBSP round was lower than the European target rate of 70% (Perry et al. 2006), and similarly for re-attendance, evidenced in Study 3 on the second MBSP round. Screening programmes can only be effective and indeed cost-effective (Feig 2006) if the attendance of the target screening population is consistent with recommended intervals (Coyle et al. 2014; Achat et al. 2005; Banks et al. 2002) in order to achieve health benefits (Ritvo et al. 2012). Moreover, Study 2 showed that health beliefs were significant predictors of uptake of the first MBSP invitation. Similarly, the findings of Study 4 concluded that it is the health beliefs of women who never attend for mammography during their lifetime that should be targeted. Whether health beliefs are predictive of women's adherence to recommended time intervals for mammography at organized or private screening in Malta is unknown.

Organized BS programmes are offered for free to asymptomatic women by many countries in Western Europe and North America (Labrie et al. 2017), with time intervals between mammograms depending on the varying recommendations of different countries (Eichholzer et al. 2016). In Europe, the EU Council recommends a two-year time interval for women aged 50-69 (Perry et al. 2006; Advisory Committee on Cancer Prevention 2000). However, countries implement these recommendations as they consider fit (Labrie et al. 2017). For instance, Norway adheres to the recommended EU thresholds, while a biennial nationwide screening programme for women aged 50-75 is offered in the Netherlands (National Institute for Health and the Environment 2015) and regionally organized screening programmes are offered in Switzerland for women over 50, with the age limit varying between 69-74 years (Swiss Cancer Screening 2015). Notable exceptions for the screening time interval is by the UK and Malta who opted for a three-year time interval (Benson et al. 2013).

Substantial disparity remains to date across countries on attendance at regular time intervals (Anagnostopoulos et al. 2012) with recent and regular attendance being studied less often than initial attendance (Whelehan et al. 2013; Achat et al. 2005; Aro et al. 2001). For instance, the more privatized system in the United States may enable less access to mammography than the social health care system found in the UK (Leung et al. 2015), suggesting that national context is important and worth exploring.

The Maltese NHS adopts a mixed model approach comprising elements from both the public (organized) and private sectors and this is one possible reason for non-participation in the organized screening programme (MBSP) or non-attendance at recommended three-year time intervals. Prior to the MBSP rollout across Malta, asymptomatic women could self-refer privately for mammography and symptomatic women were referred by a general practitioner (GP), breast surgeon or gynaecologist, either to the public symptomatic breast unit or to the private sector for mammography. Despite having the availability and efficiency of nationally-organised screening programmes, some women may still opt for the service privately (Francois et al. 2012; Bihrmann et al. 2008) but will be counted as non-compliant in the context of invitation-based BS (Aro et al. 2001). Similarly, screening mammograms taken and read in private clinics (Bihrmann et al. 2008) remain widely used in America and in European countries such as France, Luxembourg and Switzerland (Ferrat et al. 2013; Bihrmann et al. 2008; Chamot et al. 2007; Autier et al. 2002).

In order to understand if Maltese women are adherent with recommendations for BS, data were analysed in an effort to describe adherence to the recommended three-year time interval between mammograms at a private/government organised BS programme in Malta. Study 5 built on the findings of Study 2 (Marmarà et al. 2017b), which suggests that health beliefs and illness perceptions vary between women who accept or refuse a BS invitation to the organized BS programme in Malta. STROBE guidelines (**Appendix 4.4.2**) have guided the presentation of the study findings.

4.5.1 Aims and Objectives

The aim of Study 5 was to explore if health beliefs, illness perceptions, knowledge, sociodemographic factors and heath status are associated with adherence to recommended three-year time intervals, thus meeting RQ 2d:

RQ 2d: Which significant factors (i.e. health beliefs, illness perceptions, knowledge, socio-demographic factors and health status) are associated with adherence to timely mammography practices in Malta?

In reaching this RQ, the analysis has targeted the following objectives:

(1) To determine mammography screening use within or exceeding the recommended three-year frequency in Malta;

(2) To explore associations between socio-demographic factors, health status, knowledge, health beliefs and illness perception variables of adherent and non-adherent women.

4.5.2 Methods

The full details of the methods used in this study are described in Chapter 4, Study 2 (**Section 4.2.3)**. As discussed in Study 1, ethics approval was obtained from SREC (**Appendix 4.1.2**) and HEC (**Appendix 4.1.3**).

4.5.2.1 Measures

The measures have been described in detail in Chapter 4, Study 1 (**Section 4.1.4.2**). The key variable of interest in this study was adherence to the recommended three-year time interval between mammograms. Screening mammography uptake in the past three years was self-reported for women who opted to go to a private clinic for a mammography. For those who had attended the MBSP, attendance or non-attendance was verified objectively using screening records. Women were asked with a yes/no response if they had a mammogram within the past three years (ADHERENT) or whether they had exceeded the three-year frequency (NON-ADHERENT). Furthermore, they were asked to identify the location of their mammogram if they had undergone the screening test recently.

4.5.2.2 Statistical analysis

Throughout the analyses, basic statistics were presented through the use of mean values or percentages. A Chi-square test was used to test for any significant associations between two categorical variables. The Shapiro-Wilk test was applied to determine whether variables were normally distributed. Since only the variable (causes of BC) was normally distributed, the Independent Samples t-test (parametic test) was used for the latter construct to compare two independent samples, while the Mann-Whitney test was used for the non-normal distributed variables (non-parametric test) i.e. for all the other 13 constructs which were not normally distributed (p < 0.001). Missing data was minimal and reported in Study 2 (**Table 4.2.1**). Statistical significance was established at $p < 0.05$ for all analyses. Since those who never attended for mammography anywhere (n=56) were already analysed in further detail in Study 4, the following analysis focused on those who underwent at least one mammogram in their lifetime.

4.5.3 Results

4.5.3.1 Sample characteristics

The sample characteristics are available in **Section 4.2.3.1**

4.5.3.2 Mammography screening practices

Figure 4.4 presented the mammography screening practices by Maltese women. From the total sample of 404 women, 80.2% (n = 324) had undergone a mammogram in the previous three years (ADHERENT), 5.9% (n = 24) had exceeded the three-year time interval (NON-ADHERENT) and 13.9% (n = 56) had never had a mammogram. Out of the 404 women, 60.1% (n = 243) had attended the MBSP and 39.9% (n = 161) had never attended the MBSP. Out of the 39.9% (n = 161) of women who had not attended the MBSP, 65.2% (n = 105) had undergone mammography elsewhere (at a private practice); 82.9% (n = 87) of these women had undergone a mammogram within three years (ADHERENT) while 17.1% (n = 18) had undergone a mammogram that exceeded the recommended regular three-year time interval (NON-ADHERENT). Out of the 60.1% (n = 243) of women who underwent a mammogram at the MBSP, 97.5% (n = 237) had undergone a mammogram within the three-year time interval (ADHERENT), while 2.5% (n = 6) exceeded the three-year time interval (NON-ADHERENT). When applying a Chi-square test to compare NON-ADHERENCE to private practice versus NON-ADHERENCE to MBSP (17.1% versus 2.5%), this result was found to be significantly associated ($\chi2 = 24.6$, $p = 0.000$), implying that MBSP users are significantly more adherent than those attending privately.

4.5.3.3 ADHERENT *versus* NON-ADHERENT subgroup analyses

Sociodemographic characteristics and health status

There was no significant association between sociodemographic variables (e.g. age) or health status (e.g. breast condition or disease) and adherence to three-year time intervals for BS.

Knowledge of breast screening frequency

Knowledge of recommended time interval was significantly associated with women's adherence to the three-year time interval for mammography ($\chi 2 = 5.5$, $p = 0.020$). 12.5% of the non-adherent group were unsure about the recommended frequency while only 3.1% of the adherent group were unsure of the recommended time interval.

Health beliefs

The following health beliefs were significantly associated with adherence to the recommended three-year time interval for mammography (**Table 4.5.1**): 'having a routine mammogram would make you anxious about BC' ($p = 0.040$), 'if your GP advises you to attend, you will attend' ($p = 0.038$), 'hearing about BC and BS in the media or news makes you think about getting a mammogram' ($p = 0.030$), or 'reminder letters', 'reminder phone calls or text messages' would help you to get a mammogram' ($p = 0.000$ respectively). Women who fear or distrust the medical team ($p = 0.003$) or who feel they have too many other problems in life ($p = 0.001$) was significantly associated with non-adherence to the recommended three-year time interval. Women who do not agree that reminder letters, reminder phone calls or text messages would help them get a mammogram ($p = 0.000$ respectively) was significantly associated with non-adherence to the recommended three-year time interval.

Table 4.5.1 - Health Belief items

	ADHERENT versus NON-ADHERENT	
Health Beliefs	**χ2**	***p*-value**
There is no possibility of getting BC *(r)*	5.5	0.239
Your chances of getting BC are high	0.3	0.960
There may be the possibility of developing BC in your lifetime	7.8	0.055
When you get a mammogram, you feel good about yourself	5.9	0.115
When you get a mammogram, you do not worry as much about BC	3.6	0.302
Having a mammogram will help you find lumps early in your breasts	0.9	0.819
If you find a lump through a mammogram, the treatment for BC may not be as bad	0.7	0.863
Having a mammogram will decrease your chances of dying from BC	1.2	0.744
Having a mammogram will help you find a lump before it can be felt by yourself or a health professional	1.5	0.676

Having a routine mammogram would make you anxious about BC	8.3	0.040*
Having a routine mammogram would make you worry	3.2	0.522
You fear having a mammogram because you might find out that something is wrong	5.3	0.257
You fear having a mammogram because you do not know the procedure or what to expect	2.8	0.418
You fear having a mammogram because you know someone (family or friend) with BC	7.0	0.136
It is embarrassing for you to have a mammogram	6.0	0.055
Undergoing mammography will be painful or uncomfortable	3.8	0.284
Having a mammogram is time consuming	2.7	0.258
You are discontent with BS personnel as they have been rude to you	n/a	n/a
You have fear or distrust in the medical team	13.9	0.003*
Having a mammogram would expose you to unnecessary radiation	4.7	0.197
You have too many other problems in your life than to get a mammogram done	14.9	0.001*
You are not old enough to have a mammogram periodically	0.4	0.823
If your GP advises you to attend for a mammogram, you will attend	8.4	0.038*
If your relatives or friends advise you to attend for a mammogram, you will attend	1.3	0.741
If someone close to you has been diagnosed with BC, you will attend for a mammogram	3.2	0.362
Hearing about BC and BS in the media or news makes you think about getting a mammogram	8.9	0.030*
Reminder letters would help you to get a mammogram	20.9	0.000*
Reminder phone calls or text messages would help you to get a mammogram	20.9	0.000*
Routine educational talks regarding BC awareness would help you to get a mammogram	6.7	0.820
You feel confident that if you had a mammogram done, any abnormalities in your breasts will be detected	4.7	0.318
You can arrange other things in your life to get a mammogram	1.5	0.821
In case you need a mammogram, you will find a place to get it done	1.8	0.752
You can make an appointment for a mammogram	1.7	0.800
You can arrange transportation to get a mammogram	1.6	0.812
You can talk to people at the BS centre about your concerns	n/a	n/a
You can find a way to pay for a mammogram if you need to	2.3	0.511

*Significant at α=0.05; *(r) = reverse scored.*

Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree. For certain items, responses were re-grouped to ensure the feasibility of the Chi-square test.

Illness perceptions

The following illness perceptions were significantly associated with adherence to the recommended three-year time interval for mammography (**Table 4.5.2**): 'your mental attitude' (p = 0.008), 'family problems or worries' (p = 0.035), your emotional state' (p = 0.000), 'your personality' (p = 0.006), and 'you get anxious when you think about BC' (p = 0.044).

Table 4.5.2 - Illness Perception items

	ADHERENT *versus* NON-ADHERENT	
Illness Perceptions	**χ2**	***p*-value**
The presence of a lump or thickening in the breast	3.2	0.361
Nipple discharge	4.1	0.254
Sudden nipple retraction	7.0	0.072
Change in shape or appearance of the nipple	7.9	0.052
Breast swelling, dimpling, redness or soreness of the skin	3.6	0.305
Skin changes of the breast	4.7	0.193
A sudden change in breast size	1.5	0.682
Aching breasts	6.2	0.185
Stress or worry	2.8	0.250
Your mental attitude (e.g. thinking about life negatively)	12.0	0.008*
Family problems or worries	6.7	0.035*
Overwork	7.5	0.057
Your emotional state (e.g. feeling down, lonely, anxious, empty)	22.0	0.000*
Your personality	12.3	0.006*
Hereditary - it runs in the family	3.2	0.360
Diet or eating habits	1.9	0.590
Poor medical care in the past	1.4	0.699
Your own behaviour	3.8	0.282
Ageing	0.8	0.663
Smoking	0.5	0.927
Alcohol	0.0	0.979
A germ or virus	2.9	0.234
Pollution in the environment	2.8	0.428
Altered immunity	0.4	0.933
Chance or bad luck	1.0	0.908
Accident or injury	1.2	0.875
BC will last a short time	0.6	0.904
BC is likely to be permanent rather than temporary	4.8	0.089
A patient with BC goes through cycles in which her illness gets better and worse	1.6	0.800
BC has major consequences on a patient's life	2.1	0.559
BC will not have much effect on your life	2.4	0.662

BC would strongly affect the way others see you	4.4	0.351
BC has serious economic and financial consequences	0.8	0.840
BC would strongly affect the way you see yourself as a person	2.7	0.446
BC would threaten a relationship with your husband or partner	3.6	0.461
If you had BC, your whole life would change	0.6	0.902
If you developed BC, the chances of living a long life would decrease	0.8	0.844
There is a lot which you can do to control the symptoms if BC occurs	1.3	0.869
The course of BC will depend on your actions	1.7	0.646
Your actions will have an effect on the outcome of BC	1.1	0.787
There is no treatment that will help to improve BC	4.0	0.406
The treatment provided will be effective in controlling or curing BC	0.5	0.926
The negative effects of BC can be prevented or avoided by the treatment given	1.0	0.914
You have a clear picture and understanding of BC	2.6	0.455
BC is a mystery to you	1.7	0.786
You get anxious when you think about BC	8.1	0.044*
BC makes you feel afraid	0.7	0.875
You get worried when you think about BC	0.7	0.871

*Significant at α=0.05

Chi-square test was applied for all illness perceptions; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree. For certain items, responses were re-grouped to ensure the feasibility of the Chi-square test.

Comparisons of constructs between Adherent and Non-Adherent women

Mann Whitney test and Independent Samples t-test were applied to compare 'ADHERENT' and 'NON-ADHERENT' groups against all 14 health belief/illness perception constructs. There were statistically significant differences in perceived barriers and cues to action (p = 0.000, p = 0.039 respectively) between adherent and non-adherent women (**Table 4.5.3**).

Table 4.5.3 - Comparisons between the frequency of mammography use and health beliefs/illness perception constructs

	ADHERENT (n = 324)	NON-ADHERENT (n = 24)	Test Statistic	*p*-value
Perceived Susceptibility	M=9.6, SD=1.0	M=9.4, SD=0.9	3,641.0[a]	0.577
Perceived Benefits	M=24.0, SD=1.8	M=23.9, SD=1.3	3515.0[a]	0.387
Perceived Barriers	M=27.2, SD=4.7	M=31.1, SD=5.0	5540.5[a]	0.000*
Cues to action	M=27.4, SD=3.2	M=26.0, SD=3.5	2919.0[a]	0.039*
Self-Efficacy	M=24.8, SD=2.7	M=24.5, SD=2.1	3666.5[a]	0.615
BC Identity	M=30.6, SD=2.1	M=30.3, SD=3.4	4136.5[a]	0.582
BC Causes	M=55.9, SD=7.2	M=57.0, SD=6.9	-0.7[b]	0.467
Cancer Timeline: Acute/Chronic	M=6.1, SD=0.9	M=5.9, SD=1.0	3515.5[a]	0.402
Cancer Timeline: Cyclical	M=3.6, SD=0.7	M=3.7, SD=0.6	4271.0[a]	0.327
Consequences	M=28.2, SD=2.5	M=28.5, SD=2.7	4247.5[a]	0.446
Personal Control	M=11.8, SD=0.8	M=11.9, SD=0.6	3905.5[a]	0.951
Treatment Control	M=9.9, SD=0.7	M=10.0, SD=0.5	4166.5[a]	0.397
Illness Coherence	M=6.9, SD=1.2	M=7.3, SD=0.9	4538.0[a]	0.139
Emotional Representations	M=12.2, SD=2.1	M=12.7, SD=1.8	4348.0[a]	0.320

*Significant at α=0.05, [a] Mann Whitney test, [b] Independent Samples t-test

The findings show that women who were NON-ADHERENT to the three-year time frequency for mammography use perceive higher barriers and lower cues to action than ADHERENT women.

4.5.4 Discussion

This study facilitates understanding of the determinants of adherence to the recommended three-year interval for mammography use in Malta, which aid to the design of evidence-based and culturally-sensitive BS interventions for the Maltese population. Those who attend for mammography at the recommended time intervals may already understand screening benefits, have come to terms with screening barriers, and have confidence in their abilities to get screened (Anagnostopoulos et al. 2012). Similarly, findings by Moodi et al. (2012) suggest that women who previously had at least one mammogram in their lifetime had higher levels of health motivation, perceived benefits, and perceived self-efficacy to BS and fewer perceived screening barriers. This further proves that previous mammography use strongly predicts subsequent screening (Anagnostopoulos et al. 2012; Moodi et al. 2012).

Study 5 showed that there were some Maltese women who did not attend for mammography in a timely manner. Consistent with Champion's HBM and Leventhal's CSM, in this study it was the 'perceived barriers' and 'cues to action' constructs that explain the variance between the ADHERENT and NON-ADHERENT groups. Hence, women may need to overcome barriers to seeking mammography and follow tailored cues to action in order to attend BS at recommended time intervals.

A plausible explanation for the disappearance of an effect of socio-demographic factors in subgroup analyses on adherence in this study is that they represent 'carriers', as described by Lagerlund (2002), of already established health-related behaviours. This is evidenced in all my studies on attendance to first invitation to MBSP (Marmarà et al. 2017b), re-attendance (Marmarà et al. 2019, in press) and lifetime mammography use (Marmarà et al. 2018a), where different socio-demographic and health status variables were non-significant predictors of BS uptake.

Knowledge of BS frequency was found to be significantly associated with adherence to recommended three-year time intervals as in Study 2 (Marmarà et al. 2017b), Study 3 (Marmarà et al. 2019, in press) and Study 4 (Marmarà et al. 2018a). This shows that women who were unsure of screening recommendations were less likely to attend for mammography at recommended three-year intervals. This study's findings are consistent with studies that examined the relationship in average risk women over 50 years where women who reported screening according to the respective national guidelines were significantly more likely to adhere than women who reported less frequent time intervals (Ritvo et al. 2012; Edwards et al. 2009; Rakowski et al. 2006). Ritvo and colleagues expanded on such data, showing that it becomes more consequential with findings that the belief about recommended screening intervals predicts screening adherence in women with a family history of BC (Ritvo et al. 2012). The results of Study 5 underscore the significance of communicating and reiterating a screening interval recommendation to women such that they develop strong beliefs about the need to screen at that recommended three-year time interval.

The findings also suggest that those attending an organised screening programme such as, the MBSP, are more likely to adhere to screening recommended time intervals when compared with those attending the private sector. In order to reach greater adherence to recommended time intervals, women should receive further information on the recommended screening frequency and the benefits of being part of an organised programme (WHO 2014; Ferrat et al. 2013). For example, in Malta, private screening does not have the same quality controls as the MBSP such as higher quality of mammographic interpretation through special training of the readers and mammographers, double-reading and consensus reads (Heywang-Köbrunner et al. 2011). For instance, a mammogram in organised screening is read by two radiologists, who interpret at least 5,000 screening mammograms a year. This is the recommended volume set by the European Guidelines for Quality Assurance in BS (WHO 2014; De Gelder et al. 2009; Bihrmann et al. 2008; Frede 2005; Gabe and Duffy 2005) and the desirable individual level of experience set in the UK (National Accreditation Committee 1994). Moreover, based on a similar screening context as our local system, other studies raise awareness that organized screening leads to inequality reductions, higher quality assurance, and more timely screens than opportunistic screening (Heywang-Köbrunner et al. 2011; Ouedraogo et al., 2011; Palència et al. 2010).

While private screening remains unregulated, quality cannot be guaranteed which is why national screening programmes are recommended (Borg et al. 2013; Heywang-Köbrunner et al. 2011). Therefore, a key benefit of a national screening programme is that women can be individually monitored to ensure that they are conformant with screening guidelines and that they are adequately monitored in terms of robust quality assurance measures.

4.5.5 Strengths and limitations

Although Study 5 was limited to the Maltese setting, much of the developed world has organised screening programmes and access to the same body of scientific evidence, and thus the findings are likely to be broadly applicable across such countries. However, no study could be found that had similarly and simultaneously assessed sociodemographic and psychological variables as predictors of timely attendance and specifically attendance at organized or opportunistic screening. Moreover, none were found which utilised HBM and CSM as the theoretical framework. The major strength of this study is the rich dataset, which allowed the analyses of diverse subgroups. Since this study was cross-sectional, it precluded looking at cause-and-effect relationships over time. While a Chi-square test showed that women who attend private screening were less likely to be regulated in their attendance when compared to MBSP attendees, it cannot be ruled out that women attending private screening would be less likely to attend screening regularly even if they attended MBSP. This could be due to the characteristics of women attending private screening. Although screening attendance was confirmed through screening records, records of private mammography were self-reported and hence, subject to bias. Self-reported data could also have affected the observed difference between women attending private screening and the MBSP. Objective measurement would require data from private clinics, which was not possible to obtain, since no data records from private screening in Malta are nationally available to date. As a first step, it would be necessary to identify reliable and validated measures for regular mammography use that can be used simultaneously in government organised and private screening programmes. While limited studies to date have been of sufficient dimension to provide results on irregular attendance (Coyle et al., 2014), qualitative studies would contribute towards understanding why beliefs and perceptions influence timely adherence.

4.5.6 Conclusions

In conclusion, women's knowledge, health beliefs and illness perceptions were found to be significantly associated with timely mammography adherence. The results also suggest that attendance at an organised BS programme improves adherence to recommended time intervals when compared with those attending the private sector for screening. In order to reach greater adherence to recommended time intervals, women should be made more aware of the recommended screening time intervals and on the benefits of being part of an organised programme. Women can be individually monitored through the national BS programme to ensure that they are conformant with screening guidelines. Screening programmes should target women's health beliefs, in particular perceived barriers and cues to action, which have emerged as the most important factors to distinguish between adherent and non-adherent women to improve adherence to recommended time intervals. Further qualitative research is required to understand in more depth why women choose opportunistic screening over an organised programme.

Chapter 5

Interventions based on the Health Belief Model and Common-Sense Model to increase mammography uptake: a systematic review and narrative summary

5.1 Introduction

This chapter presents a systematic review of quantitative literature to explore interventions to improve breast screening (BS) uptake among women. Studies 2-5 (Chapter 4) suggest that HBM and CSM constructs are associated with BS behaviours in Malta. Therefore, as part of the process of intervention development, it was important to find out if interventions that address HBM / CSM constructs existed and what was their effect, thus meeting RQ 3: *What types of interventions (which have employed the HBM and/or CSM) are effective at increasing mammography uptake?* The objectives of Study 6 and thereby this chapter was to describe study design and methods, report intervention effectiveness on BS behaviour, and to describe theories, procedures, functions and content of the interventions.

5.2 Background

Health promotion interventions have a large contribution to early breast cancer (BC) detection and improved survival (Agide et al. 2018). Numerous interventions such as telephone or postal reminders, text messaging, education, individual counselling, and physician interventions have been conducted to increase BS participation and tested to evaluate their effectiveness (Kerrison et al. 2015; Camilloni et al. 2013; Gardner 2013; Guy et al. 2012; Jensen et al. 2012; Lakkis et al. 2011).

In the year 2000, Jepson and colleagues conducted a monumental systematic review to evaluate the determinants of screening and interventions that increase screening uptake (Jepson et al. 2000). This review found 65% of intervention studies and 82% of determinant studies were undertaken in the US or Canada. Both countries differ from the UK and Malta in the recommended ages and screening intervals and in the organisation of screening programmes. Since Jepson's review, some systematic reviews have concentrated on a specific type of screening, such as increasing BS uptake (Bonfill et al. 2001), or on specific types of interventions concerning '*personalized risk communication'* (Edwards et al. 2006) or '*patient decision aids'* (O'Connor et al. 2009), or on specific populations (Lu et al. 2012), or outcomes related to participation, like the impact of female screening on future attendance and women's health beliefs (Bankhead et al. 2003), or the impact of interventions among lower socioeconomic groups (Spadea et al. 2010). Although a recommended approach is to provide patient education or advice, this is often insufficient for generating and maintaining behaviour change as patients' health decision-making is not typically driven by the lack of knowledge alone but by multiple influencing factors (Heath et al. 2015), such as health beliefs and illness perceptions.

Theories aid the understanding of complex phenomena by providing tentative explanations for why and under what circumstances behaviours occur as well as an understanding of an intervention's effectiveness, or lack thereof (Heath et al. 2015). Theoretically-informed interventions can then target these factors, leading to better outcomes (Michie and Prestwich 2010). For example, a meta-analysis of tailored interventions to promote mammography screening (Sohl and Moyer 2007) found that tailored interventions that used the Health Belief Model (HBM) and included a physician recommendation produced the strongest effects in promoting screening compliance. Hence, evidence places an emphasis on the use of theory in developing and evaluating complex (*i.e.*, multi-component) interventions (Craig et al. 2008).

Several reviews have documented the HBM and CSM's performance in predicting health behaviours (Hagger et al. 2017; Jones et al. 2014), but to the best of my knowledge, no systematic reviews have addressed their utility in the design or efficacy of these interventions in relation to mammography screening uptake. It is believed that the results of this systematic review could be used as a guideline for the future design and implementation of BS interventions targeted at Maltese women.

5.3 Methods

5.3.1 Contributors

The team who contributed to this systematic review were as follows. DM (Danika Marmarà), the principal investigator, conceived the study and design, conducted the searches, selected and screened articles for inclusion, conducted the systematic review and drafted its written content. GH (Gill Hubbard), the researcher's primary supervisor, independently screened and reviewed 10% of articles, as suggested by Trivedi et al. (2013) and discussed any discrepancies with DM. RP (Robert Polson), an information specialist at the University of Stiring, aided the researcher to conduct the searches in electronic databases. AM (Andrea Mohan), a doctoral researcher at the University of Stirling, discussed data extraction with DM and checked full text articles to resolve disagreements by consensus. The risk of bias assessment of each study was independently conducted by two reviewers (DM, AM).

5.3.2 Search strategy

The search strategy was guided by the PRISMA guidelines (Moher et al. 2009) to identify all relevant articles. The researcher elicited support from RP to conduct the searches. A comprehensive primary search of the literature from January 2000 to September 2015 was conducted. The review was limited to start from 2000 since Jepson's review (Jepson et al. 2000) included the articles up to 2000. Thirteen electronic databases were searched, namely: CINAHL, PsycINFO, MEDLINE via OVID, EMBASE, Pubmed, Scopus, Cochrane, Web of Science, Prospero, University of York, Centre for Reviews and Dissemination database suite and Joanna Briggs (**Appendix 5.1**). The searches primarily used relevant keywords referring to mammography screening (e.g., BS, mammogram) combined with terms describing intervention types (e.g., campaign, outreach, navigation) to identify articles (An example of a search using CINAHL is given in **Table 5.1**).

A further supplementary search was conducted through eight electronic databases to search specifically for interventions up to August 2016 that used the HBM and CSM. The electronic databases for the supplementary search included: CINAHL, EMBASE, MEDLINE via OVID, Scopus, Cochrane, Web of Science, Prospero and University of York, Centre for Reviews and Dissemination database suite. The keywords referring to mammography screening (e.g., BS, mammogram) were combined with terms describing the theoretical models (e.g., HBM, CSM) (**Appendix 5.2**).

Table 5.1 - Example of search terms used in CINAHL

Search ID#	Search Terms	Search Options	Actions
S15	S6 AND S14	**Limiters** - Published Date: 20000101-20151231; English Language **Search modes** - Boolean/Phrase	(293)
S14	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13	**Search modes** - Boolean/Phrase	(299,456)
S13	(MH "Patient Navigation")	**Search modes** - Boolean/Phrase	(52)
S12	(MH "Health Promotion+")	**Search modes** - Boolean/Phrase	(32,040)
S11	(MH "Health Education+")	**Search modes** - Boolean/Phrase	(75,340)
S10	(MH "Audiovisuals+")	**Search modes** - Boolean/Phrase	(64,739)

S9	audiovisual* or audio-visual* or "audio-visual aid*" or "audiovisual use*" or "audio-visual use*"	**Search modes** - Boolean/Phrase	(2,052)
S8	"patient education" or "patient educat*" or "health educat*"	**Search modes** - Boolean/Phrase	(65,877)
S7	"attitud* to health" or "attitude to health" or attitud*	**Search modes** - Boolean/Phrase	(155,755)
S6	S4 AND S5	**Search modes** - Boolean/Phrase	(896)
S5	campaign* or educat* or interven* or program* or promot* or outreach* or navigat*	**Search modes** - Boolean/Phrase	(721,791)
S4	S1 AND S2 AND S3	**Search modes** - Boolean/Phrase	(1,906)
S3	(MH "Mammography") OR "breast screen*"	**Search modes** - Boolean/Phrase	(5,997)
S2	(MH "Health Screening+") OR "mass screen*"	**Search modes** - Boolean/Phrase	(43,101)
S1	(MH "Breast Neoplasms+") OR "breast cancer*" OR "breast tum?r*"	**Search modes** - Boolean/Phrase	(38,954)

5.3.3 Eligibility criteria and selection process

Randomised controlled trials (RCTs) have been labelled as the gold standard of medical knowledge and therapeutic evidence since the 1980s (Jones and Podolsky 2015). They have improved the quality of health care by clarifying benefits and setbacks of health interventions (Bothwell et al. 2016). However, certain challenges and limitations of RCTs arise from establishing appropriate inclusion criteria to standardizing interventions and determining the most relevant outcomes (Bothwell et al. 2016). To overcome these challenges, RCTs, which aimed to increase mammography use in asymptomatic populations, which had mammography use as an outcome, and which utilised the theoretical frameworks for this study i.e. the HBM and/or CSM, were eligible for inclusion. The primary outcome of interest to evaluate the success of interventions was the post-intervention difference in the proportion of women who underwent mammography screening in the intervention and control groups (screening rates). Electronic search results were downloaded into Refworks bibliographic software for screening and later retrieval. Two reviewers (DM, GH) were involved in selecting articles for inclusion. A full list of articles was obtained and screened for duplicates by the main reviewer (DM). Titles and abstracts of articles were independently reviewed (DM) to identify articles against predefined inclusion criteria, based on language, date, type of study, participants, type of intervention, theory and outcomes (**Table 5.2**).

Table 5.2 - Inclusion and exclusion criteria

Language and Date	All papers not in the English language were excluded because of the lack of translation services. Primary studies dated 2000 – 2016 (including the supplementary model searches) were included. Jepson (2000) included all primary studies of interventions prior to this date.
Type of study	Only RCTs were included because this is the most robust and ‘gold’ standard for measuring the effect of interventions on BS uptake. Comparison groups can include usual care, no intervention or other interventions. Therefore, controlled non-randomized studies, controlled before-and-after studies and experimental studies were excluded. Excluded studies: pilot studies, opinion pieces, newspaper reporting, policy documents, guidelines or studies of interventions that did not report the effect of the intervention on BS uptake.
Type of intervention	All interventions aimed at increasing mammography rates were included e.g., community-based (such as group education in the workplace, schools or a particular geographical region), mass media, small media or those targeting individuals (such as client reminders i.e. text messages, reminder phone calls, one-on-one education, client incentives among others) or targeting economic barriers (such as reducing structural barriers or reducing client out-of-pocket costs). Interventions to alter the screening test or process were excluded (such as new screening tests that are less invasive, decrease pain, and are more accurate and timely) because no change in the screening test or process is envisaged in Malta. Studies that included BS together with other screening programmes (e.g. cervical screening) were included as long as the BS interventions were reported separately.
Intervention theory	Interventions designed to address all/some of the constructs derived from the HBM and/or CSM were included. HBM constructs: *perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy.* CSM constructs: *BC identity, causes, timeline (acute/chronic and cyclical), consequences, personal control, treatment control, illness coherence and emotional representations.* No other additional established psychological model informed the intervention.
Intervention populations	Since the recommendation of cancer screening tests varies in developing and developed countries (Agide et al. 2018), the study population included women of all age groups.
Outcomes	Primary outcome measure was a change in BS uptake rates of individuals who were screened by mammography. Studies were excluded if: - they only reported secondary outcome measures such as women’s knowledge

	of, and attitudes and intentions towards BS; - the primary outcomes reported repeat mammography screening; - they solely evaluated breast self-examination (BSE) or clinical breast examination (CBE); - they focused on patients with existing BC or survivors.

All potentially relevant articles were obtained in full. Reference lists of relevant articles were hand-searched to identify any appropriate studies that could potentially be included in the review. The search strategy is summarized in **Figure 5.1**.

5.3.4 Narrative synthesis

Narrative synthesis was used to organize the evidence from the studies – an approach used when studies are too methodologically diverse to be combined to produce a statistical data summary i.e. meta-analysis (Higgins and Green 2011; Centre for Reviews and Dissemination 2009). The narrative synthesis was conducted in four stages.

First, data extraction was conducted by one reviewer (DM) using a data extraction template designed for use in this review. For all studies, data were extracted on study design, sample size, sample characteristics, theory, type of intervention, intervention duration, and study outcomes. Second, data extraction forms were used to produce a narrative descriptive summary of all RCTs, methods and bias, rationale, theories, procedures, functions and content. Third, data were discussed and checked by another reviewer (AM), with reference to the full text article. Both reviewers (DM, AM) collectively identified and discussed patterns between intervention characteristics (e.g., rationale, theories, procedures, functions and content), the effect of the intervention on BS uptake and the extent to which these characteristics might explain variation in the size/direction of effect. Fourth, the strengths and limitations of the evidence-based approaches to increase BS uptake were discussed by both reviewers and summarised. Disagreements were resolved by consensus among the two reviewers.

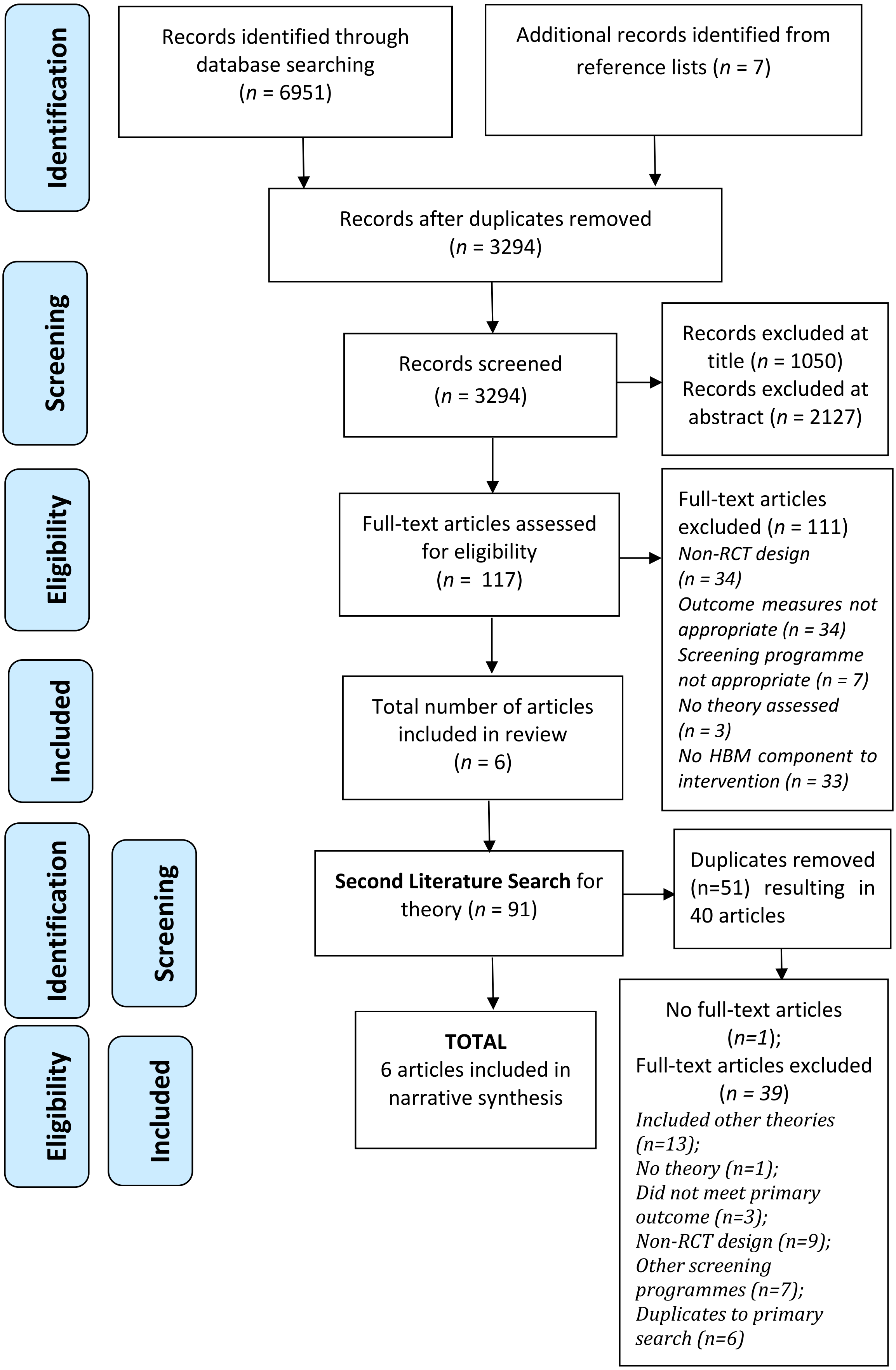

Figure 5.1 – Search strategy for the identification of intervention studies based on the Prisma flow diagram using the HBM and/or CSM to improve mammography uptake

5.3.5 Quality assessment

The quality of the studies was assessed using five data extraction forms used for data collection: the FBI Consort 2010 checklist (Schulz et al. 2010), FBI TIDieR checklist (Hoffmann et al. 2014), FBI Function checklist (Michie et al. 2011), FBI Theory checklist (Michie and Prestwich 2010), and the Cochrane risk of bias tool (Higgins and Green 2011). These data extraction forms are described below.

5.3.5.1 Methods

The CONSORT checklist (Consolidated Standards of Reporting Trials) (Begg et al. 1996) was used to describe the reporting of each trial through a 25-item checklist (Moher et al. 2010), including the study's aims and objectives, methods (e.g., design, participants, interventions, outcomes, sample size), randomization and statistical techniques, participants and numbers analysed, results and discussion, and other information such as trial registration, protocol accessibility and source of funding.

5.3.5.2 Intervention description

A Template for Intervention Description and Replication (TIDieR) checklist and guide (Hoffmann et al. 2014) was used for each study to assess the completeness of intervention description, and ultimately the replicability of interventions. This 12-item TIDieR checklist includes the following: brief name, why, what (materials), what (procedure), who provided, how, where, when and how much, tailoring, modifications, how well (planned) and how well (actual). If studies provided a rationale, theory or goal of the elements essential to the intervention to increase uptake, this was reported under the section 'Why'; the materials and procedures used were reported under the section 'What'; the professional delivering the intervention was reported under the section 'Who provided' and any training provided for the deliverer was also recorded; where, when and how long the intervention was delivered were reported under the sections 'Where' and 'How much,' respectively; any 'tailoring' or 'modifications' to the intervention were reported under these sections; mammography adherence was reported under the section 'How well.' If the intervention included other screening behaviours (e.g., cervical screening), these were not described.

5.3.5.3 Intervention function

A function checklist was used to categorise intervention functions (Michie et al. 2011). Nine functions are designated in the checklist, namely education, persuasion, incentivisation, training, restriction, environmental restructuring, modelling and enablement. Four of these functions (coercion, restriction, environmental restructuring, and modeling) place more emphasis on external influences and less on personal agency (Michie et al. 2011). Only the intervention functions for women were reported. If the intervention had more than one function, these were selected accordingly.

5.3.5.4 Theory coding scheme

The 19-item Theory Coding Scheme (Michie and Prestwich 2010) was used to describe the theoretical basis of interventions by providing a clear description of how to code each item. Each item required a yes/no/don't know response and the coder to identify the supporting evidence (location) in the study. All 19 items are presented within the following six categories, which can be used to assess the explicit application of theory:

(1) Is theory/model mentioned? (items 1 to 3);

(2) Are the relevant theoretical constructs targeted? (items 2, 5, 7-11);

(3) Is theory used to select recipients or tailored interventions? (items 4 and 6);

(4) Are the relevant theoretical constructs measured? (items 12 and 13);

(5) Is theory tested? (items 14-18);

(6) Is theory refined? (item 19).

This coding scheme provided a method for the systematic appraisal of theoretical components of interventions as well as more general behaviour change theories and models (Hubbard et al. 2016).

5.3.5.5 Risk of bias

For the risk of bias assessment, the Cochrane Risk of Bias tool (a domain-based evaluation tool) was used (Higgins and Green 2011) to assess risk for selection, performance, detection, attrition, reporting, sampling or any other source of bias, respectively. For each study, the six risk of bias domains were addressed through a pre-specified question about the adequacy of that RCT in relation to each domain, and judgement made on the risk of bias (high, low or unclear) for that domain. Risk of bias was undertaken by two reviewers (DM, AM), with disagreements resolved by consensus.

5.4 Results

The primary search identified 6951 potentially relevant articles (CINAHL (293), PsycINFO (221), MEDLINE (1556), EMBASE (1829), Pubmed (1832), Scopus (78), Cochrane (224), Web of Science (548), Prospero (1), University of York, Centre for Reviews and Dissemination database suite (356), Joanna Briggs Institute (13)), which were reduced to 3294 articles after removing duplicates. An additional 7 articles were identified through reference lists of included articles. Following review of titles and abstracts, 117 full text articles were retrieved. Of the 117 articles assessed to determine eligibility, six met the selection criteria.

The second literature search identified 91 potentially relevant articles (CINAHL (6), EMBASE (13), MEDLINE (16), Scopus (17), Cochrane (16), Web of Science (23), Prospero (0) and University of York, Centre for Reviews and Dissemination database suite (0)), which were reduced to 40 articles after removing 51 duplicates. No articles were found to be eligible and none included the CSM. In total, six articles were included in the final narrative synthesis (**Figure 5.1**).

5.4.1 Study characteristics and target group

Five out of the six studies were conducted in the US (Wu and Lin 2015; Wang et al. 2012; Sadler et al. 2011; Bodurtha et al. 2009; Duan et al. 2000) and one in Turkey (Secginli and Nahcivan 2011). The primary target group for mammography uptake varied across studies (**Table 5.3**). The majority of studies were carried out in America, whereby two studies targeted women (mainly African Americans) ≥40 years in US (Sadler 2011; Bodurtha et al. 2009), another American study targeted mainly White, African American and Hispanic women aged 50-80 (Duan 2000) and two studies targeted Chinese-American women in US over the age of 40 (Wu and Lin 2015; Wang et al. 2012). One study targeted Turkish women aged ≥ 41 years in Turkey (Secginli and Nahcivan 2011).

5.4.2 Outcome measures

Mammography attendance in all studies was self-reported (**Table 5.3**). One study (Secginli and Nahcivan 2011) also included self-reported CBE and BSE frequency as primary outcomes, one study reported screening intentions (Bodurtha et al., 2009) and three studies included knowledge of BC and screening to assess programme effectiveness (Wang et al.

2012; Sadler et al. 2011; Secginli and Nahcivan 2011). Common variables reported at baseline included:

- Age (n = 6) (Wu and Lin 2015; Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011; Bodurtha et al. 2009; Duan et al. 2000);
- Educational level (n = 6) (Wu and Lin 2015; Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011; Bodurtha et al. 2009; Duan et al. 2000);
- Household income (n = 5) (Wu and Lin 2015; Wang et al. 2012; Secginli and Nahcivan 2011; Bodurtha et al. 2009; Duan et al. 2000);
- Health insurance (n = 4) (Wu and Lin 2015; Wang et al. 2012; Secginli and Nahcivan 2011; Bodurtha et al. 2009).

Four studies reported that they had adjusted the covariance during analysis (Wu and Lin 2015; Wang et al. 2012; Sadler et al. 2011; Bodurtha et al. 2009). While older age, insurance coverage, and low acculturation were associated with greater screening intention and uptake in the intervention group for two studies (Wu and Lin 2015; Wang et al. 2012), none of the potential moderators (age, race, family history, perceived risk) were significant in Bodurtha et al. (2009). Similarly, in Sadler et al. (2011), there were no significant differences in age, education level, or any of the baseline measures used to assess outcomes (CBE and mammography use). Two studies reported secondary outcome measures: Bodurtha et al. (2009) reported CBE, BSE and mammography intentions; Sadler et al. (2011) reported adherence to recommendations for CBE. Follow-up varied from 1 month to 18 months; this represents a weakness of the shorter durations being unable to report comparable duration of mammography uptake for comparison.

Table 5.3 - Methods and results of included studies

Study and Country	Age group (years)	Sample*	Eligibility criteria	Outcome measures / Length Follow-up	Comparison groups *(Interventions described fully in Table 5.4)*	Findings
Wu and Lin 2015; US	≥ 41	193 women: 96 (I), 97 (C); power calculation.	Self-identified Chinese or Taiwanese American; ≥ 41years; No mammogram within past 15 months; No BC diagnosis; Can read and speak English or Chinese.	Self-reported mammography (screening or diagnostic). 4-month F/U telephone interviews.	2 arm: I = Tailored individual telephone counselling; C = NCI Brochure (mammography pamphlet on breast health).	Greater intervention effect among participants who resided in US 10 years or less in I (more participants obtained mammogram) than C. For older women (≥ 65 years) and recent immigrants, 51% of I and 25% of C had obtained mammography at 4 months F/U. 40% of women (n=34) (I) and 33% of women (n=27) (C) obtained mammogram after intervention; no significant difference.
Wang et al. 2012; US - Washington and New York	>40	664 Chinese-American women: 225/664 (Cultural video I), 217/664 (Generic Video I), 222/664 (C); power calculation.	Self-identified Chinese-American; >40 years; Lived in the Washington, DC or New York City metropolitan areas; Had no personal BC history; Non-adherent to ACS annual mammography screening guideline;	Self-reported receipt of mammography screening. 6 months F/U telephone interviews.	3-arm: I = Two theoretically guided DVDs: 1) a culturally-targeted video; 2) a linguistically-appropriate but non-targeted video (referred to as the cultural video and the generic video); C = Chinese BC fact sheet.	No significant increase in mammography uptake in cultural and generic video group compared to C at 6-months post-intervention. Significant effect observed only in one subgroup (low-acculturated women in cultural video group had a significant greater increase in self-reported mammography than fact sheet (C) at 6-months post-intervention). Women having obtained mammography had a significantly lower score on perceived barriers

			No medical appointment for a mammogram within the six months following the enrollment period.			(p<0.0001) than those who had not obtained mammography 6-months post-intervention. Both cultural and generic video groups had fewer perceived barriers at F/U than C (p<0.05).
Sadler et al. 2011; US - San Diego, California	20-81 years; 40+ in BC (I) group.	984 African American women: 219/428 (I), 209/428 (C) power calculation.	Self-identified African American women; 20-81 years; Receiving services at a participating salon with any of the salons' cosmetologists.	Self-reported adherence to mammography screening. Secondary outcomes: adherence to recommendations for CBE, participants' awareness and perceptions of their vulnerability for BC. 6 months F/U telephone surveys.	2 arm: I = Salon-based BC education program; C = training program about diabetes	Significantly higher rates of mammography compared to women in diabetes group.
Secginli and Nahcivan 2011; Turkey	≥ 41	190 women: 97 (I), 93 (C); power calculation.	≥ 41 years; No mammography or CBE within the previous 12 months; Not practicing regular BSE; No BC history.	Self-reported mammography, CBE and BSE frequency (primary outcomes). Secondary outcomes: BSE proficiency, breast health knowledge, and health beliefs (perceived susceptibility, benefits/barriers to	2 arm: I = 120-min BHP program based on HBM including a breast health education, film, BSE instruction, booklet, calendar and a card designed specifically for the study.	Significant improvement in BSE rates, proficiency and breast health knowledge among Turkish women. No anticipated effect on CBE and mammography rates. BHP program effective in increasing perceived BC susceptibility, perceived mammography benefits and BSE, and confidence of BSE.

				mammography and BSE, confidence in performing BSE). 3-6 months F/U surveys.	C = general information except breast health.	No significant difference between the 2 groups for perceived mammography barriers.
Bodurtha et al. 2009; US (Virginia)	≥40	899 women: 449 (I), 450 (C); power calculation.	≥ 40 years; Not pregnant; Nonparticipants in the trial's pilot study; No history of BC or CIS.	Self-reported mammography behaviour (primary outcome). Secondary outcomes: CBE, BSE, and mammography intentions. 1, 6, or 18-months F/U surveys.	2 arm: I = Risk-tailored information messages (education and risk assessment (WISER) C = general information about BC prevention practices.	No significant effect overall on mammography screening at 18 months. No significant differences in CBE, BSE, or mammography intentions.
Duan et al. 2000; US - Los Angeles	50-80	1443 women: 397 (I), 416 (C); no power calculation.	Black, Hispanic, and White women; 50-80; Residing in Los Angeles County.	Self-reported annual mammography screening. 1-year telephone F/U surveys.	2 arm: I = One session telephone counselling individualized to address barriers, education, persuasion, conducted annually for 2 years C = Survey only	Mammography adherence maintained among baseline adherent-participants and reduction of non-adherence rate from 23.5% to 15.8% ($p < 0.05$).

* Studies vary in how sample size is reported.

BHP - Breast health promotion; VCUHS - Virginia Commonwealth University Health System ; I - Intervention; C – Control; F/U – Follow-up; BC – Breast cancer; CIS - carcinoma in situ; ACS - American Cancer Society; BSE – Breast Self-Examination; NCI - National Cancer Institute .

5.4.3 Intervention characteristics

Table 5.4 describes key intervention components, with a particular focus on health belief components. Three were mammography behaviour only interventions (Wu et al. 2015; Wang et al. 2012; Duan et al. 2000); two included mammography, CBE and BSE (Secginli and Nahcivan 2011; Bodurtha et al. 2009), and one included mammography and CBE (Sadler et al. 2011). Two studies involved a breast health education program (Sadler et al. 2011; Secginli and Nahcivan 2011); two delivered individualized telephone counselling (Wu et al. 2015; Duan et al. 2000); one study provided face-to-face risk tailored information messages (Bodurtha et al. 2009), and one study mailed dvd materials (2 videos) (Wang et al. 2012).

Health professionals (nurse, consultants in psychology, oncology nursing and statistics) or behaviour change counsellors, delivered the interventions in three studies respectively (Wu et al. 2015; Secginli and Nahcivan 2011; Duan et al. 2000); one involved trained bilingual interviewers (Wang et al. 2012); one did not make reference to who delivered the intervention (Bodurtha et al. 2009). One study mentioned that training was provided to the intervention deliverers i.e. cosmetologists (Sadler et al. 2011) and that training a single educator proved sufficient to permeate the entire salon with the health message. English language classes were offered to two Chinese community coordinators to recruit potential participants in another study (Wu et al. 2015), while trained peer counsellors were supervised to conduct the brief year 1 telephone follow-up in the study by Duan et al. (2000).

Intervention duration mostly included one session for all studies, except for one study that mailed intervention material (Wang et al. 2012), following which participants were called two-to-four weeks after materials were mailed to confirm receipt and review of the materials. Four studies specified where the intervention was delivered; only one was in a healthcare (academic) practice (Bodurtha et al. 2009). Four studies reported tailoring or modifying the intervention (Wu et al. 2015; Wang et al. 2012; Secginli and Nahcivan 2011; Bodurtha et al. 2009).

In addition, most programmes were carried out in a community setting (n=5) (Wu et al. 2015; Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011; Duan et al.

2000) and two of these studies used multiple intervention strategies to meet participants' multi-dimensional needs (Wang et al. 2012; Secginli and Nahcivan 2011), e.g., a combination of access-enhancing strategies and involvement in participants' social networks (Wang et al. 2012). Moreover, cultural and social values were integrated in three studies such that programme design and delivery addressed participants' culturally determined fatalistic views and attitudes towards BC and BS (Wang et al. 2012) and respecting culturally or religiously constructed norms in conveying relevant information (Wu and Lin 2015; Sadler et al. 2011).

5.4.4 Intervention function

Table 5.4 describes the intervention function for the mammography behaviour component of the intervention. Interventions could be categorised as having more than one function. An intervention function in all studies was categorised as 'education' beause the interventions aimed to increase knowledge or understanding of, for instance, lifetime risks, lifestyle recommendations and instructions for scheduling mammogram/genetic counselling visits (Bodurtha et al. 2009). Only one study was categorised as 'enablement' because the counseling was individualized to address barriers to increase mammography uptake (Duan et al. 2000). An intervention function in two studies was categorised as 'training' i.e., individual training was received to enhance their ability to build confidence in their understanding of the BSE technique (Secginli and Nahcivan 2011) or to enhance their ability to pass on health promotion messages (Sadler et al. 2011). An intervention function in five studies was categorised as 'persuasion' because the intervention emphasised communication or tailored messages to proactively engage participants in discussions anticipated to encourage them to adhere to recommended BS guidelines (Wu et al. 2015; Wang et al. 2012; Sadler et al. 2011; Bodurtha et al. 2009; Duan et al. 2000).

Table 5.4 - Intervention description

Author	Behaviours	Materials and procedures	Intervention function(s)	Deliverers	Setting / Duration	Tailoring
Wu and Lin 2015	Mammography	Individual telephone interviews conducted in Mandarin, Cantonese, or English. I: A Web-based, individually tailored program (tailored messages) for the telephone counseling component. C: mammography pamphlet on breast health developed by the NCI (explaining the procedure of mammography and the importance of early detection through mammography). Not stated whether these pamphlets were mailed to participants' homes or given during face-to-face contact.	Education; persuasion; incentivisation	Research staff conducted baseline surveys using CATI system. Two senior investigators were consultants in psychology, oncology nursing, and statistics. Staff conducting interviews had at least a bachelor's degree in health-related field and completed a 2-day intensive training.	Community setting. 20-30 minutes interview; Intervention telephone calls up to 1 hour.	Yes. The counselling content provided individualized messages pertinent to the individual participant based on her responses at baseline assessment.
Wang et al. 2012	Mammography	I: Two theoretically guided videos: 1) a culturally-targeted video (cultural video) and 2) a linguistically-appropriate but non-targeted video (generic video). DVD format, 18 minutes duration, and included two segments: 1) a soap-opera style production and 2) a female physician's recommendations. Intervention materials mailed to participants' homes within 1-week after randomization. C: Chinese BC fact sheet. The mailed two-sided color-printed sheet included concise information about the development of BC,	Education; persuasion; incentivisation	Trained bilingual interviewers conducted baseline and 2 F/U assessments.	Community setting. First F/U survey held 2-4 weeks after materials were mailed. Second F/U assessment administered 6 months post intervention to measure	Yes. Group tailoring rather than individual tailoring: Only the cultural video incorporated Chinese cultural beliefs.

		Asian women's risk for BC, BC symptoms, and ACS BS guidelines.			screening behaviour.	
Sadler et al. 2011	Mammography, CBE	Face-to-face contact (cosmetologists and clients) at 20 beauty salons. Verbally delivered health messages were reinforced by posters, pamphlets, booklets and brochures in plexiglass stands throughout salons. Cosmetologists received 4 hours of one-on-one training and an additional 4 hours of reading materials. Cosmetologists in BC training arm were given soft plastic BC model and string of clay beads.	Education; persuasion; training	20 Cosmetologists. Twenty of the 24 stylists consented to participate in the study.	Community setting. One session at client's salon visit. ITT analysis	No
Secginli and Nahcivan 2011	Mammography, CBE, BSE	Program delivered face-to-face in small groups of 5-8 women. Breast health education (teaching session and film), BSE instruction, a booklet, a calendar, and a card: Health education: 35-min teaching session using a flip chart. Film (15-min): providing BSE instructions BSE instruction (15 min): in a separate room, building confidence to complete all BSE steps, silicon breast model exercises (standard size five lumps). 27-page booklet given as BSE reminder. Educational calendar: key points about BSE, CBE and mammography and remembering the right days to perform BSE. Card: one page, colour card providing an example of correct BSE method.	Education; training; modelling	The first author presented the program (Nurse-delivered).	Community setting. One intervention session.	Yes. The educational calendar designed to address key points about BSE, CBE, and mammography. The BSE card was based on the card obtained from Susan G. Komen BC Foundation (2007).

Bodurtha et al. 2009	Mammography, CBE, BSE	Face-to-face intervention. Information sheets containing personal 5-year and lifetime risks, HBM (barriers, seriousness and benefits) factors, lifestyle recommendations and instructions for scheduling mammogram/genetic counselling visits. Access not specified.	Education; persuasion	Not described.	Clinical practice setting. Duration not described	Yes. Risk-tailored information messages (education and risk assessment). I: Handouts addressed traditional HBM constructs (barriers, BC seriousness, individual BC risk, benefits of yearly mammogram). Nutrition and physical activity recommendations included. No specific tailoring of invitation script.
Duan et al. 2000	Mammography	Part-time peer counselors, hired from participating churches assigned to telephone counseling, called participants from churches to provide individualized mammography counseling over the phone. *Unclear materials*: Counseling individualized to address barriers. Women were informed about their risk status and BC rates. Encouraged to ask their physicians for referral and information about convenient screening facilities.	Education; persuasion; enablement	A survey firm collected the baseline telephone data. Trained and supervised peer counsellors conducted the brief year 1 telephone F/U.	Community setting. One individualized telephone counselling session conducted annually for 2 years.	Not described. It is only mentioned that individualized mammography counseling was provided by telephone.

ITT - Intention-to-treat analysis; I – Intervention group; C – Control group; CATI - Computer Assisted Telephone Interview

5.4.5 Theoretical framework and constructs

The underpinning theoretical approaches adopted in each study are summarised in **Table 5.5**. All six studies utilised the HBM, but this was often not in depth. No RCT was found adopting the CSM as the conceptual framework to increase mammography uptake.

Only one study targeted all constructs found within the HBM (Bodurtha et al. 2009), followed by five constructs in Sadler et al. (2011). Interventions targeted perceived mammography barriers in all studies, followed by perceived mammography benefits in 5 studies (Wu and Lin 2015; Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011; Bodurtha et al. 2009), perceived susceptibility of BC in 4 studies (Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011; Bodurtha et al. 2009), self-efficacy in 3 studies (Wu and Lin 2015; Secginli and Nahcivan 2011; Bodurtha et al. 2009), perceived severity of BC in 3 studies (Wang et al. 2012; Sadler et al. 2011; Bodurtha et al. 2009) and cues-to-action in 2 studies (Sadler et al. 2011; Bodurtha et al. 2009). The knowledge variable was less likely to be addressed in the interventions (three studies) (Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011).

Three studies reported which scale was used to measure health beliefs i.e., Champion's Health Belief Model Scale (CHBMS) in Secginli and Nahcivan (2011) and Wu and Lin (2015) and the Chinese Mammography Screening Beliefs Questionnaire in Wang et al. (2012). No studies reported if or how theory was used to select recipients or tailored interventions of whether theory was adapted. Three studies reported when the targeted constructs were measured. Health beliefs were assessed at baseline and 6-months post intervention in Secginli and Nahcivan (2011). Health beliefs were administered before and after the intervention in Wang et al. (2012). Baseline and six month follow-up surveys were carried out in Sadler et al. (2011). Although one study reported that perceived benefits, barriers, self-efficacy, and knowledge related to BS were measured, it did not report the results of the constructs at 4-month follow-up telephone survey (Wu and Lin 2015).

Justification for HBM use and the reasons why certain HBM constructs were the target in interventions was provided in only three studies (Wu and Lin 2015; Sadler et al.

2011; Secginli and Nahcivan 2011). These justifications were based on earlier research, which had identified the important and modifiable constructs related to improved mammography adherence.

5.4.6 Effects of programmes on outcome measures and tools used in measuring outcomes

5.4.6.1 Effect on mammography uptake

Mammography uptake was self-reported in all studies, with inconsistent results (**Table 5.4**). Wu and Lin (2015), Secginli and Nahcivan (2011) and Bodurtha et al. (2009) did not find any significant difference between the intervention and control groups. Wu and Lin (2015) further performed a sub-group analyses of insurance status, age and length of residence in US in assessing the intervention effect on mammogram uptake. A significant difference between groups was noted in women having insurance coverage to undergo mammography (56% I versus 34% C). Wang et al. (2012) revealed that only low-acculturated women in the intervention group had significantly increased mammography uptake six months post-intervention ($p < 0.05$). In Duan et al. (2000), the telephone counselling intervention maintained mammography adherence among baseline adherent-participants and reduced the non-adherence rate at one-year follow-up from 23.5% to 15.8% ($p < 0.05$). Similarly, in Sadler et al. (2011), women in the BC intervention group (BC education sessions offered in beauty salons) reported significantly higher mammography rates compared to women in the control group who had received information about diabetes during the same six-month timeframe. At baseline, there were no significant differences in reported mammography adherence and CBE. Given the high attrition rate by follow-up, the intention-to-treat (ITT) analysis did not produce significant differences between groups at follow-up. However, the ITT analysis showed similar trends to the completers analysis, such that women in both treatment arms reported significantly ($p < 0.05$) higher mammography rates at follow-up compared to baseline.

Table 5.5 - Theoretical models

Study	Is theory/ model mentioned?	Are the relevant theoretical constructs targeted?	Is theory used to select recipients or tailored interventions?	Are the relevant theoretical constructs measured?	Is mammography behaviour-related theory tested?	Is theory adapted?
Wu and Lin 2015	HBM with justification	Yes. Three HBM constructs (perceived benefits, barriers, self-efficacy). Knowledge variable related to BC screening	Not reported	Perceived benefits (5 items), barriers (15 items) and self-efficacy (Champion's 10-item measure) measured (4-point Likert-type scale). Knowledge (13-item scale developed by principal investigator.	Self-reported data on demographic variables, knowledge, beliefs, and screening behaviours at baseline and 4 months. I: mammography screening increased to 40% (n=34) compared with 33% (n=27) for C at 4 months; not statistically significant.	Not reported
Wang et al. 2012	HBM – no justification	Yes. Four HBM components (perceived susceptibility, perceived severity, perceived benefits, perceived barriers). Knowledge variable.	Not reported	Four validated subscales: perceived susceptibility, severity, benefits, and barriers from the Chinese Mammogram Screening Beliefs Questionnaire (Wu and Yu, 2003).	The cultural video, generic video, and fact sheet increased mammography use by 40.3%, 38.5%, and 31.1% from baseline, respectively. A significant intervention effect observed only in one subgroup: The cultural video significantly increased mammography screening among low-acculturated women over the fact sheet (OR=1.70, 95% CI=1.04, 2.78). Both video groups reported fewer barriers after I than C group.	Not reported
Sadler et al. 2011	HBM with justification	Yes.	Not reported	Yes. Measure not reported, except for baseline and	Yes. Women in I engaged in mammography screening with	Not reported

		Five constructs: susceptibility, severity, benefits, barriers, and cues to action.		F/U surveys (assessed BC awareness, personal exposure to BC, personal vulnerability, steps to reduce personal risk of BC mortality, and adherence to guidelines).	significantly greater frequency than women in C who had received information about diabetes during the same six months.	
Secginli and Nahcivan 2011	HBM with justification	Yes. Four constructs: perceived susceptibility, benefits to mammography and BSE, barriers of mammography and BSE, confidence in performing BSE).	Not reported	Yes. Champion's Health Belief Model Scale (CHBMS) was used to measure health beliefs of susceptibility (5 items), benefits of BSE (6 items), benefits of mammography (6 items), barriers to BSE (6 items), barriers to mammography (5 items), and confidence (11 items) by using five-point Likert responses. Health beliefs were assessed at baseline and 6-month post-intervention.	Yes. I: significant changes pre- to post-test in perceived susceptibility, benefits of BSE and mammography, and confidence (all increased), perceived barriers to mammography (decreased). No significant changes in I for perceived barriers to BSE. C: significant changes pre- to post test in confidence, and barriers to mammography (all increased), and perceived susceptibility, barriers to BSE, and benefits of mammography (all decreased). At 6-months, mean scores were significantly higher in I for all health belief scales ($p < 0.05$) except for barriers to mammography ($p = 0.116$).	Yes
Bodurtha et al. 2009	HBM – no justification	Yes All 6 HBM constructs.	Not reported	Not reported	Not reported	Not reported
Duan et al. 2000	HBM – no justification	Yes. One construct: Barriers.	Not reported	Not reported	Not reported	Not reported

5.4.6.2 Effect on mammography intentions

One study reported women's screening intentions to obtain a mammogram (Bodurtha et al. 2009). The former asked participants to report their intention by rating how likely they were to get a mammogram in the coming year. Responses were dichotomized as 'Definitely or Very likely' vs. 'Unlikely', 'Somewhat likely' or 'Not sure'. No statistical difference was found in mammography intentions by intervention condition overall.

5.4.6.3 Health beliefs about breast cancer and screening

Studies show contradictory results for changes in beliefs about BC and screening (**Table 5.5**). Three studies (Wu and Lin 2015; Wang et al. 2012; Secginli and Nahcivan 2011) used the sub-scales of a standard, validated scale in different languages i.e., Champion's Health Belief Model Scale (CHBMS) (Wu and Yu 2003; Champion et al. 1997; Champion 1993) to evaluate changes in health beliefs about BC and mammography screening, in the areas of perceived susceptibility (Wang et al. 2012; Secginli and Nahcivan 2011), perceived benefits and barriers (Wu and Lin 2015; Wang et al. 2012; Secginli and Nahcivan 2011), perceived severity (Wang et al. 2012), and self-efficacy (Wu and Lin 2015; Secginli and Nahcivan 2011). Secginli and Nahcivan (2011) found that at 6-months post-intervention, the mean scores were significantly higher in the intervention group for benefits, self-efficacy and susceptibility ($p < 0.05$) except for barriers to mammography ($p = 0.116$). Wang et al. (2012) found that participants in the intervention group who obtained a mammogram during the follow-up period reported significantly lower perceived barriers to screening six months post-intervention ($p < 0.05$) and significantly greater risk perception than that of the control group. Wu and Lin (2015) found no statistically significant differences in perceived barriers, benefits or self-efficacy between groups at 4-months post-intervention. The other three studies did not report the scales used to measure health beliefs (Sadler et al. 2011; Bodurtha et al. 2009; Duan et al., 2000).

5.4.6.4 Effect of knowledge of breast cancer and screening

The content of the intervention played an important role in increasing breast health knowledge and changing participants' screening behaviour. Key BS messages were targeted in three studies (Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011), such as facts on BC, information on the effectiveness and importance of screening, screening recommendations, myths or misconceptions, and health beliefs about cancer and screening. However, the changes in BC knowledge levels before and after the intervention produced inconsistent results.

The knowledge scores in Secginli and Nahcivan (2011) showed a significant increase in the intervention group over time ($p < 0.001$), but the knowledge scores in Wang et al. (2012) and Sadler et al. (2011) showed no statistical significant difference in knowledge scores between groups. This could be due to the diversity of instruments used to assess knowledge. Two studies used two different but validated knowledge tests to assess knowledge of BC and screening, with higher scores meaning greater knowledge (Wang et al. 2012; Secginli and Nahcivan 2011). The latter used a 22-item breast health knowledge (BHK) form to assess knowledge at baseline, immediate post, and 3- and 6-month follow-up period. Wang et al. (2012) used a previously validated 10-item instrument to measure knowledge at baseline and 2-4 weeks follow-up. The instrument used in Sadler et al. (2011) to assess knowledge at baseline and six-month follow-up was unreported, and hence considered of unknown validity.

5.4.7 Risk of bias

The results of the 'risk of bias assessment' are presented in **Table 5.6**. All trials were judged as unclear or at high risk of bias in at least some domains. In the majority of studies, the risk of bias from not blinding trial personnel were identified as high risk or unclear, while for blinding outcome assessors, the majority of articles (five studies) were unclear. One study was assessed as having a high risk of bias in the random sequence generation (Bodurtha et al. 2009), while another study was considered to have a high risk of bias for allocation concealment (Secginli and Nahcivan 2011). Three studies were assessed as having a high risk of bias for addressing incomplete outcome data (Wang et al. 2012; Sadler et al. 2011; Bodurtha et al. 2009). Three studies (Wu and Lin 2015; Secginli and Nahcivan 2011; Duan et al. 2000) did not use ITT analysis.

Table 5.6 - Risk of bias

	Design	Selection bias		Performance bias	Detection Bias	Attrition bias	Reporting bias	
Authors		**Random sequence generation**	**Allocation concealment**	**Blinding participants/ personnel**	**Blinding outcome assessment**	**Incomplete outcome data**	**Selective reporting**	**Other bias**
Wu and Lin 2015	Prospective RCT (2-arm) single-blind study - the efficacy of an individually tailored telephone counselling vs. NCI mammography brochure (control)	Unclear	Unclear	High	Unclear	Low; No ITT analysis.	Low	High
Wang et al. 2012	RCT (cluster) (3-arm) – a culturally-targeted video and a generic video vs. BC fact sheet (control)	Low	Unclear	Unclear	Unclear	High; ITT analysis.	Low	Low
Sadler et al. 2011	RCT (cluster) - BC education sessions offered in beauty salons vs. a comparable diabetes education program (control)	Low	Low	High	Low	High; ITT analysis.	High	Unclear
Secginli and Nahcivan 2011	RCT – nurse-delivered breast health promotion vs control (general information except breast health).	Low	High	Unclear	Unclear	Low; No ITT analysis.	Low	Unclear
Bodurtha et al. 2009	RCT - Risk-tailored information messages (education and risk assessment) vs. control (general information about BC practices, including mammography, not tailored to women's risk level and did not address HBM factors).	High	Unclear	Unclear	Unclear	High; ITT analysis.	Low	Unclear
Duan et al. 2000	RCT (cluster) - Telephone counseling vs. control	Unclear	Unclear	High	Unclear	Low; No ITT analysis.	Unclear	Unclear

5.5 Discussion

This is the first systematic review of interventions to explore the effectiveness of intervention strategies to increase mammography uptake based on two key theoretical models – HBM and CSM. This review sought to provide information on the programme characteristics that could potentially inform the development of future interventions for the Maltese population. Six RCTs were found to have used the HBM as the theoretical basis to guide the development of intervention strategies in promoting mammography compliance. There is a clear gap in the literature regarding interventions to improve mammography uptake through theoretical frameworks such as the HBM and CSM, evidenced by the identified small number of studies. This is an important finding considering the high prevalence of BC and female mortality worldwide (Ferlay et al. 2013).

Apart from one study carried out in Turkey (Secginli and Nahcivan 2011), the other five studies were carried out in US, limiting the generalisability of the findings to other settings. The US healthcare system is based on private insurance, supplemented by Medicare for over 65s (Gardner 2013). In contrast, healthcare services in Malta as well as in the UK are free at the point of delivery. It is therefore likely that cost is more of a barrier for low-income women to attend mammography in the US compared to other countries. Nevertheless, it is also important to consider opportunity costs, even in the Maltese health setting. Women who are paid a wage (e.g. by the hour) incur a higher personal cost due to loss of income than salaried women (Gardner 2013).

5.5.1 HBM and theoretical constructs

Application of the HBM has frequently been confirmed in BS interventions (Ceber et al. 2009), indicating the importance of the model and its impact on BS behaviours. While the model constructs include perceived susceptibility, severity, benefits, barriers, cues to action and self-efficacy, only one study in this review used the HBM in its entirety (Bodurtha et al. 2009) and not all studies measured health beliefs as outcomes. Few trials reported changes in theoretical constructs and in those that did, results were inconsistent. There was also limited reporting of how constructs were operationalized as part of the intervention.

Perceived barriers was the most frequently (n=6) targeted construct. Hence, this review confirms that perceived barriers are the strongest constructs in predicting mammography behaviours, compared to other model constructs. However, the programme in Secginli and Nahcivan (2011) was not successful in decreasing perceived barriers to mammography and BSE. One reason for this effect of perceived barriers is that participants may have paid more attention to the barriers than to the benefits in performing screening behaviours. On the other hand, participants in the intervention group in Wang et al. (2012) reported significantly lower perceived screening barriers than that of the control group six months post-intervention and significantly greater risk perception. These reveal that following the intervention, participants were more aware of barriers that impeded them from performing the screening behaviours, and tried to resolve those barriers. When people consider that the benefits gained can outweigh barriers, then it is more likely that they perform the screening behaviour (Assari 2011).

Perceived mammography benefits is indicative of one's understanding of the benefits gained from screening compliance (Glanz et al. 2008). As for benefits to mammography and self-efficacy, the mean scores were significantly higher in the intervention group in Secginli and Nahcivan (2011) but appeared not to be associated with positive behaviour change in Wu and Lin (2015). When the perceived seriousness of the disease is high, and the disease is perceived as incurable, it can produce reverse effects on BS behaviour (Eskandari-Torbaghan et al. 2014). Given the crossover between theoretical constructs and behaviour change techniques, the positive results in the latter may be a result of the individual behaviour change techniques employed, such as self-regulatory behaviours, rather than the theoretical constructs.

5.5.2 The utility of CSM

The lack of use of CSM in RCTs and in informing BS interventions, in itself, is an innovative finding and worth noting, considering that the CSM allows the testing of relations between patients' reflections on their emotional responses to an illness and outcomes, such as quality of life and emotional coping (e.g., Evans and Norman 2009; Rozema et al. 2009). It seems that CSM has mainly been used to date for the prevention and management of other chronic illness threats (McAndrew et al. 2008) and to understand the illness perceptions of specific groups of patients (Figueiras and Alves 2007), or groups at risk from a particular illness (Hughner and

Kleine 2004). There is limited information on CSM's impact among healthy individuals and their lay perceptions of serious illnesses, and whether the model has the same structure and pattern of inter-relationships (Figueiras and Alves 2007). Hence, examining the relationship between healthy individuals' models of illness and their beliefs towards preventive health actions is the first step in the planning of appropriate strategies to increase BS uptake (Figueiras and Alves 2007).

5.5.3 Outcome measures and tools used in measuring outcomes

All six studies included valid outcome measures (i.e. self-reported receipt of mammograms, CBE and/or BSE). Besides recall bias, self-reports may be subject to other biases particularly in cases where cultural tendencies towards downplaying one's own opinion and the desire to please others or to demonstrate 'politeness' may influence findings (Nakamura 2001). These cultural features might lead women in general to over report screening uptake. Verifying attendance to mammography through medical records is a reliable way of confirming data accuracy, though retrieving such records may prove difficult, particularly if women attend private clinics. Furthermore, the use of standardised, valid and reliable tools to measure outcomes can help to produce high quality data (Chan and So 2015). This review shows that Champion's standardised and validated instrument (CHBMS) is commonly used to measure health beliefs. However, different measures were adopted by studies in this review to measure uptake rates, health beliefs and/or knowledge, making comparison and findings interpretation among studies difficult. Caution should be utilised in the interpretation of results as tool reliability and validity are not reported, and hence the quality of data is questionable.

5.5.4 Intermediate outcomes

Researchers have recognised the importance and relationships between health beliefs, knowledge of screening and cancer, intentions and final behavioural outcome (Zhang 2014). Any one or a combination of the latter mediates behavioural change, in order to enact positive health action (Orji et al. 2012). Hence, besides using screening uptake as an indicator of intervention effectiveness, major intermediate outcomes, such as health beliefs, knowledge and screening intentions, were added in this review. Limited supportive evidence emerged from this review on changes in knowledge of BC (n=1) (Secginli and Nahcivan 2011) and no evidence of changes to intentions to having mammography emerged (Bodurtha et al. 2009), possibly attributed to the lack of standardised measures used across studies.

5.5.5 Demographic factors

Demographic factors, such as age, education level, household income and health insurance, have an impact on women's screening attendance other than the intervention itself (Sheppard et al. 2008). By controlling these potential confounding factors during analyses, a more accurate estimate of the intervention effect on outcome measures can be achieved (Chan and So 2015). Four studies adjusted for these covariances during analysis in this review (Wu and Lin 2015; Wang et al. 2012; Sadler et al. 2011; Bodurtha et al. 2009). During sub-group analyses, older age, insurance coverage, and low acculturation were associated with greater screening intentions and uptake in the intervention group during sub-group analyses (Wu and Lin 2015; Wang et al. 2012). None of the potential moderators were found to be significant in Sadler et al. (2011) and Bodurtha et al. (2009).

The intervention effectiveness varied with ethnic groups, as the highest increase in BS uptake was in African Americans and Chinese-American women, while the difference in mammography rates were not statistically significant among Asian American women, Caucasian and Turkish women. This reflects the fact that participants' demographic and cultural characteristics and beliefs may not be adequately addressed when designing intervention materials. Culture is a powerful and multifaceted construct that influences beliefs, attitudes and behaviour (Pasick et al. 2009) and plays an important role in explaining cancer screening disparities in racial and ethnic groups (Lee and Im 2013). Identification of the prevailing cultural factors associated with BS behaviour among women would be required to enhance population-specific health promotion programs and strategies to increase cancer screening utilization. Additionally, exploring these factors helps to facilitate the design of adequate strategies in terms of age, literacy and income.

5.5.6 Intervention design and effectiveness

The review found that intervention studies varied greatly by study population and geographic area; hence it was not possible to arrive to a generalizable conclusion on the effectiveness of any one particular intervention. First, there were differences in the delivery of intervention strategies e.g., interventions targeting Chinese American women (Wu and Lin 2015; Wang et al. 2012) adopted cultural sensitive ways to deliver these strategies (e.g. culturally-targeted video (Wang et al. 2012) and an interactive, individually tailored telephone counseling program (Wu and Lin 2015) respectively. Second, different patterns were found in relation to intervention design and effectiveness.

Among the six intervention studies with valid outcome measures, only two used multiple intervention strategies (Wang et al. 2012; Secginli and Nahcivan 2011) to target Chinese American immigrants and Turkish women respectively. Evidence was found to support multiple strategies in increasing mammography uptake among certain Asian ethnic women: reminder letter and health education booklet delivered during a home visit (among Chinese, Malay, and Indian women in Singapore) (Seow et al. 1997). Further evidence from a Cochrane report favoured five BS intervention strategies: invitation letter; mailed educational material; invitation letter plus phone call; phone call; and training activities plus direct reminders for women (Bonfill et al. 2001). In another systematic review to evaluate interventions designed to increase the rate of breast, cervical, and colorectal cancer (CRC) screening (Brouwers et al. 2011), client reminders, small media, and provider audit and feedback appeared to be reasonable strategies to increase screening uptake, but one-on-one education in particular appeared to be an effective intervention to increase BS uptake at a population level. It is clear that intervention effectiveness appears to vary among diverse populations, methods of program delivery, and study setting. Hence, it cannot be concluded in this systematic review whether employing a combination of multiple strategies based on theory was more or less effective than single interventions in increasing mammography uptake among populations. This is inconsistent with other findings by Legler et al. (2002), where multiple interventions were most effective, leading to a 27% increase in mammography uptake rates, and in Gardner (2013) where multiple interventions showed the largest difference between intervention and control groups (20.7%). In the review by Bailey (2005), peer educators (‘face-to-face’), access-enhancing and multiple interventions were effective in increasing screening though no meta-analysis was carried out to determine effectiveness. Similarly, no meta-analysis was carried out in this systematic review and hence, the most effective strategy could not be determined.

There was weak evidence to suggest that the associations were stronger in studies with a shorter length of follow-up. There was also little evidence that the association between intervention and mammography uptake rates varied by source outcome (self-reports), location (urban or rural), whether control was usual care or not, whether mammography was free-of-charge or not, or by level of randomisation. In addition, five interventions were carried out in a community setting (Wu et al. 2015; Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011; Duan et al. 2000). However, only three community-based intervention studies revealed significant effects: (i) the culturally-targeted video (Wang et al. 2012) significantly increased mammography screening among low-acculturated women over the fact sheet; (ii) the telephone counselling intervention reduced the non-adherence rate at one-year follow-up (Duan et al. 2000); (iii) the BC education sessions in beauty salons increased mammography rates significantly when compared to women who had received information about diabetes in the control group (Sadler et al. 2011). Evidence has shown that home visits, invitation letters, media campaigns, and mailed culturally sensitive print materials alone may be ineffective in increasing screening uptake (Lu et al. 2012) but the effectiveness of community-based or workplace-based group education programs increases when additional support, such as assistance in scheduling/attending screening and mobile screening services are provided (Lu et al. 2012).

Training health professionals, or bilingual interviewers, or lay educators, proved to be effective in half of the studies to improve BS use. Cultural awareness training for health care professionals and outreach educators is likely to improve cancer screening uptake as it can help women overcome language and cultural barriers (Lu et al. 2012). On the other hand, cultural taboos, fatalistic views and attitudes towards cancer and screening may make it challenging to recruit women to participate in studies focused on breast or other cancer screening uptake (Ho et al. 2005; Liang et al. 2004; Yi and Reyes-Gibby 2003). Although five studies reported statistical power to determine significance (Wu and Lin 2015; Wang et al. 2012; Sadler et al. 2011; Secginli and Nahcivan 2011; Bodurtha et al. 2009) and overall, the sample sizes were large, the validity of findings remains questionable due to uncertainty of selection bias (**Table 5.6**) and the incomparability between intervention and comparison groups.

Finally, no studies reported cost information and hence, economic evaluation of the cost-effectiveness of most intervention studies is essentially infeasible. A meta-analysis on invitation letters and telephone calls to increase mammography undertook a cost-effectiveness analysis (Page et al. 2006) and found that when a phone number was available, a letter plus telephone call intervention was more cost-effective than a two letter intervention. Hence, further research is required to determine which interventions are most cost-effective.

5.6 Limitations

This review has several limitations that need to be acknowledged. Primarily, it includes studies published in the English language, omitting studies published in other languages. Secondly, the majority of the studies were conducted in the US, limiting the generalizability of findings since culture, accessibility of health care services and BS programmes, and cost affordability may be different to other countries. Further research is clearly warranted in other countries and other ethnic minority groups. Further systematic searches for articles have not been conducted since the searches carried out until 2016 due to resource constraints. However, PsycINFO, OVID EMBASE and OVID MEDLINE auto-alerts suggest that no additional studies have been published. The variation in research methods used in the identified studies is another limitation. Therefore, the findings are to be interpreted with caution due to the variation of tools for assessing outcomes, the varying validity of the translated instruments and the differences in random assignment. Due to its quantitative nature, this review did not allow for the exploration of women's experiences with these interventions. Such experiences would be useful in highlighting important issues to researchers who are planning future interventions. Examples of these issues include the benefits to be gained from participation other than behaviour modification, and the challenges to implementing interventions.

5.7 Conclusion

This systematic review is the first of its kind to examine the effectiveness of interventions using HBM and/or CSM theory to increase mammography uptake. Overall, the findings suggest that interventions based on HBM carried out in a community setting involving culturally-targeted material, telephone counselling and BC education can improve BS rates. Although the present review is consistent with previous findings supporting the notion that theory-based interventions are somewhat effective in promoting screening uptake (Han et al. 2011, 2009) (3 out of 6 studies), more rigorous studies are required to increase the evidence-base due to the limited quality of the included studies. Interventions need to be described in their entirety to allow for the identification of effective components and replication.

In some studies, intervention success appeared to be unrelated to the HBM constructs addressed, thereby challenging the utility of this model as the sole theoretical basis for BS interventions. Therefore, multiple health behaviour models seem to be more effective at increasing health behaviour and in meeting women's complex needs (Byrd et al. 2013; Mishra et al. 2009), such as incorporating the use of CSM. The effect of interventions that draw on CSM constructs is unknown. Further research is required to evaluate intervention effectiveness and support the use of evidence-based theory, including the value of CSM. The combination of HBM and CSM may have a significant impact on how these interventions can be designed and implemented. This would help to link the identified common factors and mediators influencing screening outcomes, such as demographics, knowledge, beliefs and attitudes, as well as the cognitive and emotional representations of an illness in order to guide the design, implementation and evaluation of interventions and enhance their adaptation across cultures and populations. Notwithstanding the effectiveness of multiple health behaviour models, factors such as culture are often omitted. There is need for a comprehensive model that includes such characteristics as well as other factors and mediators altogether to improve health behaviours. As there are still many gaps in the literature with regards to what is required for an intervention to improve BS uptake, a qualitative enquiry is necessary to explore what may be needed for such an intervention. The following chapters present the rationale and methods for such qualitative studies.

Chapter 6

Recommendations of Expert Steering Groups on Breast Cancer Screening in Malta – An Overview

6.1 Introduction

As discussed in Chapter 3, Intervention Mapping (IM) was the chosen overarching framework for the intervention development process using a structured approach that moves from theory to practice (Kok 2009; Tortolero et al. 2005). In this research, Steps 2 and 3 of IM were supported through discussions held within two steering groups and included health experts located in Scotland and in Malta respectively. This chapter describes how the use of expert steering groups as part of IM helped to elicit expert input on core elements of the intervention and the most appropriate methods and strategies for implementing a future intervention. For ease of reference, the group held in Scotland is referred to as the Scottish steering group (SSG), while the group held in Malta is referred to as the Maltese steering group (MSG).

6.2 Aims

The purpose of this chapter was to identify potential theoretically informed intervention components, construct matrices of change objectives and create a logic model of change relating to changing BS behaviours in Malta. This chapter therefore comprises Step 2 of IM (see **Table 3.1**).

6.2.1 Objectives

The objectives were:

1. To develop a 'logic model of the problem' (i.e. this logic model is designed to better understand lower BS uptake rates in Malta relative to other European countries) based on:
    a) the literature review about BS determinants (Chapter 2) (Both steering groups);
    b) quantitative findings of Studies 2-5 (Chapter 4) (Both steering groups);
    c) feedback about organizational capacity in terms of:
        (i) whether the mission of the national cancer plan (2017-2021) (Ministry for Health 2017) coincides with the goals of the future intervention(s) to increase BS uptake in Malta, and
        (ii) the readiness of the local NHS for implementing a future proposed intervention(s) (MSG);

2. To develop a ‘logic model of change’ (i.e. what needs to change as a result of a potential intervention) (SSG);
3. To judge basic fit to create a “short list” of potential future interventions to carry forward to Step 3 of IM (SSG) in terms of:
    i. Improving BS uptake, and
    ii. Priority population (MSG).

6.3 Methods

6.3.1 Key experts

A qualitative study was undertaken with key experts using IM as a systematic approach (Scarinci et al. 2012). Two expert groups met to discuss the findings of the quantitative data (reported in Chapter 4) about factors that influence BS uptake in Malta, to identify specific preparatory behaviours (performance objectives, POs) and determinants (factors) related to BS, and to propose appropriate methods and practical strategies. The SSG included international academics with expertise in screening behaviour and intervention design and implementation (6 experts). The MSG included health practitioners, service managers and policy makers with expertise in health management (3 experts).

6.3.2 Setting and recruitment

The SSG met at Stirling University in Scotland in November 2016 and the MSG at Sir Anthony Mamo Oncology Centre in Malta in March 2017. The location was based on the participants’ preferences and travelling practicalities. Participant recruitment for the SSG occurred between August and September 2016, and between February and March 2017 for the MSG. Potential experts were identified through discussions with my primary supervisor (GH). Inclusion criteria for the SSG included researchers in screening behaviour and complex interventions. Inclusion criteria for the MSG included heads of departments or consultants with responsibility to make leadership decisions and policies regarding primary care, screening and cancer care processes. Identified experts were contacted by myself mainly through email to determine individual availabilities to schedule the meetings.

6.3.3 IM Step 2: Identification of outcomes, performance objectives and change objectives

The first part of IM Step 2 involved discussions with key experts on the desired outcomes of the intervention. The overall desired outcome was to increase BS uptake. Second, POs in relation to the specified outcome were identified by the SSG i.e. a checklist of what needs to happen in order to increase BS attendance. Finally, the objectives of the intervention were specified in terms of what needs to change in the theoretical determinants of BS behaviour (i.e. change objectives, COs). Each PO was therefore scrutinised separately by the SSG, and specific determinants deemed useful in changing each PO were identified. A matrix of COs (change matrix) was then formulated (through discussion with SSG) as an output of this process, detailing what will be targeted in the intervention and to help in the identification of a list of feasible interventions (SSG) based on feedback about priority population and organizational capacity fit (MSG). Although this was a time-consuming process, the SSG was required to be precise about which behaviours should be targeted and what COs (actions) were required in order to achieve the POs, and thus improving BS uptake.

6.3.4 IM Step 3: Selecting methods and practical strategies

Following construction of change matrices, the next step was to discuss appropriate methods to change BS behaviour and translate these into practical strategies. First, each determinant (e.g. barriers) that was found to be significantly associated with non-attendance (Chapter 4, Studies 2-5) was discussed by the SSG with a view to propose suitable change methods. The MSG took into account the given restraints in time and finances and characteristics of the target population and the abilities of local health educators delivering future interventions. This led to the choice of several ideas for practical intervention techniques derived from theory-based methods which were identified in the literature and translated into practical ideas, aided by the experience of the international experts.

6.3.5 Data Collection

Data collection was conducted using the same enrollment and qualitative data collection processes during both steering groups. All experts gave written informed consent (by email) prior to participation in the steering groups and written consent on the day of the group meetings

(Refer to Information Sheets (**Appendix 6.1a, b**) and Consent Form (**Appendix 6.2**)). Both steering groups were audio-recorded and transcribed verbatim by the researcher. No compensation was provided to the experts, except for one expert who travelled from Leeds to Stirling. I applied for a research post-graduate support fund of £250 to compensate for travel expenses of this SSG member.

6.4 Results

6.4.1 IM Step 1: Needs assessment and logic model of the problem

First, a discussion with key experts focused on key determinants influencing mammography non-attendance in Malta. A summary and collation of findings was presented by myself to the experts (**Table 6.1**). To assist in data reporting, the SSG organized the data from the needs assessment into a logic model of the problem (**Figure 6.1**) based on the theoretical literature (Chapter 2) and quantitative findings (**Table 6.1**). There was a high level of consistency in personal and environmental factors identified through the literature and cross-sectional data. Hence, the discussion focused on low knowledge, fear of finding BC, fear and embarrassment concerning the procedure, negative attitudes toward BS, low perceived risk and other logistical barriers such as lack of time and transportation.

Table 6.1 - Synthesis and collation of findings for Studies 2-5

Socio-demographic factors	Health status	Knowledge of BS frequency (TI)	HBM Predictors	CSM Predictors	Main Outcomes	Conclusions
FIRST BS INVITATION						
Family income	-	Non-attendees were most unsure of TI	Perceived Barriers (strongest)	Cyclical Cancer Timeline Illness Coherence	**Reasons** for non-attendance: 1. **Key** reason was **Fear** (41.0%) (i.e. of result), pain, unknown procedure, radiation, and embarrassment). 2. Private Mammography 3. Never received an invitation 4. Minor practical reasons i.e. 'busy at work' or 'home', 'transport issues', 'on vacation' and 'being ill'. High awareness of BC signs and symptoms (>80% agreement for 7 out of 8 signs), but wide variation about causation (e.g., germ or virus: 38.6% 'agree', 30.7% 'disagree'). **Strongest Predictors**: HBM, particularly perceived barriers but illness perceptions improved model accuracy to predict non-attendance when compared to HBM alone (65% vs 38.8%).	Interventions should be based on theory including HBM and CSM constructs, and should target first BS uptake and specific barriers to reduce disparities and increase BS uptake in Malta.
SECOND BS INVITATION						
-	Breast condition / disease	Non-attendees were most unsure of TI	Perceived barriers (strongest)	BC identity	First BS uptake was the strongest sole significant predictor of subsequent uptake (OR = 0.102; 95% CI = 0.037, 0.283; *p* = 0.000).	Interventions to increase BS uptake should target first invitees since attending for the first time

					The inclusion of illness perception items improved regression model accuracy in predicting non-attendance (84.6% vs 30.8%).	is a strong predictor of attendance and non-attendance for the second screening invitation.
LIFETIME SCREENING						
Family income Status (lower number of widowers attend) Non-drivers (91.5% of drivers attended vs 81.9% of non-drivers)	Breast condition / disease (100% having breast condition vs 82.9% of women without breast condition) Relatives or close friends	Non-attendees were most unsure of TI	Perceived Barriers (strongest) Cues to Action	**-**	**Health beliefs** were the strongest significant predictors to describe the variance between lifetime attendees and non-attendees. Non-attendees (n = 56) were women with a lower family income ($\chi2 = 13.1$, $p = 0.011$) who were not encouraged by their GP ($\chi2 = 4.9$, $p = 0.027$) and were more anxious ($p = 0.040$) and fearful ($p = 0.039$) than attendees.	Women who do not attend the MBSP are not a homogenous group. Future research should target women's health beliefs, and focus on women who were never screened as these require more targeted campaigns to reduce disparities.
TIMELY SCREENING ADHERENCE						
-	-	Non-attendees were most unsure of TI	Perceived Barriers (strongest) Cues to Action	-	Health beliefs were the strongest significant predictors to describe the variance between adherent and non-adherent attendees. There was significant association between adherent and non-adherent mammography attendees against organized and private screening ($\chi2 = 24.6$, $p = 0.000$).	Future research should target women's health beliefs, and focus on those who are non-compliant with recommended time intervals as these require more targeted campaigns to reduce disparities.

Note. Variable names found in different cells represent the significant variables under each construct/category.
- : no variable/s found to be significantly associated, TI = Time Interval

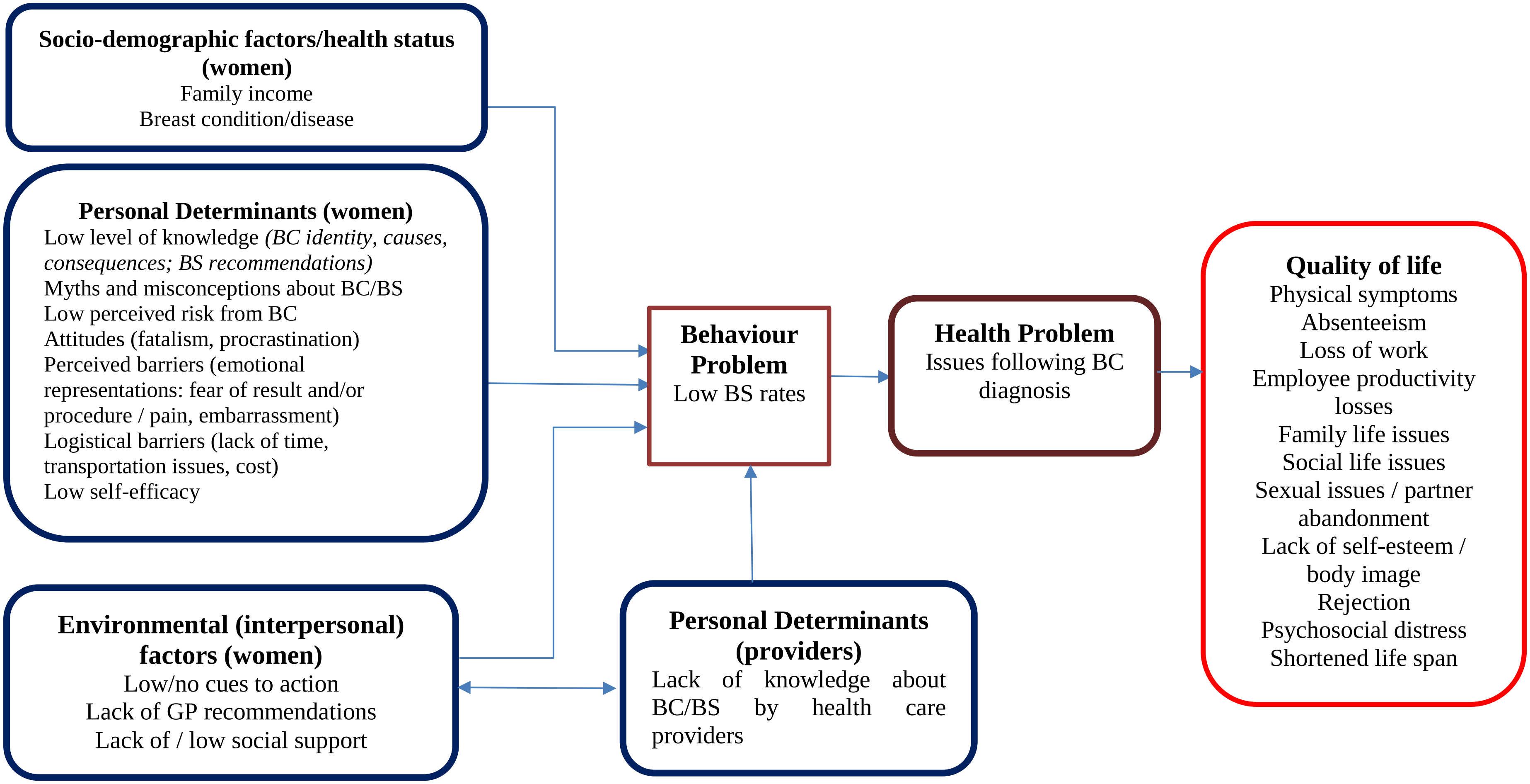

Figure 6.1 - Logic model of the problem

6.4.2 IM Step 2: Performance Objectives and Matrices of change objectives

Based on the needs assessment (Step 1), both steering groups considered whom to target prior to deciding on the delivery of an intervention. Both groups discussed whether the most important target group were attendees, non-attendees or those who attended privately. It was agreed that lifetime non-attendees were the most difficult to reach group and challenging to recruit for group discussions. Hence, the overall behavioural outcome was defined as *"Non-attending women will attend for BS within 6 months of a missed appointment or after having received the intervention"*. It was agreed in both committees respectively that the 'barriers' construct in the HBM was the most significant component to target in a future intervention.

Following the latter discussion, the following POs were developed for two groups (individuals and healthcare providers) i.e., what participants need to do to attend BS, and what healthcare providers need to do to aid women to attend (see **Table 6.2**). These POs address preparatory behaviour for BS use.

Table 6.2 - Behavioural outcomes with associated performance objectives

Behavioural outcome for women	**Behavioural outcomes for healthcare providers**
Non-attending women will attend for BS within 6 months of a missed appointment or after having received the intervention.	*Healthcare providers will facilitate women's attendance to BS.*
Performance objectives	
PO1. Woman considers to have a mammogram.	**PO1.** Unit directors will facilitate transportation to the centre.
PO2. Woman sets an appointment or contacts the centre.	**PO2.** Healthcare providers will design and develop culturally and linguistically tailored intervention/s and related materials.
PO3. Woman arrives at the centre and experiences having a mammogram.	**PO3.** Physicians will make a referral for mammography, when necessary.
PO4. Woman obtains results of the mammogram.	
PO5. Woman makes a reminder for next appointment.	

The next step was for the SSG to create a matrix of change objectives (COs) for each subgroup (**Table 6.3, 6.4**) by placing POs in the left column, and personal or external changeable determinants in the middle of the matrix. Then, for each determinant and the corresponding PO the SSG asked: *What has to change in relation to the determinant so that the Maltese population can achieve the desired PO?* These COs were recorded in the right column cells of the matrix. During the discussion, changeable determinants of screening behaviour were identified by the SSG based on factors that were significant from the survey findings that were considered both important and changeable to the target group. Knowledge, barriers and benefits, self-efficacy, perceived social norms on screening and awareness of peer behaviour regarding mammography were selected as the most important determinants for women. Other important environmental determinants were the availability of screening and its accessibility. Socio-cultural determinants were considered not to be changeable in a short intervention, but were considered to tailor the interventions culturally. Attitude was also considered an important determinant to be incorporated in a future intervention and was added to the determinants. For healthcare providers, knowledge, barriers and benefits, attitude and standards of care were considered as the most important personal determinants to BS.

Table 6.3 - Matrix cells of change objectives for Maltese women

Behaviour: *Non-attending women will attend for BS within 6 months of a missed appointment or after having received the intervention.*							
Performance Objectives (PO)	**Personal Determinants**				**External Determinants**		
	Knowledge (K)	*Perceived Barriers and Benefits (PBB)*	*Attitude (A)*	*Self-Efficacy (SE)*	*Perceived Social Norms (PSN)*	*Peer/Family Support (PFS)*	*Availability / Accessibility (AA)*
PO1. Woman considers to have a mammogram	K1a. Understands the meaning of BC and its related risks K1b. Understands that mammography screening can detect BC early K1c. Identifies herself at risk of developing BC K1d. Aware that the risks of developing BC will impact family and social life	PBB1a. Considers that pain caused by undergoing mammography is tolerable PBB1b. Considers overcoming fear of BC and of screening test PBB1c. Considers other barriers to screening	A1. Increases recognition of importance of screening	SE1a. Expresses confidence in her ability to overcome barriers SE1b. Demonstrates ability to manage competing demands	PSN1. Believes that other women will consider to obtain a mammogram	PFS1. Friends/family encourage her to consider attending for mammography	AA1. Unit sends an invitation letter
PO2. Woman sets an appointment or contacts the centre	K2a. Describes where to call and where to go K2b. Identifies date of booked appointment	PBB2a. Considers how to get to the centre PBB2b. Plans on how to overcome other barriers	A2. Believes in her role to request a mammogram if her doctor has not recommended one	SE2. Expresses confidence in her ability to call for an appointment	PSN2. Believes that other women will contact the centre and ask their doctor for a referral	PFS2. Friends/family encourage her to set an appointment	AA2. Unit arranges convenient date and time

PO3. Woman arrives at the centre and experiences having a mammogram	K3a. Describes the unit's location K3b. Describes the procedure K3c. Describes BS recommendations	PBB3. Expresses greater benefits than barriers to mammography	A3a. Believes that BS can be cured through effective treatment A3b. Describes the embarrassment from the test as minimal A3c. Realizes that mammography pain is tolerable and waiting time is short	SE3. Expresses confidence in obtaining mammography	PSN3. Believes that other women obtain mammography	PFS3a. Contacts relative or friend for support by accompanying her for the test PSF3b. Contacts relative or friend to facilitate transportation.	AA3. Unit facilitates date and time
PO4. Obtain results of the mammogram	K4a. Describes how to obtain the results K4b. Describes what can be seen on a mammogram	PBB4. Expresses benefits to being informed of the result	A4a. Describes the relief of having a normal result A4b. Describes the positivity of being able to acquire treatment for BC if found	SE4. Expresses confidence in being able to acquire the results and to understand them	PSN4. Believes in other women's ability to obtain the result	PFS4a. Relative or friend ask her about the result PFS4b. Relative or friend provide support by accompanying her for follow-up tests	AA4. Unit informs her about how and when she shall receive the result
PO5. Woman makes a reminder for next appointment	K5. Describes a plan on where and when to go for the next mammogram	PBB5. Expresses benefits in regular mammography	A5. Believes that regular mammography can detect BC early	SE5a. Expresses confidence in being able to call and schedule her next appointment. SE5b. Expresses confidence in her ability to obtain her next mammogram	PSN5. Believes that other women like her can obtain their next mammogram	PFS5. Relative or friend encourage her to schedule her next appointment	AA5. Unit arranges convenient date and time for her next screening

Table 6.4 - Matrix cells of change objectives for healthcare providers

Performance Objectives (PO)	***Personal Determinants***			
	Knowledge (K)	*Perceived Barriers and Benefits (PBB)*	*Attitude (A)*	*Standards of Care (SOC)*
PO1. Unit directors will facilitate transportation to the centre.	K1. Recognize transportation as a barrier to screening	PBB1. Believe that providing this service will be of benefit to women	A1. Believe that accessibility is part of the unit's role	SOC1. Recognize that other clinics facilitate transport to their unit.
PO2. Healthcare providers will design and develop culturally and linguistically tailored intervention/s and related materials.	K2a. Understand Maltese women's cultural beliefs on health and screening maintenance. K2b. Realize that Maltese women lack BC/BS related knowledge. K2c. Recognize that uptake to the MBSP is lower among Maltese women than in other European countries. K2d. Recognize that Maltese women are more likely to be diagnosed with an advanced stage of BC if they do not attend for mammography	PBB2. Recognize that women need to overcome barriers to BS.	A2a. Believe in their role to help women obtain mammography. A2b. Believe that cues to action aid BS uptake.	SOC2. Recognize that other providers deliver culturally sensitive interventions.
PO3. Physicians will make a referral for mammography, when necessary.	K3. Describe morbidity and mortality from BC for Maltese women	PBB3. Believe that a recommendation will help women overcome barriers	A3. Believe that a recommendation will increase BS uptake	SOC3. Recognize that guidelines for referral to mammography are met by other providers

6.4.3 IM Step 3: Intervention Design - *Selecting Theoretical Methods and Strategies*

The systematic review findings (Chapter 5, Study 6) were discussed with both the SSG and the MSG to identify change methods based on the theoretical literature that would address the COs, and to determine which types of practical strategies could be most effective at changing BS behaviour in Malta. In this step, the SSG converted the logic model of the problem to a logic model of change to create the foundation for comparing interventions, methods and strategies that were found to be effective (Chapter 5, Study 6) to the needs of the Maltese population (**Figure 6.2**). To do this, the SSG brainstormed theoretical methods to change specific determinants identified in Step 2. These included modelling (Bandura 1986), information transmission (Fernandez et al. 2005), persuasion (McEachan et al. 2008), facilitation, skills training, and entertainment education (Bandura 1986; Singhal and Rogers 1999). The group mostly focused on knowledge, barriers, cues to action, self-efficacy and emotional representations based on the theoretical constructs of HBM and CSM. Proposed methods included culturally congruent role models and their stories, guided practice and counseling for problem-solving and overcoming barriers, and persuasion. On the other hand, the MSG considered the acceptability of a potential intervention to the Maltese population i.e. that the delivery would be suitable to the target population, the costs involved would be reasonable, the design of intervention materials and its essential elements would be effective with screening users, and that the intervention would be culturally congruent to Maltese women. Hence, the logic model of change was completed by adding theory- and evidence-based change methods that were suited to influencing the determinants.

Further qualitative research was suggested in order to explore the perceptions of the target group (‘lifetime non-attendees’) in more depth, in terms of their perceived barriers and what they personally would consider as potential interventions to aid their attendance to BS (IM Step 3).

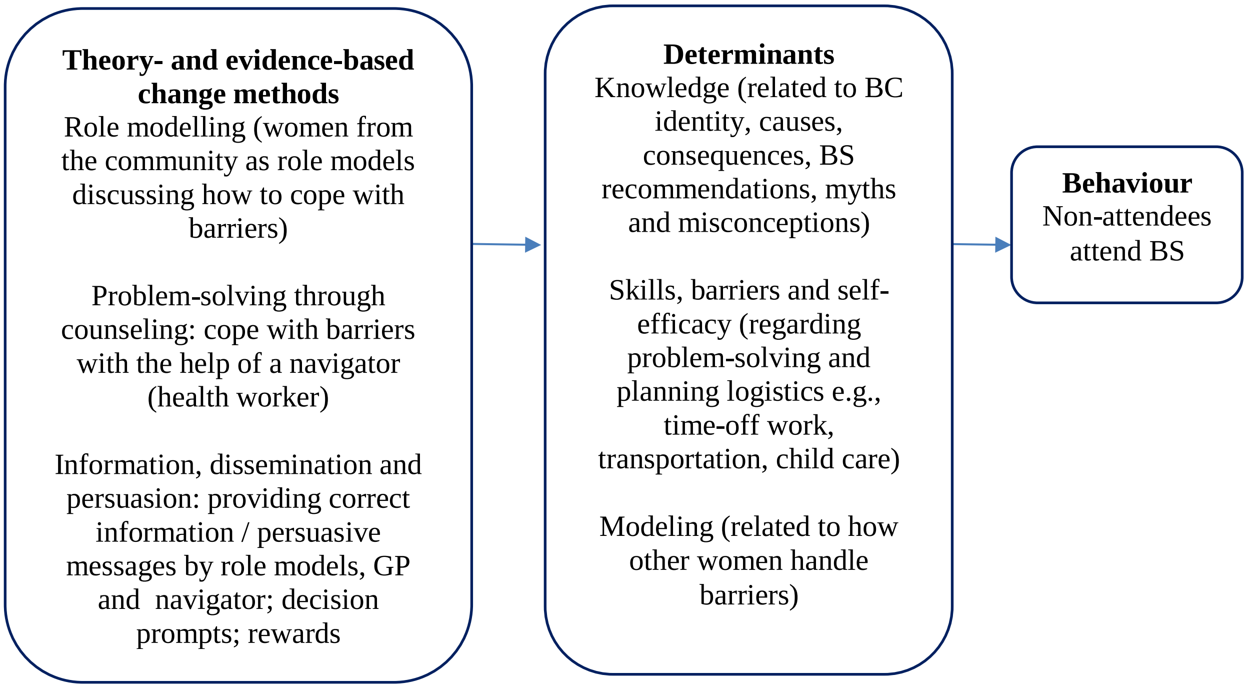

Figure 6.2 - Logic model of change

Based on the evidence and organizational fit, the following were the recommendations of both steering groups:

- HBM-based interventions show promise but more rigorous study designs that include all HBM constructs and use validated measures are required.
- Theoretical interventions based on CSM in combination with HBM have not been developed or tested; these could be effective in increasing mammography uptake.
- Community-based interventions involving linguistically appropriate material and cultural sensitive components (e.g., fatalistic views and attitudes towards BC and BS, respecting culturally or religiously constructed norms in conveying relevant information) show promise of improving uptake.
- Community wide campaigns could encompass multiple components (e.g. containing many different activities), and including elements of social support, such as counselling, education, community events, group walks, role models and their stories. Since a wide range of interventions were contained within this grouping, common elements were the focus on building, strengthening and maintaining social networks through the use of strategies such as buddy systems and discussion groups.

- Individually adapted interventions. The SSG focused on the strong evidence of the effectiveness of cues to action to suggest that interventions tailored to personal goals also appeared to be effective. Common elements of these interventions include: behavioural self-monitoring, prompting barrier identification and reinforcement through self-rewards. Problem-solving could occur through barrier-focused counseling (change method) delivered via a telephone call by a navigator (delivery) to cope with barriers.
- Practical strategies identified to operationalize the method 'entertainment education' include testimonials and role-model stories of women who had BC and survived, as well as people talking with their physician about BS to overcome barriers.
- Intervention content may include:
  - information messages individualized to address barriers;
  - addressing myths or misconceptions and providing facts on BC;
  - information on BC prevalence rates, risk assessment, the effectiveness and importance of screening and screening recommendations;
- Intervention materials may include:
  - culturally-targeted materials incorporating cultural beliefs;
  - interactive, tailored telephone counselling programs involving individualized counseling messages specific to addressing perceived barriers and misconceptions about BC risks;
  - education sessions about the importance of BC early detection e.g., synthetic breast models to show how BC lumps might feel;
  - point of decision prompts e.g., having signs by lifts, escalators, billboards and shop windows to encourage people to make use of BS.

6.5 Discussion and reflections

The use of expert steering groups in this research sets an example in the field of screening and fills a number of important roles, such as providing expert insight on screening determinants, determining what POs need to be fulfilled, prioritizing goals, assessing potential risks to the success of an intervention, and advising on change methods and strategies. The use of steering committees also served to instil a framework of collaboration between experts on theory- and evidence-based development of health interventions (Wolfers et al. 2007). To the best of my knowledge, it appeared that there were no examples in the literature on the use of steering committees for developing interventions to increase BS uptake. In the literature, the concept and responsibilities of a steering committee is neither clearly defined (Lechler and Cohen 2009) nor perceived in the context of screening programmes. The literature suggests that steering groups solely responsible for the implementation of projects do not widely exist (Lechler and Cohen 2009). Committees are often set up by senior management teams of an organization to initiate and monitor projects by providing oversight into project budget, duration, risk, number of competencies (technologies), and visibility (Lechler and Cohen 2009). In this research, the SSG and MSG consisted of senior executives or researchers from different organizations to provide expert input in the field of screening and interventions. Hence, the use of steering groups as part of IM will add to the development of practice for the design of culturally sensitive interventions in the BS field.

I experienced that using IM in research development and in practice requires flexible handling of a more compressed IM framework than that described in the literature, since the application of IM took more time than was available. The difficulties with the application of IM according to its protocol is also found in the literature (Wolfers et al. 2007; Kok et al. 2006; Perez-Rodrigo et al. 2005) and our experience of using IM was similar to other researchers (McEachan et al. 2008; Kwak et al. 2007; Wolfers et al. 2007; Fernandez et al. 2005). Kwak and colleagues argued that the IM protocol is often applied to simple and uni-dimensional behaviours and can therefore be difficult to apply to multi-dimensional behaviours (Kwak et al. 2007). Despite the IM being time-consuming, it allowed us, as group members, to create a comprehensive, tightly focused and preparatory, theory-based intervention package. Although IM is a valuable guide to take the right steps in developing an intervention, it includes the risk of remaining in a lengthy endless process of doing further research on determinants, developing matrices for further specified POs, and moving iteratively between needs assessment, further exploratory research, intervention development and pre-testing. The knowledge of time and resources are unavailable in the day-to-day practice of public health services (Wolfers et al. 2007), and applying IM according to its full textbook instructions is therefore difficult in the practice of local screening programmes.

Although the role of steering groups is not clear-cut, I learnt to appreciate the great value that a team of experts brings to research. The collaboration between experts and myself was most helpful to combine the setting of specific practical objectives with theoretical insights of more general validity. My main tasks were to make sure that the targets of the IM steps were reached, and to organize and manage the consultation sessions with the experts. Therefore, I made every effort to ensure that the discussions were consistently in accordance with the theoretical strategies and fitted within the change objective matrices. Due to the experience of the experts in screening and implementation of interventions among diverse target groups, the SSG were best suited to create the logic model of change rather than the MSG. On the other hand, the preferences for the target group was best suited for MSG experts as they provided more detailed judgement of fit for potential interventions in terms of cultural fit, organizational capacity fit and cost-effectiveness.

A variety of interventions were suggested by both steering groups to change behaviour by targeting knowledge, barriers, cues to action, self-efficacy and emotional representations as the key essential constructs. However, if the stepwise IM process has made one thing clear, it is that little is known about what specific intervention could be most suitable to change determinants and screening behaviour of Maltese women. Although the committees were valuable to provide expert advice based on change methods and practical strategies, more research in this field is warranted in order to develop evidence-based interventions. Further research with non-attendees can contribute to this goal. It was agreed that further in-depth research with the 'lifetime non-attendees' is required through qualitative methods. This informed the next stages of this research.

6.6 Strengths and Limitations

The group discussions were held among a chosen group of experts. Their expertise contributed to further exploration of the evidence on behavioural determinants on BS uptake among women in Malta, a population that had not been researched before. The composition of the committees varied, consisting of Maltese experts and a broader international representation with varying contexts. This fed into the strengths of using IM as an overarching framework as it allowed a multi-disciplinary approach among experts, providing clear guidance on the application of theoretical evidence, and producing a systematic approach into the overall design of a potential intervention. These strengths are possible since IM allows researchers to clearly describe the relationship between interventional goals, POs, COs, appropriate methods and practical strategies. Some IM weaknesses for the undertaken IM steps include the training required to address each IM step (Fernandez et al. 2005). Although the matrices inform the content of potential intervention strategies, IM does not provide sufficient guidance for the development of specific intervention materials, how to construct key messages and does not specify what essential elements they should incorporate.

6.7 Chapter summary

Overall, the findings suggest that a research study can be positively influenced by the involvement of steering groups. The use of steering groups has shown a direct effect on decision-making through their proposed recommendations for this research, and an indirect effect on research performance by shaping and refining the context of IM processes. This affirms the importance of improving research effectiveness through the use of steering groups. From an organizational perspective, understanding their role will help form the integrative structural elements that need to be in place to gain full value from their investment in health management processes. Although time-consuming, steering groups agreed that using IM improved the overall planning of a future intervention which will greatly contribute to its success. Without this expertise, it is likely that the IM process would have been more difficult to accomplish. Further research is warranted to address the effective replication and dissemination of IM steps among other populations.

This chapter also served to discover gaps in knowledge, the realisation for further research with non-attendees, and identifying potential methods (e.g., barrier-focused counselling, entertainment education) and practical strategies (e.g., telephone calls, testimonials, role-model stories) to be undertaken in a future intervention. It also allowed to create systematic and visual matrices, and logic models to share an understanding of the relationships among the activities required to carry out an intervention and the changes required, focusing particularly on barriers, cues to action, self-efficacy, knowledge and emotions. The next chapter presents findings gathered from the World Café event as a participatory method for community engagement.

Chapter 7

Patient and Public Involvement: A World Café event - *'Science Espresso'*

7.1 Introduction

The purpose of this chapter is to describe how members of the public i.e. women and men were engaged in a Patient and Public Involvement (PPI) event through the World Café method, to enhance the understanding of the quantitative findings of this research. PPI is emerging as a critical component in successful implementation of health research findings (Hoddinott et al. 2018). The National Institute for Health Research advisory group supporting PPI in the UK (NIHR INVOLVE) has defined involvement as "research being carried out "with" or "by" members of the public (i.e. patients, potential patients, carers, people who use health and social services, people from organizations representing those who utilise services) (INVOLVE 2015) rather than "to," "about" or "for" them" (Hayes et al. 2012). This implies that PPI involves the active contribution of patients and members of the public from informal discussions to decisions about the research itself from study conception to dissemination (Hoddinott et al. 2018). While PPI is recommended from the earliest research stages through to dissemination of findings (Boote et al. 2015), there is limited information on the reporting of PPI in terms of the context, process, and impact of public involvement (Crocker et al. 2016). PPI is still in its recognition stages (Brett et al. 2014) and further research on the impact of PPI is required.

In view of the limited evidence for best practice (Kreis et al. 2013), frameworks such as the Public Involvement Impact Assessment Framework (PiiAF) (Popay et al. 2014) and Guidance for Reporting the Involvement of Patients and the Public (GRIPP) (Staniszewska et al. 2011) have been developed. The reporting checklists 'Guidance for Reporting the Involvement of Patients and the Public' (GRIPP2-LF i.e. long form and GRIPP2-SF i.e. short form) are the first international, evidence based, community consensus informed guidelines for the reporting of PPI in research. GRIPP2-SF, which includes five items on aims, methods, results, outcomes, and critical perspective of a PPI activity (Staniszewska et al. 2017), was used to report public involvement in this research.

7.2 Aim

The aim of this PPI activity was to collaboratively involve and engage members of the public to enhance the understanding of the quantitative findings (studies 2-5) and the systematic review in this research and to inform the design of future BS interventions in Malta.

7.2.1 Objectives

The objectives of this PPI activity were two-fold:

(1) To gain an understanding of patient and public perceptions to health and screening practices;

(2) To understand patient and public views on effective communication channels and interventions to increase mammography uptake in Malta.

7.3 Methods

7.3.1 Study design

Two World Café *type* focus groups were conducted as a participatory, effective and flexible method for hosting a PPI event. The World Café event is also referred to as a 'Science Espresso' in this thesis. This method facilitates group dialogue and reflection in a relaxed and comfortable atmosphere (i.e. a café-style ambience) (Estacio and Karic 2016). World Cafés allowed for participant engagement through sharing individual and collective ideas (Sheridan et al. 2010) on BC and BS. Hence, this PPI event was informed by World Café and focus group literature in the following ways.

Cafés have been named in different contexts to meet specific goals, for example 'Knowledge Cafés', 'Creative Cafés', 'Strategy Cafés', 'Leaderships Cafés', and 'Community Cafés'. The World Café concept originated in California at the home of Juanita Brown and David Isaacs in 1995 when a morning large-circle dialogue was disrupted by rain (http://www.theworldcafe.com/about-us/history/). The method is based on the realisation that best ideas emerge from informal processes, such as coffee breaks and dinners (Sheridan et al. 2010). In World Cafés, all participants are regarded as experts of their own lived experience and experiential knowledge. In café conversations, participants are allowed to set their own direction in response to the main café question, therefore no perspective is privileged over others. Cafés thus build a collective network of authentic knowledge among the participant community

(Brown and Isaacs 2005), with the key principle being that local community knowledge is privileged as it sets the agenda (Sheridan et al. 2010) rather than allowing professional knowledge to take the lead. Moreover, there is no pressure to reach consensus among participants since diverse perspectives are encouraged and valued.

Focus groups encourage peer-to-peer interactions by exploring areas of divergence and convergence (Hiratsuka et al. 2017). These interactions provide a setting for enabling discussion on multiple issues and exploring possible solutions (Duggleby 2005). World Café *type* focus groups have not been utilised in primary care or prevention (MacFarlane et al. 2017) nor in screening research. Hence, to the best of my knowledge, this piece of work is one of the first to report on World Cafés on BS.

7.3.2 Setting

With its official opening on 26th October 2016 and located in Kalkara (Malta), the Esplora Interactive Science Centre is Malta's first visitor attraction seeking to cultivate a scientific culture of research among visitors. The renovated centre consists of several interconnected buildings and outdoor spaces, with main exhibition halls, landscaped gardens and activity centres for visitors to experience hands-on workshops and entertaining science shows.

My proposal submitted to engage members of the public in research on BS was submitted to Esplora and was chosen from among numerous submissions as one of the final six '*Science Espressos*' (**Figure 7.1**). *Science Espressos* formed part of SPARKS - a European project funded by the Horizon 2020 Framework Programme of the European Union (SPARKS Grant agreement No. 665825). SPARKS took place among 33 partners from 29 European countries between July 2015-2018, and was designed to awaken an interest and awareness among citizens about the concept and practice of responsible research and innovation (RRI). A creative exhibition touring in the 29 countries combined research with hands-on activities to engage patients and the public through *Science Espressos*. The scope of the experience gained through the project aimed to fuel policy recommendations at the EU, national, regional and local levels to facilitate the development of and enrich RRI processes in the fields of health and medicine.

Hence, the *Science Espresso* on BC and BS was chosen as an open community event organised at Esplora on the 30th August 2017 to engage the general public in local research.

Figure 7.1 - The Six Science Espressos chosen from among numerous research submissions as part of the SPARKS European project

7.3.3 Recruitment

An open invitation to the general public was made in preparation for this event but the public was encouraged to register for the *Science Espresso* in order to have an idea of the expected attendance prior to the event. Although World Cafés tend to have at least twelve participants, no upper limit is recommended (Dickson and Tholl 2014). For example, a World Café event hosted 1,000 tables in several cities on a single day in Israel as part of a series of social justice protests (Hartman 2011), while sixty people attended a Café event in Ohio in 2005 on hunger issues (Wheatley and Frieze 2011). Therefore, Esplora's Programme Development Executive members (PDEM) provided online registration and contact numbers of the centre since it was acknowledged that a large number of attendees would be unmanageable, requiring considerable space. Members of the public were recruited primarily through word-of-mouth at cultural events, social media, TV and radio stations. I was invited on TV and radio programs to promote the event. Event advertising was also done through Facebook promotion among community organizations and female closed groups (**Figure 7.2**).

7.3.4 Procedures

The participatory activity was modelled after a café, with coffees and refreshments, allowing group members to establish a brief rapport with one another throughout the event. I conducted the *Science Espresso* on a late afternoon to accommodate participants with various work schedules. Husbands and wives were encouraged to attend the event together; this strategy helped recruitment dramatically, particularly that of men. Prior to the start of the session, all attending members of the public were provided with an information sheet (**Appendix 7.1a, b**) and were assured that all information would be reported in this thesis as collaborative feedback. Socio-demographic data were gathered prior to the start of the *Science Espresso* (**Appendix 7.2a, b**). The attendees were then seated around two tables (females and males respectively) with coloured markers and large flipcharts provided to encourage participants to write, draw and capture key emerging ideas.

Figure 7.2 - Facebook promotion of the Science Espresso

An executive member from Esplora introduced the *Science Espresso* by setting the context, sharing the Café etiquette rules, and putting participants at ease. The executive member then introduced the two table 'hosts' i.e. myself and a male research assistant from the local community who was formally paid and trained prior the event. I welcomed the participants, outlined the topic of the *Café*, together with the background and main findings of Studies 2-5 (**Table 6.1**). What followed was the opening of the café discussion where I posed a single open-ended question to the participants, *'Based on the findings presented to you, what does BC mean to you?'* Such an open ended question allowed participants to break into two groups (males and females) around two tables respectively. Since all men and women were comfortable to communicate in both languages, the discussions were conducted in English and Maltese as they pleased. Participants discussed the first question put forward by the host for 15 minutes and moved to the second table to discuss the second question '*What do you know about BS practices?'* thus serving as travellers, carrying key ideas, themes and questions into the next conversation. This process carried on for another three questions: *'Do you see a mammogram as important in your life / your partner's / mother's life?', 'What motivates you / makes it difficult for you / your partner / your mother to attend for screening?'* and *'In what ways can we best encourage you to attend for a mammogram?'* The table hosts briefly shared the main ideas from the table's previous conversation. The participants were encouraged to connect ideas from their previous table conversations and build on each other's contributions, during which the table 'hosts' took notes. In the final round of the *Science Espresso*, participants were encouraged to synthesize key points. In conclusion, I summarised and discussed all the feedback received in a large group conversation, making the key points visible to all participants to share insights with everyone. The PPI event lasted around two hours in total.

7.4. Results

7.4.1 Members of the public

Sixteen members of the public aged 18-69, residing in various localities in Malta, attended the *Science Espresso*. Hence, women and men sat at two tables of ten and six respectively. The ten female participants were 18 to 69 years of age. This age range happened to be well-suited to include women of screening age (i.e. 50 – 67 years currently being screened with the target to expand to 69 years), and younger women (<50 years) not yet invited to the MBSP. The sample included women with a level of education that varied between secondary level (n=4) and a tertiary education level (n=6). Of the 10 women, 4 were employed full-time. One of the latter women was a Director of a research company. Two women were retired, 3 were students and 1 was unemployed. Seven females were married or cohabitating while 3 women were single. One female had BC and was a member of a BC support group in Malta. The other women had no cancer but suffered from other health conditions, e.g. a light stroke. Six women had a relative with cancer, while 7 women had a friend with cancer. Two women had undergone a mammogram within the past 12 months, 3 women had undergone a mammogram within the past 2-3 years, while 5 women had never experienced a mammogram.

The ages for males varied between 30 and 57 years. The sample included men with a level of education that varied between diploma level (n = 4) and degree level (n = 2). All males were employed full-time. Four males were married or cohabitating, 1 was divorced and 1 was single. None had cancer; however, 2 men had a friend with cancer while 3 men had a relative with BC.

7.4.2 Addressing PPI objectives 1-2

To address objective 1, members of the public sought to explore their own beliefs and perceptions in relation to the quantitative findings of this research. The discussions focused on barriers and facilitators to screening and reasons for the latter perceptions. Regarding objective 2, the discussions sought to understand what communication channels and interventions would be effective to increase mammography uptake in Malta. The findings are divided into six categories as presented during the debriefing at the end of the café. Different sub-categories were outlined for each category by female members (FM) and male members of the public (MM) respectively and are tabulated in **Table 7.1**.

7.4.3 Category 1: The mammography procedure

7.4.3.1 Meaning 1: Prior experience of the examination

Female members discussed how positive experiences encourage mammography attendance and re-attendance. This was dependent on their satisfaction with mammography, the environment and support staff at the facilities. Female members who had participated in screening commented on their personal experiences of the procedure, e.g. the relaxing atmosphere at the screening unit had helped them to relax while waiting for the procedure. Additionally, FM2 spoke of the care received from radiographers, which was a motivating factor to re-attend for another mammogram. On the contrary, some female members spoke about how they *"hated it"* and that mammography *"felt so cold"*.

7.4.3.2 Meaning 2: Perceptions of the examination

Women's perception of mammography was discussed in relation to fear of pain and the related anxiety. Women discussed the need for reassurance and a step-by-step explanation of the procedure. Men discussed how women may instigate fear between themselves by exaggerating the level of mammography pain.

Table 7.1 – Categories and sub-categories as expressed by female and male members of the public

Category of findings	**Sub-categories (women 18-69 years)**	**Sub-categories (men 30-57 years)**	**Interpretation of findings (meaning)**
The mammography procedure	Fear Pain or discomfort Expectations of the service Risk perception Touch Personal needs	Fear Pain	Prior experience of the examination Perceptions of the examination
Supportive networks	Lack of GP recommendation Experiences of friends and other women Daughter-initiated screening appeals to mothers	Lack of GP recommendation Partner support	Role of health providers The influence of family and friends
Screening facilitators	Family Convenience Accessibility Early detection beliefs Knowledge	Early detection beliefs Knowledge	Able to overcome barriers
Screening barriers	Fear of having BC Pain or discomfort Embarrassment Radiation Accessibility Negative health care experience Negative screening experience Long waiting time for result	Fear of having BC Perception of pain or discomfort Cost, accessibility, and competing priorities (family and work)	Emotional issues Personal risk of mortality Practical issues Lack of information and communication Lack of trust in the health system Negative screening experiences
Communication channels	Bulk emails Printed leaflets/brochures TV Radio Social media	TV Internet	Able to attend through effective communication materials
Interventions to encourage BS and awareness	Pharmacies Nail technicians Hair salons Beauty therapists GP recommendation Social media	Partner encouragement and support Marketing through Billboards GP recommendation	Able to attend through effective interventions

7.4.4 Category 2: Supportive networks

7.4.4.1 Meaning 1: Role of health providers

Although GP recommendations to undergo mammograms were identified as key facilitators to mammography attendance, members reported that, similarly, their own doctors do not recommend mammograms or screening tests and if they did, they would consider the recommendations. Women and men discussed how they look for information from health providers and are eager to learn about screening information and prevention practices from their doctors. Another table discussion focused on the inconsistency and/or lack of doctors' recommendations on interval screening that act as screening barriers.

7.4.4.2 Meaning 2: The influence of family and friends

Female members discussed how women are eager to talk to other women regarding BC experiences to make decisions about screening and treatment. Men, on the other hand, discussed how they do not talk to other men regarding health-related decisions but consider their partner to be the key person to influence their decision-making. On the contrary, women discussed how their male partners are often not the key persons to trigger women's health-seeking action. Women tend to be influenced by health providers and view their partner's recommendations as a means of support once they have triggered a health action or when they are concerned about their health. Women described men's support as their main pillar of strength.

The family was a major motivator for women to get screened for BC. Female members expressed the need to be there for their families and wanting to avoid having their family care for them. As a result, personal health was described as important to them. Younger female participants expressed how they would discuss breast issues with their mother and that they would encourage her to go every time screening is advertised on the media.

Experiences of older women who had friends or relatives diagnosed with BC was a significant motivator for their participation in screening. FM4 described her personal experience, such that as soon as she found out a friend or relative was diagnosed with BC, this triggered her BS attendance on a regular basis.

7.4.5 Category 3: Screening facilitators

7.4.5.1 Meaning 1: Able to overcome barriers

Both female and male members discussed how BC can be adequately controlled so that treatment would be more effective, leading to improved survival. Men considered early detection to be the only way for “cure”. Both groups emphasised the importance of having correct and timely information from care providers in order to make informed choices. Other facilitators included family support such as providing transportation and receiving BS invitations and reminders.

7.4.6 Category 4: Screening barriers

7.4.6.1 Meaning 1: The impact of emotional issues

When screening barriers were discussed, the emotion of fear was the most prominent expression regarding BC within both groups. Female and male members discussed how the word ‘cancer’ brings fear and that the thought of having cancer instils a sense of death. They also discussed that embarrassment and privacy are factors that inhibit women from getting mammograms. Women described how uncomfortable it would feel to have other persons touching a sexual body part such as the breast.

7.4.6.2 Meaning 2: Personal risk of mortality

Fear was linked to receiving a BC diagnosis and metastasis, such that the spread of cancer could lead to long-term physical pain and mortality. Perceptions by men focused specifically on mortality as a death sentence, such that BC *“quickly kills you. It starts to eat you up.”*

7.4.6.3 Meaning 3: Practical issues

Both groups mentioned accessibility and competing priorities as practical issues due to family and work commitments. Recommendations included easier access to the clinic, more available parking spaces and more flexibility in the appointment hours and dates. Men also spoke about the importance of family commitments and how this may at times take priority even over their own health.

7.4.6.4 Meaning 4: Lack of information and communication

Another barrier revolved around the lack of information that instigates fear. Young female members and men spoke of how the risk of getting BC and other diseases are not discussed enough in the family and that family conversations can facilitate attendance to screening tests.

7.4.6.5 Meaning 5: Lack of trust in the health system

Members of the public went into detail to explain why they or their families did not trust medical professionals and spoke about the lack of trust in terms of a systems-level issue and lack of navigation through health care such that *'a patient is lost in the system'*. Some men also spoke about how their parents instilled this lack of trust in the medical team. Two younger women questioned the potential for unnecessary exposure to radiation during mammography and that this could be a result of professional incompetence.

7.4.6.6 Meaning 6: Negative health experiences

Common barriers to attending mammography were prior health experiences. Female members associated negative feelings with the mammography procedure experience, relating it to the pain experienced and the cool temperature of the "plates," while men spoke of the rough treatment given during consultations and long waiting times to receive health results. Members reported pain as a factor that affected their willingness to go for routine mammograms.

7.4.7 Category 5: Communication channels

7.4.7.1 Meaning 1: Able to attend through effective communication materials

Men agreed upon the internet and TV, but not the radio, to be ideal channels for disseminating information. Older women preferred bulk emails, printed leaflets or brochures, TV and radio sources. It was discussed how the internet is not considered an adequate communication channel for older women but appropriate for younger females as many do not have access to it and information provided online is generic.

7.4.8 Category 6: Interventions to encourage breast screening and awareness

7.4.8.1 Meaning 1: Able to attend through effective interventions

Men's comments reflected the effectiveness of partners' encouragement, marketing through billboards and GP recommendations as effective interventions. The role of the GP was also considered by female members as one of the most effective strategies to raise BC awareness and screening. On the contrary to women, male members considered phone calls to be a nuisance. While younger women suggested social media interventions, older women's suggestions reflected a more focused array of activities, such as information dissemination primarily in pharmacies, followed by beauty salons, hair and nail salons. The role of pharmacists was considered important and was thoroughly discussed among all female members.

7.5 Discussion

There is a growing body of literature about the relevance of community-based participatory approaches to enable meaningful dialogue and engagement (INVOLVE 2015). Moreover, it has become increasingly imperative for patients, families and community members to be engaged in the design and development of tailored interventions (Hayes et al. 2012). To date, this unique Maltese study has used the World Café method to explore patient and public views on BC and BS. In addition, group dynamics enabled Maltese women and men feel more comfortable to discuss the topic (Lee-Lin et al. 2012; Fontana and Frey 1994). Six categories were discussed; the interpretation of findings have important implications for healthcare professionals and family members to assist and encourage BS uptake in the Maltese community.

In this PPI event, both women and men alike emphasised the importance of the GP's role towards effective health outcomes. An Irish study found that participants felt that the GP should be more pro-active in the prevention of cancer, primarily through the provision of both verbal and written information (Keeney et al. 2007). Nonetheless, GP's possible issue of time constraints was examined in an American study, which sought to determine the amount of time required for a primary care physician to provide recommended preventive services to an average patient panel (Yarnall et al. 2003). The authors contended that the primary care physicians cannot achieve preventive service goals unassisted since the amount of time required is overwhelming. Nonetheless, presentation of patients with more advanced disease (Sant et al. 2009; Berrino et al. 2007) i.e. late presentation by patients are most likely explanations for late onward referral by general practitioners or lack of GP recommendations and adequate support. Such evidence highlights that family doctors could play a key role in cancer screening and prevention due to their frequent contact with the public and within the family unit (Ganry and Boche 2005).

Women discussed how they are often encouraged by other women's experiences to attend for screening. In turn, once women decide to trigger a personal health action, they inevitably receive support and recommendations from their partner, which in turn might sustain women's receptivity toward a screening invitation. Nonetheless, this is often and highly dependent on the relational aspects and strength of the interpersonal communication between the couple (Hsiung and Richard 2003). On the other hand, men saw their personal role as a supportive network to women's screening decisions. This PPI provides an argument for training both partners and the primary health care practitioners in health promotion.

The support of significant others such as daughters may also be fundamental to women's participation in screening activities. The economic and cultural conditions have greatly influenced how families have evolved across the years (Haldeman 2012; Cherlin 2005), such as the boundaries of parent-child communication in the past (Glenwick and Mowrey 1986) and parenting styles (Pittman and Chase-Lansdale 2001) – as might be showcased by some older men and women in this PPI, who have never discussed health or breast issues with their parents or more specifically with their mothers. It is precisely the recognition of this general shift of communication boundaries between parent and child throughout recent years (Nixon et al. 2012) that provides the impetus for exploring the feasibility of a daughter-initiated intervention. Early detection of breast and cervical cancers is known to be one preventive behaviour that may provide the adolescent daughter with a unique opportunity to provide encouragement to her mother or guardian to obtain screening (Mosavel and Wilson Genderson 2013; Browne and Chan 2012). The mother-daughter relationship in this PPI provides the primary context for exploring message design strategies for developing an adolescent-initiated screening appeal.

While many of these barriers are shared with other populations, i.e. accessibility, competing priorities and fear (Fayanju et al. 2014; Filippi et al. 2014; Baron-Epel et al. 2009), some barriers may be more explicit to Maltese men and women. Men were familiar with many of the barriers that women experience when trying to access a mammogram, similar to other American Indian men's perceptions of BS barriers for American Indian women (Filippi et al. 2014). It may be worth tackling barriers among Maltese men to encourage them to support their partner by facilitating women's attendance and adherence to recommended screening guidelines. Some older Maltese women and men considered the BS topic to be of a private matter, similarly to the study among American Indian men in Kansas and Missouri (Filippi et al. 2014). Embarrassment and privacy issues may need to be addressed through family-based education.

Cultural differences exist over pain in society, supporting the idea that minor discomfort perceived by men is considered much less severe than intense pain as experienced by some women (Markle et al. 2004). It was interesting to note in this PPI men's perception of pain as compared to that of women. Men described the mammography procedure as an exaggeration of mammography pain, which is perceived to be continuously instigated by other female influences. Nonetheless, ignoring or disregarding women's true feelings of pain may lead to their avoidance of screening tests. Studies have also found that the radiographers' supportive care led women to have positive experiences of the screening procedure (Myklebust et al. 2009; Poulos and Llewellyn 2005) and that lack of communication during mammography increased pain (Davey 2007). Hence, the provision of a comfortable and supportive environment during the mammogram can positively influence women's perceptions and motivation in screening participation.

Members of the public seemed receptive to and supportive of enhancing BS among the general Maltese population. Recommendations from men were towards screening promotion on TV and the internet as their preferred communication channels. On the other hand, women opt for more culturally-tailored media that is simple and easily accessible. Men offered suggestions to improve BS uptake by incorporating partner or family-based support. This finding indicates that communication dynamics are changing within families and that gender relations in reference to BS awareness are an important topic for future research.

On the other hand, women showed primary preference in pharmacist-led interventions as pharmacists encounter women on a weekly basis. Community pharmacies are increasingly recognised as an important setting to raise public awareness of cancer signs and symptoms as well as causes and risk factors of the disease. In Malta, community pharmacies are privately owned and are not subsidised by the state. On average, patients visit pharmacies more frequently than general practice and they are often more accessible than doctors (Department of Health 2008). Besides, pharmacies are found within every locality in Malta, are easily accessible on foot or by public transport and are open at more convenient times such as evenings and weekends. Moreover, a pharmacist is often a patient's first port of call when symptoms occur. A clinical audit on bowel cancer conducted by the Royal

Pharmaceutical Society highlighted the potential of pharmacies to reach symptomatic individuals who may not otherwise visit their GP. The two-week audit found 70% of pharmacies saw at least one patient with symptoms of bowel cancer (Cancer Research UK 2015). Moreover, the audit showed that men tended to present less frequently to general practice than women; hence pharmacies may represent an opportunity to engage men in health screening. These results were similar to those in a lung cancer audit (Cancer Research UK 2015). The audits showed that in the majority of cases, pharmacists took the most appropriate course of action, by either making a GP referral or over the counter medicines sale. The above audits highlight the key role that pharmacies can play in early cancer detection.

7.6 Limitations

This PPI event was strengthened by a widespread approach to recruitment (word-of-mouth at cultural events, social media, posters and TV/radio promotion). This piece of work contained two primary limitations. First, the number of members was small in comparison to the representation of men and women in the Maltese population. Hence, views of those who did not attend may differ to those who attended. Yet, this limitation is minimal since generalizability is not a goal of PPI. The objectives of PPI require multiple and diverse discussions, for which one World Café event can only provide a starting point. Second, the *Science Espresso* was conducted in the Southern area of Malta, which may have been a limited geographic location for easy access by women and men who live in the centre and northern regions of the island. However, the aim of this PPI event was to engage the public to enhance my understanding of BC and BS issues. Moreover, the representation of women and men as members of the public derives from different parts of the country. Another potential limitation may center around the fact that the café discussions were conducted on a culturally sensitive topic. This may have hindered participants' willingness to openly show their true feelings, particularly from a male perspective.

7.7 Conclusions

The PPI groups contributed to the understanding of the quantitative findings and provided women and men's views on health, screening practices and potential effective BS interventions. The cultural, social and healthcare-system factors as related to BS need to be addressed. Encouraging healthcare providers such as GPs to reinforce motivating factors and address inhibiting factors during their clinical encounters can potentially improve BS utilization in Malta. In addition, researchers may better identify enhanced involvement of partners and daughters in health decision-making if researchers use study models that emphasize household dynamics. Creating or using models that stress gender and household dynamics may be better suited to capture the changing positions and nuances of Maltese men's supportive roles in relation to decisions that pertain to women's health, including BS. The receptivity on the part of the parent and daughter positions the daughter-mother relationship as an ideal conduit for sharing BS information, improving education and developing child-initiated health interventions.

This PPI activity also identified potential interventions to encourage BS attendance in the Maltese community. Key strategies include tailoring health education messages and tackling fear on a personal level. A one-to-one intervention can be effectively delivered at suitable locations frequented regularly by women such as pharmacies to empower women with necessary resources and knowledge.

7.8 Reflections

PPI was found to be useful through the provision of meaningful input by members of the public. Based on the research's relevance to user needs, members of the public felt engaged in interpreting the findings, identifying issues and proposing solutions. Creating a dialogue with members of the public helped to make this research more patient and client centred. The PPI contributed missing voices of women and men and their perspectives that are not often heard in quantitative or qualitative research. This also builds a case to involve members of the public at various phases in the planning, implementation, management and evaluation stages of research. The potential problems with regard to PPI may be similar to challenges of involving patients in quality improvement initiatives. PPI may not be optimised for a particular research field or target group, resulting in risks of superficial engagement and inefficient use of resources. Moreover, finding patients and members of the public was challenging for me as it was time-consuming to spread the word on digital and social media. It can be difficult to recruit people with ill health, caring responsibilities and hard-to-reach groups such as those living in vulnerable social circumstances. Evidence shows that the most disadvantaged or marginalised in society are the hardest to access and engage (Bonevski et al. 2014). If more time was allocated to recruit a larger number of patients and members of the public, it would have made this event more successful. However, the fact that I went out in the community rather than expecting members of the public to attend at a hospital, health centre or in an academic setting helped to facilitate trust and engagement. Further consideration is required on who, where and how to engage patients and members of the public, the provision of training for PPI representatives and the flexibility required to tailor PPI to the research topic, methods and resources available. The next chapter presents the findings of face-to-face interviews with non-attendees.

Chapter 8

Non-attendance to Mammography Screening: A Qualitative Study among Non-attendees in Malta

8.1 Introduction

Despite the availability of breast screening (BS), non-attendees still struggle to access or respond to screening invitations (Benoit et al. 2003; Benoit and Carroll 2001; Browne 2000). Study 4 (Chapter 4) found that perceived barriers and cues to action were the strongest predictors of lifetime non-attendance and that non-attendees were more likely to be women with a lower family income, widowers, non-drivers, without a breast condition, who had no relatives or close friends with cancer, who were less encouraged by a physician, unsure of the screening frequency, and who were more anxious and fearful. Furthermore, public perceptions and involvement were achieved through the PPI activity using the World Café method (Chapter 7). However, both pieces of work did not explore in depth the health beliefs, illness perceptions and other determinants among Maltese women of eligible screening age who never attended for mammography. Inadequate understanding of women's underutilization of BS may constrain policy makers' ability to develop effective interventions (Rosicki 2010). In order to understand these factors, it is essential to explore the broader contexts - such as psychosocial, economic and structural issues that affect health-seeking behaviour among lifetime non-attendees who require a different and more targeted approach than those who have attended in the past but not routinely.

Evidence suggests that the above factors are better examined through qualitative methods rather than through survey alone (Kue et al. 2013; Lamyian et al. 2007; Thierry 2004). Gaining a more detailed understanding of women's beliefs and perceptions may help explain why mammography uptake does not appear to be sustained at a population level in Malta. In addition, determining women's sources of information may help explain gaps in knowledge or misconceptions about BC and BS. The most influential key messages that help determine women's health behaviours are those that women receive close to home, in their own 'world' (Kumar and Preetha 2012; Stoto et al. 1990). Hence, the recognition of these facilitating factors and barriers is the first step in persuading lifetime non-attendees to make better decisions about preventive and protective self-care (Lamyian et al. 2007). The data from this study (Study 7) will feed into the recommendations for potential interventions to increase BS uptake in Malta.

8.2 Aims

The aim of study 7 was to gain a better understanding of factors that influence BS non-attendance among lifetime non-attendees in Malta and to explore their knowledge and risk perceptions to guide the development of a future intervention to increase BS uptake. To address these aims, and to address RQ 4, *Which factors influence non-attendance among lifetime non-attendees and which interventions are considered appropriate to increase BS uptake in Malta?*, the following objectives were identified:

(1) To gain a better understanding of beliefs, perceptions, attitudes, barriers and knowledge regarding BS among lifetime non-attendees;

(2) To determine which interventions and channels are appropriate for communicating with women about BC and BS.

8.3 Methods

8.3.1 Design

Study 7 employed qualitative methods and is reported in accordance with consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al. 2007) (**Appendix 8.1**). A qualitative methodology was chosen for this study as it was well-suited to capture individual stories and can situate women's experiences in larger social, economic and historical contexts.

Face-to-face semi-structured interviews are the most commonly used technique in qualitative research (Eisenhardt and Graebner 2007; Press 2005). Although costly in time (Bowling 2009), face-to-face interviews provide the opportunity for probing and analysis of in-depth issues needing attention (Frankfort-Nachmias and Nachmias 1992). In the context of BS, this deeper exploration helps to elaborate the understanding of how and why women behave the way they do (Farooqui et al. 2013). Hence, the acquisition of a rich source of data about BS barriers, beliefs, perceptions and individual experiences enables an understanding of both individual (attitudinal, knowledge-based, skills-related, risk assessment) and organisational barriers (Farooqui et al. 2013; Gill et al. 2008). An advantage of semi-structured interviews is that the researcher can adapt the questions as necessary, clarify doubt and ensure that the responses are properly understood, by repeating or rephrasing questions (Bowling 2009). Non-verbal cues can be detected through frowns, nervous tapping and other body language, unconsciously exhibited by participants (Bowling 2009). Hence, the researcher is able to take note of the latter through field notes written during the interviews.

8.3.2 Setting

I conducted all face-to-face interviews (n=20) with female participants at their homes around Malta. The location was based on all participants' preferences following a choice of locations. Interviews were carried out between December 2017 and February 2018. All interviews were conducted privately with only the researcher and the participant present for the interview.

8.3.3 Participants

From the larger quantitative study of 404 women, 13.9% of women (n=56) had never attended for mammography anywhere ('lifetime non-attendees'). These participants had responded in the population-based survey (Study 2) that they were willing to be contacted further for research purposes. The same eligibility criteria (**Section 4.2.2.3**) also applied to this study.

8.3.4 Sample and sampling strategy

A purposeful sampling strategy was adopted by selecting a small number of cases that maximize the diversity of women (heterogeneous sample) relevant to the objectives (**Section 8.2**). From 56 lifetime non-attendees, I selected at least three women per sociodemographic/health status group that had emerged as significant factors associated with lifetime mammography practices in Study 4. Hence, women were selected from, but not limited to, the following groups: 'low family income', 'widowers', 'non-drivers', 'no breast condition/disease', and 'no relatives or close friends with cancer'.

According to Guest et al. (2006), Green and Thorogood (2014) and Adler and Adler (1987), 15 to 20 interviews are suitable to obtain sufficient data for analysis in qualitative studies. Although it initially appeared that data saturation was reached after 15 interviews, a further five interviews were conducted to confirm this, after which recruitment ceased.

8.3.5 Recruitment

A research assistant (RA) i.e. a senior nurse and researcher in Malta, contacted potential participants by telephone to confirm that they had never been screened. During this telephone call, potential participants were given further information about the study objectives and to confirm whether they were willing to participate in a more in-depth interview. Potential participants were informed that they would receive honorarium of twenty euros upon interview completion. Although it is recognized that informed consent must be obtained under circumstances that minimize potential coercion or undue influence, the researcher was aware not to obscure women's risk perception and not to expose subjects to risk of harm or to induce prospective subjects to consent to participate against their better judgement (undue inducement) (Bentley and Thacker 2004). The researcher only made use of the financial incentive to facilitate recruitment by helping make participation a revenue-neutral experience, compensate women for their time and contribution (Halpern et al. 2015) and use it as an incentive for women to overcome barriers to participation in this study (Ulrich et al. 2005; Bentley and Thacker 2004).

Those who were interested in taking part in this study were invited for a face-to-face interview with the researcher and were given a choice of locations. The interview was scheduled by RA between the researcher and the participant, according to the availability of the participant. RA confirmed the participant's postal address and mailed the information sheet to the participant (**Appendix 8.2a, b**) in order to ensure that the information sheet was received at least 48 hours before signing the consent form during the interview (**Appendix 8.3a, b**). RA used a socio-demographic questionnaire (**Appendix 8.4a, b**) to screen women for eligibility. Hence, participants' sociodemographic data were primarily obtained from the previous cross-sectional data (Study 2) and further confirmed through this brief socio-demographic questionnaire. A debrief was provided following completion of the interview to provide a summary about this study and information on the MBSP (**Appendix 8.5a, b**).

8.3.6 Data collection

Each participant took part in one audio-recorded interview by the researcher at the participant's home using a topic guide (**Appendix 8.6a, b**) informed through existing literature. The questions during the interviews did not have a specific order and were asked in accordance to participants' responses. During the interviews, I repeated and summarized what the participants said to prevent misunderstandings and took field notes to facilitate the interview process. Interviews lasted between 55 and 77 minutes and were conducted in the Maltese language (as the preferred language by all participants). Participants signed informed consent forms (**Appendix 8.3a, b**) before the start of the interview. Consent was also sought from the participants for audio-recording. **Figure 8.1** shows the flow of participants through the study.

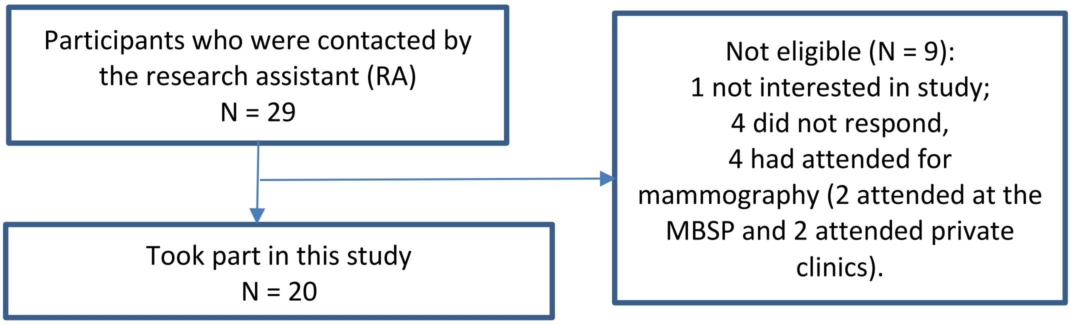

Figure 8.1 - Flow of participants through the study

8.3.7 Measures

8.3.7.1 Socio-demographic questionnaire

Sociodemographic data were collected to describe the sample characteristics, women's health status and health behaviours (**Appendix 8.4a, b**).

8.3.7.2 Interview topic guide

The interview guide was developed in light of this research's conceptual framework (HBM and CSM). A semi-structured topic guide (**Appendix 8.6a, b**) was developed after an extensive literature search (Farooqui et al. 2013; Ferrat et al. 2013; Todd and Stuifbergen 2011; Lasser et al. 2008; Lamyian et al. 2007; Fort and Ahmed 2005; Markovic et al. 2005; Mele et al. 2005). This guide consisted of a series of open-ended questions covering illness perceptions regarding BC, BC prevention and knowledge of screening, mammography beliefs, past health-related experiences, medical help seeking behaviour, interactions with healthcare providers, friends and relatives, BS facilitators and barriers, and effective interventions that would facilitate their attendance for mammography. Participants were given the opportunity to talk freely and at ease, but prompts were included in order to keep the discussion focused within the broad topic. The guide was piloted with two women (housewives of eligible screening age), but no changes were required. This pilot data was not included in the main analysis.

8.3.8 Ethical considerations

This study was approved by the NHS, Invasive or Clinical Research (NICR) Committee, (SREC14/15 – Paper No.18, Version 4) (**Appendix 8.7**) and by the Maltese HEC (HEC11/2014) (**Appendix 8.8**). Participants were mailed an information sheet (**Appendix 8.2a, b**) containing information about the study, contact details of the Health Director General and that of an independent contact to report any concerns or complaints about the study. All respondents were informed of their right to refuse answering any question posed by the interviewer, how anonymity and confidentiality would be preserved and that they could withdraw from the study at any time.

8.3.9 Data Analyses

8.3.9.1 Socio-demographic questionnaire

Descriptive statistics were produced. Specifically, the mean age of the sample was calculated, and percentages were produced to show the proportion of participants in each category.

8.3.9.2 Thematic analysis of interviews

Interviews were transcribed verbatim by myself and codes were assigned to each participant to protect the woman's identity. Each interview was translated from Maltese to English by a qualified translator. Each interview was checked twice by a trained transcriptionist / translator (SD) and myself for accuracy of translations.

The analysis followed the six phase guide to thematic analysis, a qualitative method outlined by Braun and Clarke in their paper on using thematic analysis in psychology: (i) familiarisation, (ii) generation of codes, (iii) searching for themes, (iv) reviewing themes, (v) defining the themes and (vi) writing the report (Braun and Clarke 2006). This qualitative method was chosen due to its flexibility and potential to provide a detailed and rich, yet complex account of the data (Braun and Clarke 2006). It is also a useful method for comparing similarities and differences between data and summarising key features of a large body of data. I listened to the interview recordings as part of the familiarisation process, and read all of the transcripts several times to ensure I was fully immersed in the acquired data.

8.3.9.3 Coding

Following the familiarisation phase, I generated an initial list of codes. Through discussion with RA, I amended and refined the codes until a single list was agreed. Subsequent stages of the analysis were conducted manually by myself. Coding the transcripts involved selecting parts of the text and assigning codes to these sections, also ensuring that the context of the quote was also captured. More than one code was assigned to the same text passages, where relevant. This initial coding was very detailed in order to identify all of the relevant pieces of text. If new codes emerged during the coding of later interviews, these were added to the list and earlier interviews were recoded to ensure that no passages were left out. A selection of transcripts (n = 5) were then coded by RA to verify their consistency. There was high agreement on the coding; minor discrepancies were resolved following discussion between RA and myself.

8.3.9.4 Themes and sub-themes

Broad themes were pre-set and derived from the survey results and World Café *type* focus groups. These themes included: (i) attitudes, feelings, beliefs and perceptions, (ii) knowledge, (iii) social network experiences and (iv) perceived effective interventions. Sub-themes emerged from this qualitative study and were strongly influenced by the interview topic guide and pre-set study objectives because the discussion was facilitated in this way.

Once the coding was completed, I reviewed the coded transcripts to search for common sub-themes that reflected the pre-set themes. This process was also conducted independently by RA. The list of sub-themes were then compared and discussed in detail between RA and myself with the scope of refining the list. Some sub-themes, although interesting, were not relevant to the specific area of interest and did not add further value to the understanding of BS factors. For example, some participants talked about the role of stress in their children's lives. Hence, these were not included in this chapter. Once the final list of sub-themes was concluded, each sub-theme was named and given a written description. The sub-themes were then checked against all the transcripts to ensure that they were applicable to the majority of the sample.

8.3.9.5 Validity

Credibility and conformability of data were established in three ways (Lamyian et al. 2007). First, the researcher revised the main outcomes of the discussion with participants before ending the interview in order to summarise what had been discussed, to add any further comments and for participants to provide any feedback on the data. Moreover, following data analyses, I contacted the participants by telephone and provided a summary of the emergent sub-themes to determine whether the codes and sub-themes were true from their point of view (*member check*). Second, the interviews enabled an in-depth prolonged engagement with participants, thereby allowing for a more detailed understanding of women's beliefs and perceptions. Third, as a further validity check, RA checked half of all transcripts (*peer check*) to confirm the aptness of the results, to ensure their reliability and trustworthiness, and to refine the analysis and emergent sub-themes (Anderson 2010). RA interpreted the raw data of these transcripts independently by searching for emerging sub-themes, which ultimately were congruent with that of the researcher. The results were also checked with two women (the same two women who participated in pilot-testing the topic guide) to confirm the aptness of the sub-themes and outcomes.

8.4 Results

8.4.1 Participants

Socio-demographic and health characteristics of the female participants are shown in **Table 8.1**. The mean age of the sample was 59.9 years (SD: 2.2 years). The majority were married, housewives and did not drive (85% respectively). Educational attainment varied between primary (25%) and secondary (75%) education level. Less than half of the participants (45%) had an income of less than €10,737 while 55% of women had an income between €10,737 and €16,113. From the sample, 90% named a family doctor. Furthermore, the absolute majority had no breast condition or disease (90%). There were 70% of non-attendees who had a family history; 15% of these had close friends with cancer. Those who had no family history (30%) had no close friends with cancer. With regards to women's perception of their current health status, 60% perceived the latter as 'good', 25% perceived this as 'fair', while 10% considered it to be 'poor'. Of our total sample, 75% had never had a clinical breast examination (CBE), 25% had never performed a breast self-examination (BSE), 45% had never undergone a smear test while 85% had never undergone a faecal occult blood test (FOBT).

Table 8.1 - Participant characteristics

Code	Age (years)	Marital status	Education	Occupation	Income	Do you drive?	Do you have a family physician (GP) who provides medical care and advice to you?	Have you ever had any type of breast condition or disease?	Do you have a family history or close friends with
NA1	58	Married	Secondary	Housewife	Between €10,737 – €16,113	No	Yes	No	No
NA2	64	Widowed	Primary	Pensioner	Less than €10,737	No	Yes	No	No
NA3	61	Married	Primary	Housewife	Less than €10,737	No	Yes	No	Yes
NA4	60	Married	Secondary	Housewife	Between €10,737 – €16,113	No	Yes	No	Yes
NA5	58	Married	Secondary	Housewife	Less than €10,737	No	Yes	No	Yes
NA6	62	Separated/Divorced	Secondary	Housewife	Less than €10,737	No	Yes	No	No
NA7	56	Married	Primary	Housewife	Between €10,737 – €16,113	Yes	Yes	No	No
NA8	58	Widowed	Secondary	Pensioner	Less than €10,737	No	Yes	No	Yes
NA9	61	Married	Secondary	Housewife	Between €10,737 – €16,113	No	Yes	No	Yes
NA10	59	Married	Secondary	Housewife	Less than €10,737	No	Yes	No	Yes
NA11	60	Married	Secondary	Housewife	Between €10,737 – €16,113	Yes	Yes	Yes	No
NA12	59	Married	Secondary	Housewife	Between €10,737 – €16,113	No	No	No	Yes
NA13	61	Married	Primary	Housewife	Less than €10,737	No	Yes	No	No
NA14	64	Married	Primary	Housewife	Less than €10,737	No	Yes	No	Yes
NA15	59	Married	Secondary	Private employee	Between €10,737 – €16,113	No	Yes	No	Yes
NA16	57	Married	Secondary	Housewife	Between €10,737 – €16,113	No	Yes	No	Yes
NA17	59	Married	Secondary	Housewife	Between €10,737 – €16,113	No	No	No	Yes
NA18	62	Married	Secondary	Housewife	Less than €10,737	No	Yes	Yes	Yes
NA19	62	Married	Secondary	Housewife	Between €10,737 – €16,113	No	Yes	No	Yes
NA20	58	Married	Secondary	Housewife	Between €10,737 – €16,113	Yes	Yes	No	Yes

8.4.2 Key sub-themes

Regarding objective 1, the analysis sought to explore women's health beliefs, perceptions, attitudes and feelings of BC and BS. These findings are presented as sub-themes 1-5 below (**Section 8.4.3**). Knowledge was also investigated among non-attendees. These findings are presented as sub-theme 6 (**Section 8.4.4**). The analysis also sought to explore how non-attendees perceived BS barriers as a result of their social networks and the reasons for the latter perceptions. These findings are presented as sub-theme 7 (**Section 8.4.5**). Regarding objective 2, the analysis sought to explore what interventions and communication channels would be effective to increase BS uptake in Malta. These findings are presented as sub-theme 8 (**Section 8.4.6**). These eight sub-themes are sub-divided into identified elements, which were then compared to see whether they were related to the same idea or issue. When an identified element placed under one sub-theme was more related to another sub-theme, this was moved accordingly. All related elements were grouped together to form one or more categories (**Table 8.2)**.

Table 8.2 - Classification of subthemes expressed by non-attendees

Themes	Subthemes	Detected Elements	Categories
Personal beliefs, perceptions, attitudes and feelings	Perceived severity	Feeling well Lack of perceived severity Optimism Spiritual beliefs	Perception of good health Absence of symptoms
	Fear	Fear of cancer diagnosis and its related treatment side effects Fatalism Mammography pain Radiation Mastectomy Embarrassment Experiences of relatives with cancer Not seeing children and grandchildren grow	Fear of death Physical pain Altered body image Shame Not being there for the family
	Competing health priorities	Other personal health problems Cancer in a family member	Postponement
	Emotional distress	Depression and Anxiety Low self-esteem	Low self-confidence
	Negative health experiences	Physical accidents Other surgical operations Late diagnoses Death of relatives/friends	History of trauma Lack of trust in the health care system
Knowledge and awareness	Insufficient BC/BS information	Misinformation	Lack of knowledge
Social network experiences	Cultural factors	Lack of physician-patient relationship Lack of family/partner support Loneliness and isolation	Ineffective health communication Rejection
Perceived effective interventions	Able to attend through effective cues to action	Lack of support Lack of cues to action	One-to-one counselling GP and partner recommendations Sharing personal experiences

8.4.3 Theme 1: Personal beliefs, perceptions, attitudes and feelings

Five sub-themes emerged from data analysis to reflect Theme 1. These sub-themes include: perceived severity, fear, competing health priorities, emotional distress, and negative health experiences.

8.4.3.1 Sub-theme 1: Perceived severity

Perceived severity was characterised as not needing the test because women perceive themselves as healthy and believe in God. This sub-theme was categorised as women's perception of good health and absence of symptoms.

Category 1: Perception of good health

Various misconceptions of good health were evident in the participant's lack of awareness of risk and perceived BC severity, hence perceiving themselves healthy and not needing the test:

> *"There is no need to go and search for it (BC) because I am sure that I am healthy." (NA15, 59 years)*
>
> *"I don't need to go. I feel well overall." (NA19, 62 years)*

Some non-attendees described the word 'cancer' as a disease that 'brings negativity' and wanted to view life in an optimistic manner, excluding the negativity around them:

> *"I am a person that tries not to think negatively and I feel good about myself and positive. This disease (BC) brings sadness, so I just don't think about it." (NA10, 59 years)*

While participants discussed how their faith in God helped alleviate fears about uncertainties in life, disease and death, four women abdicated their personal responsibilities in preventing BC by resorting to prayer and leaving everything in God's hands:

> *"I am determined that when I get to know I have cancer, I will live that remaining year of my life in peace. I will be leaving it in God's hands. He will take me when he wants to. I could die tomorrow, we all have to die some day or other. We weren't created to be here." (NA8, 58 years)*
>
> *"I can prevent cancer through prayer. I cannot do much." (NA1, 58 years)*

Category 2: Absence of symptoms

According to some participants, absence of symptoms was one reason cited by women for not undergoing the test:

"I should feel something to go for a breast check-up" (NA16, 57 years)

One participant stated that she would only visit her doctor if she detected any symptoms in her breasts, but was unwilling to visit a doctor otherwise.

"I might do mammography only if I see BC, and if I see it, it means I can feel it. Only then will I go to my doctor." (NA10, 59 years)

8.4.3.2 Sub-theme 2: Fear

Women considered fear as a critical factor to inhibiting mammography attendance. Five categories were identified related to fear: fear of death, of physical pain from the procedure or from treatment side-effects, altered body image, shame and not being there for the family.

Category 1: Fear of death

Fear of having to face a cancer diagnosis contributed to non-attendance among eighteen Maltese participants, particularly among women whose family and friends had died from the disease. Women spoke of how they had seen their relatives suffer and died from the disease:

"I don't want to have to face the possibility of having a positive result. I have seen my family suffer too much due to BC. My mother had intestinal cancer and died." (NA5, 58 years)

"People don't get cured after getting BC. It is simply a death sentence." (NA19, 62 years)

The majority of participants expressed how their perception of cancer is an unchangeable fate that cannot be prevented or cured:

"If cancer forms in the breasts, you cannot do anything about it. It is nature and no one can control it. There's no reason to stay beating around the bush. You die anyway. That's your fate." (NA7, 56 years)

Category 2: Physical pain

Women reported having fear of the mammography procedure itself, as they had heard other women talk of pain during the test:

"It's in my head…that idea of intense pain during mammography. My sister had done it once and she had felt pain. If my sister says it, then it is true." (NA7, 56 years)

"I do challenge ill health. I had a hysterectomy and went for it with courage but the fact that I know that I am going to feel pain, I can't take it. That is what I was told by other women. They press the breasts between two plates and squash them. It isn't for me." (NA14, 64 years)

Women also spoke of how their relatives had suffered from physical intense pain due to the chemotherapy:

> *"My mother (with intestinal cancer) died of intense pain. Chemotherapy kills you literally. She looked yellow with treatment and could hardly walk. Her veins were worn out." (NA5, 58 years)*

> *"I saw my aunt who entered the oncology centre physically well. Then they gave her chemotherapy. She had a pipe in her neck and deteriorated. She then passed away." (NA8, 58 years)*

Additional fears arose about the mammogram that were distinct from procedural pain or discomfort. Four women mentioned that they feared the effects of radiation exposure, which hindered their attendance and reflected misinformation that was never clarified by health professionals:

> *"The exposure to radiation scares me. It can be harmful to our health and damages my breasts." (NA11, 60 years)*

> *"My husband was fine but after being treated for brain cancer he got worse. It's about those X-rays they gave him. The cancer spread even more." (NA9, 61 years)*

Category 3: Altered body image

Some women spoke of their fear of having a mastectomy. They associated surgical treatment with having physical pain post-surgery and a distorted body image, resulting in embarrassment and a loss of their femininity:

> *"I fear having a mammogram because I cannot imagine losing my breasts and passing through that physical pain with drain pipes all over and long-term physiotherapy. This would mean not being a woman anymore, losing my role as a mother. Breasts are part of a woman's beauty; it inflicts harm on something that symbolizes femininity and motherhood." (NA11, 60 years)*

> *"I would feel embarrassed with no breast." (NA3, 61 years)*

Category 4: Shame

Some participants also mentioned how they felt shame in exposing themselves in front of others, particularly if the health professional was male:

> *I already feel embarrassed about the thought of having to expose my breasts in front of them (radiographers) because they might find it awkward. I actually feel ashamed." (NA11, 60 years)*

> *"I wouldn't accept having a male professional checking me. It's a woman thing." (NA20, 58 years)*

Category 5: Not being there for the family

Five women spoke of how they feared not seeing their children or grandchildren grow and how this fear led them to refuse BS attendance to spare the family from suffering:

> *"I want to see my children grow. It scares me not to see them get married and have their own children, because life is beautiful that way. But the fear is too big an obstacle for me. I don't want my children to pass through suffering because of me." (NA6, 62 years)*

8.4.3.3 Sub-theme 3: Competing health priorities

The most important competing health priorities deterring women from screening included the presence of other personal health problems, and cancer in a family member. These were categorised as postponement.

Category 1: Postponement

Due to their current health condition, some women were determined to postpone mammography attendance to tackle their priorities:

> *"Right now I am a diabetic patient and I have a CT scan booked to check upon some glands. I also have high blood pressure and my blood tests are being sent abroad for review. It isn't the time for a mammogram." (NA15, 59 years)*

> *"I have other health problems which are more important than having screening tests for something that may develop one day. The truth is I've lost some weight, so I am getting some tests done. This is my priority." (NA1, 58 years)*

Many women reported that they were very busy with family obligations, because family members were experiencing or had experienced cancer. Women considered that taking care of their family needs during this difficult time was a priority over their own health:

> *"My husband has been suffering from brain cancer for nine years. Abroad, they could not operate on it as it touches the nerves. Since we have a family, I need to take care of him and all at the moment." (NA13, 61 years)*

> *"I cannot cope with my current issues, then if needs be it will have to be in the future." (NA15, 59 years)*

8.4.3.4 Sub-theme 4: Emotional distress

Category 1: Low self-confidence

Three women reported having emotional distress, including symptoms of depression and anxiety, existential distress and loneliness. This led them to realise that they had low self-esteem.

"Depression messes with your memory. I am on medication and feel very sluggish and nauseated every morning. Leaving the house is difficult and distressing. I've been very low to the point where I don't even want to go out and I'm regularly missing health appointments. I worry that my legs will be amputated due to diabetes and no one will be there for me. It's very depressing and it actually destroys my self-esteem." (NA20, 58 years)

Losing one's sense of control and fearing disease progression and disability were also common concerns:

"I am always worrying about what's coming next. Will I get cancer myself now after my husband? What will be my next limitations? Will I be disabled? I'm losing my focused frame of mind." (NA9, 61 years)

"I have always been one who likes taking control of things. Cancer could go to my brain, liver, anywhere really. My father's lung cancer went to the liver." (NA18, 62 years)

Low self-esteem causes women to feel weak and powerless, avoiding BS participation.

"I have a low self-esteem and am not hopeful about the future, and so I do not pay much attention to my own health. I know this may be something wrong with me but that's the way I feel about life. Weak, powerless, pointless." (NA20, 58 years)

Additionally, anticipation of results are likely to provoke anxiety in non-service users:

"After experiencing a personal physical accident and passing through a lot, it is daunting for me to wait for a result. I get very anxious and so I don't go for it (mammography)." (NA1, 58 years)

8.4.3.5 Sub-theme 5: Negative health experiences

Category 1: History of trauma

Prior health care experiences for non-attendees were negative, life events related to prior physical accidents and previous traumatic operations:

"I passed through a very bad car accident and spent 14 days in ITU with a torn liver and an internal haemorrhage, and had to undergo many surgical operations, a nightmare, and also ended up diabetic. I don't want to experience all those tests again. Going to hospital again gives me the shivers. You don't experience trauma then, the trauma comes out afterwards and you carry it for life." (NA1, 58 years)

Category 2: Lack of trust in the health care system

Other dimensions of lifetime traumas arose from the experience of relatives who died of cancer. These experiences reflected issues of lack of trust in the health care system, due to concerns of 'wrongful' health care, physician incompetence, medical errors (unintentional harm) or unethical experimentation (intentional harm).

"That doctor killed my mum. It's better if she hadn't taken that treatment because she would still be alive. I blame it on them, on the hospital." (NA20, 58 years)

"My dad died at the age of 54. We took him to hospital and asked the doctors to arrange his cannula but instead they gave me a strong injection in his leg and died. We don't even know what the injection was for and the doctor had just come from another ward. Now do you think these doctors wouldn't do the same during mammography?" (NA4, 60 years)

Women also related their friends' experiences who reportedly had a screening mammogram and ultimately were diagnosed with late-stage cancer. As a result, women described negative associations between prevention and disease because they had experienced the loss of their own friends:

"Many do mammography, but the doctors do not always find it (BC). My friend did her mammogram and had the all-clear result but in reality, she had it. Eventually, she lost her breast and then her existence." (NA13, 61 years)

8.4.4 Theme 2: Knowledge and awareness

8.4.4.1 Sub-theme 6: Insufficient information

All women identified the importance of receiving information about BC and BS. However, participants had misconceptions, and were occasionally misinformed.

Category 1: Lack of knowledge

One women stated that other tests or scans replace mammography, while another woman said that having breast-fed her children helped her avoid having BC.

"I do not need the test. I did a CT (computed-tomography) scan and my breasts were checked during that scan." (NA6, 62 years)

"I've never thought about the possibility of having BC as I breast-fed my children. My sister had seven children and never went too. She died a normal death at 83 years." (NA19, 62 years)

When asked about the possible causes of cancer, five women mentioned a familial BC history to be the main risk factor. However, these participants did not think that having various screening tests were necessary, except for having regular blood tests. Women considered lifestyle to be more important for general health and disease prevention:

"Any woman can get BC, but people with a history of BC in their family, like myself, can get it even more, and those having unhealthy lifestyles too." (NA2, 64 years)

"We don't have it (BC) in the family, so I don't think I have a higher risk of getting it but it still scares me as I am not very healthy." (NA20, 58 years)

None of the women gave correct information about screening time frequency and stated that they had no idea about how often one should be screened. One woman said that mammography should commence at menopause while another woman stated that mammography should commence after 30 years of age following professional advice.

> *"I don't know anything about how often one should attend. Perhaps during menopause?" (NA11, 60 years)*
>
> *"I once spoke to a health professional who told me I should have started mammograms in my thirties" (NA20, 58 years)*

Some women knew how to perform BSE through information provided on the media. They explained that they performed BSE while having a bath or whenever they remembered to do so. Three women were worried that they failed to detect breast lesions:

> *"I know how to examine my breasts. They show this on TV." (NA20, 58 years)*
>
> *"I do worry when I check my breasts … that I do not detect what is really in there." (NA2, 64 years)*

8.4.5 Theme 3: Social network experiences

Members of the public rely on BS information obtained from health care professionals, and through experiences dependent on the effect and impact of cultural factors. Detected elements included: lack of physician-patient relationship, lack of family/partner support, loneliness and isolation. Ineffective health communication and rejection were earmarked as important categories affecting women's screening behaviour.

8.4.5.1 Sub-theme 7: Cultural factors

Category 1: Ineffective health communication

Thirteen women reported that their GP had never encouraged them or did not provide adequate recommendations about screening benefits.

> *"My doctor has not encouraged me to go for mammography." (NA2, 64 years)*
>
> *"My doctor used to tell me that if I wasn't up for it (mammography), I would be doing well not to go because he used to tell me… 'I showed you how to check your breasts, so that's enough'. And when I received the letter, he told me that I don't need to go." (NA8, 58 years)*

Some women recognised the powerful role that physicians play in encouraging screening compliance and that an ineffective physician–patient relationship may lead to women's non-attendance to BS. Four women said they would have a mammogram if their physicians recommended it.

> *"I don't speak to my doctor about breast tests. I don't have that close relationship with him. And since I don't ask, he hasn't ever mentioned it (mammography). I would need to be really pushed to go for one. I would prefer if my GP spoke to me about it." (NA2, 64 years)*

> *"It's not like we have a solid relationship except for the occasional visit." (NA15, 59 years)*

Category 2: Rejection

Women's major concern was that having a mastectomy or further treatment would precipitate rejection and abandonment by their partner. Lack of family support and family rejection were also common concerns in women's daily lives.

> *"I had a friend whose husband rejected her when she had her breast removed. If I had to have (a breast) removed, I'd think that he'd seek another woman and that I'm no longer attractive to him." (NA10, 59 years)*

> *"I've got four children, all married but none of them take me to health appointments or anywhere really. I feel rejected and alone. Let alone how much I will be able to cope if I found out that something was wrong." (NA20, 58 years)*

> *"I'd really want that extra push from my family. My husband doesn't encourage me to go for a mammogram." (NA5, 58 years)*

8.4.6 Theme 4: Perceived effective interventions

All non-attendees reported that national BC campaigns held in Malta do not trigger them to go for mammography. They felt that the ongoing media coverage in October was too long which would make them change the television channel if they came across screening discussions. Instead, non-attendees preferred one-to-one counselling, partner and GP recommendations, and sharing personal experiences on the media as more effective cues to action.

8.4.6.1 Sub-theme 8: Able to attend through effective cues to action

Category 1: One-to-one counselling

Several women reported that being contacted and counselled over the phone were facilitating factors:

> *"A one-to-one telephone conversation would encourage me although deep down I would be scared." (NA15, 59 years)*

"Speaking to you really helped me think it through." (NA7, 56 years)

Category 2: GP and partner recommendations

Four women said they would have a mammogram if their physicians recommended it:

> *"I would prefer if my doctor spoke to me about mammography. I would consider his recommendations seriously." (NA2, 64 years)*

Furthermore, recommendations from a woman's partner would encourage three women to attend BS:

> *"My husband is my closest link to health care. If he says so, I would consider his advice." (NA5, 58 years)*

Category 3: Sharing personal experiences

More than half of non-attendees reported that the most frequent source of BC and BS knowledge was through listening to others who shared their personal experiences of the disease. The experiences of relatives or friends or experiences shared on the media i.e. through television and radio, would motivate them to attend.

> *"If you chat with a friend or relative about their cancer experience, you get encouraging first hand information." (NA2, 64 years)*

> *"Women who experience cancer often speak their hearts out. That's very encouraging." (NA18, 62 years)*

Non-attendees were reluctant to receive brochures, pamphlets and listen to educational talks as the latter did not seem to increase knowledge and awareness of BC and BS among non-attendees or to motivate them to attend. Non-attendees would discard brochures, pamphlets or booklets if received at home:

> *"Once I receive them (brochures, pamphlets, booklets), they're immediately discarded." (NA7, 56 years)*

8.5 Discussion

Building on the findings of quantitative data (Studies 2, 4), this study used thematic analyses to explore for the first time and in further depth women's reasons for non-attending BS in Malta, as well as their beliefs, perceptions, attitudes and knowledge of BC and BS. This qualitative study also provides valuable insight regarding potential interventions in Malta. While the current study confirmed the findings of the cross-sectional data such that there are a number of psychosocial factors impeding attendance, it provided new knowledge by informing the understanding of these factors.

This study delineated that although all women had heard about mammography, non-attendees were unable to take an adequately informed decision about BS and could not share in the decision-making process due to a number of barriers. According to the participants in this study, fear was a primary barrier to BS attendance. Maltese women's fear surrounding BC and BS seems to encompass many factors but certainly includes fear of a cancer diagnosis, fear of pain, fear of death, fear of radiation, fear of embarrassment and of the medical establishment. The belief that "it is better not to know" has been reported as a barrier to screening in studies focusing on Hispanic women (Austin et al. 2002) and among Turkish women (Kissal and Beşer 2011). Such fears also inhibit or delay women's visit to a physician until they feel pain or experience a symptom (Lamyian et al. 2007). As one participant put it in this study: *"I have to feel pain due to a lump or due to cancer itself to take care and do something about it, perhaps go to the doctor then."* Fear is the most extensively studied emotional variable in the literature (Lamyian et al. 2007; Gbenga et al. 2005) and includes fear of mastectomy, fear of death and fear of an altered body image, among others (Borrayo et al. 2005; Ogedegbe et al. 2005; Young and Severson 2005). The role of participants' fear emerges either as a facilitator or as a barrier in the context of screening behaviour (Kissal and Beşer 2011).

The absence of symptoms suggests that the benefits of screening programmes are either poorly understood or that screening is rejected as a premature intervention or because women did not have a strong belief in preventive care. In a qualitative study among 187 low-income, minority women in New York, this preventive care paradigm has been reported to be positively correlated with women's health outcomes when faced with other chronic diseases (Gbenga et al. 2005; Cohen et al. 1994). Women often consider non-attendance as 'carelessness' which leads to neglect, reluctance and postponement as part of their actions (Kissal and Beşer 2011). Women in our study described using neglect and postponement as coping strategies for tackling their fears that resulted in cultural norms to delay care or not seek BS. Similarly, according to a study by Montazeri and colleagues, around 25% of patients with breast symptoms had delayed seeking medical help for more than 3 months (Montazeri et al. 2003).

Another main finding in this study is that women were not motivated to perform BS due to fear of not seeing their children grow and due to the lack of emotional support from family and friends. Women's perceived main role in life seems to be attending to the family and children (Khazaee-pool et al. 2014; Taha et al. 2012). This literature provides significant evidence to support the notion that women's fear of not being present within the family if BC occurred superceeds women's consideration of screening benefits. Our findings are consistent with previous studies, whereby social and emotional support from women's immediate networks such as family members, specifically husbands/partner, and siblings advocacy, could motivate women to improve their BS practices (Khazaee-pool et al. 2014; Kalsta et al. 2013; Kawar 2013; Torres et al. 2013).

Furthermore, this study showed that a lack of support from family members often causes existential rejection, distress, depression, isolation, neglect and loneliness. The concept of *loneliness* includes both the objective dimension of being alone and the subjective dimension of feeling lonely (Dahlberg 2007). Loneliness has been described extensively in relation to death (Sundström et al. 2018) but not in relation to BS practices. Hence, this study provides innovative qualitative data regarding *existential loneliness* in the BS context, and how non-attendees related aspects of existential loneliness when considering aspects in the health care context. Additionally, women's low self-confidence in this study was similar to the effect of women's low self-efficacy in cancer prevention practices in studies by Miller (2005) and Otero-Sabogal et al. (2003). The present study found that social network experiences are important to build self-confidence because they serve as a source of advocacy to increase the effectiveness of health information and aid the understanding of cultural factors.

In this study, women spoke about how they felt embarrassed to expose their breasts in front of others. The reason for this fear of embarrassment is mostly related to privacy matters of sexual organs and is considered not a topic of discussion by women (Khazaee-pool et al. 2014). Literature suggests that women tend to cover their breasts, and consider not to be touched by others (Suh 2008; Lee 2000) or only by female professionals (Marmarà et al. 2015). Iranian women believe that their breasts are sexualized for male satisfaction and hence, almost all women in an Iranian study did not visit male doctors due to modesty (Khazaee-pool et al. 2014). This is consistent with previous qualitative studies, which reported that physicians' gender can affect whether women decides to attend or not for screening tests, such as Pap smears, mammography and CBE (Kwon 2013; Taha 2012; Kwok 2011). This implies that the concept and meaning of ‘shame’ for women can be avoided through tailored cultural information (Wang et al. 2012).

Other competing priorities such as having relatives with cancer or other personal health concerns e.g., other examinations such as surgical interventions, were observed as inhibiting factors for participants in this study. The finding that women fail to prioritise their own health also replicates other findings (Trigoni et al. 2008; Payne 2006). In their in-depth interviews with 30 women aged 45-65 in Crete, Trigoni et al. (2008) found that women’s family obligations were one of the reasons for their delayed BS behaviour. Taking time to care for the family was also a BS barrier among 31 Iranian women (Lamyian et al. 2007).

Screening non-attendance can also be attributed to underlying spiritual beliefs such that faith in God attenuates women’s fear and reduces the perceived BC threat. Bener et al. (2002) confirmed this assertion in their qualitative study on screening behaviour among women in the United Arab Emirates. Cancer-related fatalism has been defined as the perception that individuals have limited influence to change the course of the disease, to detect it early or to prevent it (Lamyian et al. 2007). As shown in this study, fatalism may lead to BS non-attendance as some Maltese women equated mammography with an impending BC diagnosis, contributing to increased fears of the health care system. The role of spirituality and its impact on health behaviours can be found in a significant body of literature within the African-American community (Guidry et al. 2003; Mansfield et al. 2002; Phillips et al. 1999; Jennings 1996). The belief that God or a higher power controls both positive and negative outcomes i.e. divine control, is often conceptualized as a component of fatalism (Umezawa et al. 2012; Morgan et al. 2008; Peek 2008; Schieman et al. 2006). Fatalistic beliefs in this study, such as *"having cancer is like getting a death sentence"* or that *"screening tests would ultimately lead to death"*, *"cancer is in God’s hands"* and that *"there is very little one can do to prevent getting cancer"*, were barriers for Maltese women from seeking BS. Literature suggests religious, cultural and spiritual beliefs can be facilitating factors to overcome this propensity in women (Islam et al. 2017), such that empowering messages can be tailored to appeal to Maltese women to take responsibility for themselves and will contribute to ameliorating health disparities.

Women's negative health care experiences were often the result of poor patient-provider communication in this study. It was clear that the health care team failed to adequately communicate with the patient in several instances about what was happening to their relatives' health and why. This lack of information left women feeling vulnerable and had a negative overall impact on how they experienced and interpreted their health care encounter. Similarly, findings by Partin and Slater (2003) found negative experiences associated with health care services. This study found that barriers to non-attendance particularly included history of trauma due to relatives' experiences with cancer and lack of trust in clinicians and mammography due to prior traumatic health experiences. It is known that fear of the health care system and subsequent denial/repression is one mechanism (of many) by which negative health care experiences may facilitate delays in seeking health care (Lamyian et al. 2007), resulting in worse health outcomes such as late-stage diagnoses and higher mortality rates. Literature shows that traumatic exposure is common among low-income uninsured primary care patients (Medrano et al. 2004; McCauley et al. 1997). Traumas are often related to domestic violence, rape or childhood abuse (Green et al. 2006; Miranda et al. 2006) but none have been found in relation to BS literature. Trauma exposure have been associated with decreased routine or preventive health care (Rheingold et al. 2004; Farley et al. 2001; Robohm and Buttenheim 1996) and are tied to substantial health care system costs (Walker et al. 2003, 1999) due to negative mental health effects, including anxiety, depression, and interpersonal problems (Consedine 2004; Roth et al. 1997; Weaver and Clum 1995; Green 1994), as well as negative physical health effects (Green and Kimerling 2004; Schnurr and Green 2004; Friedman and Schnurr 1995) and disability (Seng et al. 2006).

In the extant literature, effective health communication has been found to be a very important motivating factor to BS behaviour (Lamyian et al. 2007; Bener et al. 2002). In this regard, this research found that women would consider a recommendation by the GP to attend for screening and to improve their knowledge on BC and BS. However, most participants in this study had not received any advice from their physician while some had received negative advice towards screening. Insufficient information about screening may partly explain the discordance between women's beliefs and scientific evidence, and could result in women absorbing incorrect information. This may be adding to women's confusion about BS guidelines.

A large number of participants in this study reported that they followed information on the media, particularly television programmes and radio stations. Information obtained from the latter platforms or social media may be unreliable as certain health claims may not be supported by sufficient evidence (Marx et al. 2008; Chew et al. 2002). Moreover, several studies have raised concerns about the completeness and quality of reporting health information (Korownyk et al. 2014; Bala et al. 2013). These findings further highlight a need for women to be directed to appropriate information about cancer screening, possibly by health professionals, and the need to disseminate accurate information through appropriate platforms to target hard-to-reach patient populations. Non-attendees suggested various communication channels as facilitators to BS, such as one-to-one counselling, GP/partner recommendations and support, and listening to other women's personal health experiences. Hence, effective interventions should focus on supporting personal strategies that build upon individual coping styles and preferences, for example counselling women to develop personalised care plans.

8.6 Strengths and limitations

There are strengths and limitations of having conducted this qualitative enquiry. First, conducting a qualitative study is important prior to developing an intervention for BS uptake that has been under-researched in Malta. It allows for the tailoring of an intervention through the identification of new knowledge on key factors to be targeted and of interventions required to change these factors. Intervention design can be improved through users' input that is captured through qualitative enquiry (Craig et al. 2008).

Another strength of this study is that it used a qualitative exploration to investigate knowledge and risk perception of BC and BS. Other studies have used questionnaires to assess such factors (Sobani et al. 2012; Anagnostopoulos et al. 2012; Okobia et al. 2006) which limit the understanding of the extent to which participants understand the disease. This study was not limited in this regard and importantly, it allowed for any misconceptions and misinterpretations to be identified, which strengthens the case for providing BS education to non-attendees. A qualitative approach also allowed the researcher to observe how non-attendees received and processed information about BC and BS, which indicates that all aspects of an intervention should be communicated simply and in a 'language' that women can understand (Mohan 2017).

The thematic framework was an independent and iterative process. To ensure rigour and project fidelity, the same researcher conducted all of the interviews. I documented the steps and the decisions made to save the auditability for other researchers to perform these steps in future studies. This enabled the data to be explored in depth while simultaneously maintaining an effective and transparent audit trail, which enhances the rigour of the analytical processes and the credibility of findings (Ritchie and Lewis 2003). Through this analytical framework, I was able to systematically and explicitly apply the principles of undertaking qualitative analysis to a series of interconnected stages that guided the process, enabling me to move back and forth across the data until a coherent account emerged. This resulted in constant sub-theme refinement (Smith and Firth 2011).

This study has some limitations. First, the risk perceptions for non-attendees were not objectively measured. Instead, non-attendees self-assessed their BC risk. It has been highlighted in the literature that many women either underestimate or overestimate their actual BC risk (Fehniger et al. 2014; Apicella et al. 2009). It would therefore have been useful to see how women's perceptions of their personal BC risk compared to their actual risk.

Second, while there is an indication that non-attendees had limited knowledge of BC and BS (**Section 8.4.4**), their actual knowledge and health literacy levels were not measured. The knowledge and health literacy levels of non-attendees are important as evidence revealed that inadequate health literacy was strongly associated with lower mammography performance (Rakhshkhorshid et al. 2018; Pagán et al. 2012). Therefore, it would have been useful to compare non-attendees' knowledge level and health literacy to see how this may have impacted on their responses regarding BC and BS knowledge and their risk perception.

Third, variation in relation to cancer-related health education (Livingston 2012), beliefs, attitudes and behaviours (Azubuike and Okwuokei 2013) is likely to exist between countries and regions, limiting generalizability of findings.

8.7 Conclusions

For the first time, this study provides valuable, in-depth qualitative insights into women's beliefs, perceptions, knowledge and attitudes for women's lack of BS use in Malta. The study builds upon previous research in the Maltese context and other settings but uniquely, provides health care providers and policy makers in Malta with qualitative evidence specific to their local population for the future development of effective interventions to increasing BS uptake.

This in-depth data suggests that there is a growing understanding of the importance of tackling fear of BS and reducing fear of preventive health care more generally. Fear of BS among Maltese women is multi-faceted, and reflects shared experiences within the health care setting as well as the psychosocial context in which women live. This study identifies a prominent role for primary care physicians, the family, particularly husbands, and the health care system in general to address barriers to mammography utilization within the Maltese population. The majority of participants in this study had not received professional advice from physicians, which may in part explain why they were not fully informed about screening benefits. This had led several participants to opt out from seeking screening information relying only on symptoms. In order to ensure that women are properly informed about the role of screening, it is important that they receive sufficient advice from their physician, are supported through their immediate networks such as their partner/spouse, and are directed to appropriate sources of information.

Despite a cancer diagnosis in the family prompted some lifestyle changes in women, it was not the primary motivator to attend BS. Participants seemed to be overcome by fear of death and traumatic histories from experiences of relatives with cancer or personal traumas. Factors related to practical and emotional support throughout a woman's life are important to non-attendees, and approaches assisting individuals to express these at an early stage should be assimilated into health care practices to increase women's self-confidence. It is vital that healthcare professionals refer to the patient's wider support networks and make the necessary referrals to appropriate services, while policy makers should ensure that services providing psychological, social and emotional support are accessible to women in general. The impact of physical and psychosocial variables on levels of personal resilience and self-confidence should inform the planning and delivery of future screening interventions. In addition, health care organisations should provide appropriate support to women who have experienced any personal traumas as this may be the first point of call for women seeking help.

Chapter 9

General Discussion, Recommendations and Conclusion

9.1 Introduction

The purpose of this chapter is to summarise and discuss the synthesis of findings in relation to the research questions and current literature regarding BC and BS. This is followed by a discussion of the implications of the research's findings for theory, methods and practice and to conclude what interventions are likely to be effective in Malta. Finally, it outlines the strengths and limitations of this research and provides recommendations for future work and an overall conclusion to this research.

The overall aim of this research was to explore the barriers and facilitators to BS uptake through an understanding of Maltese women's health beliefs, illness perceptions and other determinants of BC prevention and BS practices, with the aim of developing a future intervention to increase BS uptake among Maltese women. A mixed methods approach was utilised in this thesis to ensure the most appropriate methods were selected to address the 4 RQs (**Section 1.8**). The contribution of this thesis will be discussed in terms of its mixed design to collect and analyse data, synthesize results and inform a future intervention, in relation to health psychology theory and the application of the overarching Intervention Mapping framework (Bartholomew et al. 1998) to guide the mixed methods approach.

9.2 Summary and synthesis of findings

9.2.1 Is the adapted tool i.e. Maltese Breast Screening Questionnaire (MBSQ) valid and reliable?

Study 1 aimed to translate, adapt and pilot-test the quantitative tool used for this research. The innovative part of this study is the combination, adaptation and translation of the two scales, CHBMS-MS and IPQ-R, to develop the Maltese Breast Screening Questionnaire (MBSQ) for the Maltese scenario. Having high validity showed how accurately the study measurements assessed the explored constructs, while high reliability implies that measurements can be reproduced with accuracy by producing identical results if measured repeatedly (Heale and Twycross 2015). The preliminary evidence of the psychometric properties assessment of the MBSQ showed promise of being a valid and reliable instrument that could be used among Maltese women to assess their health beliefs and illness perceptions towards BC and BS practices.

9.2.2 Which significant factors are associated with breast screening uptake to a first invitation at the MBSP, re-attendance, lifetime mammography use and timely adherence in Malta?

The level of knowledge was found to be significantly associated with attendance to a first and second screening invitation, lifetime mammography use and adherence to recommended time intervals. In quantitative study 2, which aimed to understand the determinants and psychosocial factors associated with a first MBSP invitation, participants held high awareness of BC signs and symptoms, but wide variation in knowledge about BC causes and its related risk factors. Moreover, non-attendees were the most unsure of BS recommended practices and had higher emotional barriers. Overall, the knowledge of BC prevention and BS practices appears comparable to the published literature. Studies have shown that most people have limited or basic knowledge of BC and BS practices (Liu et al. 2014; Charkazi et al. 2013; Guvenc et al. 2012; Dandash and Mohaimeed 2007), such as among Arab women (Elobaid et al. 2014; Bener et al. 2001). This calls for urgent renewed health education and tailored information on the importance of screening while addressing misunderstandings, debunking screening myths and improving knowledge gaps. Advice in the BS context may be particularly influential given that healthcare professionals play a central role in health promotion and lifestyle information towards patients and the general population (Jonsdottir et al. 2011), such that discussions initiated by a health professional have been associated with healthier behaviours among cancer survivors (Jones and Courneya 2002). This raises the need for appropriate training among health care professionals (as part of their Continued Professional Development) on how to provide information and advice about BC symptoms, lifestyle factors and screening recommendations. This also presents a perfect opportunity for GPs to raise the topic of BC and screening during consultations and may involve a discussion between the GP and the patient to address any queries and assess the patient's needs.

Studies 2-5 showed that HBM constructs, primarily perceived barriers, were the strongest predictors of non-attendance to a first and second invitation to the MBSP and to lifetime attendance and timely adherence, followed by cues to action. These findings suggest that interventions to increase BS uptake in Malta should address health beliefs, in particular perceived barriers such as fear, since these emerged as the strongest predictors of uptake throughout the analyses. The combination of both HBM and CSM constructs provided improved prediction of BS non-attendance, when compared to HBM alone, which is an innovative finding in BS research. These results imply that interventions should be based on theory including both HBM and CSM constructs, since those interventions that also address illness perceptions, such as BC causes and consequences, may increase their effectiveness.

In all the quantitative analysis, attendees were more likely to perceive their susceptibility to BC, believed BC to be life-changing and considered cues to action to aid attendance to mammography. Evidence shows that those who attend for routine mammography may already understand screening benefits, have come to terms with barriers to undergo mammography (Farhadifar et al. 2016), and have confidence in their abilities to get screened (Anagnostopoulos et al. 2012). On the other hand, nonadherent women were in stronger agreement about the painful procedure and were less likely to consider cues to action as beneficial. This is consistent with other studies where women describe mammography as painful (Marmarà et al. 2015; Carney et al. 2002) and consider cues to action, such as GP recommendations, to increase uptake (Keeney et al. 2007). Moreover, the findings of study 3 showed that attending for the first time is a strong predictor of uptake to the second cycle. These results further support the evidence that those who obtain at least one mammogram are more likely to sustain screening practices (Anagnostopoulos et al. 2012; Allen et al. 2008; Moodi et al. 2012). Therefore, if non-attendees can be persuaded to attend once, they are likely to re-attend, unless their screening experience has been a negative one. Hence, interventions should target first time invitees to increase mammography uptake.

Non-attendees consisted of a heterogeneous group of women with diverse reasons for non-attendance. Study 4 found that 86.1% of the study sample were lifetime attendees, some of whom had attended for mammography at private clinics rather than at the MBSP, while 13.9% were lifetime non-attendees. Non-attendees were more likely to be anxious and fearful women without a breast condition, who had no relatives or close friends with cancer, and who were less encouraged by a GP, and had limited knowledge of BS practices. These are also some of the reported reasons in the literature (Anagnostopoulos et al. 2012; Aro et al. 2001; Lagerlund et al. 2000). It was not known to date which significant predictors describe the variance between lifetime attendees and non-attendees. Study 4 found that the most significant variables to describe the differences between lifetime attendees and non-attendees were perceived benefits, barriers, cues to action, self-efficacy and emotional representations. Hence, the health beliefs of women who have never attended for mammography during their lifetime should be targeted, particularly perceived barriers and cues to action, since these emerged as the strongest predictors to lifetime non-attendance. Although it is acknowledged that lifetime non-attendees are an extremely difficult group to target (Cockburn et al. 1997), this research recommends to target women who have never participated in BS primarily and those who are invited for the first time by the MBSP.

Whether these beliefs and other factors are predictive of adherence with recommended time intervals for mammography at organized or private screening in Malta was unknown and hence was explored in this research. It is, however, known that in order to achieve health benefits, women must attend BS regularly at recommended time intervals (Coyle et al. 2014; Ritvo et al. 2012). Maltese women have been routinely invited to undergo mammography at three-year intervals at an organized programme (MBSP) or could opt to attend privately. Study 5 explored the predictors for Maltese women screened within or exceeding the recommended three-year frequency in organized or private screening in Malta. No significant associations were found between adherent or non-adherent women in relation to sociodemographic or health status variables. A plausible explanation for the disappearance of an effect of socio-demographic factors in subgroup analyses on adherence in this study is that they represent 'carriers' of already established health-related behaviours (Anagnostopoulos et al. 2012; Moodi et al. 2012). This is consistent in all of the quantitative studies (Studies 2-5), where different socio-demographic and health status variables were non-significant predictors of BS uptake (**Table 6.1**). The findings of Study 5 suggest that to increase routine and timely mammography practices, women who are non-adherent to recommended time frequency guidelines should be targeted, together with their health beliefs, predominantly perceived barriers and cues to action, which emerged as the most important predictors to timely attendance. Women who attend at longer intervals may also need to overcome barriers to seeking mammography and follow tailored cues to action in order to attend at recommended intervals (Ritvo et al. 2012; Edwards et al. 2009; Rakowski et al. 2006). Women should therefore receive further information on the recommended screening frequency and the benefits of being part of an organised programme in order to reach greater adherence to recommended time intervals (WHO 2014; Ferrat et al. 2013).

9.2.3 What types of interventions are effective at increasing mammography uptake within populations?

9.2.3.1 Findings of the systematic review

The findings of the systematic review are novel since interventions to increase mammography uptake through the use of HBM and/or CSM theory has not been previously explored, and therefore adds to the literature on interventions in the BS field. The use and combination of HBM and CSM may help to link factors and mediators influencing screening outcomes, and the cognitive and emotional illness representations to guide the design, implementation and evaluation of interventions across diverse cultures and populations. The findings of this review showed that only one study used the HBM as a whole and not all studies measured health beliefs as outcomes. Perceived barriers were most frequently targeted when designing interventions, a finding that reiterates the quantitative findings in this research. The findings of the review also showed that interventions based on the HBM carried out in a community setting involving culturally-targeted material, telephone counselling and BC education were more likely to be successful than face-to-face risk tailored information messages or a nurse-delivered breast health promotion program to improve mammography uptake. However, further research is required to prove the effectiveness of any one particular intervention or multiple strategies based on theory to improve BS uptake that could be adopted for the Maltese population because of discrepancies in the findings.

No RCTs were found using the CSM as a theoretical framework and the effect of interventions that draw on CSM constructs is yet unknown. The reason may be attributed to the fact that it has generally been used for the prevention and management of other chronic illness threats (McAndrew et al. 2008) and to understand the illness perceptions of groups at risk from a particular illness (Hughner and Kleine 2004). Therefore, there is limited information on the impact of CSM among healthy individuals and their lay perceptions of BC (Figueiras and Alves 2007). Hence, the lack of use of CSM in RCTs and in informing BS interventions, in itself, is an innovative finding and this research primarily showed how incorporating CSM constructs in BS research aids the prediction of BS non-attendees. Further research is required to evaluate intervention effectiveness and support the value of CSM by examining whether the model has the same pattern of interrelationships between healthy individuals' models of illness and their beliefs and perceptions towards preventive health actions.

The findings of this review have considerable implications for the development of BS interventions to help improve screening behaviours among Maltese women. Although several theory-based behaviour change interventions have shown promise with regard to improving mammography uptake rates, they are not necessarily appropriate for implementing on a large scale, as they are resource intensive. For example, although the BC education program in the study by Sadler et al. (2011) was successful to increase mammography rates, it relied on training cosmetologists, while the culturally-targeted DVD materials were mailed to participants in the RCT by Wang et al. (2012). There is thus a need for the design and development of effective, yet inexpensive interventions, which can be rolled out on a large scale.

9.2.3.2 Expert steering groups

Steps 2 of Intervention Mapping (IM) were supported through the setting up of two steering groups by the researcher, involving key health experts who met up in Scotland and in Malta respectively to identify potential theoretically informed intervention components, construct matrices of change objectives and create a logic model of change relating to changing BS behaviours in Malta. This included discussions between experts to identify specific preparatory behaviours related to BS (performance objectives, POs) and determinants (factors) to BS uptake. The expert groups also discussed appropriate methods that could be used among the Maltese population in order to identify change methods that would address the change objectives (COs). Practical strategies, that could be most effective at changing BS behaviour in Malta, were discussed based on feedback about priority population and organizational capacity fit. POs were developed for two groups (individuals and healthcare providers) (**Table 6.2**). These POs addressed preparatory behaviour by women for BS use, and what health providers need to do to aid women to attend. Intervention developers can thus identify exactly what needs to change in order to accomplish the PO, and ultimately the intervention outcome (McEachan et al. 2008). Women's limited knowledge, attitudes, low perceived risk, personal and logistical barriers, emotional concerns, low self-efficacy and the lack of cues to action were selected as the most important determinants for women. For healthcare providers, knowledge, barriers and benefits, attitude and standards of care were considered as the most important personal determinants to BS. Socio-cultural determinants were considered not to be changeable in a short intervention, but were considered to tailor the interventions culturally.

Both groups concluded that the ‘barriers’ construct was the most significant component to target in a future intervention and that the non-attendees were difficult to reach but the most important target group. Hence, the need for further qualitative work was suggested by both committees in order to explore in more depth the health beliefs and illness perceptions of lifetime non-attendees. Similarly, this need is highlighted in the literature since participation in BS is a complex phenomenon that has many dimensions (Sterlingova and Lunden 2018). Notwithstanding, there are a limited number of qualitative studies that have investigated the phenomenon of non-participation within organized BS programmes from the perspective of non-attending women (Sterlingova and Lunden 2018; Manjer et al. 2015; Johansson and Bertero 2003).

No single method was identified by both steering groups as being more effective than others to change behaviour, increase knowledge or measure an intention to change. Theoretical change methods that were considered to possibly be applicable to the POs were skills training, peer education, group discussions and individual counselling, focusing on barriers to change, social aspects of screening use, and disseminating information. Two further methods were discussed: entertainment education (Serra et al. 2017; Singhal and Rogers 2004; Bandura 1986) i.e. employs formats based on entertainment to promote educational messages (Serra et al. 2017) and role modelling i.e. real-life role models identified as peers of the target population who communicate key messages (having same language, similar cultural and social norms) (Serra et al. 2017; Alegria et al. 2009; Kok et al. 2004). These overarching methods also include other change methods such as consciousness raising and providing women with cues to action (HBM theory).

In this research, eliciting expert opinion was very useful to aid and influence the decision-making process. For example, following upon their proposed suggestions, I thoroughly considered carrying out qualitative research among non-attendees. The use of steering committees also had an indirect effect on research performance, as the expert members helped to shape and refine the context of research processes. Since there is a general lack of research on the role of committees to guide research studies and their implementation processes, the use of steering groups in the field of cancer screening can be considered as a first step in reducing this gap. However, there is the need to better understand their role in realizing value as a structural element of research and intervention management. From an organizational perspective, further understanding of their role will help form the integrative structural elements that need to be in place to gain full value from their investment in health management pathways.

9.2.3.3 Patient and Public Involvement

Chapter 7 aimed to understand the use of the World Café process as a PPI event to engage collective community perspectives on BC and BS and effective interventions to increase BS uptake in Malta. It can be concluded that combining PPI with mixed methods research benefitted the quality and rigour of this research, gaining wider perspectives of the Maltese population. PPI groups provided perspectives that were different from those heard from research participants who participated in the national survey or qualitative interviews. Mutual trust between researchers and members of the public whose voices are less often heard was established in this PPI.

Since the Maltese population tend to be community-centered (Ciappara 2015), families within the community are key to providing social support to women (Filippi et al. 2014; English et al. 2008). The community is, therefore, an ideal setting for health promotion (Merzel and D'Afflitti 2003) and in particular, to improve BS uptake (Engelman et al. 2011). The lack of social support in community settings emerged as an interpersonal factor to BS uptake when formulating the logic model of the problem (**Figure 6.1**). Hence, the notion of patient and public involvement (PPI) is integral to the understanding of community perspectives on BC and screening, and may enhance understanding of social roles in BS decisions of Maltese women. Given the importance of community engagement, obtaining scientifically based evidence of the most effective ways of stimulating community change is essential for planning future interventions in Malta.

This PPI activity found that partners/husbands and daughters can be potential conduits to health decision-making including BS. In the literature, men's perceptions, knowledge, attitudes and beliefs about BC and BS are widely ignored (Thomas 2010; Flores and Mata 1995), possibly because BC in men is uncommon (accounting for less than 1% of all BCs and less than 1% of all carcinomas in men) (Giordano et al. 2006) or because people often assume that men cannot acquire the disease (Thomas 2010; Flores and Mata 1995). Limited evidence suggests that women rely on male family members for support and protection (Donnelly et al. 2017). Men saw their personal role as a supportive network to women's health decisions. Hence, men can influence women to accept an invitation to attend BS programmes (Donnelly et al. 2017; Chamot and Perneger 2002). Moreover, relevant information available to men about BC is scarce (Robinson et al. 2008; Peate 2001). Therefore, understanding Maltese men's perspectives and knowledge of BC and BS through PPI enhanced the understanding of men's social roles in health decisions, particularly when it comes to BS among Maltese women.

On the other hand, this PPI activity has shown that the mother-daughter relationship and communication norms within the family provide the primary context for exploring message design strategies for developing an adolescent-initiated screening intervention. Research suggests that mothers are receptive to BS appeals (Mosavel and Wilson Genderson 2016; Browne and Chan 2012), particularly those of their adolescent daughters (Mosavel 2009). Children can be appropriate channels for health messaging and education, positively impacting their own health and that of their families (Onyango-Ouma et al. 2005), as children or youths can persuade their mother to improve health-related behaviours (Mosavel and Wilson Genderson 2016; Ayi et al. 2010; Mwanga et al. 2008; Onyango-Ouma et al. 2005). In an Australian study exploring the potential for adult daughters (18-39 years) to deliver mammography promotion messages to their screening-eligible mothers (Browne and Chan 2012), both mothers and daughters were amenable to a two-way conversation on the topic when prompted, although the mammogram communication that occurred was primarily in the downward direction (from mother to daughter). Similarly, in a survey among American college women that examined the types of BC prevention information-seeking information given to mothers (Kratzke et al. 2014), screening information was found to be the most frequent type of information that daughters provided to their mothers. Therefore, young females could potentially serve as opinion leaders for their mothers regarding cancer screening. For this reason, effective interventions promoting BS should consider both younger and older female generations as well as men's beliefs and perceptions related to, and their respective engagement in, BS to further increase BS uptake.

Men do not seem to chat with other men regarding health-related issues but consider their female partner to be key in influencing their health decision-making. Previous studies have shown that men are less knowledgeable about health-related issues than women and are less likely to assume health responsibilities for others (Norcross et al. 1996; Flores and Mata 1995; Umberson 1992). Nonetheless, in Geneva, men seemed at least as likely as women to support initiatives promoting BS (Chamot and Perneger 2002). This PPI activity also found that women tend to be influenced more by their health care provider and once women decide to trigger a personal health action, they inevitably receive support and recommendations from their partner, which in turn might sustain women's receptivity toward a screening appeal. This finding challenges the assumption that men take critical decisions and women simply comply; rather, the findings paint a picture of a more iterative pathway and dynamic relationship in the health decision-making processes of families. Hence, men may contribute to shaping the social norm on BS and support initiatives related to mammography utilisation and their partner's health decision-making.

Fear of BC emerged as the main BS barrier among members of the public. For those who had not attended for mammography or were too young for the procedure, mammography instilled fear and their perception of the procedure was one of pain. The literature shows that painful mammography experiences stop women from attending subsequent mammograms (Askhar and Zaki 2017) and that women have ready formed expectations about BS before receiving information from the screening programme, which also compromise the perception of balance between screening benefits and harm (Henriksen et al. 2015). The perception of pain varied between men and women in this PPI, such that minor discomfort perceived by men was considered much less severe than intense pain as experienced by some women. Men described the mammography procedure as an exaggeration of mammography pain continuously instigated by other women. Literature that deals with men's knowledge of BS practices is not available to compare with the results of this study. Men's perspective may have an indirect impact on women's screening decision as women may perceive their partner's perspective as a lack of understanding of their fears and worries and a lack of emotional receptivity and compassionate care. The challenge of minimizing the gap between men's perceptions and actual experiences seems to be not just a matter of limited opinion but a consensus between men. The perception of men should be further investigated, together with the effect of how facts are framed for men and illuminate the context in which men base their interpretations of experiences and information.

Men offered recommendations that incorporate men or family-based support to promote BS. The preferred communication channels for men were TV, internet, billboard advertisements and GP recommendations, while women preferred culturally-tailored media through bulk emails, printed leaflets and brochures, TV and radio channels. Women gave higher preference to one-to-one interventions that can be effectively delivered at suitable locations frequented routinely by women such as community pharmacies, followed by nail, hair and beauty salons. Both women and men emphasised the importance of the GP's role towards effective health outcomes, a finding reiterated in the quantitative findings of this research (Chapter 4) and in the literature review (Chapter 2).

9.2.4 Which factors influence non-attendance among lifetime non-attendees and which interventions are considered appropriate to increase mammography screening uptake in Malta?

Study 7 aimed to understand the factors that influence non-attendance in more depth. Qualitative data analysis revealed eight sub-themes relating to personal beliefs, perceptions, attitudes and feelings, knowledge, social networks and perceived interventions. This study confirmed the findings of the survey data and that there are numerous factors influencing attendance but provided new knowledge by informing a better understanding of these factors.

This study revealed a number of unmet needs that continue to require additional support and resources, particularly in the domains of psychosocial health. Fear was reiterated as a main barrier impeding BS attendance and included fear of mastectomy, fear of death, fear of pain, fear of an altered body image, and fear of not being with the family. Research suggests that such emotional factors (Remennick 2006) such as fear of losing femininity and sexuality (Ferrat et al. 2013) and fear of social stigma may be reasons for not seeking immediate medical help or screening (Khazaee-pool et al. 2014; Filippi 2013; Engelman 2012). Although a cancer diagnosis in the family appeared to have prompted lifestyle changes, it was not a motivator to attending mammography in this study. Rather, participants seemed to be overcome by fear of a personal cancer diagnosis, its related death, traumatic histories and personal traumas. Some participants described negative associations between prevention and disease because they had experienced past personal traumas, family/friends' experiences of the disease or negative health care experiences. These concerns were often related to their trust in practitioners and the health service, such that some doubted whether the care pathway was truly effective and as a result reverted to other means for cancer prevention. This is consistent with other populations, such as the Chinese community (Zhang 2014) who often revert to Western medicine as an alternative treatment (Rochelle and Marks 2011). These findings imply that healthcare providers should be aware of the diversity and alternative healthcare seeking behaviour among populations. In addition, these findings highlight an area for improved support and education to ensure that women are fully supported and informed about BS benefits. Interventions that are specific to trauma-related experiences in the health care setting are less developed (Mealer et al. 2009) and to the best of my knowledge, there is no literature related to lifetime traumatic experiences or more specifically, prior traumatic health experiences in relation to BS uptake.

Other barriers to BS reported in the literature are lack of social support from family, spouses and friends (Lamyian et al. 2007; Nahcivan and Secginli 2007; Kearney 2006). This study similarly showed that women lacked support from family members. However, this study found that lack of social support led women to experience existential rejection, distress, depression, isolation, neglect and loneliness. These emotional factors have not been thoroughly investigated in the BS field. Factors related to practical and emotional support throughout a woman's life are important to women, and that approaches assisting individuals to express these at an early stage should be assimilated into health care practices. Moreover, the majority of participants in this study had not received professional advice from physicians, which may in part explain why they were not fully supported and informed about mammography benefits. This had led several participants to opt out from seeking screening information relying only on symptoms or pain. Evidence has shown that an estimated 20%–30% of women will wait at least 3 months before seeking help for BC symptoms (Richards et al. 2000). In order to ensure that women are properly supported and informed about screening benefits, it is important that they receive sufficient advice from their physician, are supported by their partner/spouse and family members, and are directed to appropriate sources of information.

The findings of this study suggest that healthcare professionals should refer to the patient's wider support networks and make the necessary referrals to appropriate services, while policy makers should ensure that services providing psychological, social and emotional support are accessible to women in general. Futhermore, health care organisations should provide appropriate support to women who have experienced any personal traumas as this may be the first point of call for women seeking help. Such factors may influence each other, and targeting one factor may help to bring positive change in another (Mohan 2017). If left untackled, women may experience mental health issues such as depression, anxiety and stress. Women could be taught how to accomplish self-care activities, and perform behaviour change techniques. Action planning, goal-setting and positive social interactions can aid to reinforce a woman's self-esteem and perceived self-efficacy (Michie et al. 2011; Mohan 2017).

9.3 Contributions towards health psychology theory

Theoretical models aid the understanding of mechanisms involved at increasing BS uptake among Maltese women. The theoretical contribution of this study was that the factors related to mammography screening use among Maltese women were explored in relation to the HBM (Becker et al. 1977) and CSM (Leventhal et al. 1984). Despite the prevalence of using HBM and CSM to understand the beliefs and perceptions related to behaviour change among diverse populations, there was no knowledge on their application to the Maltese population prior to this study. The HBM is useful in explaining and predicting health behaviours by focusing on the attitudes and beliefs of individuals (Jahanlou et al. 2013; Janz and Becker 1984). On the other hand, the key CSM construct is the concept of illness representations or 'lay' beliefs about illness (Hale et al. 2007) through the understanding of cognitions (the perceived reality of the health threat) and associated emotional responses (such as fear, anxiety or worry) (Leventhal et al. 1998). The findings provide further support for models containing the CSM constructs to account for a larger proportion of the overall variance in BS utilisation and cancer control prevention. The findings also support the evidence that illness representations are individualised based on personal experiences and culturally available knowledge (Wyke et al. 2013).

The findings of the thematic analysis showed that Maltese women's screening-decision process regarding BS non-utilisation covered all HBM and CSM variables. The findings of the quantitative data also indicated the fact that HBM constructs, in conjunction with CSM constructs, improved the accuracy to predict non-attendance. There are also other factors influencing BS uptake among women from the Maltese community in addition to the constructs of HBM and CSM. For example, it was evident from the PPI event and qualitative interviews that social network experiences and prior personal traumatic histories were important factors that influenced BS behaviour among Maltese women. Previous research has documented that social network experiences (DiMatteo et al. 2000), prior trauma and poor post-trauma social support (Cordova et al. 2017) may act as barriers to taking health actions in general. Hence, BS interventions should also consider these factors when targeting the Maltese population in order to target psychosocial factors that are likely to act as barriers to BS utilisation.

9.4 Contributions to the use of mixed methods

The benefits of using a mixed methods approach has been described in this thesis in order to explore health beliefs, illness perceptions and other determinants to BS uptake in Malta. In this research, quantitative data were employed by way of generating numerical data or data that could be transformed into usable statistics through statistical techniques. In practice, this method is used to quantify beliefs, attitudes, behaviours and other defined variables and generalizing it across a group of individuals to explain a particular phenomenon (Carson et al. 2001). Since limitations in quantitative research include being unable to understand complex factors and to predict human behaviours in-depth (Kura 2012), the use of qualitative methods are employed to gain further insights to the underlying reasons, beliefs, motivations and behaviours (Bowling 2009). Thematic analysis was used in the analysis of qualitative data obtained to identify all salient themes due to its flexible approach in specifying the similarities of a group of participants and individual experiences (Braun and Clarke 2006). In addition, thematic analysis provided a rich and detailed, yet complex account of data for examining the perspectives of different research participants (King 2004), generating unanticipated research insights.

In the context of the World Café event, six categories were discussed related to health attitudes, knowledge, role of health providers, family and friends, experience and perceptions of the mammography procedure, screening facilitators, screening barriers, the effectiveness of communication channels and effective interventions to encourage screening and awareness. However, some of the categories were somewhat influenced by the researcher's theoretical orientation on the topic. On the other hand, the qualitative face-to-face data analysis among lifetime non-attendees revealed eight sub-themes which were strongly influenced by the interview topic guide and pre-set objectives of the study. Although thematic analysis provides the empirical evidence for the development of a future intervention, it fails to take into account the influence of researchers' role during analysis (Taylor and Ussher 2001). The identification of themes are affected by the researcher's own theoretical position and values (Taylor and Ussher 2001). Hence, this requires reflexivity from among researchers to reflect upon and clearly articulate their position and subjectivities (i.e. world view, perspectives, biases) (Sutton and Austin 2015). Additionally, this thesis has demonstrated how both empirical evidence and theory can be used to guide the selection of appropriate intervention methods that best fit the future design of BS interventions and practical strategies in Malta.

9.5 Contributions to the use of Intervention Mapping

Intervention Mapping (IM) (Bartholomew et al. 2006) has been used successfully to plan, implement and evaluate interventions to increase uptake of disease prevention programmes (Garba and Gadanya 2017). This current study has provided a good understanding of the role of IM to explore the determinants to mammography utilisation in Malta and to plan and propose recommendations for the development of future interventions. The use of mixed methods was based on the stepwise IM framework to bridge the gap between theory and practice, and to guide, identify, measure and synthesize findings on the determinants, barriers and facilitators to BS uptake with the aim of developing a future, theory-based intervention among Maltese women. Hence, IM served as a framework for this study that described the iterative path from the identification of gaps to problem solving and proposing recommendations. While many studies only describe the development of disease prevention interventions using IM (Garba and Gadanya 2017), this study took into account and provided all possible details of the processes involved in that development (e.g. sampling techniques, methods of data collection and analysis, study design), thereby improving the methodological quality and validity of the studies.

The studies carried out in this thesis covered the following steps. IM Step 1 (needs assessment) was accomplished through a literature review of barriers and facilitators, systematic review of theoretical interventions as well as quantitative and qualitative studies. The systematic review showed that culturally tailored interventions in a community setting are more effective in terms of increasing BS uptake. Because the target population was Maltese women in this study, the needs assessment also included a cross-sectional survey, a PPI event involving females and males, as well as qualitative interviews with non-attendees so that the psycho-social factors related to non-attendance to mammography, could be better understood.

IM Step 2 (the development of matrices of change objectives) formed the foundation for the development of a future intervention by specifying the detailed information about who and what will change due to the intervention (Bartholomew et al. 2006). On the basis of the needs assessment, the POs, which are the more specific and detailed behavioural objectives, were developed for two groups (individuals and healthcare providers) with the scope of future intervention development (**Tables 6.3 - 6.4**). The developed matrices of COs provided a guide for the discussion on the selection of methods and strategies towards mammography behavioural change.

The aim of IM Step 3 was to provide recommendations for potential interventions and practical strategies based on the evidence and organizational fit to achieve the change objectives defined in Step 2. To do this, the following question was considered: *'How can the change objectives be achieved?'* The interventions and strategies were proposed based on: (1) the findings from the systematic review of theoretical interventions (Chapter 5), (2) the findings of the quantitative and qualitative studies in this thesis (Chapters 4, 8), (3) the feedback from the expert steering groups (Chapter 6) and PPI event (Chapter 7), and (4) the resources available in Malta (which were discussed with the MSG).

This study set out to use IM as a way of identifying and articulating the essential elements of a potential intervention. However, the challenges in practice included the identification of other evidence-based interventions and deciding whether and how they could be adapted for a new setting and new population such as the Maltese community. Planners need to assure that interventions match the new setting's capacity, health problem, context, and the at-risk population (Mihalic et al. 2008). However, intervention evaluations rarely report on which features of an intervention constitute the essential elements to make the intervention successful (Elliott and Mihalic 2004). Step 4 (intervention design), Step 5 (specification of adoption and implementation) and Step 6 (creation of programme evaluation) were not within the scope of the current research but will be considered in future work.

9.6 Implications for practice and dissemination of findings

Opportunities exist to enhance awareness and support for women and men's role in BC education and screening decisions. This research provides valuable information to healthcare providers, researchers, screening leads and public health educators as the findings can aid to design culturally sensitive interventions to improve screening behaviours. Overall, the implications of the research results were two-fold. I began an extensive community dissemination process, including dissemination to the scientific and lay communities. Dissemination to the scientific community has included scientific articles and oral conference presentations, as well as public talks and television/radio recordings during Pink October in Malta, as well as international publications and conference presentations. By exploring in further depth the views of participants in this research, I was in a better position to better influence and inspire the 2017 and 2018 BS campaigns, aiding the national development of culturally-tailored BC information and educational materials that promote awareness, screening and resources designed specifically for the local community.

October is the month where worldwide annual campaigns are organised to highlight the importance of breast awareness, education and research. In 2017 and 2018, 'Pink October' campaigns in Malta were led by the Maltese Prime Minister's wife, who also founded the Marigold Foundation (http://marigold.org.mt/) to raise public awareness and funds for BC research and other rare diseases. For the first time in Malta, more focused campaigns were conducted based on the quantitative findings of this research (**Appendix 9**). The main objective of both campaigns were set to encourage women to face their fear of BC and BS. An eye catching key message was displayed on social media, local television and radio stations, public locations and billboard promotions for the duration of the month of October. The main key message was drawn up as *'Face Your Fear' – Would you rather sit in the dark or turn on the light?* (**Figure 9.1**). The campaigns also included raising awareness among young adults in schools, as well as in public and private organisations.

Figure 9.1 - Key message for Pink October campaign held in Malta in 2017

A systematic review of interventions (Austoker et al. 2009) found good evidence that the BC Awareness Month in the US promotes diagnosis of BC at an early stage and some evidence that educational interventions by community health advocates and public education campaigns downstage BC. Media awareness campaigns are often a person's natural option to stay in synchronization with the global perspective and should be seen as the cornerstone for health communication interventions because of the myriad of communication techniques and channels that could be used to increase awareness and knowledge of health problems and interventions (DeJong 2010; Kreps and Sivaram 2008). It is also believed that mass media channels have the power to reach and inform large audiences, while interpersonal channels are more influential in motivating attitudinal change. Television, for instance, has the power to shape how we think and relate to each other (Lee 2010). However, in health communication studies, scholars have found that educated women prefer to access newspapers, magazines and medical journals than watch television health programmes. They have argued that women rely on the print media as one of its major sources of information on cancer, and women read magazines for BC information (Kreps and Sivaram 2008; Leask et al. 2010). This represents an opportunity to engage with the harder-to-reach group. Similar results were found in a study by Nelson and Salawu (2016) whereby it was concluded that mass media messages should be considered as the main mechanism to improving breast care among women in South-West Nigeria.

Some health campaigns are designed simply to raise general awareness of a particular health threat, while other campaigns have more specific goals, such as convincing individuals to reduce risky behaviours (Jacobsen and Jacobsen 2011). The aim of a breast campaign is for women to take the most appropriate course of action to detect cancer early, by either making a GP referral or attending a screening mammogram (Robb et al. 2009). Catalano et al. (2003) examined the relationship between early BC awareness efforts and diagnoses, using quarterly diagnosis data from 1975 to 1997 in three metropolitan areas that sponsored awareness month activities during the early years of locally-sponsored BC awareness months. They found that BC diagnosis rates increased in each of these cities in the last quarter of the calendar year after the first community-based awareness months were started in 1985. Since the beginning of the BC awareness movement in the US, both screening rates and diagnosis rates have increased markedly. Breen (2007) reports that the proportion of women who reported having had a mammogram in the previous two years increased significantly from 29% in 1987 to about 70% in 1999. Along the years, an additional contributing factor may be that the increased use of computer-generated annual reminders and automatic scheduling have increased the number of women who undergo routine screening (Kaczorowski et al. 2009).

The impact and success of the local multimedia national campaigns and reported levels of cancer awareness and mammography uptake amongst the Maltese population are yet to be evaluated. Nonetheless, the findings of this thesis have informed the development of the Maltese campaign in a number of ways, not only by aiming to target fear but also through the potential of developing interventions aimed at increasing mammography uptake based on theory and evidence-based findings. Following the 2017 and 2018 local campaigns, there are plans to incorporate further findings of this study in subsequent campaigns. Broader engagement regarding what is most important to citizens could further support the development of a tailored intervention to increase BS uptake in Malta.

9.7 Strengths and limitations of the current research

There are strengths and limitations that need to be considered in the interpretation of results. This section outlines some of the common strengths and limitations, which are applicable across several of the studies in this thesis. The strengths and limitations of each study have been outlined in the relevant chapters.

9.7.1 Strengths

There are advantages of having conducted quantitative and qualitative studies. First, conducting quantitative and qualitative research before designing an intervention for a topic that has been under-researched is vital, as it allows for the idenfication of key factors to be targeted and change mechanisms and the subsequent tailoring of the intervention. It also enables the input of participants to be captured and incorporated into the intervention design (Craig et al. 2008). Exploring women’s views is in line with recommendations on how to drive health promotion in the health setting (Springer et al. 2017). IM provided helpful guidance in exploring the factors that influence BS behaviour.

The quantitative part of this research produced a rich dataset, which allowed the analyses of diverse subgroups. This facilitated data in relation to a first and second MBSP invitation, lifetime screening practices and timely screening adherence. No research could be found that had similarly and simultaneously assessed sociodemographic and psychological variables as predictors of BS behaviours.

A qualitative enquiry also allowed the researcher to explore health beliefs, illness perceptions and knowledge levels of women in further depth. Other studies have used questionnaires to assess health beliefs (Anagnostopoulos et al. 2012; Huaman et al. 2011; Champion et al. 2008), illness perceptions (Petrak et al. 2015; Anagnostopoulos et al. 2012) and knowledge of BS behaviour (Dundar et al. 2006). These questionnaires limit understanding of how well people understand the disease as they provide a list of potential variables for participants to choose, thereby prompting women to select the associated risk factors. These limitations were overcome through qualitative research, allowing for any misconceptions and misinterpretations to be identified, which strengthens the case for improving knowledge among the Maltese community.

9.7.1.1 The role of a Maltese researcher

I played a vital role in aiming to reduce any potential bias such as 'response bias' and 'measurement error' in this research, by using my research and interviewing experience throughout the data collection process. Racial differences between the researcher and participants may have a substantial impact on the 'genuineness' and 'accuracy' of how participants respond to research questions (Rhodes 1994). Sharing the same ethnicity and gender between the researcher and participants may have allowed participants to feel more comfortable to discuss their beliefs and experiences with BS and prevention. Notwithstanding that I, 'the researcher', and participants had no racial or ethnic differences in the entire research, data collected might be affected by social-desirability response bias as participants may still be more likely to respond in a more positive way to reach the expectations of 'the researcher' (Anagnostopoulos et al. 2012; Gunaratnam 2003).

BC is a sensitive and private topic for the Maltese community, and women feel embarrassed when talking about their breasts and exposing them infront of others (Marmarà et al. 2015). The literature review (Chapter 2) indicated that BS compliance may be influenced by culture and health beliefs. This research was conducted by a Maltese, bilingual female researcher with fluency in both Maltese and English languages. Maltese participants in this research stated that they had no difficulties in understanding and speaking Maltese as it is Malta's national language. However, English is also our official language, though not all Maltese individuals can converse in English. Hence, using a Maltese researcher can eliminate the language barrier. Participants may also express some beliefs, perceptions and characteristics of the Maltese culture, which are difficult to express in English. Therefore, sharing the same cultural background and language between 'the researcher' and participants can definitely facilitate quantitative and qualitative research and aid 'the researcher' to obtain rich and in-depth information from participants.

9.7.2 Limitations

9.7.2.1 Self-reported data

The use of self-reported data throughout this thesis is a significant limitation and subject to bias. There are no national data records from private practices currently available to date in Malta. Therefore, it was not possible to capture data of repeat mammograms at another facility as this is not recorded on the screening database. Hence, self-reports for private mammography was used to measure lifetime mammography and adherence to timely mammography rather than having objective measures from private clinics. Self-reported data could also have affected the observed difference between women attending private screening and the MBSP. Since data collection was dependent on women's memory about recalling past mammography events, this may have caused recall bias effects (Hassan 2005). However such a recall bias is more likely to be minimal as women tend to recall health events (Rheingold et al. 2004) that threaten their stability in life.

9.7.2.2 Cross-sectional data

With the exception of Chapter 4, Study 3 (which included a prospective design) and Chapter 8, Study 7 (which was qualitative in nature), all survey data in this thesis (Chapter 4, Studies 2-5) were cross-sectional. Therefore, although associations between variables were examined, a temporal relationship between exposure and outcome cannot be established and hence, it is not possible to infer causation. For example, in Study 5, those not meeting the screening interval guidelines were more likely to want advice on some topics. The researcher inferred from this that individuals with less healthy behaviours were aware that they needed to be screened for BC, and therefore wanted advice to help them make this change in screening behaviour. However, it is equally possible that those who were meeting screening recommendations were knowledgeable about screening and had already sought out information which had helped them to attend, and were therefore less interested in receiving further screening advice. Evidence has shown that some psychosocial factors, including illness perceptions maintain relative stability over time (Rutter and Rutter 2007). However, further prospective longitudinal research is warranted to confirm these findings and to validate the direction of causal associations with a strict amount of control to explore how certain variables (such as perceived control over BC) at time 1 change at time 2 and how the latter relates to mammography utilisation (Petrak 2013). Furthermore, the strength of the statistical association between variables and the theoretical plausibility of the presumed causal relationships should be assessed (Taris and Kompier 2003).

9.7.2.3 Qualitative data

Although the findings of face-to-face interviews (Chapter 8, Study 7) have limitations in generalization, the aim of qualitative research is to explore the interaction between variables within a certain context rather than to generalize the findings to the whole population (Yardley 2008). Thereby, the results of these studies fulfilled the purpose of the methodology. It is recognised that women in different organisations and with different societal values may express different views (Parker et al. 2015). However, since the MBSP shares much in terms of rationale, purpose and implementation with its counterparts in the UK and many European countries, it is likely that the findings of this current research will be at least partially transferable to these contexts.

Finally, it is possible that experts who participated in the steering groups were somehow different from those who did not; the researcher, however, sought to minimise such potential bias by ensuring that experts from a range of backgrounds and professed opinions about screening were involved.

9.8 Future research

While the studies in this thesis have provided interesting results on BS determinants and potential interventions, there are still a number of gaps in the literature warranting further investigation. First, the researcher plans to complete steps 4, 5 and 6 of IM in further work. The future intervention to improve BS among non-attendees could be revised according to feedback received from the intended participants and health service providers to ensure that the designed intervention materials are culturally relevant and the intervention could be adequately implemented. The final intervention could be assessed in practice to explore whether the intervention could decrease non-attendance and hence determine actual behaviour change as the primary outcome, followed by changes in cancer-related knowledge, health beliefs, illness perceptions and intention to go for BS. A RCT would be required to establish the evidence for intervention efficacy (Akobeng 2005). A further intervention could be developed to target non-adherent women, together with their health beliefs, predominantly perceived barriers and cues to action, to increase routine and timely mammography practices. Further research is warranted to prove the effectiveness of any one particular intervention or multiple strategies based on theory to improve BS uptake that could be adopted for the Maltese population.

The findings of this study can be used by health professionals as a guide to develop culturally and linguistically appropriate educational materials to promote breast health and screening among Maltese women. In addition, the results can help to evaluate whether the existing educational materials are suitable. Additionally, it would be worth exploring the causal relationships between psychosocial factors related to BS generated by this research and mammography uptake.

Study 1 provided preliminary evidence of the psychometric properties assessment of the scales. As these were preliminary findings, further psychometric testing of the scales is recommended to obtain further evidence of the instrument's reliability and validity among women with varied backgrounds and diverse perspectives. Study 3 in this thesis was conducted among a small sample, so it is not possible to generalise the findings. More research is required among a larger representative sample to investigate whether uptake to a first screening invitation is a significant predictor of subsequent screening in Malta. It would also be interesting to measure health beliefs and illness perceptions before and after screening. Further qualitative research is required to understand in more depth why women choose opportunistic screening over an organised programme.

Since the findings suggest scope for community family physicians to be more proactive, a focus group study among local GPs could be conducted to explore the association between their attitudes towards BS and women's participation in screening programmes. The barriers reported by Maltese participants together with the perspectives from healthcare providers would provide richer data on the development of training programmes targeted for healthcare providers to provide effective healthcare services among the Maltese community.

Future in-depth research could also target the health beliefs, illness perceptions and assess the risk factors for BC among young women and those at high-risk as these groups of women may hold different understandings and beliefs of health and prevention from older women or low-risk women. This was evidenced in the PPI event among the younger female generation.

This research found two levels of influence: individual (intrapersonal) factors such as knowledge, attitudes and behaviour, and social (interpersonal) factors such as social networks and support systems. Other multiple influences exist such as organizational (institutional) factors for social institutions with organizational characteristics and regulations for operation; community factors for relationships among organizations, institutions and networks; and policy factors for local, state and national laws and policies (Sallis et al. 2008; McLeroy et al. 1988). Further qualitative exploration of organizational, community and policy barriers will serve to design multi-level frameworks with incorporated theoretical elements, together with concepts that have been shown consistently to increase BS uptake.

9.9 Conclusion

This was the first research to explore women's health beliefs and illness perceptions as well as barriers and facilitators to BS uptake in Malta. This research utilised a mixed methods approach and involved a wide selection of participants, and international and local key players in healthcare services, and could therefore provide a comprehensive picture of the BS topic. Besides aiding intervention developers to provide culturally and linguistically appropriate health interventions in Malta, the findings of this thesis will enable healthcare providers and policy makers to be cognizant of the real issues that act as barriers among the Maltese community to improve mammography screening uptake. This research encompassed various studies but integrated the work and findings through an overarching framework, Intervention Mapping, to inform a future theory-based BS intervention.

The innovative part in Study 1 is the combination, adaptation and translation of two scales for the Maltese scenario. The preliminary evidence of the psychometric properties assessment of the MBSQ showed promise of being a valid and reliable instrument to be used among Maltese women. The findings of Study 2 indicate that it was the combination of both

HBM and CSM contructs that provided improved prediction of non-attendance, when compared to HBM alone, which is an innovative finding in BS research. No studies prior to Study 3 existed on women's reattendance at the MBSP or on screening predictors to the second MBSP round. Study 3 found that interventions should particularly target non-attendance to first screening invitations. Study 4 found that fear is a key factor in relation to lifetime non-attendance and that cues to action aid lifetime attendance. Study 5 found that women who attend private screening were less likely to be regulated in their attendance when compared to MBSP attendees. Furthermore, women's knowledge level, and their beliefs and perceptions were found to be significantly associated with timely mammography adherence. Studies 2-5 showed that HBM constructs, primarily perceived barriers, were the strongest predictors of non-attendance to a first and second invitation to the MBSP and to lifetime attendance and timely adherence, followed by cues to action. The systematic review (Study 6) is the first of its kind to explore interventions that used HBM and/or CSM theory to increase mammography uptake. Study 6 found no interventions that used CSM in the design of BS interventions, which is also an innovative finding. Perceived barriers were most frequently targeted when designing interventions, a finding that reiterates the quantitative findings in this research. Reviewed interventions based on the HBM carried out in a community setting involving culturally-targeted material, telephone counselling and BC education were more likely to be successful to improve mammography uptake.

The steering groups provided a more holistic approach towards understanding BS uptake from the expert perspectives. Both groups concluded that perceived barriers are the most important construct to target in future interventions. Experts supported multiple interventions, including physician recommendations, education and counselling. The PPI event was the first to report on World Cafés in BS research and included both Maltese women and men for their contribution to this topic. Members of the public identified the involvement of partners and daughters in health decision-making. Moreover, for the first time, Study 7 provided valuable, in-depth qualitative insights into Maltese women's beliefs, perceptions, knowledge and attitudes for the lack of mammography use. Qualitative findings found that health-related knowledge was low, fear was the key barrier to non-attendance, and that socio-cultural factors, particularly support networks, household dynamics, traumatic histories and mental health approaches, impeded attendance. Women's lifetime traumatic experiences is novel in the BS field.

In conclusion, this research recommends to target women who have never participated in BS primarily and those who are invited for the first time by the MBSP. The findings from this research show that, due to the interplay of several individual, social and cultural influences on women's health beliefs, illness perceptions and knowledge levels, a multi-factorial, systematic approach is required including multiple, theoretical interventions to increase BS uptake in Malta. Interventions should include BC and BS education, telephone counselling and physician recommendations, and incorporate support networks and household dynamics to improve the psychosocial well-being of women on levels of personal resilience and self-confidence. A potential intervention should target health beliefs, particularly overcoming perceived barriers to a first BS invitation while providing cues to action to motivate and encourage women to attend. The inclusion of illness perceptions shall improve the accuracy with which non-attendance rates are predicted. Fear was the strongest predictor to non-attendance across all the studies. Hence, since emotional factors strongly influence Maltese women's screening behaviours, fear should be addressed in future intervention development, together with women's social network experiences, prior traumatic experiences, poor post-traumatic social support and approaches to mental health. The intervention would be more effective within a community setting, such as in local community pharmacies, and the application of theory including elements of both HBM and CSM, is advocated as an integral and innovative step in intervention design, implementation and evaluation.

This thesis has presented, for the first time, a combination of novel sources of information to understand the barriers and facilitators to BS uptake. It is hoped that the above findings shall be useful to policy makers and intervention developers to design screening interventions both at a local and international level.

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Appendix 4.1.1 - Version of Study 1 published in the *Journal of Nursing Measurement*

Journal of Nursing Measurement, Volume 25, Number 3, 2017

Maltese Translation and Adaptation of Champion's Health Belief Model Scale and the Revised Illness Perception Questionnaire for Breast Screening Among Maltese Women

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Background and Purpose: Translating, adapting, and piloting Champion's Health Belief Model Scale for Mammography Screening (CHBMS-MS) and Revised Illness Perception Questionnaire (IPQ-R) among Maltese women. Methods: The Maltese questionnaire (Maltese Breast Screening Questionnaire [MBSQ]) was developed through 9 steps. Bilingual women (n = 15) completed MBSQ at 2 time points. Results: During forward-backward translations (Steps 1–4), 4 English controversial terms were raised. Twelve experts agreed on terminologies during adaptation process (Step 5). Following face validity (n = 6; Step 6), 3 items were deleted. Following reconciliation (Step 7) and proofreading (Step 8), MBSQ consisted of 121 items. Pilot testing (Step 9) showed positive correlation (CHBMS-MS = .87, IPQ-R = .85; $p < .001$); high Cronbach's alpha (CHBMS-MS = .93, IPQ-R = .92); overall acceptable internal consistency (CHBMS-MS = .69–.83, IPQ-R = .75–.93); and acceptable test–retest reliability correlations: CHBMS-MS (Maltese = .62–.76; English = .61–.84), IPQ-R (Maltese = .63–.82; English = .61–.91; $p < .001$). Conclusions: Maltese and English scale items demonstrated high reliability and validity preliminary values.

Keywords: breast cancer screening; Champion's Health Belief Model Scale; the Revised Illness Perception Questionnaire; reliability; validity

Breast cancer is the primary site of cancer in Maltese women (Malta National Cancer Registry, 2015). Over the last decade, an average of 280 women were diagnosed yearly with breast cancer in Malta (Malta National Cancer Registry, 2015). Breast screening (BS) by mammography has shown to decrease breast cancer mortality rates in women aged 50–69 years by 25%–30% (Greif, 2010). By the end of Malta's first BS round, the rates of participation were below European benchmarks (i.e., acceptable participation [>70%] or higher desirable level [>75%] specified in European guidelines; Eurostat, 2014), such that less than 60% of women aged 50–60 years had accepted their invitation (Marmarà, Curtis, & Marmarà, 2015).

http://dx.doi.org/10.1891/1061-3749.25.3.486

BS uptake is influenced by a multitude of factors (Mamdouh et al., 2014). In particular, studies have demonstrated that beliefs about breast cancer and screening (Huaman, Kamimura-Nishimura, Kanamori, Siu, & Lescano, 2011) as well as illness perceptions (Anagnostopoulos et al., 2012) are important predictors of mammography compliance (Anagnostopoulos et al., 2012). However, little is known why Maltese women are less likely to have a screening mammogram than their European counterparts. This is because a gap exists in our understanding of factors impacting Maltese women's decisions to undergo BS, partly because of the lack of instruments locally validated for this aim. The instruments chosen for translation and adaptation were selected from the extent literature, which shows that health beliefs and illness perceptions are key determinants of BS behavior (Anagnostopoulos et al., 2012; Champion et al., 2008; Moss-Morris et al., 2002).

The aims of our study were threefold: (a) to translate and adapt existing scales, that is, Champion's Health Belief Model Scale for Mammography Screening (CHBMS-MS) and the Illness Perception Questionnaire (IPQ-R) from English to Maltese (CHBMS-MS-M + IPQ-R-M = MBSQ) so that these could subsequently be used to examine why women in Malta attend/do not attend BS when invited; (b) to determine whether Maltese women interpret consistently the meaning of questions in Maltese and English; and (c) to pilot test the reliability and validity of the Maltese and English versions of CHBMS-MS and IPQ-R. Because the English language is an official language but not our national and sole mother tongue language, we aimed to pretest not only the Maltese version but also the English version because some Maltese women may opt to respond in the language they prefer.

BACKGROUND AND CONCEPTUAL FRAMEWORK

History and Development of the Champion's Health Belief Model Scale

The health belief model (HBM), developed in the early 1950s, is a behavior prediction model, comprising six fundamental constructs: perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, cues to action, and self-efficacy (Jahanlou, Lotfizade, & Karami, 2013). Champion developed and validated a scale in 1984 (Champion's Health Belief Model Scale [CHBMS]), consisting of 36 items to measure perceived susceptibility to breast cancer as well as perceived benefits and barriers to BS (Champion, 1984). In 1999, CHBMS-MS, excluding the breast self-examination used in the original studies, showing significant correlation between mammography compliance and high scores in the Susceptibility and Benefit subscales, whereas perceived barriers were associated with lower screening compliance (Huaman et al., 2011).

The scale was originally validated in Indiana, United States by Champion (Champion, 1999) in a cohort of 804 women aged 50 years and older in a population of Whites (68%) and African Americans (30%), accounting for 54% of the variance and showing adequate construct validity and reliability. Since then, Champion's HBM scale has been tested for reliability and validity around the globe and translated for Iranian (Hashemian, Shokravi, Lamyian, Hassanpour, & Akaberi, 2013; Taymoori & Berry, 2009), Lithuanian (Zelviene & Bogusevicius, 2007), Malaysian (Parsa, Kandiah, Mohd Nasir, Hejar, & Nor Afiah, 2008), Arabic (Mikhail & Petro-Nustas, 2001), Korean (Lee, Kim, & Song, 2002), Chinese Australian (Kwok, Fethney, & White, 2010), Turkish (Secginli & Nahcivan, 2004; Norman & Brain, 2005; Lunt, Bowen, & Lee, 2005), African American (Champion et al., 2008), and Spanish-speaking American women (Medina-Shepherd & Kleier, 2010). Findings of these studies have provided support for the validity and reliability of these HBM-based scales, although poor construct validity was shown in a Peruvian-translated version (Champion et al., 2008) and in a Spanish version (Esteva et al., 2007).

Because HBM is widely cited (Noar & Zimmerman, 2005), we used CHBMS-MS (Champion, 1999) to translate, adapt, and test among Maltese women. HBM, however, only explains some of the variation in BS behavior such that it does not consider the impact of emotions (such as fear; Norman & Brain, 2005), nor does it accommodate social and environmental influences of past behavior (Lunt et al., 2005) which is why other models have been incorporated in studies to understand BS uptake (Cameron, 2008). In response to HBM's limitations, an instrument associated with the common-sense model (CSM) of health and illness behavior (Cameron, 2008) was also translated, adapted, and tested.

History and Development of the Revised Illness Perception Questionnaire

In the late 1960s and early 1970s, Leventhal explored how fear messages in relatively acute situations might lead individuals to respond to the health threat communication by taking health-promoting actions (Broadbent et al., 2015), such as wearing seat belts or giving up smoking (Leventhal, Hudson, & Robitaille, 1997). Subsequent research by Leventhal and colleagues in 1980s led to the development of the CSM of self-regulation, which proposes that individuals develop two parallel, yet interrelated, representations of the stimulus (cognitive and emotional) in response to a perceived threat (Leventhal et al., 1997). Hence, CSM provides a framework for understanding how individual symptoms and emotions experienced during the health threat or diagnosis influence illness perceptions and guide subsequent coping behavior (Diefenbach & Leventhal, 1996). This model was later used to understand illness prevention and preventive behavior intentions (Figueiras & Alves, 2007).

The Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996) was developed in light of self-regulation theory to provide a quantitative assessment of the five components of illness representation—*identity*, *cause*, *timeline*, *consequences*, and *control/cure* in Leventhal's self-regulation model (Moss-Morris et al., 2002). These five dimensions have been studied in breast (Anagnostopoulos et al., 2012) and colorectal screening (Orbell et al., 2008).

Subsequent measures include the Brief Illness Perception Questionnaire (B-IPQ; Broadbent et al., 2015), the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002), which examines illness beliefs and behaviors within specific groups of patients, or groups at risk from an illness, and an adapted version of the IPQ-R for "healthy" individuals (IPQ-RH) in recognition of the unique characteristics of asymptomatic populations (Figueiras & Alves, 2007). To remedy shortcomings in the original IPQ scale, the IPQ-R was developed by Moss-Morris et al. (2002) as a more comprehensive, psychometrically acceptable, quantitative measure to include measures of perceptions of illness duration ("acute/chronic timeline"), fluctuation in illness over time ("cyclical timeline"), perceptions of "treatment control" and "personal control" over illness, "illness coherence" (how clear and comprehensive an individual feels her illness to be), and "emotional representations" (feelings of depression, upset, anger, worry, and anxiety). Subsequently, the IPQ-R has been validated for use in diverse diseases or healthy populations (Chen, Tsai, & Lee, 2008), with language-specific validated IPQ measures, such as Italian (Giardini, Majani, Pierobon, Gremigni, & Catapano, 2007), Swedish (Brink, Alsén, & Cliffordson, 2011), Greek (Giannousi, Manaras, Georgoulias, & Samonis, 2010), Croatian and Lebanese (Petrak, Sherman, & Fitness, 2015), and Portuguese (Figueiras & Alves, 2007) versions. However, it has not yet been adapted and validated for Maltese asymptomatic and/or symptomatic women. Hence, we adapted the IPQ-R in this study to make it appropriate for both healthy women and those with cancer.

METHODS

Data Sources and Study Design

The study was conducted during June 2015, as part of a larger cross-sectional study about BS in Malta. The parent study was approved by the School Research Ethics Committee at the School of Health Sciences, University of Stirling (SREC14/15-Paper No. 18v4), and by the Maltese Health Ethics Committee (HEC 02/2015). Permission to use the scales (CHBMS-MS and IPQ-R) was sought from the respective authors (Prof. Victoria Champion in 2013 for CHBMS-MS use and Prof. Rona Moss-Morris in 2014 for IPQ-R use). Permissions were also received from the chief medical officer, the chief executive officer (Primary Health Care Department), and the health data protection officers in primary and secondary care in Malta.

Sample and Procedures

Four translators were recruited for the translation pathway as follows: two translators (i.e., a European translator working in Brussels who was also a bilingual native speaker of both Maltese and English languages and a Maltese expert translator) translated the instrument from English to Maltese (Steps 2–3) and two different bilingual translators (i.e., a bilingual expert from the Health Ministry and an expert interpreter at the University of Malta) back-translated the instrument from Maltese to English (Step 4).[1] An expert panel ($n = 12$) was set up to ascertain content validity and to verify that it is clinically meaningful to experts in the clinical area (Anagnostopoulos, Dimitrakaki, Niakas, & Tountas, 2013). The 12 members comprised the lead researcher for this study, the 4 expert translators/interpreters, a statistician with 10 years' experience in statistical research and analysis, 2 mammographers (Maltese and Scottish radiographers), a BS client, a breast cancer survivor, a consultant, and a clinician.

A focus group was conducted with a convenience sample of asymptomatic women ($n = 6$) to pilot test the adapted Maltese version of the instrument. Three of the women were housewives (53, 55, 58 years, respectively) who had attended BS, two were public employees (59, 60 years, respectively) who had not attended BS, and the other was a retired 62-year-old midwife who had also not attended BS when invited.

A convenience sample of 15 women ($n = 15$) participated in structured face-to-face interviews to assess comprehensibility and suitability of the research instrument and to ensure understanding of all scale items in both languages. Women were recruited from the BS center and were BS attendees, aged 50–60 years. The convenience sample was recruited because it was felt that such women would be interested in engaging with such a topic (Creswell & Plano Clark, 2011), thereby giving access to a range of women with different backgrounds (Kaltsa, Holloway, & Cox, 2013). Women with prior history of breast cancer or breast surgery, those who sought breast cancer treatment, as well as nonbilingual women were excluded.

Participants were assured that they had no obligation to participate, that their participation was voluntary, and that they could withdraw from the study at any time without the need to give any reason. The cover letter provided information to the women on how the researcher would protect their anonymity and confidentiality through coding. Following explanation on the nature of the research, informed consent was obtained from the participants.

Translation and Adaptation

Figure 1 illustrates the pathway in which the translation and adaptation of the mentioned scales was undertaken, based on published methods (Champion, 1984, 1999; Yilmaz & Sayin, 2014).

Steps 1–2: Identification of Scales and Forward Translation

Following the identification of validated scales by the researcher, initial translation of the questionnaire from English (original) to Maltese (target) languages was performed by two expert translators. This bilingual team first prepared their own translated versions; they

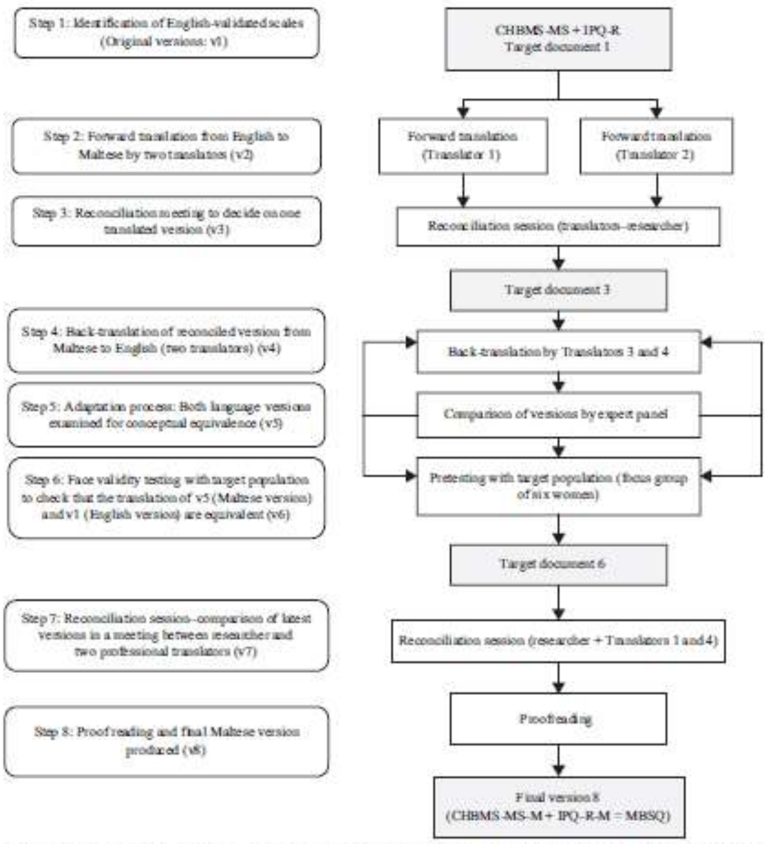

Figure 1. Translation, adaptation, face, and content validity (Maltese Breast Screening Questionnaire [MBSQ] pathway). CHBMS-MS = Champion's Health Belief Model Scale for Mammography Screening; IPQ-R = Revised Illness Perception Questionnaire; CHBMS-MS-M = Champion's Health Belief Model Scale for Mammography Screening–Maltese version; IPQ-R-M = Illness Perception Questionnaire–Maltese version.

then gave their versions to each other to verify each other's work and finally came up with collaborative decisions about the translation.

Step 3: Reconciliation Session

The two experts met up with the researcher in a "reconciliation session" in Malta and reviewed the translation together for inconsistencies with the original English scale and to ensure that the language was kept simple to be understood by Maltese women.

Step 4: Back-Translation Into English

The adequacy of the Maltese translated instrument was evaluated using the back-translation technique. The Maltese version was back-translated into English (original language) by another team of experts (i.e., not the original translators in Steps 2–3).

Step 5: Adaptation Process

Both language versions were examined for conceptual equivalence by the expert panel (n = 12) which included the lead researcher and statistician for this study, the four translators (Steps 2–4), screening/medical professionals, and lay women. The back-translation and the original English instrument version were compared with attention given to grammar and the meaning conveyed by the words. In this "adaptation" process, the cultural and social characteristics of the translation are protected as much as possible (Kulis, Arnott, Greimel, Bottomley, & Koller, 2011).

Step 6: Face Validity Testing

A focus group was conducted with a convenience sample of asymptomatic women (n = 6) to pilot test the adapted Maltese instrument version. This cognitive debriefing procedure (Wild et al., 2005) was followed to ascertain face validity of the instrument, to ensure clarity and comprehensibility of the items, to highlight inappropriate items or response options, and to identify and test translation alternatives and modifications. This ensures that conceptual equivalence and cultural appropriateness are achieved (Anagnostopoulos et al., 2013). This group of screened/nonscreened women tested the instrument's face validity and determined its cultural appropriateness and the accuracy of the translation, similar to the undertaken Turkish process (Yilmaz & Sayin, 2014). The researcher read the translated text aloud to the participants, following which each item was scored on a 5-point scale.

Step 7: Reconciliation Session

The scales were modified in a "reconciliation session" so that they could be administered by an interviewer, where two translators met up with the researcher in Malta to review the final version.

Step 8: Proofreading

Following proofreading, the final Maltese version was produced and entitled the Maltese Breast Screening Questionnaire (MBSQ). The following procedures were used to test the MBSQ:

Test–Retest Reliability. The final version (MBSQ) from Step 8 was then tested for reliability (Step 9). An estimation of *stability* is commonly assessed by a test–retest reliability analysis, where the questionnaire is given to the same person or set of respondents, in the same way, on two different occasions, usually with an interval of 2–6 weeks

(Yilmaz & Sayin, 2014). In this study, a convenience sample of 15 bilingual women, aged 50–60 years, were recruited by the researcher from the BS center to assess test–retest reliability of the Maltese and English subscales, respectively. Participants responded to the questionnaire through face-to-face interviews on two occasions separated by a 2-week interval, a test–retest period considered appropriate (Streiner, Norman, & Cairney, 2014). These women were contacted by a research assistant and two convenient times were arranged with each participant. The interviews were conducted in the participants' homes. Participants were informed that they were free to choose only one language. However, all participants were willing to complete the survey in both languages and opted to complete the survey first in Maltese followed by the English language at both time points (Day 1, Day 14) to test and retest for stability and reliability of responses in the same language. The scores were then correlated.

Instrument Scoring. Items were answered on a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*), similarly used in other studies (Anagnostopoulos et al., 2013; Huaman et al., 2011; Yilmaz & Sayin, 2014). Possible scores ranges include 3–15 for susceptibility, personal control, treatment control, and emotional representations, respectively; 6–30 for benefits; 13–65 for barriers; 7–35 for cues to action and self-efficacy; 8–40 for breast cancer identity and consequences; 18–90 for the causal scale; 2–10 for acute/chronic timeline and illness coherence; and 1–5 for cyclical timeline. Higher scores indicated stronger agreement.

Approaches to Reliability and Validity Assessments. Reliability was evaluated by *Cronbach's alpha* for internal consistency (reliability) and *test–retest correlation*. In terms of reliability, lower values indicate no internal consistency of the tool ($.00 \leq \alpha < .40$ not reliable, $.40 \leq \alpha < .60$ low reliability, $.60 \leq \alpha$ .80 high reliability, $.80 \leq \alpha < 1$ very high reliability; Buyukozturk, 2012; Tekindal, 2009; Yilmaz & Sayin, 2014). If Cronbach's alpha score is low, then the corrected item–total correlations for values of <.30 are considered (minimum acceptable item–total correlation is .30; Yilmaz & Sayin, 2014). Such low values might be considered satisfactory if item deletion does not improve the overall alpha value (Buyukozturk, 2012). Test–retest scores for each dimension were computed for the Maltese and English measures, respectively, using *Pearson's correlations* at both time points (T1, T2) for an estimation of reliability over time. Test–retest reliability refers to the correlation coefficient which should be at least .6 (Balci, 2011; Buyukozturk, 2012; Huaman et al., 2011; Tekindal, 2009). Construct validity, a measure that confirms the extent to which inferences can be made from scale scores in relation to the latent, theoretical construct of interest (Pruitt et al., 2010), was supported through Pearson's correlations to test the associations between subscales for each measure. Quantitative data analysis was performed using the SPSS Version 21.

RESULTS

Translation and Adaptation

Four queries of subcultural word comprehension were raised by the bilingual translators, which required consensus. The term *breast lumps* in the original instrument was translated to *boċoċ f'sidrek*. The second controversial term was *mammogram*, for which two panel members argued that some women in the target population may not be aware of early diagnostic breast tests. Although *mammografija* in the translated instrument was acceptable, the general known term was *mammogram*. Following this debate, the panel decided that both words were suitable and could be used interchangeably (i.e., mammogram, mammografija). A third controversial term was *thickening of the breast*. Following discussion, the panel decided on the phrase *ħxuna tat-tessuti tas-sider*. Another word discussed by all group members was *nipple*. Several controversies arose on whether to use the word *nipple* as is, *nippla*, or the pure technical phrase *ras il-bizla*. Most members argued that some women in the target population are not aware of the technical phrase but are familiar with the English term. This was then literally translated to *nipil*.

Because most women perceive breast cancer as a serious threat (Lagerlund, Sparén, Thurfjell, Ekbom, & Lambe, 2000), it was decided that the construct "perceived severity" would not be measured using HBM (Anagnostopoulos et al., 2012). Further removal of the item in the HBM-related scale would also avoid duplication because the seriousness of breast cancer was addressed in the IPQ-R scale. Moreover, because the use of both HBM and CSM often fails to address contextual constraints such as low income and education level that may influence women's screening behavior, sociodemographic and socioeconomic factors as well as lifetime mammography use were added because of the acknowledgement of their contributions as BS determinants (Anagnostopoulos et al., 2012; Jepson et al., 2000; Lagerlund et al., 2000). The panel further added cues to action (such as physician recommendations and family history), which are often omitted from empirical studies through HBM use (Anagnostopoulos et al., 2012). Finally, based on these conclusions, the original version of the instrument consisted of 124 items and was presented to the focus group ($n = 6$) for testing.

Face Validity

From the original 50-item IPQ-R, two items were removed from the cancer timeline domain ("Breast cancer will last for a long time"; "I expect to have breast cancer for the rest of my life") because they were found to confuse the women and cause consistent heightened anxiety in responders, resulting in a 48-item Maltese (M) version (entitled IPQ-R-M). Participants were asked to report their personal views about breast cancer rather than their perceptions of an illness personally affecting them. For example, "My illness has serious economic and financial consequences" was replaced with "Breast cancer has serious economic and financial consequences"; "My illness will last for a long time" was replaced with "Breast cancer will last for a long time" following which reverse scoring was eliminated for this item to read "Breast cancer will last for a short time" because of the misunderstanding, confusion, and anxiety experienced by all women. The IPQ-R risk factors domain title were also amended to read "Risk/Lifestyle Factors," whereas the sections "personal" and "treatment" control were categorized under the heading "Curability/Controllability." For the lifetime mammography use domain, 1 item was deleted to avoid overlap ("a mammogram prior to breast screening" yes/no). Hence, the final Maltese instrument (MBSQ), comprising the Maltese (M) scales CHBMS-MS-M and IPQ-R-M, consisted of 121 items that were clustered into 11 subscales for sociodemographic and health status (20 items), 4 subscales for lifetime mammography use (17 items), 5 subscales for health beliefs (36 items), and 7 subscales for illness perceptions (48 items).

The earlier-mentioned method found the instrument to be acceptable and ready for use in psychometric testing among the target population. Of the convenience sample of 15 women ($n = 15$), the mean age was 54.5 years ± 3.2 years (*SD*); 6 women were from below-average-income families (lower than €16,113), 11 women were housewives, and 12 women had up to a secondary education level.

Instrument Scoring

For the scope of preliminary mean instrument scoring, the mean values at Time 1 in Maltese were analyzed (refer to mean Maltese T1 in Table 2). Subscale scores were retrieved as the mean of items (following reverse scoring [r] for only one item "There is no possibility of getting breast cancer" in the Perceived Susceptibility subscale). Higher scores for Health Belief subscales, for instance, indicate more susceptibility, benefits, barriers, cues to action and self-efficacy (Champion, 1999). Maltese women scored highest for perceived benefits and lowest for perceived barriers, and highest for cyclical timeline and lowest for acute/chronic timeline.

Internal Consistency and Correlation Analysis: Psychometric Estimates of Reliability

Table 1 presents measures of central tendency (mean), variability (standard deviation), and alpha coefficients for the scales. In terms of reliability, Cronbach's alpha value was .93 for CHBMS-MS and .92 for IPQ-R (Table 1). Such a result in excess of .80 shows high

TABLE 1. Internal Consistency of the Subscales for the Champion's Health Belief Model Scale for Mammography Screening and Revised Illness Perception Questionnaire Scales

	M (Maltese)	*SD*	*M* (English)	*SD*	Cronbach's Alpha (Maltese vs. English)	Inter-Item Correlation (Pearson)
Health beliefs	3.15	1.33	3.16	1.29	.93	.87
Perceived susceptibility	3.04	1.24	2.88	1.22	.91	.83
Perceived benefits	4.03	0.71	4.03	0.57	.75	.69
Perceived barriers	1.99	1.01	2.06	1.02	.88	.78
Cues to action	3.72	0.92	3.37	0.85	.86	.75
Self-efficacy	4.00	1.02	4.00	1.02	.90	.81
Illness perceptions	3.20	1.19	3.20	1.19	.92	.85
Breast cancer identity	3.72	0.82	3.70	0.84	.92	.85
Causes of breast cancer	2.78	1.18	2.76	1.20	.90	.82
Timeline (acute/chronic)	2.58	1.09	2.70	1.12	.88	.79
Timeline (cyclical)	3.90	0.76	4.07	0.74	.86	.75
Consequences	3.56	1.17	3.60	1.15	.93	.87
Personal control	3.68	0.91	3.66	0.95	.90	.82
Treatment control	3.31	1.29	3.19	1.18	.90	.81
Illness coherence	2.98	1.19	3.03	1.19	.86	.88
Emotional representations	3.09	1.28	3.08	1.21	.96	.93

Note. The Pearson correlation test was tested against a p value of .001. All Pearson correlation values were found to be statistically significant with a p value $< .001$.

internal consistency (reliability; Huaman et al., 2011). Cronbach's alpha estimations of each subscale were as follows: Health Beliefs-Susceptibility ($\alpha = .91$), Benefits ($\alpha = .75$), Barriers ($\alpha = .88$), Cues to Action ($\alpha = .86$), Self-Efficacy ($\alpha = .90$), whereas for Illness Perceptions-Breast Cancer Identity ($\alpha = .92$), Causes of Breast Cancer ($\alpha = .90$), Timeline Acute/Chronic ($\alpha = .88$), Timeline Cyclical ($\alpha = .86$), Consequences ($\alpha = .93$), Personal Control ($\alpha = .90$), Treatment Control ($\alpha = .90$), Illness Coherence ($\alpha = .86$), Emotional Representations ($\alpha = .96$). These values showed that the scale items measured similar features with high reliability because each dimension was expected to have an alpha of at least .7 (Huaman et al., 2011). Hence, preliminary high Cronbach's alpha values indicated that the Maltese instrument had internal consistency.

Reliability Over Time

The CHBMS-MS and IPQ-R subscales demonstrated acceptable stability over a 2-week period for all measures. Responses were compared between Time 1 (T1) and Time 2 (T2) after 2 weeks for both Maltese and English versions, respectively. Test–retest scores for all dimensions showed Pearson correlation coefficients higher than .6 for both languages. For test–retest reliability (Maltese; Table 2), Pearson's correlation coefficients for CHBMS-MS-M and IPQ-R-M were .79 and .75, respectively. For test–retest reliability (English), Pearson's correlation coefficients for CHBMS-MS and IPQ-R were .83 and

TABLE 2. Test–Retest Correlations of the Theoretical Variables (Maltese)

	M (Maltese T1)	*SD* (T1)	*M* (Maltese T2)	*SD* (T2)	Cronbach's Alpha	Test–Retest Correlation (Pearson)
Health beliefs	3.17	1.27	3.13	1.38	.88	.79
Perceived susceptibility	3.07	1.18	3.02	1.32	.86	.76
Perceived benefits	4.06	0.73	4.00	0.70	.71	.62
Perceived barriers	2.13	1.04	1.86	0.95	.80	.67
Cues to action	3.69	0.96	3.76	0.87	.77	.63
Self-efficacy	3.85	0.98	4.15	1.04	.79	.65
Illness perceptions	3.18	1.19	3.21	1.19	.86	.75
Breast cancer identity	3.74	0.92	3.70	0.71	.76	.63
Causes of breast cancer	2.80	1.17	2.76	1.20	.84	.72
Timeline (acute/chronic)	2.63	1.13	2.53	1.07	.81	.68
Timeline (cyclical)	3.93	0.70	3.87	0.83	.83	.71
Consequences	3.45	1.17	3.66	1.17	.88	.78
Personal control	3.49	1.04	3.87	0.73	.72	.68
Treatment control	3.42	1.23	3.20	1.34	.90	.81
Illness coherence	2.87	1.25	3.10	1.13	.80	.67
Emotional representations	3.11	1.25	3.07	1.32	.90	.82

Note. The Pearson correlation test was tested against a p value of .001. All Pearson correlation values were found to be statistically significant with a p value $< .001$. T1 = Time 1; T2 = Time 2.

TABLE 3. Test-Retest Correlations of the Theoretical Variables (English)

	M (English T1)	*SD* (T1)	*M* (English T2)	*SD* (T2)	Cronbach's Alpha	Test–Retest Correlation (Pearson)
Health beliefs	3.19	1.23	3.126	1.341	.905	.83
Perceived susceptibility	2.84	1.09	2.91	1.35	.85	.75
Perceived benefits	4.06	0.53	4.00	0.62	.78	.71
Perceived barriers	2.21	1.03	1.91	0.98	.82	.70
Cues to action	3.71	0.93	3.75	0.77	.71	.61
Self-efficacy	3.92	0.99	4.09	1.05	.91	.84
Illness perceptions	3.21	1.16	3.18	1.22	.85	.74
Breast cancer identity	3.73	0.90	3.68	0.78	.87	.78
Causes of breast cancer	2.83	1.20	2.70	1.21	.76	.61
Timeline (acute/chronic)	2.73	1.08	2.67	1.18	.85	.74
Timeline (cyclical)	4.00	0.76	4.13	0.74	.78	.64
Consequences	3.58	1.06	3.62	1.23	.83	.72
Personal control	3.49	0.97	3.82	0.91	.80	.67
Treatment control	3.18	1.17	3.20	1.20	.95	.91
Illness coherence	2.97	1.13	3.10	1.27	.90	.82
Emotional representations	3.09	1.15	3.07	1.29	.92	.86

Note. The Pearson correlation test was tested against a p value of .001. All Pearson correlation values were found to be statistically significant with a p value $< .001$. T1 = Time 1; T2 = Time 2.

.74, respectively (Table 3). Hence, all of the subscale items met the criteria of reliability and were retained.

Construct Validity

When applying correlation analysis between the English and the Maltese versions (Table 1), the Pearson correlation values for CHBMS-MS and IPQ-R were .87 and .89, respectively. All correlation values exceeded .6 and showed a significant correlation between the items of both versions ($p < .001$). The Pearson correlation values were tested at the .05 level of significance.

When applying a Pearson correlation between the two time points, the Pearson correlation value was .778, showing a strong positive correlation between the two time points. Such an association was found to be significantly different ($p < .001$).

DISCUSSION

This study focused on translating, adapting, and pilot testing the validity and reliability of two existing scales for use among Maltese women. We found that it was feasible to translate and adapt these scales and that the translated instrument shows promise of acceptable validity and reliability. The high correlation values obtained are suggestive of strong validity of scale items. Moreover, completeness was high (100% of participants answered all the questions), thereby indicating that the instrument was easy and simple to administer.

Results of the translation and adaptation pathway and focus group analysis provided useful information on the understanding of items. Evidence suggests that although measures may be valid and reliable across diverse cultures, researchers are encouraged to modify and reword subscale items, taking into account cultural settings and any linguistic origins of their populations under exploration (Abubakari et al., 2012). This led to some items being omitted from the original scales because they either duplicated other items or failed to convey a clear expression of the intended objectives.

Overall positive and high correlation of the total inter-item correlation (Pearson) was obtained in our study for health beliefs (.87) and illness perceptions (.85) and high Cronbach's alpha (CHBMS-MS = .93, IPQ-R = .92) denoting overall acceptable internal consistency. In our study, internal consistency ranged from .69 to .83 for health beliefs. Similarly, internal consistency reliability ranged from .69 to .83 in Gözüm and Aydin's (2004) study, from .64 to .79 in Hashemian and colleagues' (2013) study, and was above .73 for all scales in Champion and colleagues' (2008) study among African American women. A high consistency was observed in our study between the three perceived susceptibility scale items. Champion similarly reported high internal consistency of items for this subscale and observed a proper fit (.82) using confirmatory factor analysis (Champion, 1999). However, we could not confirm our subscales through confirmatory factor analysis because our reported findings were limited to our small sample in comparison, although our aim was not to elicit the most important factors that explain health beliefs and illness perceptions. Therefore, our findings can only be considered as preliminary values for the instrument's internal consistency.

In our study, test–retest reliability correlations were from .62 to .76 for CHBMS-MS-M (Maltese) and ranged from .61 to .84 for CHBMS-MS (English). In Hashemian and colleagues' (2013) study, test–retest reliability correlation ranged from .67 to .92 for health belief subscales and ranged from .67 to .92 for the Persian scale version among Iranian women (Hashemian et al., 2013). Our test–retest data for the health beliefs dimensions shows that perceived susceptibility and perceived benefits appear to remain the most consistent over the 2-week time period. This may suggest that women will take action to screen for or control illness if they believe they are susceptible to it, especially if the illness is viewed to potentially have serious personal consequences and if they believe that the benefits of screening outweigh the barriers for doing so.

In Medina-Shepherd and Kleier's (2010) study, test–retest correlations for control group women ($n = 20$) were perceived susceptibility (Spearman's rho: $r = .57$), perceived benefits ($r = .63$) and perceived barriers ($r = .83$). In Champion's original validation study in an American city (Champion, 1999), test–retest scores were .62 (susceptibility), .61 (benefits), and .71 (barriers). Our findings were similarly significant for test–retest correlation (.76, .62, .67, respectively, for Maltese version; .75, .71, .70, respectively, for English version), whereas all five CHBMS-MS subscales in our study show similar psychometric properties to more recent findings (Medina-Shepherd & Kleier, 2010; Yilmaz & Sayin, 2014). A test–retest score $<.80$ indicates that women did not reply in the same way at the second time point (Yilmaz & Sayin, 2014), which could mean that women did not read the scale items in the same way at both time points. However, according to the test–retest results, women answered the scale items similarly in both sessions, indicating that the scale has strong stability over time. Our test–retest results were generally higher than those reported in the Medina-Shepherd and Kleier's (2010) study and Champion's (2010) study. This difference may be attributed to the small sample in our study.

Our preliminary findings for Cronbach's alpha coefficients were .91 (susceptibility), .88 (barriers), .75 (benefits), .86 (cues to action), and .90 (self-efficacy). Similarly, Cronbach's alpha coefficient for Champion's subscales were also reported between .77 and .90 among Chinese American women (Wu & Yu, 2003), and were found to be equal to .88 (barriers) and .93 (benefits) in a Malaysian study (Parsa et al., 2008), .89 and .73, respectively, among African American women (Champion et al., 2008) but lower (.63 for benefits) in Medina-Shepherd and Kleier's (2010) study. Among Iranian women with family history of breast cancer, Cronbach's alpha coefficients were .72 (susceptibility), .75 (seriousness), .82 (benefits), and .76 (barriers), although a limitation in the Iranian study is that all participants had a family history of breast cancer which can be considered to guide further prevention and increase women's susceptibility for this disease (Hashemian et al., 2013). A controversial HBM subscale is perceived barriers (Hashemian et al., 2013) because of the diverse individual and environmental barriers present in different communities (Park et al., 2011). However, none of the items of this subscale in the original version of the questionnaire were omitted because women considered all items to be equally important.

The original IPQ-R demonstrates higher internal consistency (Cronbach's alphas range from .75 to .89) than the original IPQ and good test–retest reliability ranging from .46 to .88 over 3 weeks (Moss-Morris et al., 2002). In our study, the IPQ-R scale similarly demonstrated a relatively high degree of internal consistency (Cronbach's alpha = .75–.93), with overall Cronbach's alpha >.70 (α = .86 [Maltese] and .85 [English]). Our test–retest data of the IPQ-R dimensions is homogeneous with the original IPQ and IPQ-R versions (Moss-Morris et al., 2002; Weinman et al., 1996) and show that the IPQ-R has acceptable levels of stability over 2 weeks. Test–retest reliability (Pearson's) correlations were computed between the IPQ-R completed at the two time points with correlations above .6, that is, .63–.82 (Maltese) and .61–.91 (English). Breast cancer identity, causes, and emotional representations appear to remain the most consistent over this time period for the Maltese language. This suggests that patients possibly attribute a relatively high or low number of symptoms to their illness and experience a wide range of emotional issues. As for the English version, treatment control and emotional representations remain most consistent. These findings provide evidence toward the validity and reliability of the IPQ-R as a suitable measure of illness perceptions in the context of BS. IPQ-R dimensions prove to be useful measures on how the illness "makes sense" holistically to symptomatic or asymptomatic women and may play an important role in longer term adjustment and symptom response. The IPQ-R also allows researchers to investigate how emotional representations affect coping behaviors and illness outcomes (Moss-Morris et al., 2002). Moreover, cognitive beliefs that the illness has severe consequences is cyclical in nature and out of one's personal control seem to strongly affect women's emotional responses.

Implications

The Maltese and English versions of the CHBMS-MS and IPQ-R can be used by nurses and other health care professionals as measures to assess Maltese women's health beliefs and illness perceptions concerning breast cancer and screening. Nurses have frequent patient contact in various health care settings and are known to be valuable change agents and patient advocates (Arabi, Rafii, Cheraghi, & Ghiyasvandian, 2014). An important breast health promotion opportunity for public health nurses is raising public awareness on breast cancer by educating women about the importance of practicing screening. Likewise, nurses and health care professionals can structure patient education and counseling sessions guided by the conceptual theoretical framework proposed in this study to ensure comprehensiveness of approach and content. For instance, information on breast cancer risks, susceptibility to breast cancer, signs and symptoms of breast cancer, and its consequences, as operationalized by different HBM and CSM constructs, can increase patients' knowledge to improve screening use (Noar & Zimmerman, 2005). Moreover, health care providers can use the HBM and CSM to understand patients' needs, employing constructs of the models to guide patient interviewing. For instance, a BS invitation may be based on factors that influence BS behavior such as existing perceptions of benefits and barriers and on psychological and social factors (Kaltsa et al., 2013). Nurses can therefore assess women's level of perceived risk and target their teaching about health-promoting behaviors to reduce risk perception by educating women about the risk factors for breast cancer. If women are aware they may be at risk for developing breast cancer, they may perceive themselves at risk and participate in screening. Counseling may be required to increase the likelihood that a woman attends for screening by increasing women's confidence. Particular focus on the appointment related to screening could provide an opportunity for targeted interventions to increase BS uptake, such as assisting women with scheduling an appointment, ensuring that guidelines and information is provided about the recommended intervals between mammograms and addressing the importance of regular screening. This will ultimately affect the quality of an individual's life and reduce the allocation of resources needed to treat those who develop breast cancer.

Because individuals possess multifaceted cognitive representations of various diseases (Lykins et al., 2008), nurses can support patients to explore beliefs and perceptions by helping them to relate personal accounts about their families, their culture, and their illness perceptions, including causal attributions for the disease (Richer & Ezer, 2000). Achieving this may be more attainable if nurses and health care providers are knowledgeable, competent, and feel supported in providing education and counseling in the clinical setting. This presents a challenge for all health care disciplines considering that health implications span the entire health care continuum. Furthermore, the gap in competency includes lack of recognition of the relevancy of screening to nursing practice which may impact the uptake of continuing education in this area. To overcome these challenges, robust interventions are needed with reliable measures that can adequately assess the outcomes of these strategies. Validated instruments for nursing and patient assessment should be made available in clinical settings as a priority. With reliable measures to inform the required interventions and outcomes associated with their implementation, nurse-led interventions make it possible to design cost-effective strategies focused on reducing disparities across diverse populations and increasing quality within health care systems.

Limitations

Although our preliminary internal consistency and test–retest reliability correlation scores were relatively similar or higher to those reported in prior validation studies of the CHBMS and IPQ-R research, we recognize this study's limitations. First, the reported findings cannot be generalized because these are limited to a convenience sample. Our goal was not to obtain a representative sample but rather to obtain an indication of the instrument's reliability and validity among women with varied backgrounds and diverse perspectives. For greater applicability, it is recommended that this instrument be tested among a larger sample. Second, recruitment of these women may have led to a biased sample of women with no socioeconomic inequalities. We acknowledge that those who participated may have been more interested in and knowledgeable about screening as compared with those who would not attend for screening. Third, for those who participated in this study, the formal consent to participate sets them apart from those who would refuse such an invitation. Moreover, although women were asked to express their true feelings, they may have responded in a way that is considered socially acceptable. Despite these limitations, our rigorous approach to translating and adapting the instrument gives us confidence in the instrument's acceptability and readiness for use to collect data from the target population.

CONCLUSION

The translation, adaptation, and preliminary evidence of the psychometric properties assessment of the MBSQ shows promise of being a valid and reliable instrument that can be used among Maltese women to assess their health beliefs and illness perceptions toward breast cancer and screening practices and provides insights for the planning of effective interventions. Because these are preliminary findings, further psychometric testing of these scales is recommended to include diverse socioeconomic strata, educational levels, and geographic location. Future studies should include factor analyses on the current scale items using a larger sample size. Further research to measure women's health beliefs and illness perceptions on breast cancer and screening is also warranted.

NOTE

1. Both the English and Maltese versions of the instrument (Health Beliefs, Illness Perceptions and Determinants of Breast Screening Update in Malta: A Cross-Sectional Survey) are available from the authors upon request.

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Acknowledgments. The authors wish to acknowledge Prof. Victoria Champion and Prof. Rona Moss-Morris for developing the Champion's Health Belief Model Scale for Mammography Screening (CHBMS-MS) and Revised Illness Perception Questionnaire (IPQ-R) scales, respectively, and for providing the opportunity to translate and adapt it into the Maltese culture and language. The authors also wish to thank the translators, the panel members, and all the participants of the study. This study was developed as part of the activities of the PhD in Health offered by the University of Stirling (United Kingdom). The PhD program is part-financed by the Malta Government Scholarship Scheme (MGSS), Government of Malta.

Correspondence regarding this article should be directed to Danika Marmarà, MSc, BSc (Hons), Cancer Care Pathways Directorate, Sir Anthony Mamo Oncology Centre, Level 1, Triq Dun Karm, Msida, MSD 2090 Malta. E-mail: attard.danika@gmail.com

Appendix 4.1.2 – SREC Approval

UNIVERSITY *of* STIRLING

PH/SN

4 June 2015

Danika Marmara
13, Sinfonija
Triq L-Anglu
Zebbug ZBG2273
Malta

Web: http://www.stir.ac.uk/health-sciences/research/ethics/

Professor Pat Hoddinott
Chair
School Research Ethics Committee

School of Health Sciences
University of Stirling
Stirling FK9 4LA

Tel: +44 (0) 1786 466404
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Dear Danika

Health Beliefs, Illness Perception and Determinants to Breast Screening Uptake in Malta: A Cross-Sectional Survey

SREC 14/15 – Paper No.18 – Version 4

Thank you for responding to the SREC communication dated 12 May 2015, and enclosing the revised document:

- Appendix D1 - Tool Validity and Reliability Testing: Covering Letter Information Sheet. Paper No.18 V4

We are now pleased to approve this study by Chair's Action, and would wish you and your team all the best.

May I remind you of the need to inform SREC prior to making any amendments to this protocol, of any changes to the duration of the project and provide notification of study completion. A site file of all documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the SREC page of the School's website:

http://www.stir.ac.uk/health-sciences/research/ethics/

Appendix 4.1.3 - MHEC Approval

KUMITAT
DWAR L-ETIKA FIS-SAHHA

Dipartiment ta' l-Informazzjoni fuq is-Sahha u Riċerka
95, Telghet Guardmangia ,
Guardamangia PTA 1313
Malta

Our Ref: HEC 02/2015
Your Ref:

HEALTH
ETHICS COMMITTEE

Department of Health Information & Research
95, Guardamangia Hill,
Guardamangia PTA 1313
Malta

Tel: (+356) 25599000
Fax: (+356) 25599385
Email: hec@gov.mt

24th[th] February, 2015

Ms Danika Marmara
Cancer Care Researcher
Director
Cancer Care Pathways
Sir Paul Boffa Hospital
Floriana

Health Beliefs, Illness Perceptions and determinants to Breast Screening Uptake in Malta

The Health Ethics Committee would like to inform you that the above mentioned application has been reviewed and assessed, and is giving its approval to carry out the study.

The Health Ethics Committee would like to inform you that the above mentioned application has been reviewed and assessed, and is giving its approval to carry out the study.

Regards,

Dr Neville Calleja
Secretary

Appendix 4.1.4 – Permission to use Champion’s scale

INDIANA UNIVERSITY

SCHOOL OF NURSING

Center for Research and Scholarship

April 11, 2013

Danika Attard, BSc, MSc, MLJ
ALCM, ATCL, LLCM, Dip. ABRSM, LRSM
Senior Radiographer
National Breast Screening Programme
Postgraduate Researcher
Scotland

Dear Ms. Attard,

Thank you for your interest in my work. You have permission to modify and use the Champion Health Belief Model instrument as long as you cite my work and send me an abstract of your completed project. You also have permission to translate the scale into Maltese language.

Sincerely,

Victoria Champion

Victoria Champion, Ph.D., R.N., F.A.A.N.

Distinguished Professor

Edward W. and Sarah Stam Cullipher Endowed Chair

Associate Director Cancer Prevention and Control/Population Sciences

Indiana University Simon Cancer Center

VC:dd

Appendix 4.1.5 – Permission to use the IPQ-R scale

Hi Danika

That's fine. I advise you to do some pilot work on the IPQ-R with your population so that you can make some appropriate amendments. You may want to consider including some form of identity questionnaire as experiencing symptoms is often what encourages people to attend screening even though there are none.

Best wishes

Rona

Rona Moss-Morris
Professor of Psychology as Applied to Medicine
Health Psychology Section, Psychology Dept.,
Institute of Psychiatry, KCL,
5th floor Bermondsey Wing
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Appendix 4.1.6a - Covering Letter (English version)

Title: ***Health Beliefs, Illness Perceptions and Determinants to Breast Screening Uptake in Malta: A Cross-Sectional Survey***

Dear Participant,

I am a postgraduate researcher, currently conducting a local study that aims to identify the key barriers and facilitators to Breast Cancer Screening uptake in Malta and to address the barriers through the development of a theory and evidence-based intervention. You are invited to take part in this study, where structured telephone interviews will evaluate your health beliefs, illness perceptions and determinants associated with breast screening uptake. In addition, we will be looking at certain background factors to assess their impact on the knowledge and attitudes about breast cancer screening behaviours. By helping us to gather this information, we may be able to improve beliefs, attitudes and screening behaviours for breast cancer.

Consequently, this telephone survey shall be conducted with a random sample of Maltese and Gozitan women who were invited to the Breast Screening programme and attended or did not attend the service. Questions regarding factors related to breast screening and breast cancer shall be explored with you and these questions should only take approximately 20 minutes of your time.

Confidentiality, Anonymity and Voluntary Participation

All the information collected will be treated in strict confidence by preserving your confidentiality and anonymity at all times. At no time will your identity be revealed. Your participation is entirely voluntary and you are therefore under no obligation to participate. You may withdraw from the study at any time, without the need to give any reason. If you refuse to take part, care, medical treatment and your right for further examinations will not be affected. It is important to understand that you will not be paid for participating in this study.

Benefits and Risks

As a participant in this study, you may gain insight into your decision making process. The risks involved are minimal. Since a few items deal with breast cancer and breast screening behaviours, you may experience some anxiety while answering these questions. It is not the intent of the researcher to offend or embarrass you. If, for any reason, you experience distress during the questions being asked, please feel free to notify the researcher. If, for any reason, you experience distress during the questions being asked, please feel free to notify the researcher so that the researcher can direct you to a lead radiographer [Ms. _________] and/or a practice nurse [Ms. _________] at [17, Lascaris Wharf, Valletta] who are trained and have experience to deal with regular arising women's issues at the screening programmes and you may discuss further any issue or distress on a one-to-one basis with these professionals.

Results of the Study

The results of this study will be shared with the members of the principal investigator's expert working group members. The study findings shall be of great value to the Screening Management and shall assist policy makers and the Ministry of Health to plan and implement the appropriate interventions required to increase uptake as well as develop strategies for future age extensions and subsequent screening cycles. This study is in line with the strategy for cancer care for the Maltese Islands (National Cancer Plan 2011-2015) by assessing local population needs. Moreover, the data gathered shall assist health authorities when formulating national policies in order to reduce social inequalities for health service delivery.

Questions, Queries or Complaints

I, the researcher of this study, will be very happy to answer any of your questions or queries about the study or your rights as a participant in the study. If you do have further questions or any queries that might arise during the study, do not hesitate to may contact me on [+356 79005111] or email me on [danika.marmara@gov.mt].

If you have any concern and/or grounds for complaints, please do not hesitate to contact the screening coordinators at the National Breast Screening Programme in writing to the following address [17, Lascaris Wharf, Valletta VLT 1921] or by email on [mbsp.mhec@gov.mt] or by phone if you so wish on [21227470 or 21227471]. Such complaints will be followed up specifically by the Head/Delegate of the Screening Programme and/or the Chief Executive Officer of the Primary Health Care Department.

Informed Consent

If you agree to participate in the study, I will take that as evidence of your informed consent to participate in this study. If you also agree to be contacted further for more in-depth discussions, you are providing your consent to participate in further research. Your data could also be used for further analysis of subsequent screening cycles. I look forward to your feedback. I thank you in advance for your co-operation.

Danika Marmarà

Director (Cancer Care Pathways)

Postgraduate Researcher, University of Stirling

Appendix 4.1.6b - Covering Letter (Maltese version)

Ittra ta' Akkumpanjament

Titolu: Konvinzjonijiet dwar is-Saħħa, Perċezzjonijiet ta' Mard u Determinanti għat-Teħid ta' Skrining tas-Sider f'Malta: Stħarrig Trażversali

Għażiża Parteċipanta,

Jiena riċerkatriċi postgradwatorja, bħalissa qed nagħmel studju lokali bil-għan li nidentifika l-ostakli u l-faċilitaturi ewlenin għall-Iskrining kontra l-Kanċer fis-Sider f'Malta u nindirizza l-ostakli permezz ta' żvilupp ta' intervent ibbażat fuq it-teorija u fuq l-evidenza. Int mistiedna tipparteċipa f'dan l-istudju, fejn se ssir evalwazzjoni permezz ta' intervisti strutturati bit-telefown tal-konvinzjonijiet dwar is-saħħa, perċezzjonijiet ta' mard u determinanti marbutin mal-iskrining tas-sider. Barra minn hekk, se nkunu qed inħarsu lejn ċerti fatturi fl-isfond biex nivvalutaw l-impatt tagħhom fuq l-għarfien u l-attitudnijiet dwar l-approċċ lejn l-iskrining kontra l-kanċer fis-sider. Billi tgħinna niġbru din l-informazzjoni, aħna nkunu nistgħu ntejbu l-konvinzjonijiet, l-attitudnijiet u l-approċċ lejn l-iskrining kontra l-kanċer fis-sider.

Konsegwentement, dan l-istħarriġ bit-telefown għandu jsir permezz ta' kampjun aleatorju ta' nisa Maltin u Għawdxin li ġew mistiedna għall-programm tal-Iskrining tas-Sider u li jkunu rrikorrew għas-servizz jew le. Il-mistoqsijiet li se jsirulek huma dwar il-fatturi marbuta mal-iskrining tas-sider u l-kanċer fis-sider u dawn il-mistoqsijiet għandhom jieħdu madwar 20 minuta mill-ħin tiegħek.

Kunfidenzjalità, Anonimità u Parteċipazzjoni Volontarja

L-informazzjoni kollha miġbura se tiġi trattata strettament kunfidenzjali billi nħarsu l-kunfidenzjalità u l-anonimità tiegħek il-ħin kollu. Fl-ebda ħin m'aħna se niżvelaw l-identità tiegħek. Il-parteċipazzjoni tiegħek hija għalkollox volontarja u għalhekk m'għandek l-ebda obbligu li tipparteċipa. Tista' tirtira fi kwalunwe ħin minn dan l-istudju, mingħajr il-ħtieġa li tagħti raġunijiet. Jekk tirrifjuta milli tipparteċipa, dan mhux se jaffettwa l-kura, it-trattament mediku jew id-dritt tiegħek li jsirulek xi testijiet oħra. Hu importanti li tifhem li mintix se titħallas talli tipparteċipa f'dan l-istudju.

Benefiċċji u Riskji

Bħala parteċipanta f'dan l-istudju, tista' tikseb xi forma ta' għarfien fil-proċess tat-teħid tad-deċiżjonijiet tiegħek. Ir-riskji involuti huma minimi. Minħabba li ċerti entrati jittrattaw il-kanċer fis-sider u l-approċċ lejn l-iskrining tas-sider, jista' jkun li tħossok nervuża int u twieġeb dawn il-mistoqsijiet. Mhuwiex il-ħsieb tar-riċerkatriċi li tpoġġik f'sitwazzjoni antipatka jew li timbarazzak. Jekk, għal kwalunkwe raġuni, tħossok skomda meta tkun qed tiġi mistoqsija, tiddejjaqx tgħid lir-riċerkatriċi. Barra minn hekk, inti ser tkun diretta wkoll lejn professjonisti speċjalizzati bhal radjografa [Ms. _________] u infermiera [Ms _________] fi [17, Lascaris Wharf, Valletta] li huma mħarrġa u ghandhom esperjenza biex jittrattaw kwistjonijiet tan-nisa li jattendu fil-programmi tal-Iskrining u inti tista' tiddiskuti aktar magħhom kwalunkwe kwistjoni fuq bażi individwali ma' dawn il-professjonisti.

Riżultati tal-istudju

Ir-riżultati ta' dan l-istudju se jitqassmu lill-membri tal-grupp ta' ħidma ta' esperti tal-investigatur prinċipali. Is-sejbiet tal-istudju għandhom ikunu ta' valur kbir għall-Amministrazzjoni tal-Iskrining u għandhom jgħinu lill-fassala tal-politika u lill-Ministeru tas-Saħħa biex jippjanaw u jimplimentaw interventi xierqa meħtieġa biex jiżdied l-għadd ta' nies li jirrikorru għas-servizz kif ukoll biex jiżviluppaw strateġiji għal estensjonijiet tal-età fil-ġejjieni u ċikli ta' skrining sussegwenti. Dan l-istudju hu konformi mal-istrateġija għall-kura tal-kanċer għall-Gżejjer Maltin (Pjan Nazzjonali tal-Kanċer 2011-2015) billi jivvaluta l-ħtiġijiet tal-popolazzjoni lokali. Barra minn hekk, id-data miġbura għandha tgħin lill-awtoritajiet tas-saħħa huma u jifformulaw il-politiki nazzjonali sabiex inaqqsu d-differenzi soċjali fl-għoti ta' servizzi tas-saħħa.

Mistoqsijiet, Dubji jew Ilmenti

Jiena, ir-riċerkatriċi ta' dan l-istudju, lesta nwieġeb kwalunkwe mistoqsija jew niċċara kwalunkwe dubju li jista' jkollok dwar l-istudju jew id-drittijiet tiegħek bħala parteċipanta f'dan l-istudju. Jekk ikollok xi mistoqsija jew dubju li jistgħu jqumu matul l-istudju, toqgħodx lura milli tikkuntattjani fuq [+356 79005111] jew ibgħatli email fuq [danika.marmara@gov.mt].

Jekk għandek xi tħassib u/jew lok għal ilment, jekk jogħġbok ikkuntattja lill-koordinaturi tal-iskrining tal-Programm Nazzjonali tal-Iskrining tas-Sider billi tikteb f'dan l-indirizz [17, Lascaris Wharf, Valletta VLT 1921] jew tibgħat email [mbsp.mhec@gov.mt] jew jekk trid tista' ċċempel fuq [21227470 jew 21227471]. Tali lmenti jiġu segwiti speċifikament mill-Kap/Deputat Kap tal-Programm tal-Iskrining u/jew mill-Kap Eżekuttiv tad-Dipartiment tal-Kura tas-Saħħa Primarja.

Kunsens Infurmat

Jekk taqbel li tipparteċipa fl-istudju, nieħu dak bħala evidenza tal-kunsens infurmat tiegħek biex tipparteċipa f'dan l-istudju. Jekk inti taqbel ukoll li tiġi kkuntatjata għal aktar diskussjonijiet fil-fond, inti qegħda tagħti l-kunsens tiegħek biex tipparteċipa f'aktar riċerka. Id-data tiegħek tista' ukoll tiġi użata għal aktar analiżi ta' ċikli oħra sussegwenti għall-Iskrining tas-Sider. Nistenna b'interess ir-rispons tiegħek. Nirringrazzjak bil-quddiem tal-kooperazzjoni.

Danika Marmarà

Direttriċi (Cancer Care Pathways)

Riċerkatriċi postgradwatorja, l-Università ta' Stirling

Appendix 4.1.7a - Consent Form (English version)

Client Identification Number for this study: ______________

In participating in this study, I am giving my consent to participate in the research study entitled '***Health Beliefs, Illness Perceptions and Determinants to Breast Screening Uptake in Malta: A Cross-Sectional Survey'***. The researcher has explained to me the purpose and detail of the study and any difficulties which I raised about the study have been adequately answered.

I understand that the results obtained for this study in which I am participating may be reported or published or used for medical or scientific purposes. However, I shall not be personally identified in any way without my express written permission as I have been assured that my answers will be treated with the utmost confidentiality and that my identity will not be made public.

I have been informed that participation is entirely voluntary and I am therefore under no obligation to participate in this study. I may withdraw from the study at any time, without the need to give any reason. If I refuse to take part in this study, any medical treatment, care and my right for further examinations will not be affected. I am not receiving any remuneration for participating in this study. I have also been informed that my data could be used for further analysis of subsequent screening cycles.

I hereby give consent to participate in this research study ❑
I hereby withhold consent to participate in this research study ❑

I have been well-informed that the researcher [Danika Marmara'] is the contact person to answer any queries that I may have regarding the study or regarding my rights as a participant in this study. If, for any reason, I experience distress during the questions being asked, I shall notify the researcher so that the researcher can direct me to a lead radiographer [Ms. _________] and/or a practice nurse [Ms. _________] at [17, Lascaris Wharf, Valletta] who are trained and have experience to deal with regular arising women's issues at the screening programmes and I may discuss further any issue or distress on a one-to-one basis with these professionals.

If I have any concern and/or grounds for complaints, I can contact the screening coordinators at the National Breast Screening Programme in writing to the following address [17, Lascaris Wharf, Valletta VLT 1921] or by email on [mbsp.mhec@gov.mt] or by phone if I so wish on [21227470 or 21227471]. Such complaints will be followed up specifically by the Head/Delegate of the Screening Programme and/or the Chief Executive Officer of the Primary Health Care Department.

I would also like to be contacted again for more in-depth interviews on barriers and effective interventions to help increase breast screening uptake in Malta.

Yes ❑ No ❑

I agree to my data being used for further analysis of subsequent screening cycles.

Yes ❑ No ❑

The Participant: ______________________ **Date:** ________________

The Researcher: _______________________ **Date**: ________________

Appendix 4.1.7b - Consent Form (Maltese version)

Formola tal-Kunsens

Nurmu ta' Identifikazzjoni tal-Klijent għal dan l-istudju: ______________

Billi nipparteċipa f'dan l-istudju, jien nagħti l-kunsens tiegħi biex nipparteċipa fl-istudju ta' riċerka intitolat ***'Health Beliefs, Illness Perceptions and Determinants to Breast Screening Uptake in Malta: A Cross-Sectional Survey' (Konvinzjonijiet dwar is-Saħħa, Perċezzjonijiet ta' Mard u Determinanti għat-Teħid ta' Skrining tas-Sider f'Malta: Stħarrig Trażversali).*** Ir-riċerkatriċi spjegatli l-għan u d-dettal tal-istudju u wieġbet b'mod xieraq kwalunkwe diffikultà li kelli dwar l-istudju.

Nifhem li jista' jsir rapport tar-riżultati miksuba minn dan l-istudju li pparteċipajt fih jew li jiġu ppubblikati jew użati għal finijiet mediċi jew xjentifiċi. Madankollu, ma nista' bl-ebda mod niġi identifikata personalment mingħajr il-permess tiegħi espress bil-miktub peress li ġejt żgurata li t-tweġibiet tiegħi se jiġu trattati strettament kunfidenzjali u li l-identità tiegħi mhijiex se tiġi pubblikata.

Ġejt infurmata li l-parteċipazzjoni tiegħi hija għalkollox volontarja u għalhekk m'għandi l-ebda obbligu li nipparteċipa f'dan l-istudju. Nista' nirtira fi kwalunkwe ħin mingħajr il-ħtieġa li nagħti raġunijiet. Jekk nirrifjuta milli nipparteċipa, dan mhux se jaffettwa l-kura, it-trattament mediku jew id-dritt tiegħi li jsiruli xi testijiet oħra. Minix se nirċievi xi remunerazzjoni talli nipparteċipa f'dan l-istudju. Ġejt infurmata ukoll li d-data tiegħi tista' tiġi użata għal aktar analiżi ta' ċikli oħra sussegwenti għall-Iskrining tas-Sider.

B'dan nagħti l-kunsens tiegħi li nipparteċipa f'dan l-istudju ta' riċerka ❑
B'dan nirtira l-kunsens tiegħi milli nipparteċipa f'dan l-istudju ta' riċerka ❑

Ġejt infurmata sew li r-riċerkatriċi [Danika Marmara'] hija l-persuna ta' kuntatt biex twieġeb kwalunkwe dubju li jista' jkolli rigward l-istudju jew id-drittijiet tiegħi bħala parteċipanta f'dan l-istudju. Barra minn hekk, nista nkun diretta wkoll lejn professjonisti speċjalizzati bhal radjografa [Ms. _________] u infermiera [Ms. _________] fi [17, Lascaris Wharf, Valletta] li huma mħarrġa u ghandhom esperjenza biex jittrattaw kwistjonijiet tan-nisa li jattendu fil-programmi tal-Iskrining u jiena nista' niddiskuti aktar magħhom kwalunkwe kwistjoni fuq bażi individwali ma' dawn il-professjonisti.

Jekk ikolli xi tħassib u/jew lok għal ilment, nista' nikkuntattja lill-koordinaturi tal-iskrining tal-Programm Nazzjonali tal-Iskrining tas-Sider billi nikteb f'dan l-indirizz [17, Lascaris Wharf, Valletta VLT 1921] jew nibgħat email [mbsp.mhec@gov.mt] jew nista' nċempel fuq [21227470 jew 21227471]. Tali lmenti jiġu segwiti speċifikament mill-Kap/Deputat Kap tal-Programm tal-Iskrining u/jew mill-Kap Eżekuttiv tad-Dipartiment tal-Kura tas-Saħħa Primarja.

Nixtieq ukoll li nerġa niġi kkuntatjata għal aktar intervisti fil-fond fuq ostakli u interventi effettivi li jistgħu jgħinu biex iżidu l-attendenza għall-iskrining tas-sider f'Malta.

Iva ❑ Le ❑

Naqbel li d-data tiegħi tista tiġi użata għal aktar analiżi ta' ċikli oħra sussegwenti għall-Iskrining tas-Sider. Iva ❑ Le ❑

Il-Parteċipanta: ______________________ **Data:** _________________

Ir-Riċerkatriċi: _______________________ **Data**: _________________

Appendix 4.2.1 - Version of Study 2 published in the *BMC Public Health Journal*

Marmarà *et al. BMC Public Health* (2017) 17:416
DOI 10.1186/s12889-017-4324-6

BMC Public Health

RESEARCH ARTICLE Open Access

Health beliefs, illness perceptions and determinants of breast screening uptake in Malta: a cross-sectional survey

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Abstract

Background: Women's beliefs and representations of breast cancer (BC) and breast screening (BS) are salient predictors for BS practices. This study utilized the health belief model (HBM) and common-sense model (CSM) of illness self-regulation to explore factors associated with BS uptake in Malta and subsequently, to identify the most important predictors to first screening uptake.

Methods: This cross-sectional survey enrolled Maltese women (n = 404) ages 50 to 60 at the time of their first screening invitation, invited to the National Breast Screening Programme by stratified random sampling, with no personal history of BC. Participants responded to a 121-item questionnaire by telephone between June–September 2015. Data were analyzed using descriptive statistics, chi-square tests and logistic regression.

Results: There is high awareness of BC signs and symptoms among Maltese women (>80% agreement for 7 out of 8 signs), but wide variation about causation (e.g., germ or virus: 38.6% 'agree', 30.7% 'disagree'). 'Fear' was the key reason for non-attendance to first invitation (41%, n = 66) and was statistically significant across all subscale items (p < 0.05). Most items within HBM constructs (perceived barriers; cues to action; self-efficacy) were significantly associated with first invitation to the National Breast Screening Programme, such as fear of result ($\chi2$ = 12.0, p = 0.017) and life problems were considered greater than getting mammography ($\chi2$ = 38.8, p = 0.000). Items within CSM constructs of Illness Representation (BC causes; cyclical cancer timeline; consequences) were also significantly associated, such as BC was considered to be life-changing ($\chi2$ = 18.0, p = 0.000) with serious financial consequences ($\chi2$ = 13.3, p = 0.004). There were no significant associations for socio-demographic or health status variables with uptake, except for family income ($\chi2$ = 9.7, p = 0.047). Logistic regression analyses showed that HBM constructs, in particular perceived barriers, were the strongest predictors of non-attendance to first invitation throughout the analyses (p < 0.05). However, the inclusion of illness representation dimensions improved the model accuracy to predict non-attendance when compared to HBM alone (65% vs 38.8%).

Conclusions: Interventions should be based on theory including HBM and CSM constructs, and should target first BS uptake and specific barriers to reduce disparities and increase BS uptake in Malta.

Keywords: Breast cancer screening, Mammography, Uptake, Factors, Health belief model, Common-sense model

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Background

Breast cancer (BC) is the most prevalent cancer in Europe [1], accounting for 28.8% of all female cancer incidences [2] with 425,000 new cases diagnosed yearly [3]. BC accounts for 21% of all female cancer incidences in Malta with an average of 280 women diagnosed each year, over the last decade [4].

Early detection of BC reduces morbidity and mortality, resulting in more effective treatment regimens and better survival rates [5]. Such mortality reductions are largely dependent on interventions, such as breast self-examination, clinical breast examination and screening [6]. Despite evidence that breast screening (BS) decreases BC mortality rates by 25–30% [7–9], BC screening rates remain suboptimal in many European countries [10, 11]. Although European Guidelines for Quality Assurance in BC [12] promote an acceptable target screening rate of at least 70%, and ideally 75% of eligible women [13], less than 60% of Maltese women accepted their first screening invitation [14] from a national breast screening programme, introduced in 2009 for women aged 50–60 years [13]. Since its establishment in Malta, the Maltese Breast Screening Programme (MBSP) routinely invites women free-of-charge by letter every three years and has expanded its cohort in its second screening round to include women aged 61–66 years.

Reasons for non-attendance are well documented and multifactorial [15, 16]. The extant literature suggests that a number of factors influence BS uptake, namely: (1) health beliefs [17–19], (2) illness representations [17, 20, 21], (3) knowledge of BC signs and symptoms, its causes and consequences, and recommended BS practices [22, 23], (4) socio-demographic factors [22, 24, 25], and (5) health status (medical factors) [17, 25–27].

Theoretical framework: *The Health Belief Model and the Common-Sense Model of Illness Representation*

The Health Belief Model (HBM) was selected as one of the theoretical models for the current study, as it is widely used to identify associated variables with mammography and guides the prediction of screening behaviours [17, 18]. The HBM consists of six constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy [28, 29]. It proposes that the following factors play an important role in an individual's perception about BS, such that women are more likely to perform BS if: a) they feel susceptible (vulnerable) to BC or the risks of contracting the disease (perceived susceptibility), b) believe in the seriousness of BC and its consequences for the individual (perceived severity), c) perceive more benefits than barriers from undergoing mammography, d) have higher confidence for obtaining a mammogram, and e) if a cue to action is present [28].

HBM, however, only explains some variation in BS behaviour [29], which is why the Common-Sense Model (CSM) of self-regulation [or Self-Regulation Model (SRM)], developed by Leventhal and colleagues in 1980s, has been used to consider the cognitive and emotional representations of an illness [17]. This study was also informed by the CSM to understand how individual symptoms and emotions influence one's perception of BC, such as its likely impact upon physical and psychosocial functioning, and guide subsequent coping behaviour. Originally, illness representations comprised five components: *identity, cause, timeline, consequences,* and *cure/control* [17, 30]. These dimensions were further differentiated to include a further four dimensions: timeline cyclical; personal and treatment control; illness coherence and emotional representations [31].

Although screening behaviours can be predicted by knowledge, health beliefs and illness perceptions [17, 32], only a small body of research has jointly explored the latter to understand BS behaviour [17, 33], thereby limiting opportunities to examine if certain cognitions explain most of the variation in BS uptake. Furthermore, factors influencing uptake to a first BS invitation may differ to subsequent invitations, particularly since previous experience of BS is associated with future uptake [34]. Finally, the determinants of BS behaviour have not been studied in the Maltese population although determinants may not be comparable across different countries [35].

The primary aims of the study were:

1. To describe Maltese women's knowledge, health beliefs and illness perceptions about breast cancer and screening;
2. To identify the main reasons related to non-attendance at the MBSP;
3. To determine if health beliefs, illness perceptions, knowledge, socio-demographic factors and health status are associated with uptake to first invitation at the MBSP;
4. To determine the significant predictors to first breast screening uptake.

'Strengthening the Reporting of Observational Studies in Epidemiology' (STROBE) guidelines [36] [see Additional file 1], have been used to present the study findings in this article. This is the first study of its kind in Malta; the findings could be used to inform future strategies and interventions to improve uptake in Malta, which as already highlighted, was sub-optimal for first round screening [14]. We hypothesized that there would be significant associations between health beliefs and illness perceptions, knowledge, socio-demographic factors, health status, and BS uptake.

Methods

Study design

A cross-sectional survey of women's uptake of first invitation to the MBSP using validated tools to measure the influence of health beliefs and illness representations and using further questionnaires to measure knowledge of BS practices, socio-demographic and health status administered by telephone.

Setting

The study was carried out in Malta between June 2015 and September 2015. Since there is only one Breast Screening centre (no mobile units), located in Malta's capital city, Valletta, all data was generated from one computerized screening database and women were contacted from the centre.

Participants

The inclusion criteria were: women aged 50–60 at the time of their first screening invitation, residents in Malta or Gozo with a valid identity card number, able to communicate in English and Maltese, and with no severe co-morbidities. Women were excluded if they had ever been diagnosed with BC (n = 200), if they were invited to the second screening cycle (n = 12,210), if registered as deceased at the time of the sample selection (n = 71) and if incorrect information existed at the MBSP (n = 209) (Fig. 1).

Sample size and sampling technique

In order to ensure that the study sample was nationally representative of the screening population and to decrease the margin of error in the estimation, women were selected by a stratified random sampling technique, employed by strata i.e. district (geographical distribution), age and attendance/non-attendance to the first BS invitation. According to the MBSP, the target population was estimated to be 48,841 women who were invited during the first screening cycle [37]. Following the exclusion of subjects (numbers in parentheses) in the sampling flowchart (Fig. 1), the eligible population was calculated to be equal to 36,151 women. A sample size of 404 women was determined using a 95% confidence level and a 5% confidence interval. In order to obtain this sample size, the following number of attendees and non-attendees were randomly selected as follows: n = 243 attendees [women's reasons for attendance may provide a better insight to why people do not turn up for BS], and n = 161 non-attendees [this is representative from the actual population as 58.7% of those invited accepted their first invitation] [14]. Forty-five women refused to participate in this study (due to two reported personal reasons, i.e. lack of time due to work and family; fearful to speak about the topic under investigation). All 45 women were free to provide their own reason for non-participation. Content analysis of open-ended comments on reasons for refusal was employed, and later categorised and classified as being one of the above two reasons. Women's comments were typical reasons for refusals in similar studies [38]. Due to the women's refused participation, 449 women were eventually contacted in order to reach the necessary quota for each strata (with 90% response rate). Hence, the required total sample of 404 women was collected. Another 48 women were replaced during data collection since they were found to be ineligible during the telephone survey. All replacements were carried out in a way so as not to lose any of the sample representativeness of the population. Hence, replacements were selected with the same demographics of the non-respondent.

Data collection

The participant recruitment pathway is presented in Fig. 1. Participants were recruited by telephone, by a trained research assistant who requested initial verbal consent. If the client agreed to participate, a brief explanation of the study was provided by telephone. Thereafter, a written information letter was posted to women on that same day. Hence, women received pre-notification letters to further inform the participant about the study's aims, objectives and purpose, thus allowing the participant adequate time to read the information letter before further contact. Those who refused participation were deemed to have refused consent and were not contacted further. Scheduled appointments were set at women's most convenient date and time (in around 7 days from first phone call) so that participants would not to be caught 'off-guard' when contacted by telephone, and also so that the researcher could conduct a telephone survey which was the chosen, feasible method for this study. Telephone surveys have also been utilised successfully in the extant literature [39, 40]. In cases of non-response, three call-backs were performed on different occasions, following which the researcher moved on to contact other participants.

Subjects were provided with information regarding the specific study aim, content and estimate time to respond to the survey, and that no incentive would be provided. Respondents were assured that all the collected information would be processed anonymously and confidentially. They were also informed that they could refuse to answer any question or decline participation at any point. For those participants who affirmed they were willing to respond, verbal informed consent was obtained by

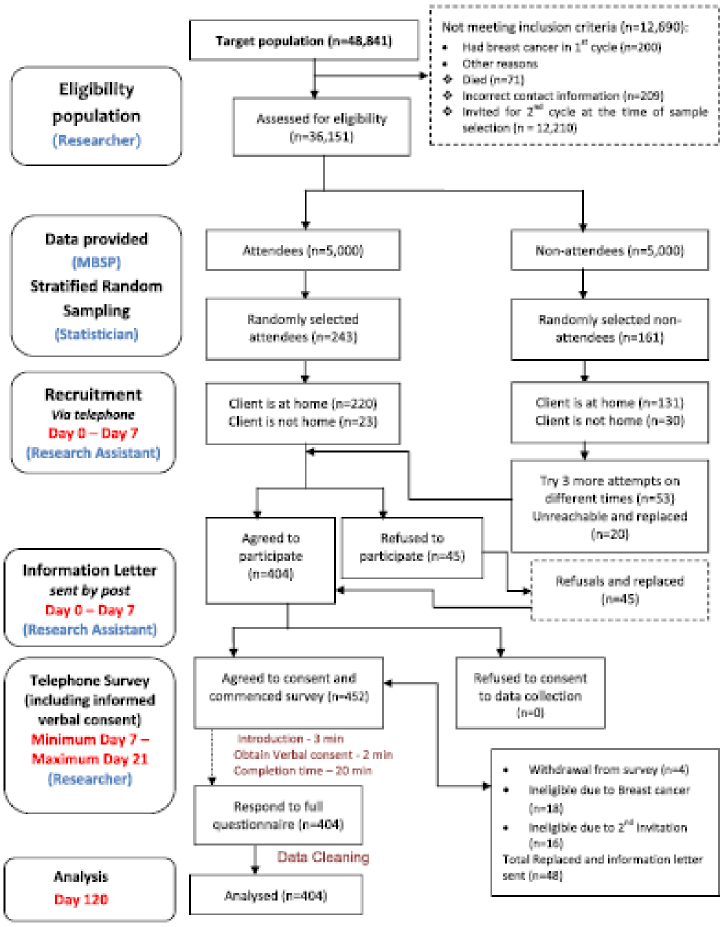

Fig. 1 Participant pathway and sampling flowchart (based on STROBE guidelines)

telephone through the use of standard procedures and guidelines [41]. Verbal consent is common practice when conducting survey interviews or interventions by telephone [39, 40, 42] and was chosen because it facilitates comprehension of study objectives and questionnaire items, and reduces the unnecessary burden entailed in a written consent form [39].

Participant recruitment by the research assistant was done manually, using paper format to record verbal consent by ticking Yes/No and to schedule appointments for the participants and the primary investigator (DM). The telephone survey was carried out by a single researcher (DM) and data entry was carried out (DM) through the use of computer-assisted technology through an online study tool (the SurveyMonkey program). Subsequently, the data were downloaded by the primary investigator (DM) from the same program. Minor formatting adjustments were made to the raw aggregate data in Microsoft Excel, and then the data were exported into the Statistical Package for the Social Sciences (SPSS). This method of handling data significantly decreased human error in the data entry process. This procedure of data storage and handling was secure, ensuring confidentiality of information provided by participants.

Measures

The questionnaire was initially developed using previously validated questionnaires (CHBMS-MS and IPQ-R) [31, 43]. The CHBMS-MS and IPQ-R scales were used after securing written permission from the authors and were translated and adapted into the Maltese language and tested for validity in a pilot study involving 15 Maltese women [more information is available from the authors]. Our findings show overall positive correlation of the total inter-item correlation (CHBMS-MS: 0.87, IPQ-R: 0.85) (p *0.001* respectively), high Cronbach's alpha (CHBMS-MS: 0.93, IPQ-R: 0.92), overall acceptable internal consistency (CHBMS-MS: 0.69–0.83, IPQ-R: 0.75–0.93), and acceptable test-retest reliability correlations: CHBMS-MS (Maltese: 0.62–0.76, English: 0.61–0.84); IPQ-R (Maltese: 0.63–0.82, English: 0.61–0.91) (p *0.001* respectively). Hence, this version of the instrument was used in this cross-sectional study.

The 121-item questionnaire is composed of four sections:

1) 11 subscales for socio-demographic and health status (20 items) related to age, residing district, education, employment, marital status, family income, car ownership/driving, illness/disability, having a GP, breast condition, family history of BC or other cancer. Response options were "yes", "no" or a series of tick boxes. Open questions were asked when it was believed to be important that women could provide further detail, for example, type of illness, breast condition or cancer site.
2) 4 subscales for lifetime BS practices (17 items) that were clustered in 4 subscales: lifetime mammography use (4 items), attendance/non-attendance to first round screening (8 items), re-attendance/intention (4 items), knowledge about recommended screening frequency (1 item). Most of the response options were mostly designed to elicit "yes", "no" or "unsure" answers. Closed questions allowed women to respond to a series of tick boxes.
3) 5 subscales for health beliefs (36 items) that were clustered into: perceived susceptibility (3 items), perceived benefits (6 items), perceived barriers (13 items), cues to action (7 items) and self-efficacy (7 items). All items had 5 response options ranging from: 1 = 'strongly disagree' to 5 = 'strongly agree'. Reverse scoring (r) was performed for only one item 'There is no possibility of getting breast cancer' so that higher values would indicate greater possibility.
4) 7 subscales for illness perceptions (48 items) that were clustered into: breast cancer identity (8 items), causal scale (18 items), cancer timeline: acute/chronic (2 items), cyclical (1 item), consequences (8 items), curability/controllability (personal control - 3 items; treatment control - 3 items), illness coherence (2 items), and emotional representations (3 items). All items had 5 response options ranging from: 1 = 'strongly disagree' to 5 = 'strongly agree'.

Ethical considerations

Ethics approval was obtained from the School Research Ethics Committee at the University of Stirling (SREC14/15-Paper No.18v4) and by the Maltese Health Ethics Committee (HEC 02/2015). After securing written permission from the Chief Executive Officer, data were obtained from the MBSP and was computer generated from the local screening register.

Variable definitions

A first invitation was defined as the first (initial) time a woman is invited to the MBSP and either attends or does not attend for the screening mammogram. Modifying factors include socio-demographic and health status variables (some of which were confirmed from women's health records from the screening database), and structural variables such as knowledge of screening frequency and of the disease. These variables were collected from the survey administered retrospectively from the time of the first screening invitation.

Data analysis

Data entry and statistical analysis were performed using SPSS® version 21.0 under direct instruction and guidance of an expert statistician. Descriptive and inferential statistics, such as percentages, frequencies, means, standard deviations and confidence intervals, were used to present the basic statistics in relation to the demographics, knowledge, health beliefs and illness perception variables. Tests for associations (Chi-square test: to determine significant associations between one categorical variable and another categorical variable) were applied to investigate the associations of health beliefs, illness representations, knowledge, socio-demographic factors and health status with uptake to MBSP. Binary logistic regression modelling, using the "Backward-elimination" method, was performed to identify the significant predictors for BS uptake. The unstandardized coefficients, standard error, the Wald value, p-values, Odds Ratios (ORs) and 95% confidence intervals (95% CIs) were calculated for each logistic regression model. The level of accuracy was included in the final outcome of the model. Missing data was minimal and reported in Table 1. Statistical significance was established at $p < 0.05$ for all analyses.

Piloting the data collection method

A pilot study was conducted with a random sample of 15 women of different age groups to assess and ascertain the practicalities of conducting the tool by telephone. In

Table 1 Sample Characteristics (n = 404)

Characteristics	Mean	SD	N	%
Age (year)				
50			20	5.0
51			45	11.1
52			42	10.4
53			48	11.9
54			56	13.9
55			44	10.9
56			29	7.2
57			44	10.9
58			27	6.7
59			37	9.2
60			12	3.0
	54.62	2.79		
Education level				
No schooling			1	0.3
Primary level			67	16.6
Secondary level			306	75.7
Tertiary level			30	7.4
Occupation				
Pensioner			5	1.2
Housewife			311	77.0
Employee			88	21.8
Status				
Single			16	4.0
Married			351	86.9
Separated/Divorced			13	3.2
Widowed			24	5.9
Family income				
Less than €10,737			102	25.3
€10,737 – €16,113			142	35.2
€16,114 – €23,563			20	5.0
€23,564 – €33,966			14	3.5
Greater than €33,966			1	0.3
Prefer not to say			125	30.9
Own a car				
Yes			338	83.7
No			66	16.3
Drive				
Yes			177	43.8
No			227	56.2
Any illness, disability or condition				
Yes			185	45.8
No			219	54.2

Table 1 Sample Characteristics (n = 404) (Continued)

Family physician (GP)		
Yes	377	93.3
No	27	6.7
Frequency of GP visit		
Only when I have a problem	358	88.6
Once a month	6	1.5
More than once a year	16	4.0
Once a year	1	0.2
Missing	23	5.7
Lumpy breasts		
Yes	30	7.4
No	374	92.6
Relatives or close friends had cancer		
Yes	330	81.7
No	68	16.8
Prefer not to say	6	1.5

order to reduce bias, a random selection of participants was computer generated from the computerized database of the MBSP; hence, attendance for first round screening was ascertained from programme records. A similar approach to the larger study for 'selection' and 'recruitment' can be similarly referred to in the participant pathway (Fig. 1). These women were contacted by a research assistant and those who agreed to participate were introduced to the researcher. A convenient time was arranged with each participant in order for the researcher to conduct the pilot survey by telephone. Verbal informed consent was sought from all 15 participants. The results from the pilot study showed that the tool was practical and feasible to conduct by telephone and that no methodological changes were required. Women participating in the pilot study were not included in the larger study. The time for scale completion had a median of 25 min (range, 15–45 min).

Results

Sample characteristics

The sample characteristics (n = 404) are presented in Table 1. Women were aged between 50 to 60 years at the time of the programme's first screening round, with a mean age of 54.6 years ±2.8 years (SD). The majority were married (86.9%, n = 351), housewives (77%, n = 311), had up to a secondary education level (75.7%, n = 306) and more than half (60.3%, n = 244) were from below average income families (lower than €16,113). Although the majority owned a family car (83.7%, n = 338), only 43.8% (n = 177) could drive. An illness, disability or condition was reported by 45.8% of women (n = 185) and 2.5% (n = 10) had cancer (other than BC). Furthermore, 81.7% (n = 330) had relatives or close friends with cancer [6.7% (mother with BC) and 21.3% (close friend with BC)]. The majority (93.3%, n = 377) reported having a named family physician (GP); however, 88.6% (n = 358) of the total sample visited a GP only when they had a problem. Furthermore, nearly 70% of women in this study reported that they were not encouraged by their GP to attend to breast screening.

Knowledge of breast screening frequency and breast cancer

The majority of women were knowledgeable of the recommended screening frequency to varying degrees (Table 2): 46.3% (n = 187) indicated yearly mammograms; 3.7% (n = 15): every 1.5 years; 43.3% (n = 175): every 2–3 years; 6.2% (n = 25) were unsure). BC identity scores were reported by above 80% of women for the majority of the sub-scale items (7 out of 8 items) (Table 3). However, there was wide variation for knowledge of causes and risk factors of BC among Maltese women (Table 3). Hereditary predisposition to the disease was the most commonly reported risk factor, followed by smoking, altered immunity and pollution. Misconceptions concerning risk factors of BC were found [e.g. a germ or virus (38.6% 'agree', 30.7% 'disagree'; accident or injury (47.5% 'agree'; 39.1% 'disagree')].

Health beliefs and illness perceptions

Women's health beliefs and illness perceptions are presented in Table 4. Subscale scores were retrieved as the mean of items (i.e. those items with which respondents are most in agreement, though a disagreement answer for barrier items represents a more positive result). In general, higher percentage scores indicate higher agreement among participants for perceived benefits of mammography (79.7%), self-efficacy (77.7%) and cues to action (76.6%), while lower scores indicate lower agreement among women for perceived barriers (45.1%). There was also higher agreement with emotional representations (82.0%), personal control items (78.7%), BC identity (76.5%) and cyclical cancer timeline perceived (72.0%), while lower agreement for BC causes (62.4%) and cancer timeline (acute/chronic) (61.0%).

When comparing health beliefs and illness perceptions among attendees and non-attendees (Tables 5–6), the majority agree that the possibility of developing BC in their lifetime is high (M = 4.0, SD = 0.3) and believe in early detection through screening (M = 4.2, SD = 0.5). Each item in the 'perceived barrier' subscale was scored by respondents with the highest level of uncertainty, such that 6 out of 13 items had a mean score of 2.5–3.5 (Table 5).

This study found that a large number of participants had higher emotional representations when they think about BC, such that they get anxious (M = 3.6, SD = 1.1), feel afraid (M = 4.3, SD = 0.7) and worried (M = 4.4, SD = 0.7), they believe that BC has major consequences on a patient's life (M = 4.3, SD = 0.6), and more specifically, their whole life would change (M = 4.2, SD = 0.6). The course of the BC pathway is believed to be dependent on their actions (M = 3.9, SD = 0.4).

Table 2 Women's Knowledge of breast screening frequency (n = 404)

	n	%
Knowledge about recommended breast screening frequency		
Every year	187	46.3
Every year and a half	15	3.7
Every 2–3 years	175	43.3
Every 4–5 years	2	0.5
Unsure	25	6.2

Reasons for non-attendance to first breast screening invitation

When non-attendees were asked to further identify reasons for non-attendance to first round screening at the MBSP (i.e. respondents were allowed to mention more than one reason), the main reported reason was fear (41.0%, n = 66), of which sub-categories included 'fear of result' (20.5%; n = 33), 'fear of pain' (10.6%; n = 17), 'fear of an unknown procedure' (depicting knowledge gap) (6.2%; n = 10), 'fear of radiation' (3.7%, n = 6) and 'embarrassment' (8.1%; n = 13). Some women had also opted for the service elsewhere (38.5%, n = 62) or had never received an invitation (13.7%; n = 22). Practical reasons were mentioned by 8.7% (n = 14) of non-attendees, which included 'busy at work' or 'home', 'transport issues', 'on vacation' and 'being ill'.

Associations between health beliefs and uptake to first screening invitation

The variables related to HBM constructs were compared with attendance and non-attendance to the first round screening at the MBSP (Table 5). In general, the majority of the HBM constructs showed statistical significance as follows:

Perceived benefits

Women who feel good about themselves when getting a mammogram ($\chi2$ = 16.7, p = 0.001) were more likely to attend their first screening invitation. On the other hand, non-attendees believe less than attendees that BS will help to detect a lump early before it can be felt ($\chi2$ = 7.8, p = 0.051).

Table 3 Women's Knowledge on breast cancer identity and causes (n = 404)

Breast cancer identity scores, n (%)			
	Disagree/Strongly Disagree	Undecided	Agree/Strongly Agree
The presence of a lump or thickening in the breast	5 (1.2)	26 (6.4)	373 (92.3)
Nipple discharge	3 (0.7)	54 (13.4)	347 (85.9)
Sudden nipple retraction	2 (0.5)	64 (15.8)	338 (83.7)
Change in shape or appearance of the nipple	2 (0.5)	29 (7.2)	373 (92.3)
Breast swelling, dimpling, redness or soreness of the skin	3 (0.7)	66 (16.3)	335 (82.9)
Skin changes of the breast	3 (0.7)	67 (16.6)	334 (82.7)
A sudden change in breast size	5 (1.2)	52 (12.9)	347 (85.9)
Aching breasts	40 (9.9)	114 (28.2)	250 (61.9)
Causes of breast cancer scores, n (%)			
	Disagree/Strongly Disagree	Undecided	Agree/Strongly Agree
Stress or worry	152 (37.6)	95 (23.5)	157 (38.9)
Your mental attitude	262 (64.9)	94 (23.3)	48 (11.8)
Family problems or worries	171 (42.3)	82 (20.3)	151 (37.4)
Overwork	281 (69.6)	59 (14.6)	64 (15.8)
Your emotional state	257 (63.6)	76 (18.8)	71 (17.6)
Your personality	262 (64.9)	94 (23.3)	48 (11.8)
Hereditary - it runs in the family	5 (1.2)	10 (2.5)	389 (96.3)
Diet or eating habits	121 (30.0)	61 (15.1)	222 (55.0)
Poor medical care in the past	98 (24.3)	90 (22.3)	216 (53.4)
Your own behaviour	174 (43.1)	172 (42.6)	58 (14.3)
Ageing	142 (35.1)	63 (15.6)	199 (49.3)
Smoking	47 (11.6)	39 (9.7)	318 (78.7)
Alcohol	80 (19.8)	60 (14.9)	264 (65.3)
A germ or virus	124 (30.7)	124 (30.7)	156 (38.6)
Pollution in the environment	65 (16.1)	49 (12.1)	290 (71.8)
Altered immunity	43 (10.6)	69 (17.1)	292 (72.3)
Chance or bad luck	205 (50.7)	37 (9.2)	162 (40.1)
Accident or injury	158 (39.1)	54 (13.4)	192 (47.5)

Perceived barriers

Although there was no significant association between anxiety and initial screening uptake, fear was found to be statistically significant across all subscale items ($p < 0.05$). Non-attendees expressed fear of a cancer diagnosis ($\chi2$ = 12.0, p = 0.017), fear of the unknown procedure ($\chi2$ = 31.9, p = 0.000), fear of radiation ($\chi2$ = 16.6, p = 0.001), consider mammography to be embarrassing ($\chi2$ = 13.6, p = 0.009) and other problems in life to be greater than getting a mammogram ($\chi2$ = 38.8, p = 0.000), and were more undecided on whether the mammography procedure is painful ($\chi2$ = 39.0, p = 0.000). On the other hand, attendees are more in disagreement with the statement: 'they are not old enough to have a mammogram periodically' ($\chi2$ = 22.6, p = 0.000) and have less fear or distrust in the medical team ($\chi2$ = 38.3, p = 0.000).

Cues to action

Women attend more if advised by their GP ($\chi2$ = 13.6, p = 0.004) and if someone close to them had BC ($\chi2$ = 13.8, p = 0.008), but do not attend more if advised by their relatives or friends ($\chi2$ = 2.0, p = 0.576). Attendees are more in agreement that hearing about BC and BS in the media or news makes them think about getting a mammogram ($\chi2$ = 15.7, p = 0.000), and similarly reminder letters ($\chi2$ = 15.4), phone calls or text messages ($\chi2$ = 15.4), and educational talks ($\chi2$ = 16.9) help them to get a mammogram done (p = 0.001 respectively).

Table 4 Instrument scoring: the percentage and mean scores for Health Beliefs and Illness Perceptions

Health Beliefs				
[a]Subscale	Minimum	Maximum	Mean Score	Percentage Score
Perceived Susceptibility	3	15	9.6	64.0%
Perceived Benefits	6	30	23.9	79.7%
Perceived Barriers	13	65	29.3	45.1%
Cues to action	7	35	26.8	76.6%
Self-Efficacy	7	35	27.2	77.7%
Illness Perceptions				
[a]Subscale	Minimum	Maximum	Mean Score	Percentage Score
Breast Cancer Identity	8	40	30.6	76.5%
Causes of Breast Cancer	18	90	56.2	62.4%
Cancer Timeline: Acute/Chronic	2	10	6.1	61.0%
Cancer Timeline: Cyclical	1	5	3.6	72.0%
Consequences	8	40	28.3	70.8%
Personal Control	3	15	11.8	78.7%
Treatment Control	3	15	9.9	66.0%
Illness Coherence	2	10	7	70.0%
Emotional Representations	5	15	12.3	82.0%

[a]All subscale items were grouped according to their respective subscale. Each subscale item had 5 response options ranging from 1 = 'strongly disagree' to 5 = 'strongly agree'

Self-efficacy

Attendees also tend to agree more that they can arrange other things in life to get a mammogram ($\chi2$ = 13.1, p = 0.011), such as finding a place to get it done ($\chi2$ = 10.9, p = 0.028), arranging an appointment ($\chi2$ = 12.1, p = 0.016) and transportation ($\chi2$ = 13.1, p = 0.011), and also paying for it if they need to ($\chi2$ = 10.3, p = 0.036).

Associations between illness perceptions and uptake to first screening invitation

Illness perception constructs were compared with attendance and non-attendance to the first screening invitation to the MBSP (Table 6). In general, Chi-square tests showed no statistical significance for BC identity items, acute/chronic cancer timeline, personal and treatment control, illness coherence and emotional representation items with first screening uptake.

Causes of breast cancer

In general, no significant association was found for most causal variables. However, attendees were more in agreement that BC could be hereditary ($\chi2$ = 13.4, p = 0.004) and considered one's own behaviour to cause BC ($\chi2$ = 10.0, p = 0.018), while non-attendees were more undecided whether one's emotional state or personality cause BC ($\chi2$ = 19.0, p = 0.000).

Cancer timeline (cyclical)

Attendees agree more than non-attendees that a patient with BC gets better and worse ($\chi2$ = 11.1, p = 0.026).

Consequences

Attendees consider more that BC has major consequences on a patient's life ($\chi2$ = 14.2, p = 0.003), has serious economic and financial consequences ($\chi2$ = 13.3, p = 0.004) and is life-changing ($\chi2$ = 18.0, p = 0.000). On the other hand, non-attendees are more undecided whether BC would strongly affect the way others see them ($\chi2$ = 14.9, p = 0.005) and consider the chances of living a long life to decrease ($\chi2$ = 9.4, p = 0.024).

Associations between sociodemographic and health status, knowledge of breast screening frequency and uptake to first screening invitation

There were no significant associations for demographic factors or health status variables with first screening uptake, except for family income ($\chi2$ = 9.7, p = 0.047). Non-attendees were the most unsure of the recommended screening frequency ($\chi2$ = 13.9, p = 0.003).

Predictors of uptake to first screening invitation

Different groups of variables and constructs were incorporated into seven logistic regression models and the 'backward-elimination' method was applied to every model to identify the significant predictors of BS uptake (Table 7).

Table 5 Comparison of Health Beliefs between attendees and non-attendees

When you received your invite to the Breast Screening programme, did you attend?	Yes		No		Total		Chi-Square test*	
Health Beliefs	Mean	SD	Mean	SD	Mean	SD	χ2	*p*-value
There is no possibility of getting breast cancer *(r)*	1.9	0.7	2.0	0.7	2.0	0.7	4.3	0.367
Your chances of getting breast cancer are high	3.7	0.7	3.6	0.8	3.6	0.8	7.1	0.130
There may be the possibility of developing breast cancer in your lifetime	4.0	0.3	4.0	0.4	4.0	0.3	1.7	0.645
When you get a mammogram, you feel good about yourself	4.0	0.4	3.9	0.5	4.0	0.5	16.7	0.001*
When you get a mammogram, you do not worry as much about breast cancer	3.8	0.8	3.6	0.8	3.7	0.8	2.8	0.423
Having a mammogram will help you find lumps early in your breasts	4.2	0.4	4.1	0.5	4.2	0.5	7.8	0.051
If you find a lump through a mammogram, the treatment for breast cancer may not be as bad	4.0	0.4	4.0	0.3	4.0	0.4	3.3	0.349
Having a mammogram will decrease your chances of dying from breast cancer	4.0	0.4	4.0	0.3	4.0	0.3	6.2	0.103
Having a mammogram will help you find a lump before it can be felt by yourself or a health professional	4.0	0.5	4.0	0.4	4.0	0.5	0.6	0.899
Having a routine mammogram would make you anxious about breast cancer	2.7	1.0	2.9	1.0	2.8	1.0	7.1	0.070
Having a routine mammogram would make you worry	2.7	1.0	2.9	1.0	2.8	1.0	3.9	0.416
You fear having a mammogram because you might find out that something is wrong	2.9	1.0	3.2	1.0	3.0	1.1	12.0	0.017*
You fear having a mammogram because you do not know the procedure or what to expect	2.2	0.6	2.5	0.9	2.3	0.8	31.9	0.000*
You fear having a mammogram because you know someone (family or friend) with breast cancer	2.6	1.1	2.9	1.1	2.7	1.1	7.1	0.132
It is embarrassing for you to have a mammogram	2.4	0.8	2.7	1.0	2.5	0.9	13.6	0.009*
Undergoing mammography will be painful or uncomfortable	3.4	1.0	3.3	0.9	3.3	1.0	39.0	0.000*
Having a mammogram is time consuming	1.2	0.4	1.3	0.6	1.3	0.5	7.2	0.067
You are discontent with Breast Screening personnel as they have been rude to you	1.2	0.5	n/a	n/a	1.2	0.5	n/a	n/a
You have fear or distrust in the medical team	1.7	0.7	2.2	0.9	1.9	0.8	38.3	0.000*
Having a mammogram would expose you to unnecessary radiation	2.2	0.6	2.5	0.8	2.3	0.7	16.6	0.001*
You have too many other problems in your life than to get a mammogram done	1.6	0.6	2.0	0.8	1.7	0.7	38.8	0.000*
You are not old enough to have a mammogram periodically	1.7	0.5	1.9	0.4	1.8	0.5	22.6	0.000*
If your GP advises you to attend for a mammogram, you will attend	4.3	0.6	4.0	0.7	4.2	0.7	13.6	0.004*
If your relatives or friends advise you to attend for a mammogram, you will attend	3.4	1.0	3.4	1.0	3.4	1.0	2.0	0.576
If someone close to you has been diagnosed with breast cancer, you will attend for a mammogram	4.2	1.0	3.9	1.0	4.1	1.0	13.8	0.008*
Hearing about breast cancer and breast screening in the media or news makes you think about getting a mammogram	3.8	0.7	3.5	0.9	3.6	0.8	15.7	0.000*
Reminder letters would help you to get a mammogram	4.0	0.4	3.8	0.7	3.9	0.5	15.4	0.001*
Reminder phone calls or text messages would help you to get a mammogram	4.0	0.4	3.8	0.7	3.9	0.5	15.4	0.001*
Routine educational talks regarding breast cancer awareness would help you to get a mammogram	3.8	0.7	3.5	0.9	3.6	0.8	16.9	0.001*
You feel confident that if you had a mammogram done, any abnormalities in your breasts will be detected	3.7	0.6	3.6	0.7	3.7	0.6	2.2	0.697
You can arrange other things in your life to get a mammogram	4.2	0.6	4.0	0.7	4.1	0.7	13.1	0.011*
In case you need a mammogram, you will find a place to get it done	4.2	0.5	4.1	0.5	4.2	0.5	10.9	0.028*

Table 5 Comparison of Health Beliefs between attendees and non-attendees *(Continued)*

You can make an appointment for a mammogram	4.2	0.5	4.1	0.6	4.2	0.5	12.1	0.016*
You can arrange transportation to get a mammogram	4.2	0.5	4.1	0.6	4.2	0.6	13.1	0.011*
You can talk to people at the breast screening centre about your concerns	4.1	0.7	n/a	n/a	4.1	0.7	n/a	n/a
You can find a way to pay for a mammogram if you need to	4.2	0.5	4.1	0.5	4.2	0.5	10.3	0.036*

*Significant at α = 0.05
(r) = reverse scored
[a]Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1 and 5, where 1 = strongly disagree and 5 = strongly agree.

Model 1 (Demographics) and Model 2 (Health status)

All items related to demographic variables were incorporated in a logistic regression model (Model 1) and health status items were incorporated into Model 2. Both demographics and health status variables were found to be non-important predictors of BS uptake, such that for both models, non-attendance was not predicted and none of the variables were found to be significantly different.

Model 3 (Health Belief items)

All items related to HBM were incorporated in a logistic regression model (Model 3). Five variables were found to be good predictors of BS uptake: 'distrust in medical team', 'fear of unknown procedure', 'other life problems', 'relatives and friends advice' and 'reminder letters' (Table 7). For this model, attendance was predicted with an accuracy of 88.5% and non-attendance was predicted with 38.8%.

Model 4 (Illness Perception items)

All IPQ-R variables were incorporated into one logistic regression model (Model 4). Seven variables were found to be good predictors: 'hereditary', 'pollution', 'a patient with BC goes through cycles in which her illness gets better and worse', 'BC has major consequences on a patient's life', 'if you had BC, your whole life would change', 'if you developed BC, the chances of living a long life would decrease' and 'BC makes you feel afraid' (Table 7). The accuracy for this model was found to be 83.5% for attendance and 37.3% for non-attendance.

Model 5 (Significant predictors from Models 3 and 4)

The above significant predictors from both models 3 and 4 were incorporated into a new single model (Model 5) and backward-elimination was applied on these 12 variables (five Health Beliefs and seven Illness Perception variables). The final model retained nine significant predictors, without excluding any of the Health Belief variables, hence showing that Health Beliefs are more significant predictors than Illness Perceptions. The model accuracy, when combining both scores, improved to 53.8% for non-attendance and 84.8% for attendance.

Model 6 (All individual Health Belief and Illness Perception items)

When all items related to Health Beliefs and Illness Perceptions were incorporated into one model (Model 6), 21 variables were found to be significantly different. The accuracy of the model improved again to 85.2% for attendees and 65% accuracy for non-attendees.

Model 7 (All 14 constructs)

When the 14 constructs (not individual items) related to Health Beliefs and Illness Perceptions were used to construct a logistic regression model (Model 7), 'perceived barriers', 'cancer timeline (cyclical)' and 'illness coherence' were found to be the significant predictors, of which the 'perceived barriers' construct was the strongest predictor. However, the accuracy for predicting the non-attendees was found to be 42.2%, which is inferior when compared to Model 5. Moreover, when removing the 'perceived barriers' variable from the latter model, the accuracy to predict non-attendance decreased sharply from 42.2% to 14.9%.

Our findings reveal that 'perceived barriers' is the most important construct to describe the variance between attendees and non-attendees. This result is further echoed in Model 5, where three predictors (from all the other predictors) are all related to perceived barriers. The above logistic regression analyses show that, although Health Beliefs are the most important predictors of BS uptake, the inclusion of Illness Perception items into one logistic regression model is important to improve the accuracy of the model (Model 5 vs Model 3).

Discussion

For the first time, this study aimed to explore factors related to Maltese women's BS behaviours, as well as their knowledge, health beliefs and illness perceptions related to BC and BS, providing answers as to why more than 40% of eligible women did not attend their first MBSP invitation.

Table 6 Comparison of Illness Perceptions between attendees and non-attendees

When you received your invite to the Breast Screening programme, did you attend?	Yes		No	Total			Chi-Square test[a]	
Illness Perception	Mean	SD	Mean	SD	Mean	SD	χ2	p-value
The presence of a lump of thickening in the breast	3.9	0.4	3.9	0.3	3.9	0.3	5.5	0.141
Nipple discharge	3.9	0.4	3.8	0.4	3.9	0.4	3.8	0.286
Sudden nipple retraction	3.9	0.4	3.8	0.4	3.8	0.4	5.8	0.121
Change in shape or appearance of the nipple	3.9	0.3	3.9	0.3	3.9	0.3	1.7	0.630
Breast swelling, dimpling, redness or soreness of the skin	3.8	0.4	3.8	0.4	3.8	0.4	2.6	0.463
Skin changes of the breast	3.8	0.4	3.8	0.4	3.8	0.4	2.1	0.555
A sudden change in breast size	3.8	0.4	3.9	0.4	3.9	0.4	0.4	0.950
Aching breasts	3.5	0.7	3.5	0.7	3.5	0.7	2.9	0.578
Stress or worry	3.0	0.9	3.0	0.8	3.0	0.9	3.9	0.140
Your mental attitude (e.g. thinking about life negatively)	2.5	0.7	2.5	0.7	2.5	0.7	6.0	0.111
Family problems or worries	3.0	0.9	2.9	0.9	3.0	0.9	3.5	0.178
Overwork	2.5	0.8	2.4	0.7	2.5	0.8	4.1	0.249
Your emotional state (e.g. feeling down, lonely, anxious, empty)	2.5	0.8	2.6	0.8	2.5	0.8	19.0	0.000*
Your personality	2.4	0.7	2.5	0.7	2.5	0.7	6.6	0.087
Hereditary - it runs in the family	4.6	0.6	4.4	0.6	4.5	0.6	13.4	0.004*
Diet or eating habits	3.3	0.9	3.2	0.9	3.3	0.9	5.6	0.131
Poor medical care in the past	3.3	0.8	3.3	0.8	3.3	0.8	2.4	0.489
Your own behaviour	2.7	0.7	2.8	0.7	2.7	0.7	10.0	0.018*
Ageing	3.1	0.9	3.1	0.9	3.1	0.9	4.9	0.087
Smoking	3.7	0.7	3.6	0.7	3.7	0.7	3.0	0.399
Alcohol	3.5	0.8	3.4	0.8	3.5	0.8	0.1	0.948
A germ or virus	3.0	0.8	3.1	0.8	3.1	0.8	3.7	0.160
Pollution in the environment	3.7	0.8	3.5	0.8	3.6	0.8	6.1	0.108
Altered immunity	3.6	0.7	3.6	0.7	3.6	0.7	1.5	0.683
Chance or bad luck	3.0	1.0	2.8	0.9	2.9	1.0	5.8	0.214
Accident or injury	3.1	0.9	3.1	0.9	3.1	0.9	1.7	0.782
Breast cancer will last a short time	2.8	0.7	2.9	0.7	2.8	0.7	4.2	0.241
Breast cancer is likely to be permanent rather than temporary	3.3	0.8	3.2	0.8	3.3	0.8	1.5	0.481
A patient with breast cancer goes through cycles in which her illness gets better and worse	3.7	0.7	3.4	0.7	3.6	0.7	11.1	0.026*
Breast cancer has major consequences on a patient's life	4.3	0.6	4.2	0.5	4.3	0.6	14.2	0.003*
Breast cancer will not have much effect on your life	1.5	0.7	1.6	0.7	1.5	0.7	11.8	0.019*
Breast cancer would strongly affect the way others see you	3.3	1.0	3.3	0.9	3.3	0.9	14.9	0.005*
Breast cancer has serious economic and financial consequences	3.9	0.6	3.7	0.7	3.8	0.6	13.3	0.004*
Breast cancer would strongly affect the way you see yourself as a person	4.1	0.5	4.0	0.6	4.1	0.6	0.7	0.875
Breast cancer would threaten a relationship with your husband or partner	3.1	0.9	3.0	0.9	3.1	0.9	2.2	0.699
If you had breast cancer, your whole life would change	4.3	0.7	4.1	0.6	4.2	0.6	18.0	0.000*
If you developed breast cancer, the chances of living a long life would decrease	4.0	0.5	4.0	0.3	4.0	0.4	9.4	0.024*
There is a lot which you can do to control the symptoms if Breast Cancer occurs	3.9	0.4	3.9	0.4	3.9	0.4	2.6	0.629
The course of Breast Cancer will depend on your actions	4.0	0.4	3.9	0.3	3.9	0.4	5.9	0.118
Your actions will have an effect on the outcome of Breast Cancer	4.0	0.3	4.0	0.2	4.0	0.3	5.9	0.118
There is no treatment that will help to improve Breast Cancer	2.0	0.6	2.0	0.5	2.0	0.5	5.8	0.211
The treatment provided will be effective in controlling or curing Breast Cancer	4.0	0.3	3.9	0.3	4.0	0.3	1.8	0.615

Table 6 Comparison of Illness Perceptions between attendees and non-attendees *(Continued)*

The negative effects of Breast Cancer can be prevented or avoided by the treatment given	4.0	0.3	3.9	0.3	3.9	0.3	5.5	0.241
You have a clear picture and understanding of Breast Cancer	3.8	0.6	3.8	0.6	3.8	0.6	0.7	0.873
Breast Cancer is a mystery to you	3.2	1.0	3.2	1.0	3.2	1.0	3.7	0.455
You get anxious when you think about Breast Cancer	3.6	1.1	3.7	1.1	3.6	1.1	2.6	0.464
Breast Cancer makes you feel afraid	4.3	0.7	4.3	0.6	4.3	0.7	1.7	0.645
You get worried when you think about Breast Cancer	4.4	0.7	4.4	0.6	4.4	0.7	1.4	0.502

*Significant at α=0.05

[a]Chi-square test was applied for all illness perceptions; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1-5, where 1 = strongly disagree and 5 = strongly agree.

Knowledge

Study findings confirm the wide variation in knowledge level of Maltese women about causes of BC and its related risk factors, though good awareness of BC signs and symptoms were reported, such as nipple discharge and sudden nipple retraction. Women's limited knowledge about BC and BS practices has been identified in a consistent body of literature [22, 32, 44, 45]. For instance, Grunfeld et al. [46] showed that only 38% of people were aware that nipple retraction was a sign of BC, and awareness of risk factors was even lower. Notably, local misconceptions (e.g., one's own behaviour, personality, emotional state, germ or virus, accident or injury could cause BC) also corroborate findings in older studies (e.g., hitting or bumping the breast), which is consistent with women's beliefs in other societies with different cultures such as the Philippines, Korea, Saudi Arabia and Australia [45–47].

Since relevant knowledge has been emphasized as a screening compliance predictor [48, 49] or a screening barrier [50], we hypothesized that there would be a significant association between knowledge and BS uptake in Malta. Our findings support this hypothesis since Maltese women who have a lack of awareness regarding screening recommendations, guidelines and BC related risk factors are more likely not to attend and this may prove difficult for women to perceive their risk [22]. Communicating risk information to the general public makes knowledge an essential element of health promotion, disease prevention and screening interventions [51]. Despite the vast array of worldwide initiatives, an overlap exists between knowledge, health beliefs and illness perceptions; the knowledge construct operationalized in BS studies does not often include identifications of specific beliefs [48]. Hence, in order for a woman to attend for her BS appointment, she must perceive the actual threat of BC, believe that cancer can be avoided by BS, and that she is capable of accessing the unit, which may include remembering her appointment, driving to or be driven to the unit, and not be afraid of the test [52].

Reasons to non-attendance

Fears, negative expectation of the screening experience and embarrassment were among the main barriers to BS in this study, similarly reported to act as barriers to attendance and re-attendance worldwide [15, 16, 45, 49, 53–59]. Minor practical barriers to non-attendance reported in our study (such as lack of time, transportation issues) are also reiterated in previous studies [16, 56, 58, 59], justifying local transportation accessibility improvements and reduction of logistical barriers [32].

Health beliefs and illness perceptions

Significant associations were mainly found for health beliefs about BS and BC i.e. the perceptions of the behaviour (barriers, self-efficacy, cues to action), while weaker associations were found for the perceptions of the illness i.e. significant associations for certain illness perception items (causes, cyclical cancer timeline, consequences) with uptake. Non-attendance to BS was related to more perceived barriers, less perceived benefits, lower self-efficacy and cues to action, and to the representations of the causes, consequences and timeline of BC. In contrast to HBM, perceived susceptibility was not significantly associated with first screening attendance in this study; a finding which corroborates results in previous studies [60–62] and contrasts others [18, 23, 62, 63]. One explanation for this finding may be due to women's lack of knowledge about BC and BS [60], such that improving women's risk assessment of developing BC may increase uptake rates. Our findings are in agreement with previous studies where positive association with perceived self-efficacy and having BS was found [62, 63]. This implies that attendees feel confident that they can arrange other things in their life to get a mammogram. However, self-efficacy was not the most important predictor for the decision to undergo screening in Malta. This result complies with a study in Cyprus [64] and contrasts the findings by Orji et al. [29].

It has also been reported that if a woman perceives mammography benefits to be higher than perceived barriers, she is more likely to adhere to BS [23, 58, 65]. However, the benefits subscale was not the most significant component

Table 7 Comparison of Illness Perceptions between attendees and non-attendees

	B	SE	Wald	P-value	OR	95% CI	Model Accuracy YES	Model Accuracy NO
Model 1: Demographics							100%	0%
Drive	-0.361	0.207	3.047	0.081	0.697	0.465, 1.045		
Constant	0.979	0.342	8.172	0.004	2.661			
Model 2: Health Status							100%	0%
Breast condition	0.174	0.265	0.430	0.512	1.190	0.708, 1.998		
Constant	0.081	0.492	0.027	0.869	1.085			
Model 3: Health Beliefs							88.5%	38.8%
Distrust in medical team	−0.573	0.153	14.051	0.000	0.564	0.418, 0.761		
Fear of unknown procedure	−0.409	0.153	7.120	0.008	0.664	0.492, 0.897		
Other life problems	−0.693	0.195	12.630	0.000	0.500	0.341, 0.733		
Relatives or friends' advice	−0.363	0.130	7.745	0.005	0.696	0.539, 0.898		
Reminder letters	0.660	0.238	7.678	0.006	1.934	1.213, 3.083		
Constant	2.336	1.091	4.585	0.032	10.335			
Model 4: Illness Perceptions							83.5%	37.3%
Hereditary	0.456	0.185	6.072	0.014	1.578	1.098, 2.268		
Pollution	0.290	0.134	4.682	0.030	1.336	1.028, 1.738		
Illness gets better and worse	0.312	0.153	4.154	0.042	1.366	1.012, 1.844		
Major consequences in life	0.420	0.195	4.640	0.031	1.522	1.039, 2.231		
Whole life would change	0.509	0.201	6.442	0.011	1.664	1.123, 2.466		
Living long decreases	−0.685	0.298	5.290	0.021	0.504	0.281, 0.904		
Fear of breast cancer	−0.363	0.176	4.264	0.039	0.695	0.492, 0.983		
Constant	−3.375	1.494	5.106	0.024	0.034			
Model 5: Health Beliefs and Illness Perceptions							84.8%	53.8%
Distrust in medical team	−0.676	0.162	17.468	0.000	0.509	0.371, 0.699		
Fear of unknown procedure	−0.612	0.166	13.629	0.000	0.542	0.392, 0.751		
Other life problems	−0.669	0.206	10.544	0.001	0.512	0.342, 0.767		
Relatives or friends' advice	−0.476	0.140	11.610	0.001	0.621	0.473, 0.817		
Reminder letters	0.687	0.251	7.470	0.006	1.987	1.214, 3.251		
Pollution	0.479	0.151	10.060	0.002	1.615	1.201, 2.172		
Illness gets better and worse	0.396	0.167	5.656	0.017	1.486	1.072, 2.061		
Whole life would change	0.855	0.221	14.924	0.000	2.351	1.524, 3.626		
Living long decreases	−0.890	0.336	7.016	0.008	0.411	0.212, 0.793		
Constant	0.113	1.742	0.004	0.948	1.120			
Model 6: Health Beliefs and Illness Perceptions							85.2%	65.0%
Fear of unknown procedure	−0.742	0.194	14.633	0.000	0.476	0.325, 0.696		
Embarrassing	−0.320	0.149	4.600	0.032	0.726	0.542, 0.973		
Distrust in medical team	−0.808	0.176	21.149	0.000	0.446	0.316, 0.629		
Other life problems	−0.735	0.234	9.843	0.002	0.479	0.303, 0.759		
Relatives or friends' advice	−0.529	0.153	11.965	0.001	0.589	0.437, 0.795		
Reminder letters	0.795	0.290	7.536	0.006	2.215	1.255, 3.907		

Table 7 Comparison of Illness Perceptions between attendees and non-attendees *(Continued)*

Arrange appointment	1.133	0.506	5.020	0.025	3.106	1.153, 8.372		
Pay for mammography	−1.669	0.580	8.286	0.004	0.188	0.06, 0.587		
Stress or worry	−0.940	0.419	5.044	0.025	0.39	0.172, 0.887		
Family problems	0.839	0.405	4.292	0.038	2.314	1.046, 5.118		
Overwork	0.539	0.216	6.262	0.012	1.715	1.124, 2.616		
Personality	−0.548	0.240	5.235	0.022	0.578	0.361, 0.924		
Hereditary	0.533	0.231	5.342	0.021	1.704	1.084, 2.677		
Pollution	0.500	0.170	8.698	0.003	1.649	1.183, 2.299		
Change or bad luck	0.432	0.140	9.568	0.002	1.54	1.171, 2.024		
Illness gets better and worse	0.398	0.185	4.629	0.031	1.489	1.036, 2.141		
Economic consequences	0.647	0.223	8.438	0.004	1.91	1.234, 2.955		
Whole life would change	0.755	0.245	9.493	0.002	2.128	1.316, 3.441		
Living long decreases	−1.177	0.373	9.956	0.002	0.308	0.148, 0.64		
Depends on your actions	0.856	0.409	4.381	0.036	2.354	1.056, 5.246		
Your actions effects outcome	−1.094	0.552	3.933	0.047	0.335	0.114, 0.987		
Constant	0.384	3.083	0.016	0.901	1.468			
Model 7: The 14 constructs							84.4%	42.2%
Perceived barriers	−0.121	0.022	31.731	0.000	0.886	0.849, 0.924		
Cancer timeline cyclical	0.432	0.154	7.893	0.005	1.54	1.139, 2.081		
Illness coherence	0.249	0.100	6.179	0.013	1.283	1.054, 1.561		
Constant	0.623	0.895	0.484	0.487	1.864			

B unstandardized coefficients; *SE* standard error; *OR* odds ratio; *CI* confidence interval

associated with BS in Malta unlike in other studies [53, 66]. It was the strong negative association between perceived barriers and screening uptake which was mainly identified in this study, similar to the findings of other studies involving American asymptomatic women [67], Israeli women [68] and other populations [61–63, 69]. It was predominantly fear that was found to be statistically significant across all subscale items. This is evidenced by women who do not attend for mammography in other countries because they perceive greater fear of BC [70–72]. A cancer diagnosis seems to be associated with a negative physical, psychological and social impact on Maltese women's ability to cope with the outcomes of the disease, which can have a profound effect on their way of life: an economical and financial impact, altered perception of others and oneself, altered relationship with their husband/partner, and that diagnosis may lead to mortality. This is noticeable in other findings [14, 71–73]. It is also likely that the fear of knowing someone with cancer is related to the cultural impact it would have on a woman's life or social local networks [72]. This consistent fear across populations stems from the belief that there is little an individual can do to alter fate (fatalism) or prevent cancer [73]. Therefore, non-attendees may be more pessimistic of early BC detection and the effectiveness of subsequent treatment, and may perceive BC as being uncontrollable, chronic and highly symptomatic with avoidance and denial coping strategies [74].

Helping to manage barriers associated with cancer and screening could be one of the main tasks addressed by interventions to increase uptake, for example through the use of patient navigators alongside access to care [75] and the identified recommendations from a physician, health care providers, family member and personal communication with other women which have been proven to be of greater importance than external cues [26, 27, 59, 76]. However, our findings are evidence that many women are not encouraged by their GP to attend to BS and would attend more if advised. This is in agreement with a previous study where screening tests are advised at suboptimal rates [59]. Similarly, in a cross-sectional study among Arab women in Qatar, only one quarter of the women interviewed said their doctors had discussed BC with them [77]. It is important to provide a local context for the lack of GP recommendation and to take into account unique aspects of the Maltese health care service. Although the state health system and private GPs provide primary health care in Malta, patients are not affiliated with a regular primary care general practitioner or group practice [78]. Besides, there exists an extent of private purchase of screening outside public health services [78]. However, little is known in Malta regarding the true supporting network of women's care pathway to date [79]. These issues, coupled with negative women's representations of BC and perceived barriers to BS may have resulted in non-attendance to first screening invitation at the MBSP.

Sociodemographic factors and health status

Our findings also demonstrate that women with a lower family income tend to attend less to screening. There is consistent evidence that lower household income demonstrates lower utilization of BS in various countries [16, 54, 80], which also seems to be associated with late stage BC presentation in London [81]. However, in regression analyses, our results revealed that the demographic and health status variables were poor and insignificant predictors of screening uptake and hence, do not provide strength to predict non-attendees. Similarly, sociodemographic factors do not appear to constitute strong predictions of non-attendance in various studies [57], which is why other determinants such as health beliefs and illness perceptions need to be explored within populations because of their importance in stimulating positive health behaviours [53].

Predictors to first breast screening uptake

Previous studies have demonstrated that beliefs about BC and BS are important predictors of uptake [17, 19, 53, 65, 73]. In our regression analysis, health belief constructs emerged as the strongest and most significant predictors of attendance and non-attendance, and that perceived barriers were the strongest predictor to describe the variance between attendees and non-attendees ($p < 0.05$). This fits well with previous literature, where interventions tailored after the Health Belief Model (HBM) were more effective in increasing BS uptake than those that were not (6 studies OR = 2.51, OR = 1.27, $p < 0.001$) [76]. Limited evidence for the effectiveness of interventions based on other models was found [82].

We found only one Greek study which similarly incorporated both HBM and CSM to explore health beliefs and illness perceptions [17], though this theoretical framework was related to lifetime mammography use as opposed to our study regarding BS uptake in an organised programme. However, their results similarly showed that illness perception dimensions did not prove to be significant predictors of mammography lifetime use. There may be a number of alternative explanations for the non-significant associations and the less significant predictions exhibited by illness representation dimensions and screening uptake in our study. Hagger and Orbell [74] hypothesized that coping may just mediate the effect of illness cognitions on the outcomes of an illness (e.g., psychological well-being, social, and role functioning). This may be due to women's focus on illness representations ('mental representation') as such, rather than on coping strategies (such as obtaining a screening mammogram or visiting a doctor) which, in turn, may possess a different set of diverse and multiple characteristics which IPQ-R does not tackle (e.g., specific beliefs about mammography risks). Therefore, it seems that it is the HBM constructs related to response efficacy (expecting that a particular health action will result in an outcome, such as undertaking mammography screening), self-efficacy, and utility beliefs (believing that taking a certain action would be worthwhile to reduce BC susceptibility or severity, if the disease did occur, while perceived benefits would outweigh perceived barriers to undertaking health actions) that are significant predictors to BS uptake, rather than the IPQ-R dimensions. However, the CSM is the only model which seriously considers the role of emotions in response to illness [83], although even here 'emotions' are often inadequately operationalised as 'anxiety', worry about, or 'fear' of symptoms. On the other hand, the HBM is considered a weak predictor of behaviour change as it does not include the formation of an intention to change behaviour as a precursor to behavioural change, does not accommodate social and environmental influences or past behaviour, and assumes that human decision-making are rational [84]. In response to each model's limitations, a combination of the two may determine behaviour likelihood [84, 85] and as shown in this study, their combination provided improved prediction of non-attendance (i.e. prediction of non-attendance improved significantly from 38.8% to 65.0% when combining all significant predictors). This suggests that interventions could be aimed to incorporate various dimensions of both models.

Limitations

Although these data can be generalizable to other screening programmes with a similar population, such as Mediterranean populations, this study has some limitations. First, a temporal relationship between exposure and outcome cannot be established because the study was cross-sectional thus excluding causal associations. Second, the study's retrospective design may have had an impact on the recall of events. Third, it was not possible to capture the data of repeat mammograms at another facility as this was not recorded on the screening database at the time of study. Such data would show more accurately women's adherence to screening guidelines [86] by using multiple points of service. Hence, future research should take into account the type of screening programme and a clear distinction of the type of mammography (screening or diagnostic mammography), since women's accuracy and consistency in reporting mammography experiences sharply declines with an increased number of lifetime mammograms [87]. Fourth, data collected might be affected by recall or social-desirability response bias i.e. having performed mammography, whether in the organized screening programme or as opportunistic screen due to its well-publicized recommendation by media and clinicians [17], thus amplifying the recall bias effects.

Additional research is required to test the interactions of HBM and CSM components in multivariate models to test threat representations and coping mechanisms. Further research to measure health beliefs and illness perceptions before and after screening could help to clarify the value of HBM and CSM in explaining the beliefs and perceptions of BC risks. Additionally, a longitudinal study design could provide a better understanding of the psychological and emotional pathways and processes involved in how individuals form beliefs and risk perceptions of a particular health threat to better understand the factors underpinning health behaviours and reduce BC risk. Further research is warranted to determine whether uptake to first screening invitation is a significant predictor of subsequent screening in Malta.

Conclusions

The present study showed that there is high awareness of BC signs and symptoms among Maltese women, but wide variation in knowledge about causes of BC and its related risk factors. Non-attendees were the most unsure of BS recommended practices and had higher emotional barriers. Interventions to increase BC screening uptake in Malta should address health beliefs, in particular perceived barriers such as fear, since these emerged as the strongest predictors of uptake throughout the analyses. However, those interventions that also address illness representations, such as causes, consequences and cyclical timeline of BC, may increase their effectiveness since these were also found to be associated with BS uptake. The CHBMS-MS and IPQ-R variables that contributed most to the regression model were perceived barriers, cues to action and self-efficacy, causes of BC, cancer cyclical timeline, BC consequences and personal control. The findings of this study indicate that it was the combination of both HBM and CSM constructs which provides improved prediction of non-attendance. To our knowledge, this is an innovative finding in BS research. This study provides valuable information to healthcare providers, researchers, screening leads and public health educators as the findings can aid to design culturally sensitive interventions to improve screening behaviours.

Additional file

Additional file 1: STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cross-sectional studies (DOCX 20 kb)

Abbreviations

BC: Breast cancer; CHBMS-MS: Champion's Health Belief Model Scale for Mammography Screening; CI: Confidence interval; CSM: Common-Sense Model; GP: General practitioner; HBM: Health Belief Model; IPQ-R: Revised Illness Perception Questionnaire; M: mean score; MBSP: Maltese Breast Screening Programme; OR: Odds ratio; SD: Standard deviation; STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

Acknowledgements

The authors wish to acknowledge Prof. Victoria Champion and Prof. Rona Moss-Morris for developing the CHBMS-MS and IPQ-R scales respectively and for providing the opportunity to translate and adapt it into the Maltese culture and language. The authors also wish to thank the translators, the panel members who assisted with the validity testing of the tool and all the participants of the study. This study was developed as part of the activities of the PhD in Health offered by the University of Stirling in Scotland.

Funding

The PhD program is part-financed by the Malta Government Scholarship Scheme (MGSS), Government of Malta.

Availability of data and materials

The datasets analysed during the current study are available from the corresponding author on reasonable request.

Authors' contributions

DM conceived the study, supervised all aspects of its conduction and wrote the manuscript. VM assisted with data analysis and interpretation of data and revised the manuscript. GH assisted with the study design and revised the manuscript. All authors helped to conceptualise ideas, interpret findings and review drafts of the manuscript. All authors read and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

Consent for publication

Not applicable.

Ethics approval and consent to participate

Verbal informed consent to participate in this study, analyze and publish the data was obtained from each participant over the phone.
Ethics approval was obtained from the School Research Ethics Committee at the University of Stirling (SREC14/15-Paper No.18v4) and from the Maltese Health Ethics Committee (HEC 02/2015).

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Received: 2 November 2016 Accepted: 27 April 2017
Published online: 08 May 2017

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Appendix 4.2.2 - STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	**Item #**	**Recommendation**	**Reported on page # (of published Study 2)**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1-2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6-9
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	6-8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	12
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	12
Bias	9	Describe any efforts to address potential sources of bias	13
Study size	10	Explain how the study size was arrived at	7-8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	12
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	12

		(*b*) Describe any methods used to examine subgroups and interactions	12
		(*c*) Explain how missing data were addressed	12
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7-8, Refer to Fig. 1
		(b) Give reasons for non-participation at each stage	7-8, Refer to Fig. 1
		(c) Consider use of a flow diagram	Fig. 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	13-15
		(b) Indicate number of participants with missing data for each variable of interest	15
Outcome data	15*	Report numbers of outcome events or summary measures	18-21
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	15-24
Discussion			
Key results	18	Summarise key results with reference to study objectives	24-31
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	31-32
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	32-33

Generalisability	21	Discuss the generalisability (external validity) of the study results	31
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	33

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix 4.2.3a - Telephone Interview: Verbal Consent (English version)

Madam,

My name is Danika Marmarà and I am a researcher who is conducting a research study regarding Breast Cancer Screening in Malta. With reference to the previous phone call you received from my research assistant in which you consented to participate in this study, I would like to ask you some questions over the phone about your health beliefs, illness perceptions and factors associated with breast screening uptake. Your participation is voluntary and should take approximately 20 minutes of your time.

Do you wish to participate? YES ❑ NO ❑

Appendix 4.2.3b - Telephone Interview: Verbal Consent (*Maltese version)*

Dokument ta' Informazzjoni u Kunsens għall-Intervisti bit-Telefown (verżjoni bil-Malti)

Sinjura,

Jiena jisimni Danika Marmara', riċerkatriċi li bħalissa qed nagħmel studju lokali fuq l-Iskrining kontra l-Kanċer fis-Sider f'Malta. B'referenza ghat-telefonata li rċevejt minghand l-assistenta tiegħi fuq din ir-riċerka li fiha inti aċċettajt li tipparteċipa, nixtieq nistaqsik xi mistoqsijiet fuq it-telefown dwar saħħtek, kif thares lejn il-mard u dak li jinfluwenzak biex tattendi ghall-iskrining tas-sider. Il-parteċipazzjoni tiegħek hija volontarja. L-istħarriġ għandu jieħu madwar 20 minuta mill-ħin tiegħek.

Tixtieq tipparteċipa? IVA ❑ LE ❑

Appendix 4.2.4a – Research tool (English version)

Health Beliefs, Illness Perceptions and Determinants of Breast Screening Uptake in Malta: A Cross-Sectional Survey

Client Unique Identifier Number: __________

Sociodemographic Variables

Q1. How old are you? ____________________

Q2. Where do you live? ____________________

Q3. What is your level of education?

(1) No schooling ❑
(2) Primary level ❑
(3) Secondary level ❑
(4) Tertiary level (Diploma) ❑
(5) Tertiary level (Degree) ❑
(6) Tertiary Level (Masters or above) ❑

Q4a) What is your occupation:

________________ Unemployed ❑ Pensioner ❑ Housewife ❑⟶ **continue to Q5**

b)Are you employed with the Goverment or private sector?
(1) Government ❑
(2) Private ❑

Q5. What is your status?

(1) Single ❑ (2) Married ❑ (3) Separated/Divorced ❑ (4) Widowed ❑

Q6. What is your family income level?
(1) Less than €10,737 ❑
(2) €10,737 – €16,113 ❑
(3) €16,114 – €23,563 ❑
(4) €23,564 – €33,966 ❑
(5) Greater than €33,966 ❑
(6) Prefer not to say ❑

Q7. a) Do you own a car? Yes ❑ No ❑
b) Do you drive? Yes ❑ No ❑

Q8. Do you have an illness, disability or condition of any kind?

Yes ❑ No ❑⟶**continue toQ9**

↓

What is it? ________________________

Q9 (a) Do you have a family physician (GP) who provides medical care and advice?
Yes ❑ No ❑

(b) How often do you visit your GP?

1. Only when I have a problem ❑
2. Once a month ❑
3. More than once a year ❑
4. Once a year ❑
5. Once every two years ❑

Q10. Have you ever had any type of breast condition or disease?

(i) Yes ❑ ***(continue to Q10a)*** No ❑ ***(continue to Q11)***

a) What type of breast condition or disease?

(i) Fibrocystic "Lumpy Breasts" ❑
(ii) Cysts ❑
(iii) Cancer in one breast ❑
(iv) Cancer in both breasts ❑
(v) Other (please specify) ❑____________________

Q11. Have your relatives or close friends had cancer?

Yes ❑ No ❑ Prefer not to say ❑

↓

If **YES**, which of the following?

Family member or friend	Breast Cancer	Other Cancer
First degree relative with breast cancer	❑ Mum ❑ Sister ❑ Daughter	Mum____________________ Sister____________________ Daughter________________
Other family member	❑ Dad ❑ Brother ❑ Grandmother ❑ Grandfather ❑ Aunt ❑ Uncle ❑ Cousin (M) ❑ Cousin (F)	Dad ___________________ Brother _________________ Grandmother_____________ Grandfather _____________ Aunt ___________________ Uncle ___________________ Cousin (M)______________ Cousin (F)_______________
Close friend	❑	________________________
Husband	❑	________________________

SECTION A: LIFETIME BREAST SCREENING PRACTICES

1 (A) LIFETIME MAMMOGRAPHY USE

(i) Have you ever done a mammogram in your lifetime?

YES ❑ (Go to (ii)) NO ❑ (Go to (iii))

IF YES:

(ii) How many times during your lifetime have you had a mammogram?

1. One mammogram only ('EVER') ❑
2. Two or more mammograms ('REPEAT') ❑

(iii) Have you had a mammogram within the past 3 years ('RECENT')?
YES ❑ NO ❑

(iiia) If 'YES', when, where and why? ________________
1. Breast Screening Unit ❑
2. Governmental Hospital (Mater Dei) ❑
3. Private Clinic ❑

(B) ATTENDANCE and NON-ATTENDANCE TO FIRST INVITATION AT THE MBSP

(i) When you received your first invite to the Breast Screening programme, did you attend?
(a)Yes ❑ (b) No ❑

If YES:		If NO:	
(ai) Would you have attended for a mammogram if:		(bi) Why not?	
1. You were not invited or sent for?	Yes ❑ No ❑	1. Lack of Knowledge or information about screening	Yes ❑ No ❑
		2. Practical Issues (e.g. lack of free time and family obligations, lack of access to child-care, difficulty getting time off work, transportation issues, other)	Yes ❑ No ❑
		3. Fear (of pain, radiation, embarrassment, of unknown procedure, of result)	Yes ❑ No ❑
		4. Other	Please specify: ____________ ____________ ____________

(ii) Did your family physician (GP) encourage you to attend for a mammogram?
Yes ❑ No ❑

(C) RE-ATTENDANCE TO THE SECOND SCREENING INVITATION AT THE MBSP

(i) If you receive a second invite, would you attend? **(INTENTION)**

Yes ❑ No ❑ Unsure ❑

(ii) *If **YES**, why? (Reason)* ________________________________

(iii) *If **NO** why? (Reason)* ________________________________

(iv) *If **UNSURE**, why? (Reason)* ______________________________

(D) KNOWLEDGE ABOUT RECOMMENDED SCREENING FREQUENCY

(i) How often do you think a woman your age should have a mammogram?

1. Every year ❑
2. Every 1.5 years ❑
3. Every 2-3 years ❑
4. Every 4-5 years ❑
5. Unsure ❑

SECTION B: HEALTH BELIEFS

We are interested in your own personal views of how you see Breast Screening and Breast Cancer. Please indicate how much you agree or disagree with the following statements about Breast Screening and Breast Cancer.

Champion's Health Belief Model Scale for Mammography Screening

B1. PERCEIVED SUSCEPTIBILITY (RISK PERCEPTION)

Scale ITEM NO.	*PERCEIVED SUSCEPTIBILITY ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	There is no possibility of getting breast cancer.					
2.	Your chances of getting breast cancer are high.					
3.	There may be the possibility of developing breast cancer in your lifetime.					

B2. PERCEIVED BENEFITS OF MAMMOGRAPHY SCREENING

SCALE ITEM NO.	*PERCEIVED BENEFITS ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	When you get a mammogram, you feel good about yourself.					
2.	When you get a mammogram, you do not worry as much about breast cancer.					
3.	Having a mammogram will help you find lumps early in your breasts.					
4.	If you find a lump through a mammogram, the treatment for breast cancer may not be as bad.					
5.	Having a mammogram will decrease your					

	chances of dying from breast cancer.					
6.	Having a mammogram will help you find a lump before it can be felt by yourself or a health professional.					

B3. PERCEIVED BARRIERS TO MAMMOGRAPHY SCREENING

SCALE ITEM No.	*PERCEIVED BARRIERS ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	Having a routine mammogram would make you anxious about breast cancer.					
2.	Having a routine mammogram would make you worry.					
3.	You fear having a mammogram because you might find out that something is wrong.					
4.	You fear having a mammogram because you do not know the procedure or what to expect.					
5.	You fear having a mammogram because you know someone (family or friend) with breast cancer.					
6.	It is embarrassing for you to have a mammogram.					
7.	Undergoing mammography will be painful or uncomfortable.					
8.	Having a mammogram is time consuming.					
9.	*If you attended for Breast Screening:* You are discontent with Breast Screening personnel as they have been rude to you.					
10.	You have fear or distrust in the medical team.					
11.	Having a mammogram would expose you to unnecessary radiation.					

12.	You have too many other problems in your life than to get a mammogram done.					
13.	You are not old enough to have a mammogram periodically.					

B4. CUES TO ACTION

SCALE Item No.	*CUES TO ACTION ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	If your GP advises you to attend for a mammogram, you will attend.					
2.	If your relatives or friends advise you to attend for a mammogram, you will attend.					
3.	If someone close to you has been diagnosed with breast cancer, you will attend for a mammogram.					
4.	Hearing about breast cancer and breast screening in the media or news makes you think about getting a mammogram.					
5.	Reminder letters would help you to get a mammogram.					
6.	Reminder phone calls or text messages would help you to get a mammogram.					
7.	Routine educational talks regarding breast cancer awareness would help you to get a mammogram.					

B5. SELF-EFFICACY (confidence in obtaining a mammogram)

Scale Item No.	*SELF- EFFICACY ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	You feel confident that if you had a mammogram done, any abnormalities in your breasts will be detected.					

2.	You can arrange other things in your life to get a mammogram.					
3.	In case you need a mammogram, you will find a place to get it done.					
4.	You can make an appointment for a mammogram.					
5.	You can arrange transportation to get a mammogram.					
6.	*If you attended for Breast Screening:* You can talk to people at the breast screening centre about your concerns.					
7.	You can find a way to pay for a mammogram if you need to.					

SECTION C: ILLNESS PERCEPTIONS

Please indicate how much you agree or disagree with the following statements specifically about Breast Cancer.

The Revised Illness Perception Questionnaire (IPQ-R)

C1. BREAST CANCER IDENTITY (Core symptoms list)

SCALE Item No.	*IDENTITY ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	The presence of a lump or thickening in the breast					
2.	Nipple discharge					
3.	Sudden nipple retraction					
4.	Change in shape or appearance of the nipple					
5.	Breast swelling, dimpling, redness or soreness of the skin					
6.	Skin changes of the breast					
7.	A sudden change in breast size					
8.	Aching breasts					

C2. CAUSES OF BREAST CANCER (personal ideas about aetiology)

SCALE Item No.	*Psychological Attributions*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	Stress or worry					
2.	Your mental attitude (e.g. thinking about life negatively)					
3.	Family problems or worries					
4.	Overwork					
5.	Your emotional state (e.g. feeling down, lonely, anxious, empty)					
6.	Your personality					
RISK FACTORS / LIFESTYLE FACTORS						
1.	Hereditary – it runs in the family					
2.	Diet or eating habits					
3.	Poor medical care in the past					
4.	Your own behaviour					
5.	Ageing					
6.	Smoking					
7.	Alcohol					
IMMUNITY						
1.	A germ or virus					
2.	Pollution in the environment					
3.	Altered immunity					
ACCIDENT OR CHANCE						
1.	Chance or bad luck					
2.	Accident or injury					

C3a. CANCER TIMELINE: ACUTE/CHRONIC (the perceived duration of Breast Cancer)

SCALE Item No.	*TIMELINE ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	Breast cancer will last a short time.					
2.	Breast cancer is likely to be permanent rather than temporary.					

C3b. CANCER TIMELINE: CYCLICAL

SCALE Item No.	*TIMELINE ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	A patient with breast cancer goes through cycles in which her illness gets better and worse.					

C4. CONSEQUENCES (expected effects and outcome)

SCALE Item No.	*CONSEQUENCES ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	Breast cancer has major consequences on a patient’s life.					
2.	Breast cancer will not have much effect on your life.					
3.	Breast cancer would strongly affect the way others see you.					
4.	Breast cancer has serious economic and financial consequences.					
5.	Breast cancer would strongly affect the way you see yourself as a person.					
6.	Breast cancer would threaten a relationship with your husband or partner.					
7.	If you had breast cancer, your whole life would change.					
8.	If you developed breast cancer, the chances of living a long life would decrease.					

C5. CURABILITY/CONTROLLABILITY

C5a. PERSONAL CONTROL (how one controls or recovers from Breast Cancer)

SCALE Item No.	*PERSONAL CONTROL ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	There is a lot which you can do to control the symptoms if Breast Cancer occurs.					
2.	The course of Breast Cancer will depend on your actions.					
3.	Your actions will have an effect on the outcome of Breast Cancer.					

C5b. TREATMENT CONTROL

SCALE Item No.	*TREATMENT CONTROL ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	There is no treatment that will help to improve Breast Cancer.					
2.	The treatment provided will be effective in controlling or curing Breast Cancer.					
3.	The negative effects of Breast Cancer can be prevented or avoided by the treatment given.					

C6. ILLNESS COHERENCE

SCALE Item No.	*ILLNESS COHERENCE ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	You have a clear picture and understanding of Breast Cancer.					
2.	Breast Cancer is a mystery to you.					

C7. EMOTIONAL REPRESENTATIONS

SCALE Item No.	*EMOTIONAL REPRESENTATIONS ITEMS*	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1.	You get anxious when you think about Breast Cancer.					
2.	Breast Cancer makes you feel afraid.					
3.	You get worried when you think about Breast Cancer.					

***THANK YOU** for taking the time to answer the survey.*

Appendix 4.2.4b – Research tool (Maltese version)

GĦODDA TAR-RIĊERKA

Numru ta' Identifikazzjoni tal-Klijent: ___________________

Mistoqsijiet Demografiċi

M1. Kemm għandek żmien? ________________

M2. Fejn toqgħod? _______________________

M3. X'inhu l-livell ta' edukazzjoni tiegħek?

(1) Ma mortx skola ❑
(2) Livell primarju ❑
(3) Livell sekondarju ❑
(4) Livell terzjarju (Diploma) ❑
(5) Livell terzjarju (Lawrja) ❑
(6) Livell terzjarju (Masters jew ogħla) ❑

M4a) X'taħdem:

_____________ Ma taħdimx ❑ Pensjonanta ❑ Mara tad-dar ❑ ⟶ **Mur għall-M5**

b) Int impjegata mal-Gvern jew fis-settur privat?

(1) Mal-Gvern ❑
(2) Fil-privat ❑

M5. X'inhu l-istat tiegħek?

1) Xebba ❑ (2) Miżżewġa ❑ (3) Separata/Divorzjata ❑ (4) Armla ❑

M6. X'inhu l-livell ta' dħul tal-familja tiegħek?

(1) Inqas minn €10,737 ❑
(2) €10,737 – €16,113 ❑
(3) €16,114 – €23,563 ❑
(4) €23,564 – €33,966 ❑
(5) Iktar minn €33,966 ❑
(6) Nippreferi ma ngħidx ❑

M7. a) Għandek karozza? Iva ❑ Le ❑
b) Issuq? Iva ❑ Le ❑

M8. Għandek xi marda, diżabilità jew kundizzjoni ta' kwalunkwe tip?

Iva ❑ Le ❑ ⟶ **Mur għall-M9**

↓

X'inhi? ______________________

M9 (a) Għandek tabib tal-familja (GP) li tirrikorri għalih għal kura u pariri mediċi?
Iva ❑ Le ❑

(b) Kemm-il darba tmur għand il-GP tiegħek?
1. Meta jkolli problema biss ❑
2. Darba fix-xahar ❑
3. Iktar minn darba f'sena ❑
4. Darba f'sena ❑
5. Darba kull sentejn ❑

M10. Qatt kellek xi tip ta' kundizzjoni jew marda f'sidrek?
(i) Iva ❑ *(Mur għall-M10a)* Le ❑ *(Mur għall-M11)*

(a) X'tip ta' kundizzjoni jew marda tas-sider?
(i) "Boċoċ" f'sidrek ❑
(ii) Ċesti ❑
(iii) Kanċer f'sider minnhom ❑
(iv) Kanċer fiż-żewġ sider ❑
(v) Kundizzjoni jew marda oħra (jekk jogħġbok speċifika) ❑

M11. Qatt kellek xi ħadd mill-qraba jew ħbieb tal-qalb tiegħek li kellu kanċer?
Iva ❑ Le ❑ Nippreferi ma ngħidx ❑
↓
Jekk **IVA**, liema milli ġejjin?

Membru tal-familja jew ħabib/a	Kancer fis-sider	Kancer iehor
Qariba fl-ewwel grad	❑ Ommok ❑ Oħtok ❑ Bintek	Ommok____________________ Oħtok____________________ Bintek____________________
Membru ieħor tal-familja	❑ Missierek ❑ Ħuk ❑ Nanntek ❑ Nannuk ❑ Zijtek ❑ Zijuk ❑ Kuġinuk ❑ Kuġintek	Missierek__________________ Ħuk ______________________ Nanntek___________________ Nannuk __________________ Zijtek ____________________ Zijuk _____________________ Kuġinuk___________________ Kuġintek__________________
Ħabiba tal-qalb	❑	________________________
Ir-raġel	❑	________________________

TAQSIMA A: L-ISKRINING TAS-SIDER MATUL ĦAJTEK

1(A) **UŻU TAL-MAMMOGRAFIJA MATUL ĦAJTEK**

(i) Qatt għamilt mammogram f'ħajtek?
Iva ❑ (Mur għal (ii)) Le ❑ (Mur għal (iii))

Jekk 'IVA':
(ii) Kemm-il darba għamilt mammogram f'ħajtek?
1. Mammogram wieħed f'ħajti ('BISS') ❑
2. Żewġ mammograms oħra jew iktar f'ħajti ('RIPETIZZJONI') ❑

(iii) Qatt kont għamilt mammogram f'dawn l-aħħar 3 snin ('RIĊENTI')?
Iva ❑ Le ❑

(iiia) **Jekk 'IVA',** meta, fejn kont għamiltu u għala? ______________________
1. Iċ-Ċentru tal-Iskrining tas-Sider ❑
2. Sptar tal-Gvern ❑
3. Fi klinika privata ❑

(B) **ATTENDENZA GĦALL-EWWEL STEDINA GĦALL-PROGRAMM TA' SKRINING TAS-SIDER**

(i) Meta rċevejt l-ewwel stedina biex tmur għall-Programm ta' Skrining tas-Sider, mort?
(a) Iva ❑ (b) Le ❑

Jekk IVA:		Jekk LE:	
(ai) Kont tmur kieku:		(bi) Għalfejn Le?	
Ma kontx mistiedna jew ma bagħtux għalik biex tmur?	Iva ❑ Le ❑	Nuqqas ta' għarfien jew nuqqas ta' informazzjoni dwar l-iskrining	Iva ❑ Le ❑
		Kwistjonijiet prattiċi (eż. nuqqas ta' ħin liberu u obbligi tal-familja, ma kellix min jeħodli ħsieb it-tfal, diffikultà biex nieħu l-liv mix-xogħol, trasport, oħrajn)	Iva ❑ Le ❑
		Biża' (li nweġġa', mir-raġġi, li nimbarazza ruħi, minn xi proċedura li ma nafx biha, mir-riżultat)	Iva ❑ Le ❑
		Raġuni oħra	Jekk jogħġbok speċifika: __________ __________ __________

(ii) It-tabib tal-familja tiegħek (GP) ħeġġek biex tmur għal mammogram?
Iva ❑ Le ❑

(C) **ATTENDENZA MILL-ĠDID GĦAT-TIENI STEDINA GĦALL-PROGRAMM TA' SKRINING TAS-SIDER**

(i) Jekk tirċievi t-tieni stedina, tmur? **(INTENZJONI)**

Iva ❑ Le ❑ Ma nafx ❑

*(ii) Jekk **'IVA'**, għala? (raġuni)* ____

*(iii) Jekk **'LE'**, għala? (raġuni)* ____

*(iv) Jekk **'Ma Tafx'**, għala? (għati raġuni)* ______________________________

(D) **GĦARFIEN DWAR KEMM-IL DARBA HU RAKKOMANDAT LI TMUR GĦAL SKRINING**

(i) Kemm-il darba taħseb li għandha tmur mara tal-età tiegħek għal mammogram?

1. Darba fis-sena ❑
2. Kull sena u nofs ❑
3. Kull 2 sa 3 snin ❑
4. Kull 4 sa 5 snin ❑
5. Ma nafx ❑

TAQSIMA B: KONVINZJONIJIET DWAR IS-SAĦĦA

Nixtiequ nkunu nafu x'taħseb dwar kif tħares lejn l-Iskrining tas-Sider u l-Kanċer fis-Sider. Jekk jogħġbok indika kemm taqbel jew ma taqbilx mad-dikjarazzjonijiet li ġejjin dwar l-Iskrining tas-Sider u l-Kanċer fis-Sider.

L-iskala tal-Mudell ta' Champion dwar il-Konvinzjonijiet għall-Iskrining tas-Sider

B1. SUXXETTIBBILTÀ PERĊEPITA (PERĊEZZJONI TAR-RISKJI)

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' SUXXETTIBBILTÀ PERĊEPITA*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	M'hemmx ċans li joħroġlok kanċer fis-sider.					
2.	Iċ-ċansijiet li joħroġlok kanċer fis-sider huma kbar.					
3.	Jista' jkun hemm ċans li f'ħajtek tiżviluppalek kanċer fis-sider.					

B2. BENEFIĊĊJI PERĊEPITI TAL-ISKRINING BIL-MAMMOGRAFIJA

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' BENEFIĊĊJI PERĊEPITI*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Meta tagħmel mammogram, tħossok tajba dwarek nnifsek.					
2.	Meta tagħmel mammogram, ma tinkwetax daqshekk dwar il-kanċer fis-sider.					
3.	Li tagħmel mammogram tgħinek ssir taf kmieni jekk					

	għandekx boċoċ f'sidrek.					
4.	Jekk issir taf b'boċċa permezz ta' mammogram, it-trattament għall-kanċer f’sidrek jista' ma jkunx daqshekk kiefer.					
5.	Li tagħmel mammogram inaqqaslek ċ-ċans li tmut b'kanċer fis-sider.					
6.	Li tagħmel mammogram jgħinek ssir taf dwar boċoċ f'sidrek qabel tkun tista' tħosshom inti stess jew professjonist mediku.					

B3. OSTAKLI PERĊEPITI GĦALL-ISKRINING BIL-MAMMOGRAFIJA

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' OSTAKLI PERĊEPITI*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Li tagħmel mammogram regolari tagħmlek nervuża dwar il-kanċer fis-sider.					
2.	Tinkwieta li kieku jkollok tagħmel mammogram regolari.					
3.	Tibża' tagħmel mammogram għax tibża' li jsibulek xi ħaġa ħażina.					
4.	Tibża' tagħmel mammogram għax ma tafx il-proċedura jew x'għandek tistenna.					
5.	Tibża' tagħmel mammogram għax taf lil xiħadd (fil-familja jew ħabiba) li għandu kanċer fis-sider.					
6.	Timbarazza ruħek biex tagħmel mammogram.					
7.	Tweġġa' jew tħossok skomda biex tagħmel mammogram.					

8.	Il-proċess tal-mammogram huwa ħin mitluf.					
9.	*Jekk attendejt għall-Iskrining tas-Sider:* Ma ħriġtx sodisfatta mill-attitudni tal-istaff fl-Iskrining tas-Sider għax ma kinux edukati miegħek.					
10.	Tibża' mit-tim mediku jew m'għandekx fiduċja fih.					
11.	Mammogram jesponik għal radjazzjoni bla bżonn.					
12.	Għandek ħafna affarijiet oħra fuq rasek milli tara li tagħmel mammogram.					
13.	M'għandekx biżżejjed età biex tagħmel mammogram kull tant żmien.					

B4. SINJALI BIEX TITTIEĦED AZZJONI

NRU TAL-ENTRATA FUQ L-ISKALA	*SINJALI BIEX TITTIEĦED AZZJONI*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Jekk il-GP tiegħek jagħtik parir biex tmur tagħmel mammogram, tmur.					
2.	Jekk il-qraba tiegħek jtuk parir biex tmur tagħmel mammogram, tmur.					
3.	Jekk xiħadd qrib tiegħek ħariġlu kanċer fis-sider, tmur tagħmel mammogram.					
4.	Li tisma' dwar il-kanċer fis-sider fil-midja jew fuq l-aħbarijiet, iġegħluk taħseb biex tmur tagħmel mammogram.					
5.	Ittri biex ifakkruk, jgħinuk biex tmur					

	tagħmel mammogram.					
6.	Telefonati jew SMS biex ifakkruk, jgħinuk biex tmur tagħmel mammogram.					
7.	Taħditiet edukattivi regolari dwar il-kanċer fis-sider jgħinuk biex tmur tagħmel mammogram.					

B5. KEMM TEMMEN FIK INNIFSEK (fiduċja li tagħmel mammogram)

NRU TAL-ENTRATA	ENTRATI TA' KEMM TEMMEN FIK INNIFSEK	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Tħossok fiduċjuża li kieku kellek tagħmel mammogram, isibu kwalunkwe problema li jista' jkun hemm f'sidrek.					
2.	Tista' tirranġa affarijiet oħra f'ħajtek biex tkun tista' tagħmel mammogram.					
3.	F'kas li jkollok bżonn mammogram, ssib post fejn tagħmlu.					
4.	Tista' tagħmel appuntament għal mammogram.					
5.	Tista' tirranġa dwar it-trasport biex tagħmel mammogram.					
6.	*Jekk attendejt għall-Iskrining tas-Sider:* Tista' titkellem fiċ-ċentru tal-iskrining tas-sider dwar x'jinkwetak.					
7.	Tista' ssib mod kif tħallas għal mammogram jekk għandek bżonn tagħmlu.					

TAQSIMA C: PERĊEZZJONIJIET TA' MARD

Jekk jogħġbok indika kemm taqbel jew ma taqbilx mad-dikjarazzjonijiet li ġejjin speċifikament dwar il-Kanċer fis-Sider.

Il-Kwestjonarju Rivedut dwar il-Perċezzjoni ta' Mard (IPQ-R)

C1. IDENTITÀ TAL-KANĊER FIS-SIDER (Lista tas-sintomi ewlenin)

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' IDENTITÀ*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Il-preżenza ta' boċċa jew ħxuna fit-tessut tas-sider					
2.	Tnixxija tan-nipil					
3.	Ġbid lura f'daqqa tan-nipil					
4.	Bdil fil-forma jew id-dehra tan-nipil					
5.	Nefħa, tikmix, ħmura jew sensazzjoni tenera fis-sider					
6.	Bdil fil-ġilda tas-sider					
7.	Bdil f'daqqa fid-daqs tas-sider					
8.	Uġigħ fis-sider					

C2. KAĠUN TAL-KANĊER FIS-SIDER (ideat personali dwar l-etjoloġija)

NRU TAL-ENTRATA FUQ L-ISKALA	*ATTRIBWIZZJONIJIET PSIKOLOĠIĊI*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Stress jew inkwiet					
2.	L-attitudni mentali tiegħek (eż. taħseb b'mod negattiv dwar il-ħajja)					
3.	Problemi jew inkwiet familjari					
4.	Xogħol żejjed					

5.	L-istat emozzjonali tiegħek (eż. tħossok mdejqa, waħdek, nervuża, bla skop)					
6.	Il-personalità tiegħek					
FATTURI TA' RISKJU / FATTURI TA' STIL TAL-ĦAJJA						
1.	Marda ereditarja – għandek fil-familja					
2.	Dietà jew drawwiet ta' ikel					
3.	Kura ħażina tas-saħħa fil-passat					
4.	Imġiba tiegħek stess					
5.	Tixjiħ					
6.	Tipjip					
7.	Alkoħol					
IMMUNITÀ						
1.	Mikrobu jew vajrus					
2.	Tniġġis tal-ambjent					
3.	Tibdil fir-reżistensa tal-ġisem għal mard (sistema immunitarja)					
INĊIDENT JEW B'KUMBINAZZJONI						
1.	B'destin jew xorti ħażina					
2.	Inċident jew korriment					

C3a. SKEDA TA' ŻMIEN: AKUTA/KRONIKA (it-tul ta' żmien perċepit tal-Kanċer fis-Sider)

NRU TAL-ENTRATA FUQ L-ISKALA	ENTRATI TA' SKEDA TA' ŻMIEN	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Kanċer fis-sider ma jdumx wisq.					
2.	Kanċer fis-sider jista ikun għal dejjem (permanenti) iktar milli xi ħaġa għal ftit żmien (temporanja).					

C3b. SKEDA TA' ŻMIEN: ĊIKLIKA

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' SKEDA TA' ŻMIEN*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Pazjenta b'kanċer fis-sider tgħaddi minn fażijiet li matulhom saħħitha tmur għall-aħjar u għall-agħar.					

C4. KONSEGWENZI (effetti u riżultati mistennija)

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' KONSEGWENZI*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Kanċer fis-sider għandu konsegwenzi maġġuri fuq ħajjet il-pazjenta.					
2.	Kanċer fis-sider ma jkollux wisq effett fuq ħajtek.					
3.	Kanċer fis-sider jaffettwa ħafna l-mod kif ħaddieħor iħares lejja.					
4.	Kanċer fis-sider għandu konsegwenzi ekonomiċi u finanzjarji serji.					
5.	Kanċer fis-sider jaffettwa ħafna l-mod kif tħares lejk nnifsek bħala persuna.					
6.	Kanċer fis-sider jhedded ir-relazzjoni tiegħek ma' żewġek jew is-sieħeb.					
7.	Kieku jkollok kanċer fis-sider, ibiddillek ħajtek ta' taħt fuq.					
8.	Kieku jkollok kanċer fis-sider, jista jonqoslok ċ-ċans li jkollok ħajja twila.					

C5. KURA/KONTROLL

C5a. KONTROLL PERSONALI (kif wieħed jikkontrolla jew jirkupra minn Kanċer fis-Sider)

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' KONTROLL PERSONALI*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Hemm ħafna x'tista' nagħmel biex tikkontrolla s-sintomi jekk toħroġlok Kanċer fis-Sider.					
2.	L-esperjenza tal-Kanċer fis-Sider jiddependi skont l-azzjonijiet li tieħu.					
3.	L-azzjonijiet tiegħek jħallu effett fuq l-impatt tal-Kanċer fis-Sider f'ħajtek.					

C5b. KONTROLL TAT-TRATTAMENT

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' KONTROLL TAT-TRATTAMENT*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	M'hemmx trattament li jgħin biex tittejjeb is-sitwazzjoni ta' pazjenta tal-Kanċer fis-Sider.					
2.	It-trattament li jingħata jkun effettiv biex jikkontrolla jew ifejjaq Kanċer fis-Sider.					
3.	L-effetti negattivi tal-Kanċer fis-Sider jistgħu jkunu limitati jew jiġu evitati bit-trattament li jingħata.					

C6. KOERENZA TAL-MARDA

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' KOERENZA TAL-MARDA*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Għandek stampa ċara u għarfien tajjeb tal-Kanċer fis-Sider.					
2.	Il-Kanċer fis-Sider hu misteru għalik.					

C7. RAPPREŻENTAZZJONIJIET EMOZZJONALI

NRU TAL-ENTRATA FUQ L-ISKALA	*ENTRATI TA' RAPPREŻENTAZZJONIJIET EMOZZJONALI*	Ma naqbilx assolutament (1)	Ma naqbilx (2)	Minix ċerta (3)	Naqbel (4)	Naqbel assolutament (5)
1.	Tħossok anzjuża meta taħseb dwar il-marda tal-Kanċer fis-Sider.					
2.	Il-Kanċer fis-Sider ibeżżgħak.					
3.	Tħossok inkwetata meta taħseb dwar il-Kanċer fis-Sider.					

GRAZZI *tal-ħin li ħadt biex weġibt dan l-istħarriġ.*

Appendix 4.3.1- Version of Study 4 published in the *BMC Public Health Journal*

Marmarà et al. BMC Public Health (2018) 18:182
DOI 10.1186/s12889-018-5093-6

BMC Public Health

RESEARCH ARTICLE Open Access

Lifetime utilization of mammography among Maltese women: *a cross-sectional survey*

Danika Marmarà[1,2*], Vincent Marmarà[3] and Gill Hubbard[1]

Abstract

Background: The knowledge of Maltese women not attending the Maltese Breast Screening Programme (MBSP) for mammography screening is scarce. Previous research has identified two distinct groups of non-attendees: those who do not attend because a mammogram was taken elsewhere and those who never attended for mammography anywhere. It is however unknown which determinants are predictive of lifetime attendance 'anywhere' and 'real' non-attendance. The present study examines the relationship between ever-using (Lifetime attendees) or never using mammography (Lifetime non-attendees) and psychosocial - as well as sociodemographic factors, with the aim to identify predictors that can inform practice.

Methods: Women's characteristics, knowledge, health beliefs and illness perceptions were compared, based on prior data of 404 women, aged 50–60 years at the time of their first MBSP invitation. The main variable of interest described women's attendance to mammography (LIFETIME ATTENDEES) and no mammography (LIFETIME NON-ATTENDEES). Data were analyzed using descriptive statistics, chi-square tests, Mann Whitney test, Independent Samples t-test, Shapiro Wilk test and logistic regression.

Results: During their lifetime, 86.1% of Maltese women (n = 348) were attendees, while 13.9% (n = 56) were non-attendees. Non-attendees were more likely to be women with a lower family income ($\chi 2 = 13.1$, $p = 0.011$), widowers ($\chi 2 = 9.0$, $p = 0.030$), non-drivers ($\chi 2 = 7.7$, $p = 0.006$), without a breast condition ($\chi 2 = 14.2$, $p < 0.001$), who had no relatives or close friends with cancer ($\chi 2 = 8.3$, $p = 0.016$), and who were less encouraged by a physician ($\chi 2 = 4.9$, $p = 0.027$), unsure of the screening frequency ($\chi 2 = 28.5$, $p < 0.001$), more anxious ($p = 0.040$) and fearful ($p = 0.039$). Perceived benefits, barriers, cues to action, self-efficacy and emotional representations were the most significant variables to describe the differences between lifetime attendees and non-attendees. Perceived barriers and cues to action were the strongest predictors for lifetime non-attendance ($p < 0.05$ respectively).

Conclusions: The health beliefs of women who have never attended for mammography during their lifetime should be targeted, particularly perceived barriers and cues to action. Further research should focus on understanding knowledge gaps, attitudinal barriers and emotional factors among 'real' non-attendees who require a more targeted approach.

Keywords: Breast cancer, Mammography, Attendance, Non-attendance, Health beliefs, Illness perceptions

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Background

Breast cancer (BC) is the most common type of cancer in women worldwide [1]. In Malta, it has topped the list of female cancers and has accounted for an average incidence of over 280 women over the last 12 years [2]. Early detection of BC renders the possibility of efficient treatment [3] which would more likely include breast conservation without chemotherapy [4]. Regular use of mammography screening at short enough intervals is a cost-effective way [5] to detect tumours early enough in order to improve prognosis, reducing mortality and thereby impacting on survival [4, 6, 7].

Across the globe, lifetime utilization and regular re-utilization of mammography has been increasing steadily across the years [3, 7–9]. Despite the known benefits of breast screening (BS) by mammography [10–12], also referred to as mammography screening (MS), various countries have still not reached the recommended acceptable (> 70%) or desirable (> 75%) EU benchmarks, according to the European Guidelines [13]. Lower utilization rates may be associated with three main factors: (a) *logistical determinants* such as the availability and accessibility of a screening center, test affordability, time from work or travelling time [3, 14, 15], (b) *psychosocial factors* such as values, expectations and beliefs which affect the way women transform knowledge regarding mammography into actual behaviour [16], and (c) socio-demographic determinants which impact on the way structural and psychosocial factors predict mammography use [17, 18]. However, most of the literature does not take into account the context of mammography provision, such as countries with dual health systems (organized and private screening).

Although general barriers to screening by mammography in Malta have been identified in our earlier study [19], our findings showed that our screening cohort consisted of attendees and non-attendees to the Maltese Breast Screening programme (MBSP); however, we recognised that the MBSP non-attendees consisted of a heterogeneous group of women with diverse reasons for non-attendance. Hence, screening non-attendees were not a single group of non-compliant Maltese women, but consisted clearly of two distinct subgroups:

(i) Women, who had obtained a mammogram outside the MBSP, possibly as a self-initiated action or routine check-up [15] or as part of private breast awareness campaigns, which may have been based on their recognition of susceptibility to BC and high self-efficacy in preventing BC [20], and
(ii)'Real' non-attendees i.e. women who have never attended anywhere for mammography during their lifetime.

Considering the fact that the Maltese National Health System (NHS) comprises both the public and private sectors, and that a national breast screening programme was introduced at the end of 2009 for women aged 50–60 years at the time [13], some women chose to go privately for a mammogram before the year 2009 and still do so to date rather than taking up the invitation to be screened at the MBSP. However, it is the diversity of 'real' non-attendees [15] that needs to be better understood in order to develop culturally sensitive interventions.

Nothing is yet known to date about those who never attend for mammography throughout their lifetime in Malta. Hence, this study was carried out to provide an understanding of the determinants of lifetime mammography screening behaviour among Maltese women who attend 'anywhere' and those who have 'never' attended for mammography. This paper is "part two" of a larger study that was conducted on breast screening uptake in Malta carried out through a national cross-sectional survey and hence, this paper is a continuation of that previous article. In this paper, data from that 2015 Maltese national survey were used to assess the relationships of lifetime mammography utilization (attendance 'anywhere') and 'real' non-attendance with socio-demographics, health status, knowledge, health beliefs and illness perception variables, based on the Health Belief Model (HBM) and Common-Sense Model (CSM). Both HBM and CSM have been used as theoretical frameworks to predict the uptake of mammography screening [21–24]. The CSM has been used to consider the cognitive and emotional representations of an illness [23] which are often omitted in the use of HBM. On the other hand, the CSM does not describe the perceived barriers and benefits to the performance of health-related behaviours [21] such as mammography use, and excludes the role of significant others such as family, friends and healthcare providers [25]. By contrast, the HBM addresses all of these, incorporating the components of perceived benefits, perceived barriers and cues to action. Following the simultaneous use of both models which were found to improve the prediction of non-attendance to the MBSP in our earlier study [19], both models were again utilised to integrate the beliefs about the illness (CSM) [26] and the individual's beliefs on the recommended behaviour [HBM] [21] in this study on lifetime mammography utilization.

Guided by the guidelines 'Strengthening the Reporting of Observational Studies in Epidemiology' (STROBE) [27] [see Additional file 1], we built on the findings of our prior study [28] which suggest that health beliefs and illness perceptions vary between women who accept or refuse a BS invitation to the organized programme. The immediate aim of our study was to gain an understanding of the determinants of lifetime mammography use among women who attend for mammography 'anywhere' and those who never attend for mammography during their lifetime ('real' non-attendance).

Objectives

In reaching our aims, this analysis has targeted the following objectives:

(1) To determine the socio-demographics, health status, knowledge, health beliefs and illness perceptions of women who attend or do not attend for mammography screening during their lifetime;
(2) To examine the most significant predictors of lifetime mammography utilization and its non-use.

Methods

Design and setting

Since this study was part of a 2015 national retrospective study, the full details of the methods are described elsewhere [19]. The MBSP was set up to serve as the only centre in Malta to offer national screening as part of an organized programme. As is the current practice at the MBSP, two views (medio-lateral and cranio-caudal) are carried out by trained radiographers (mammographers) and the mammograms are reported by trained breast radiologists. Adjunct ultrasound is carried out at a subsequent (recall) appointment when deemed necessary, for cases such as dense breasts or for further evaluation of suspected mammographic abnormalities.

A stratified random sample was ascertained from women aged 50–60 at the time of their first invitation at the MBSP who were registered on the MBSP database and who had no personal history of BC. The original study recruited a sample size of 404 women (i.e. 243 attendees and 161 non-attendees) in order to achieve a 95% confidence level and 5% confidence interval, which the present study used.

For those invited to the MBSP, attendance or non-attendance was verified through screening records but further mammography performed in private practices was self-reported. Participants were assured that their participation was voluntary and that they could withdraw from the study at any time without the need to give a reason. Information was provided to the women on how the researcher would protect their anonymity and confidentiality through coding. Prior to the commencement of the survey, participants were informed that the study was aimed at improving the understanding of women's beliefs, attitudes and perceptions on and concerns about BS and BC. Moreover, they were notified that the study had been granted ethical approval by the School Research Ethics Committee at the University of Stirling (SREC14/15-Paper No.18v4) and by the Maltese Health Ethics Committee (HEC 02/2015). As approved by the ethics committees and following standard practice when conducting surveys by telephone [29–31], a research assistant was responsible for participant recruitment, which was carried out manually over the phone (through "yes" or "no" response options), using paper format to record verbal informed consent. Following the latter method, an appointment was scheduled by the research assistant to match its suitability for each of the participants and the primary investigator (DM). The survey was completed in a median of 25 min (range, 15–45 min) and was carried out in one telephone call.

Survey development

The survey questionnaire consisted of standardized socio-demographic and health status questions as well as validated scales (CHBMS-MS and IPQ-R) [32, 33]. All measures were translated from English to Maltese using a back-translation procedure. A pre-test (n = 15) of the 121-item tool (entitled the Maltese Breast Screening Questionnaire – MBSQ) confirmed the comprehensibility, accuracy and feasibility of the questionnaire and to ensure understanding of scale items in both Maltese and English. The methods used have been published elsewhere [19, 34].

The survey questionnaire is composed of four sections, as follows:

1) Socio-demographic factors and health status were measured through 11 subscales (20 items),
2) Lifetime mammography practices and knowledge of mammography frequency were measured through 4 subscales (17 items),
3) Health beliefs were measured through 5 subscales (36 items),
4) Illness perceptions were measured through 7 subscales (48 items).

Response options were "yes", "no" or a series of tick boxes for socio-demographic factors and health status variables. Open questions were designed to encourage a more detailed and meaningful answer using the participant's own knowledge and/or feelings. Most of the response options for lifetime mammography practices and knowledge on mammography time intervals were mostly designed to elicit "yes", "no" or "unsure" answers, whereas closed questions were possible through a series of tick boxes. All items for health beliefs and illness perceptions had 5 response options (1 = 'strongly disagree' to 5 = 'strongly agree').

Classification of variables

Women were asked if they ever had a mammogram in their lifetime with a yes/no response. Women were categorized as

LIFETIME ATTENDEES if they had *ever* had a mammogram in their lifetime or LIFETIME NON-ATTENDEES if they had *never* attended for a mammogram during their lifetime. Socio-demographic and health status variables (some of which were confirmed from women's health records from the screening database), as well as knowledge of screening frequency, health beliefs and illness perception variables were collected from the survey administered retrospectively from the time of the first screening invitation at the MBSP.

Statistical analysis

The chi-square test was used for comparison of proportions between two categorical variables. The Shapiro Wilk test was applied on the 14 constructs in order to determine whether these variables are normally distributed. It was found that only the variable Causes of BC was normally distributed. Hence, parametric tests were used for this latter construct. All the other 13 constructs were found to be not normally distributed (p-value < 0.001) and hence, non-parametric tests were used for all the 13 constructs. When comparing two independent samples, the Independent Samples t-test was used for normally distributed data (parametric test) and Mann-Whitney test was used for the non-normal distributed dataset (non-parametric test). Similarly, for analysis including two of more independent samples, ANOVA was used for normally distributed data and Kruskal-Wallis test was used for the non-normal distributed datasets. Different variables and constructs were incorporated into six logistic regression models and the 'backward-elimination' method was applied to each model to identify the significant predictors of lifetime mammography use. The results of the regression are reported with 95% confidence intervals, Beta (unstandardized) coefficients, Standard Errors (SE), Walds, Odds Ratios (OR) and p-values. All tests were analysed with an $\alpha = 0.05$ level of significance; hence, any statistical test obtaining a p-value of < 0.05 was considered as statistically significant. Missing data was minimal (n = 23 for frequency of GP visit) and this missing data was reported in our previous paper [19]. Missing data was reported as is; hence this data was not excluded. The data was analyzed using SPSS version 21.

Results

Sample characteristics

Most participants (86.9%) were married (n = 351). The majority (77%) of participants were housewives (n = 311), 75.7% had a secondary level of education (n = 306) and more than half (60.3%, n = 244) were from below average annual income families (lower than €16,113). Descriptive statistics are presented in our previous paper [19].

Mammography screening practices

Mammography screening practices are presented in Fig. 1. Breast screening use (LIFETIME ATTENDEES) was reported by 86.1% of women (n = 348), of which 243 women underwent a mammogram at the MBSP. From those who did not undergo a mammogram at the MBSP (n = 161), 105 women underwent mammography elsewhere. No mammography was reported by 13.9% (n = 56) (LIFETIME NON-ATTENDEES).

LIFETIME ATTENDEES versus LIFETIME NON-ATTENDEES subgroup analyses

Chi-square tests were performed to explore associations between lifetime attendees and non-attendees, and the following variables: sociodemographic factors, health status, knowledge, health beliefs and illness perceptions.

Sociodemographic factors and health status

There was significant association between marital status and lifetime mammography ($\chi2 = 9.0$, $p = 0.030$) such that a lower number of widowers attended for mammography (66.7%) when compared to women of other statuses (single, married, separated/divorced) (≥87%). The higher their family income, the more likely it is for a woman to undergo mammography in her lifetime ($\chi2 = 13.1$, $p = 0.011$). In fact, all women who had a family annual income greater than €23,564 claimed that they acquired mammography during their lifetime while from those with a family annual income lower than €10,737, around one in every four women did not undergo mammography. In addition, those who do not drive are more likely not to attend for a mammogram ($\chi2 = 7.7$, $p = 0.006$). Our data showed that 91.5% of drivers attended for a mammogram in their lifetime as compared to 81.9% of non-drivers. All women in our sample with a breast condition or disease attended for mammography in their lifetime when compared to 82.9% of women without a breast condition ($\chi2 = 14.2$, $p < 0.001$). Moreover, those who had relatives or close friends with cancer were more likely to attend for mammography ($\chi2 = 8.3$, $p = 0.016$).

No significant association was found between lifetime mammography and age (Independent samples t-test: $p = 0.133$), district ($\chi2 = 7.8$, $p = 0.802$), owning a car ($\chi2 = 1.2$, $p = 0.267$) or having an illness ($\chi2 = 0.1$, $p = 0.709$). Although there was no significant association for level of education ($\chi2 = 5.4$, $p = 0.067$) and occupation ($\chi2 = 5.7$, $p = 0.057$), women with a higher education level and who were employed were more likely to undergo mammography in their lifetime (e.g. 93.2% {employed} versus 83.9% {housewives}). There was no significant association between having a family physician and lifetime mammography ($\chi2 = 3.5$, $p = 0.060$). However, women who were not encouraged by their GP were

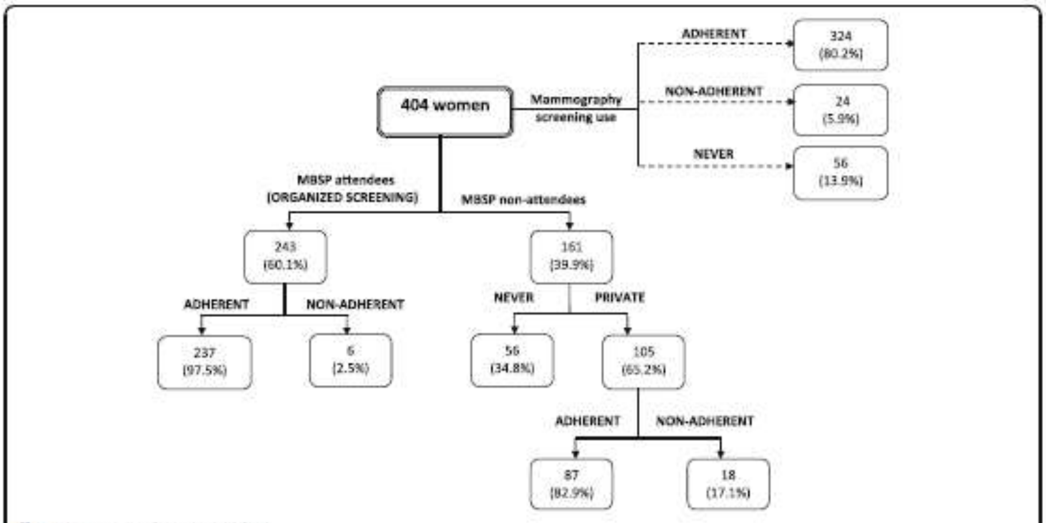

Fig. 1 Mammography use in Malta

more likely not to attend for a mammogram during their lifetime ($\chi2 = 4.9, p = 0.027$).

Knowledge of the recommended mammography frequency

Knowledge of mammography frequency was significantly associated with whether women had undergone a mammogram in their lifetime ($\chi2 = 28.5, p < 0.001$). The main difference arises with those who said they were 'unsure' about the recommended mammography frequency (48% of the latter group did not undergo a mammogram in their lifetime), whereas for women who mentioned other mammography frequency options (i.e. 'every year'; 'every 1.5 years'; 'every 2–3 years'), more than 86% of women from each individual latter groups had acquired a mammogram.

Health beliefs

All sub-scale items for perceived barriers and cues to action for mammography use were found to be statistically significant ($p < 0.05$) (Table 1). Women tend to attend less for mammography if they are in agreement with or are undecided on the following: having a mammogram *'would make you more anxious', 'more worried', 'more fearful about BC'* and *'the procedure itself'*, is *'embarrassing'* and *'time-consuming'* and *'causes unnecessary radiation'*, have *'fear or distrust the medical team'*, 'consider *other problems in life to be greater'* and feel they are *'not old enough to have a mammogram periodically'* ($p < 0.001$ respectively). Significant association is mirrored for the statement *'you fear having a mammogram because you know someone (family or friend) with breast cancer'* ($p < 0.001$). When comparing pain and discomfort with mammography use, statistical significance is mirrored ($p < 0.001$), whereby the absolute majority of the undecided group (95.8%) do not attend for a mammogram in their lifetime whereas those who are in disagreement or in agreement (≥88%) attend for mammography.

Those who underwent mammography tend to attend more for mammography if advised by their GP ($\chi2 = 54.4, p < 0.001$) or by relatives or friends ($\chi2 = 16.9, p = 0.001$). Those who are in disagreement that hearing about BC and BS in the media would trigger thoughts to get a mammogram tend to attend less. The absolute majority of those who are in disagreement that cues to action (such as 'reminder letters', 'reminder phone calls' or 'text messages') are effective, are more likely not to attend for mammography. There is also similar significant association for the vast majority of self-efficacy sub-scale items ($p < 0.001$) i.e. for attendees, the stronger is women's confidence in arranging other things in their life to get a mammogram, while for the undecided group and those who are in disagreement with self-efficacy items are more likely not to attend for mammography screening.

Illness perceptions

There is significant association for the emotional representation subscale items ($p < 0.05$) (Table 2). For lifetime non-attendees, the higher is their anxiety ($\chi2 = 8.3, p = 0.040$) and fear ($\chi2 = 8.3, p = 0.039$) of BC. The undecided group attend less for mammography when

Table 1 Health Belief items

Health Beliefs	LIFETIME SCREENERS versus NON-SCREENERS $\chi2$	p-value
There is no possibility of getting breast cancer (r)	8.4	0.077
Your chances of getting breast cancer are high	8.2	0.085
There may be the possibility of developing breast cancer in your lifetime	3.0	0.390
When you get a mammogram, you feel good about yourself	45.5	< 0.001*
When you get a mammogram, you do not worry as much about breast cancer	6.4	0.093
Having a mammogram will help you find lumps early in your breasts	19.1	< 0.001*
If you find a lump through a mammogram, the treatment for breast cancer may not be as bad	5.2	0.160
Having a mammogram will decrease your chances of dying from breast cancer	7.5	0.580
Having a mammogram will help you find a lump before it can be felt by yourself or a health professional	7.2	0.065
Having a routine mammogram would make you anxious about breast cancer	27.7	< 0.001*
Having a routine mammogram would make you worry	22.8	< 0.001*
You fear having a mammogram because you might find out that something is wrong	39.7	< 0.001*
You fear having a mammogram because you do not know the procedure or what to expect	145.8	< 0.001*
You fear having a mammogram because you know someone (family or friend) with breast cancer	20.0	< 0.001*
It is embarrassing for you to have a mammogram	40.4	< 0.001*
Undergoing mammography will be painful or uncomfortable	147.5	< 0.001*
Having a mammogram is time consuming	31.1	< 0.001*
You are discontent with Breast Screening personnel as they have been rude to you	n/a	n/a
You have fear or distrust in the medical team	32.9	< 0.001*
Having a mammogram would expose you to unnecessary radiation	27.9	< 0.001*
You have too many other problems in your life than to get a mammogram done	83.1	< 0.001*
You are not old enough to have a mammogram periodically	35.4	< 0.001*
If your GP advises you to attend for a mammogram, you will attend	54.4	< 0.001*
If your relatives or friends advise you to attend for a mammogram, you will attend	16.9	0.001*
If someone close to you has been diagnosed with breast cancer, you will attend for a mammogram	39.4	< 0.001*
Hearing about breast cancer and breast screening in the media or news makes you think about getting a mammogram	34.2	< 0.001*
Reminder letters would help you to get a mammogram	38.9	< 0.001*
Reminder phone calls or text messages would help you to get a mammogram	38.9	< 0.001*
Routine educational talks regarding breast cancer awareness would help you to get a mammogram	37.1	< 0.001*
You feel confident that if you had a mammogram done, any abnormalities in your breasts will be detected	0.6	0.960
You can arrange other things in your life to get a mammogram	49.2	< 0.001*
In case you need a mammogram, you will find a place to get it done	32.8	< 0.001*
You can make an appointment for a mammogram	36.0	< 0.001*
You can arrange transportation to get a mammogram	41.1	< 0.001*
You can talk to people at the breast screening centre about your concerns	n/a	n/a
You can find a way to pay for a mammogram if you need to	32.3	< 0.001*

*Statistically significant
(r) = reverse scored
[a]Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1 and 5, where 1 = strongly disagree and 5 = strongly agree. For certain items, responses were re-grouped to ensure the feasibility of the Chi-square test

taking into account that their emotional state ($\chi2 = 12.9$, $p = 0.002$) and their own behaviour ($\chi2 = 12.7$, $p = 0.002$) is perceived to possibly cause BC. Those who agree that BC can be caused by their own behaviour ($\chi2 = 12.7$, $p = 0.002$) or by a germ/virus ($\chi2 = 9.4$, $p = 0.009$) attend less for mammography, while those who consider BC to have major consequences in life ($\chi2 = 9.9$, $p = 0.019$) attend more.

Health beliefs and illness perception constructs

The following 4 HBM and 1 CSM constructs were found to be significantly different when comparing lifetime mammography attenders and non-attenders: perceived benefits, perceived barriers, cues to action, self-efficacy ($p < 0.001$ respectively) and emotional representations ($p = 0.033$) (Table 3).

Table 2 Illness Perception items

Illness Perceptions	LIFETIME SCREENERS versus NON-SCREENERS $\chi 2$	p-value
The presence of a lump or thickening in the breast	1.8	0.611
Nipple discharge	2.3	0.509
Sudden nipple retraction	1.1	0.769
Change in shape or appearance of the nipple	1.2	0.743
Breast swelling, dimpling, redness or soreness of the skin	0.9	0.826
Skin changes of the breast	1.7	0.641
A sudden change in breast size	1.5	0.688
Aching breasts	1.5	0.820
Stress or worry	3.0	0.223
Your mental attitude (e.g. thinking about life negatively)	2.0	0.580
Family problems or worries	2.9	0.233
Overwork	7.9	0.052
Your emotional state (e.g. feeling down, lonely, anxious, empty)	12.9	0.002*
Your personality	3.0	0.391
Hereditary - it runs in the family	9.7	0.021*
Diet or eating habits	1.5	0.679
Poor medical care in the past	0.8	0.847
Your own behaviour	12.7	0.002*
Ageing	1.9	0.395
Smoking	1.8	0.601
Alcohol	1.2	0.538
A germ or virus	9.4	0.009*
Pollution in the environment	1.4	0.709
Altered immunity	2.5	0.469
Chance or bad luck	3.0	0.562
Accident or injury	3.6	0.460
Breast cancer will last a short time	5.8	0.120
Breast cancer is likely to be permanent rather than temporary	0.9	0.650
A patient with breast cancer goes through cycles in which her illness gets better and worse	5.8	0.215
Breast cancer has major consequences on a patient's life	9.9	0.019*
Breast cancer will not have much effect on your life	6.1	0.189
Breast cancer would strongly affect the way others see you	7.8	0.100
Breast cancer has serious economic and financial consequences	5.0	0.174
Breast cancer would strongly affect the way you see yourself as a person	0.9	0.826
Breast cancer would threaten a relationship with your husband or partner	2.5	0.641
If you had breast cancer, your whole life would change	5.6	0.133
If you developed breast cancer, the chances of living a long life would decrease	4.9	0.179
There is a lot which you can do to control the symptoms if Breast Cancer occurs	0.7	0.948
The course of Breast Cancer will depend on your actions	2.9	0.400
Your actions will have an effect on the outcome of Breast Cancer	4.0	0.261
There is no treatment that will help to improve Breast Cancer	4.0	0.400
The treatment provided will be effective in controlling or curing Breast Cancer	3.1	0.371
The negative effects of Breast Cancer can be prevented or avoided by the treatment given	1.5	0.822
You have a clear picture and understanding of Breast Cancer	4.5	0.211
Breast Cancer is a mystery to you	2.1	0.720
You get anxious when you think about Breast Cancer	8.3	0.040*
Breast Cancer makes you feel afraid	8.3	0.039*
You get worried when you think about Breast Cancer	4.3	0.231

*Statistically significant
[a]Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1 and 5, where 1 = strongly disagree and 5 = strongly agree. For certain items, responses were re-grouped to ensure the feasibility of the Chi-square test

The findings show that for women who acquire mammography during their lifetime, the higher is their agreement on perceived benefits to mammography uptake, while more cues to action and greater self-efficacy help women to undergo mammography. Higher perceived barriers to mammography screening and stronger emotional representations of BC are associated with no mammography use during a woman's lifetime.

Predictors of mammography screening practices

We further explored which variables and constructs were most significant to women's attendance (LIFETIME ATTENDEES versus LIFETIME NON-ATTENDEES). A number of logistic regression models were applied (Table 4) in order to examine the variables/constructs (independent variables) which are key to identifying

Table 3 Comparisons between mammography screening use and health beliefs/illness perception constructs. For all constructs, Mann Whitney test and Independent Samples t-test were applied to compare 'LIFETIME ATTENDEES' and 'LIFETIME NON-ATTENDEES'

	LIFETIME ATTENDEES ($n = 348$)	LIFETIME NON-ATTENDEES ($n = 56$)	Test Statistic	p-value
Perceived Susceptibility	M= 9.6, SD = 1.0	M= 9.6, SD = 1.0	10,065.5[a]	0.669
Perceived Benefits	M= 24.0, SD = 1.8	M= 23.1, SD= 1.5	6816.5[a]	< 0.001*
Perceived Barriers	M= 27.5, SD = 4.9	M= 34.8, SD= 4.9	16,569.5[a]	< 0.001*
Cues to action	M= 27.3, SD = 3.2	M= 23.1, SD= 4.8	4306.0[a]	< 0.001*
Self-Efficacy	M= 24.8, SD = 2.7	M= 22.7, SD= 2.8	6114.5[a]	< 0.001*
Breast Cancer Identity	M= 30.6, SD = 2.3	M= 30.7, SD= 2.0	10,344.0[a]	0.434
Causes of Breast Cancer	M= 56.0, SD = 7.2	M= 57.4, SD= 6.9	-1.3[b]	0.186
Cancer Timeline: Acute/Chronic	M= 6.1, SD = 0.9	M= 6.2, SD = 0.9	10,213.5[a]	0.534
Cancer Timeline: Cyclical	M= 3.6, SD = 0.7	M= 3.4, SD = 0.7	8513.0[a]	0.069
Consequences	M= 28.2, SD = 2.5	M= 28.5, SD= 2.0	9909.0[a]	0.837
Personal Control	M= 11.8, SD = 0.8	M= 11.9, SD= 0.5	9890.0[a]	0.757
Treatment Control	M= 9.9, SD = 0.7	M= 10.0, SD= 0.5	10,592.0[a]	0.119
Illness Coherence	M= 7.0, SD = 1.1	M= 7.0, SD = 1.1	9857.5[a]	0.880
Emotional Representations	M= 12.2, SD = 2.1	M= 12.7, SD= 2.5	11,431.5[a]	0.033*

*Statistically significant, [a] Mann Whitney test, [b] Independent Samples t-test

differences between women who attended mammography during lifetime and non-attendees (dependent variables). Model 1 represents the demographics against attendance/non-attendance. Although 'drive' and 'status' variables were found to be significant ($p < 0.05$), this model was not found to provide any accuracy to predict non-attendance. Hence, demographics are not providing any useful prediction for the scope of this analysis. Model 2 focused on Health Belief variables only, which served as the independent variables for this model. This model predicted attendance with an accuracy of 98.3% and non-attendance with an accuracy of 48.2%. Five variables were found to be significant ($p < 0.05$) with an Odds Ratio (OR) that varies between 0.213 (fear of unknown procedure) and 3.327 (arrange transportation) for all the five variables. Model 3 focused on Illness Perception variables only, which served as the independent variables for this model. This model predicted attendance with an accuracy of 99.4% and non-attendance with an accuracy of 5.4%. Six variables were found to be significant ($p < 0.05$) with OR varying between 0.432 (fear of breast cancer) and 1.926 (major consequences in life). The above significant predictors from both models 2 and 3 were incorporated into a new single model (Model 4), both health beliefs and illness perception variables serving as the independent variables for this model. The model accuracy, when combining both scores, improved to 98.0% for attendance and 53.6% for non-attendance. The model retained six significant predictors ($p < 0.05$) with OR varying between 0.212 (fear of unknown procedure) and 3.202 (arrange transportation). When all individual Health Belief and Illness Perception items were incorporated into one model (Model 5), eight variables were found to be significantly different ($p < 0.05$) with OR varying between 0.149 (fear of unknown procedure) and 3.716 (arrange transportation). The accuracy of the model improved again to 97.1% for attendees and 58.9% accuracy for non-attendees. When the 14 constructs (not individual items) related to Health Beliefs and Illness Perceptions were used to construct a logistic regression model (Model 6), 'perceived barriers' (OR 0.776) and 'cues to action' (OR 1.196) were found to be the strongest and most significant predictors ($p < 0.05$) to describe the variance between the subgroups. However, the accuracy for predicting the non-attendees was found to be 37.5% and 96.6% for predicting attendance, which is inferior when compared to Model 4. No health status variables were found to be significant and were therefore not included in Table 4.

Discussion

The extant research identifies multifactorial reasons why women choose not to attend for mammography screening [9, 35–39], particularly psychological, socio-economic and practical factors [15, 28, 40, 41]. Hence, this study was carried out to provide an understanding of the determinants of lifetime mammography use among Maltese women who attend 'anywhere' and those who 'never' attend for mammography. This study found that four health belief constructs (perceived benefits, perceived barriers, cues to action, self-efficacy) and one illness perception construct (emotional representations) influence lifetime mammography screening practices among

Table 4 Logistic Regression Models on lifetime mammography use (LIFETIME ATTENDEES versus LIFETIME NON-ATTENDEES) against different variables and different constructs

	B	SE	Wald	*P*-value	OR	95% CI	Model Accuracy Attendance	Model Accuracy Non-attendance
Model 1: Demographics							100%	0%
Drive	0.912	0.325	7.891	0.005	2.488	1.317, 4.700		
Status	0.591	0.224	6.987	0.008	1.807	1.165, 2.801		
Constant	−4.605	0.792	33.773	0.000	0.010			
Model 2: Health Beliefs							98.3%	48.2%
Fear of unknown procedure	−1.548	0.219	50.028	0.000	0.213	0.138, 0.327		
Other life problems	−1.213	0.302	16.130	0.000	0.297	0.165, 0.537		
Relative or close friend with breast cancer	0.383	0.187	4.218	0.040	1.467	1.018, 2.114		
Reminder letters	1.099	0.307	12.826	0.000	3.001	1.645, 5.475		
Arrange Transportation	1.202	0.410	8.605	0.003	3.327	1.490, 7.427		
Constant	−1.993	2.109	0.893	0.345	0.136			
Model 3: Illness Perceptions							99.4%	5.4%
Hereditary	0.579	0.233	6.179	0.013	1.784	1.130, 2.816		
Own behaviour	−0.554	0.213	6.774	0.009	0.575	0.379, 0.872		
Major consequences in life	0.655	0.255	6.627	0.010	1.926	1.169, 3.172		
Economic consequences	0.520	0.238	4.777	0.029	1.683	1.055, 2.683		
Threatens your relationship	−0.396	0.178	4.973	0.026	0.673	0.475, 0.953		
Fear of breast cancer	−0.840	0.280	9.038	0.003	0.432	0.250, 0.746		
Constant	1.060	1.828	0.337	0.562	2.888			
Model 4: Health Beliefs and Illness Perceptions							98.0%	53.6%
Fear of unknown procedure	−1.553	0.224	48.123	0.000	0.212	0.136, 0.328		
Other life problems	−1.239	0.310	15.973	0.000	0.290	0.158, 0.532		
Relative or close friend with breast cancer	0.407	0.189	4.618	0.032	1.502	1.036, 2.178		
Reminder letters	1.123	0.316	12.638	0.000	3.074	1.655, 5.710		
Arrange transportation	1.164	0.411	8.028	0.005	3.202	1.432, 7.163		
Own behaviour	−0.612	0.288	4.536	0.033	0.542	0.309, 0.952		
Constant	−0.240	2.306	0.011	0.917	0.787			
Model 5: Health Beliefs and Illness Perceptions							97.1%	58.9%
Poor medical care	0.878	0.360	5.970	0.015	2.407	1.190, 4.870		
Own behaviour	−1.195	0.380	9.893	0.002	0.303	0.144, 0.637		
Pollution	0.603	0.283	4.543	0.033	1.829	1.050, 3.185		
Possibility of developing breast cancer	−1.295	0.658	3.876	0.049	0.274	0.075, 0.994		
Fear of unknown procedure	−1.907	0.268	50.587	0.000	0.149	0.088, 0.251		
Other life problems	−1.478	0.331	19.976	0.000	0.228	0.119, 0.436		
Reminder letters	1.256	0.321	15.352	0.000	3.512	1.874, 6.584		
Arrange transportation	1.313	0.442	8.832	0.003	3.716	1.564, 8.831		
Constant	3.476	3.406	1.041	0.308	32.328			
Model 6: The 14 constructs							96.6%	37.5%
Perceived barriers	−0.253	0.039	43.157	0.000	0.776	0.720, 0.837		
Cues to action	0.179	0.041	19.169	0.000	1.196	1.104, 1.295		
Constant	5.192	1.688	9.460	0.002	179.859			

B unstandardized coefficients; *SE* standard error; *OR* odds ratio; *CI* confidence interval

Maltese women. In particular, our findings show that women who perceive more barriers to mammography attendance (e.g. fear of pain, fear of the result), fewer benefits (e.g. lower belief in early detection), lower cues to action (e.g. no advice by a GP) and lower self-efficacy (e.g. lower confidence in one's ability to arrange other things in life), and who have higher emotional representations of BC (e.g. greater fear, worry, anxiety and who consider other problems in life to be greater) were less likely to attend for mammography during their lifetime. This is consistent with Champion's Health Belief Model and Leventhal's Common-Sense Model of self-regulation. This also implies that women who have previously experienced mammography screening may already have established health-related behaviours [42] and have therefore already recognized the benefits of undergoing regular mammography use, have already overcome personal barriers to undergo mammography, have increased their self-confidence in getting screened throughout their lifetime and have higher levels of health motivation [23, 28, 42–44]. Therefore, efforts should be focused on identifying and encouraging attendance among women who have never participated in screening [44].

Our findings emphasize the importance of adapting interventions for women with lower socio-economic backgrounds, particularly since widowers, those having lower family incomes and non-drivers were found to be significantly associated with lifetime non-attendance in this study. These women are less likely to attend for screening anywhere. Women with socio-economic disadvantages in life are less likely to take part in any mammography screening. This relationship has been shown in previous literature [45]. Having a free-of-charge, invitational, organized screening programme is one of many interventions which would help to increase mammography use. This socioeconomic difference is re-emphasized in our previous study whereby household income has solely emerged as significantly associated with attendance to first invitation at the MBSP [19]. Although not statistically significant in this present study, women with a higher level of education and in employment were found to be more likely to attend than non-employed women and those with a lower education level. These socio-economic characteristics may serve as a proxy for interaction with other people, and in the degree of social integration during a woman's lifetime. These findings may indirectly reflect social differences as well as the degree of equality regarding detection of BC and treatment received, and may help to identify prognostic factors amenable to intervention.

There were significant associations in this study between lifetime attendees and non-attendees regarding having a breast condition or BC in the family and the close relations, such that women with a breast condition or who had relatives or close friends with cancer were more likely to attend for mammography during their lifetime. Similarly, having a family member or close friends with BC was found to be associated with mammography attendance in other studies [46, 47] but contrast others [48–50]. Women most often play key roles as health managers and family caregivers [51–53] and this is not only reflected in that women more regularly than men are searching for health-related information on the Internet [54] but in women seeking a preventive action when faced with a prior personal or close relation experience that subsequently triggers them to engage in a health-related behaviour [50, 55, 56]. This corresponds with other research in other fields, particularly on mothers and children [57].

It has been acknowledged that lifetime non-attendees are an extremely difficult group to target and are a real challenge for screening management and public health officials [58]. For instance, structural and socio-economic factors such as age, income and marital status cannot be directly or easily modified [59]. Hence, although the exploration of such variables can help identify those at risk for a poor screening profile, such research offers little direction in terms of viable interventions. Therefore, in order to better understand which constructs are most significant to lifetime mammography non-attendees in Malta, our logistic regression analyses confirmed that *health beliefs* were the strongest and most important predictors to lifetime non-attendance and this result has been consistent across our previous research on first invitation to the MBSP [19], re-attendance [28] and adherence to timely mammography use [60]. This implies that lifetime non-attendees are women who were not motivated in health behaviour, have strong emotional representations of BS and BC, who highlight more barriers to screening, lower benefits and less cues to action because this is a new skill for them. This is evidenced by women who do not attend for mammography in other countries [59, 61] because they perceive greater barriers to BS.

Our data shows evidence that lifetime non-attendees were less encouraged by their GP to attend for a mammogram during their lifetime. However, it is also true that Maltese women tend to visit their GPs when they have a problem rather than on a routine basis [19]. While it is known that GPs are significantly more influential than relatives or friends at supporting the uptake of BS by mammography [55], women obtain information more often from friends and relatives than from official sources [62]. This reinforces the influence of word of mouth from friends and relatives as a means of screening promotion [55], supporting related promotional schemes worldwide [63–65]. However, while word of mouth is important, such initiatives are aimed at ensuring that information passed through word of mouth is based on factual information, rather than emotional reasons [55]. Although physician recommendation is critical for the provision of factual information (about BS, BC and adherence recommendations) [59, 66], many women still do not screen frequently enough [59]. Hence, it seems increasingly clear that interventions should be developed to target variables that are both amenable to change and for which there is scope for improvement, if breast screening rates are to be improved.

Emotional representations play a central role in models of both self-regulation and health behaviour [66] as well as in models regarding the "uptake" of health-promoting messages [67]. However, research cannot determine exactly what women are afraid of or how the diverse fear components are related to one another or to screening behaviour, particularly since contradictory findings across studies make it difficult to draw conclusions from the literature. Hence, fear, anxiety and worry are often termed to encompass nearly "everything" [59]. Our current study investigated barriers related to fear more specifically and we found that fear is certainly related to a breast cancer diagnosis, fear of pain/discomfort, fear of embarrassment, fear of the medical establishment, radiation, as well as general worry and anxiety. Similarly, other research found that fear is instilled due to an awaited result that may cause a negative impact on the self and on the family [59, 61, 68, 69], due to the pain perceived or experienced during the test [15, 44, 49, 70, 71], due to the sense of uncomfortableness whereby one exposes such an intimate body part in front of another person [44, 45, 71, 72], fear of the medical team [59, 73], fear that X-rays would cause more harm than good to the breast [15, 45] and nonspecific "cancer worry" [45, 49, 59, 74, 75] and general anxiety [76, 77]. Studies suggest that mammography-related anticipatory anxiety may contribute to poorer adherence [15, 69, 78] because women may avoid undergoing mammography to reduce their anxiety. It is possible that reports of mammography-related anxiety and catastrophizing thoughts related to mammography pain reflect women's level of general anxiety [79, 80]. This may also operate as a barrier for relatives or friends to undergo mammography or attend a particular unit [81]. Hence, such concerns need also to be taken seriously to encourage long-term adherence among attendees by finding ways how to avoid pain and maintaining client satisfaction [82, 83]. Women can be prepared for mammography by informing them about possible short-lived pain or discomfort, preferably in the invitation letter or in screening campaigns [15]. Additionally, calming self-statements or distraction techniques could be utilised to reduce the fear of pain and embarrassment during the test [23].

The undecided group of women in this study tend to attend less for mammography screening, particularly those who are unsure about: (i) self-efficacy items such as whether they can arrange other things in life to get a mammogram, (ii) screening barriers such as whether mammography is painful or uncomfortable, (iii) illness perception items such as whether one's emotional state or own behaviour causes BC, and (iv) mammography frequency recommendations). In all of our findings, limited knowledge was found to be significantly associated with attendance to the first screening invitation, re-attendance, lifetime mammography use and compliance with recommended time intervals. This calls for urgent renewed health education and tailored information on the importance of screening while addressing misunderstandings, debunking screening myths and improving knowledge gaps. All of our findings in this study, and when considered in the light of our previous results, can be used to lead the development of current non-existent, evidence-based interventions in Malta.

Strengths and limitations

Our group of 'real' non-attendees came from the same target screening group, which further strengthens the value of our data. Additionally, the rich dataset allowed for diverse subgroup analyses, which facilitated an overview of lifetime screening practices, though not without possible response bias as a possible weakness. An additional strength is that the 121-item tool (MBSQ) contains information that makes it possible to adjust the analyses for potential confounders. Some aspects of study limitations should be considered. One limitation of the study is its cross-sectional design, which does not allow for the associations of non-attendance with socio-demographic factors such as age to be studied over time. Future research is needed to evaluate a potential cause effect relation. A problem in some of the analyses is the low number of 'real' non-attendees, hence a lower level of confidence in the results for this particular group. This may have led to a type I and/or type II error in relation to some of the analysed factors. Another limitation of this study is that self-reports for private mammography was used to measure lifetime mammography rather than objective data from private mammographic screening clinics. However, no national data records from private practices are currently available to date in Malta. Hence, self-reports for lifetime mammography use was the only possible method of data collection. The findings are likely to be generalizable and broadly applicable to other populations. Although limited to the Maltese population, the representation of our heterogeneous population derives from different parts of the country. However, given the potential for cultural differences, varied health care delivery systems, and socioeconomic factors between countries, the generalizability of study results may be somewhat limited.

Conclusions

Our findings may be used to develop cognitive interventions aimed at enhancing perceived benefits, reducing perceived barriers, and modifying negative emotional representations to BC in order to motivate women to start undertaking mammography screening. In general, our results are in line with differences reported in the literature between screening attendees and non-attendees, such that non-attendees were less knowledgeable of the recommended mammography frequency, had attitudinal, emotional and motivational barriers, less socio-economic support and were less confident in themselves and the medical establishment. Additionally, our study showed that health beliefs were the most significant predictors to lifetime mammography screening behaviour. Hence, screening organizers and public health officials should target women's perceived barriers and enhance cues to action when reaching out to non-attendees. Further qualitative research is required to clarify the determinants and consequences of emotional barriers, particularly fear among the 'real' non-attending cohort, and also to evaluate the need for a more targeted approach among this hardest-to-reach group in order to understand the complexity of their behavioural barriers.

Abbreviations

B: Unstandardized coefficients; BC: Breast cancer; BS: Breast screening; CHBMS-MS: Champion's health belief model scale for mammography screening; CI: Confidence interval; CSM: Common-sense model; GP: General practitioner; HBM: Health belief model; IPQ: Illness perception questionnaire; IPQ-R: Revised illness perception questionnaire; M: Mean score; MBSP: Maltese breast screening programme; MS: Mammography screening; OR: Odds ratio; SD: Standard deviation; SE: Standard error

Acknowledgements

The authors would like to forward their gratitude to Prof. Victoria Champion and Prof. Rona Moss-Morris for developing the CHBMS-MS and IPQ-R scales respectively and for providing the opportunity to translate and adapt it into the Maltese culture and language. This study was developed as part of the activities of the PhD in Health offered by the University of Stirling in Scotland. We thank the National Screening Programme in Malta for providing access to the data.

Funding

The PhD program is part-financed by the Malta Government Scholarship Scheme (MGSS), Government of Malta.

Availability of data and materials

Data supporting the conclusions of this study are included within the manuscript. The raw datasets analysed during the current study are available from the corresponding author on reasonable request.

Authors' contributions

DM conceived the study, supervised all aspects of its conduction and wrote the manuscript. VM assisted with data analysis and interpretation of data and revised the manuscript. GH assisted with the study design, and critically reviewed and revised the manuscript. All authors helped to conceptualise ideas, interpret findings and review drafts of the manuscript. All authors read and approved the final manuscript.

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Ethics approval and consent to participate

Ethics approval was obtained via an application to the School Research Ethics Committee at the University of Stirling (SREC14/15-Paper No.18v4) and from the Maltese Health Ethics Committee (HEC 02/2015).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests regarding the publication of this paper.

Publisher's Note

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Received: 11 October 2017 Accepted: 17 January 2018
Published online: 25 January 2018

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Appendix 4.3.2 - STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cross-sectional studies

Section/Topic	Item #	Recommendation	Reported on page # (of published Study 4)
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1-2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	4	Present key elements of study design early in the paper	6-7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6-7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	6-7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-9
Bias	9	Describe any efforts to address potential sources of bias	26
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8-9
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9
		(*b*) Describe any methods used to examine subgroups and interactions	9
		(*c*) Explain how missing data were addressed	9
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	10
		(b) Give reasons for non-participation at each stage	10
		(c) Consider use of a flow diagram	10

Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10
		(b) Indicate number of participants with missing data for each variable of interest	9
Outcome data	15*	Report numbers of outcome events or summary measures	10
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	10-20
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	10-20
Discussion			
Key results	18	Summarise key results with reference to study objectives	20-25
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	26
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	27
Generalisability	21	Discuss the generalisability (external validity) of the study results	26
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	27

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix 4.4.1 - Version of Study 5 published in the *BMC Cancer Journal*

Marmarà et al. *BMC Cancer* (2018) 18:346
https://doi.org/10.1186/s12885-018-4278-9

BMC Cancer

RESEARCH ARTICLE

Open Access

A national cross-sectional study of adherence to timely mammography use in Malta

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Abstract

Background: Routine mammography improves survival. To achieve health benefits, women must attend breast screening regularly at recommended time intervals. Maltese women are routinely invited to undergo mammography at three-year intervals at an organized breast screening programme (MBSP) or can opt to attend a private clinic. Previous research shows that health beliefs, particularly perceived barriers, were the most significant predictors of uptake to the first MBSP invitation. Whether these beliefs and other factors are predictive of adherence with recommended time intervals for mammography at organized or private screening in Malta is unknown. For the first time, this paper explores the predictors for Maltese women screened within or exceeding the recommended three-year frequency in organized or private screening in Malta.

Methods: Information was obtained from a cross-sectional survey of 404 women, aged 50 to 60 years at the time of their first MBSP invitation, where women's characteristics, knowledge, health beliefs and illness perceptions were compared. The main variable of interest was women's mammography attendance within a three-year interval (ADHERENT) or exceeding three years (NON-ADHERENT). Data were analysed using descriptive statistics, chi-square test, Mann Whitney test, Independent Samples t-test and Shapiro Wilk test.

Results: At the time of the survey, 80.2% ($n = 324$) had been screened within three years (ADHERENT), 5.9% ($n = 24$) had exceeded the three-year frequency (NON-ADHERENT) while 13.9% ($n = 56$) never had a mammogram. No significant associations were found between ADHERENT or NON-ADHERENT women in relation to sociodemographic or health status variables ($p > 0.05$). Knowledge of screening frequency was significantly associated with women's mammography adherence ($\chi 2 = 5.5$, $p = 0.020$). Health beliefs were the strongest significant predictors to describe the variance between ADHERENT and NON-ADHERENT screeners. When Mann Whitney test and Independent Samples t-test were applied on mammography adherence, perceived barriers and cues to action were found to be the most important predictors ($p = 0.000$, $p = 0.039$ respectively).

Conclusions: To increase routine and timely mammography practices, women who are non-adherent to recommended time frequency guidelines should be targeted, together with their health beliefs, predominantly perceived barriers and cues to action.

Keywords: Mammography, Attendance, Adherence, Recent, Health beliefs, Illness perceptions

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Background

Breast cancer (BC) is the most common cancer among women worldwide [1, 2]. The World Health Organization (WHO) has identified prevention, early detection and managing the cancer trajectory as the three pillars in the reduction and control of the global cancer burden [3]. Based on global evidence from randomized controlled trials [4, 5], early detection through mammography screening has been documented to significantly decrease BC mortality rates [6–8], and can lead to early treatment and reduce its negative side-effects [9].

In Malta, BC is the most common type of cancer among women. Around 280 cases have been diagnosed each year in the last decade [10] with the Maltese nation ranking 18th place with the highest incidence of BC in 2012 (85.9 per 100,000) [11]. The Maltese Breast Screening Programme (MBSP) was established in 2009 for women aged 50–60 years every three years [12] and has now expanded its age range to include women aged 61–67 years. Prior to the MBSP, women in Malta could use private mammography (there are currently 7 private practices offering mammography in Malta).

Despite the availability of the MBSP, a number of women still do not attend for mammography at the MBSP or may not attend at recommended intervals. This is evidenced by data from our national cross-sectional survey [13] showing that the uptake rate for first round BS at the MBSP was lower than the European target rate of 70% [9], and similarly for re-attendance, evidenced in our pilot study on the second BS round in Malta [14]. These programmes can only be effective and indeed cost-effective [15] if the attendance of the target screening population is consistent with recommended intervals [16–18] in order to achieve health benefits [8, 16, 19].

Currently, organized breast screening (BS) programmes are offered for free to asymptomatic women by many countries in Western Europe and North America [20], with time intervals between mammograms depending on the varying recommendations of various countries [21]. In Europe, the EU Council recommends a two-year interval to women aged 50–69 years [9, 22]. However, countries implement these recommendations as they consider fit [20]. For instance, Norway adheres to the recommended EU thresholds, while a biennial nationwide screening programme for women aged 50–75 is offered in the Netherlands [23] and regionally organized screening programmes are offered in Switzerland for women over 50, with the age limit varying between 69 and 74 years [24]. Notable exception for the screening interval is by United Kingdom and Malta who opted for a three-yearly screening frequency [25].

Substantial disparity remains to date across countries on attendance at regular time intervals [2] with recent and regular attendance being studied less often than initial attendance [17, 26, 27]. For instance, the more privatized system in the United States may enable less access to mammography than the social health care system found in the United Kingdom [28], suggesting that national context is important and worth exploring. The Maltese National Health System (NHS) adopts a mixed model approach comprising elements from both the public (organized) and private sectors and this is one possible reason for non-participation in the organized screening programme (MBSP) or non-attendance at recommended intervals. Prior to the MBSP rollout across Malta, asymptomatic women could self-refer privately for mammography and symptomatic women were referred by a general practitioner (GP), breast surgeon or gynaecologist either to the public symptomatic breast unit or to the private sector for mammography. Despite having the availability and efficiency of nationally-organised screening programmes, some women may still opt for the service privately and are considered asymptomatic attendees to opportunistic screening [29, 30] but are non-compliant in the context of invitation-based BS [27]. Similarly, screening mammograms taken and read in private clinics [30] remain widely used in America and in European countries such as France, Luxembourg and Switzerland [30–33].

To date, we are not aware of any study that has explored attendance to mammography screening according to recommended time-intervals at organized or private practices. Therefore, in order to understand if Maltese women are adherent with recommendations for BS, we analysed primary survey data in an effort to describe the adherence rates. Hence, in order to analyse the differences between timely mammography adherence and non-adherence to current time interval recommendations (three-year interval), we explored several determinants, mainly health beliefs and illness perceptions. We built on the findings of our prior study [13] which suggests that health beliefs and illness perceptions vary between women who accept or refuse a BS invitation to the organized programme. 'Strengthening the Reporting of Observational Studies in Epidemiology' (STROBE) guidelines [34] [see Additional file 1], have guided the study findings in this article. This study will help to inform public health experts, policy-makers and screening management to tackle regulated routine attendance in their population-based screening programmes.

Theoretical framework

Health beliefs

Health behaviour takes place when a threat is recognized as a result of a health problem [35] and is manipulated by the individual's perception of that threat [36]. The Health Belief Model (HBM) has often been recommended when dealing with behaviours that evoke illness, such as BC [37], and is thus an excellent fit for addressing the health beliefs and perceptions of BS among women. The HBM consists of the following six main variables: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, and self-efficacy [38]. Individuals will take action to prevent, to screen for, or to control BC if they perceive themselves to be susceptible to the condition, if they believe in the seriousness of the potential consequences, if they believe the course of action would reduce their susceptibility to or the severity of the condition, and if they believe that the anticipated benefits to taking the action outweigh the barriers [38]. Based on the HBM, engaging in mammography will be predicted by women's perceptions about BC derived from their knowledge about the disease [39]. Thus, it is significant for healthcare providers to increase knowledge through education about BC and the importance and benefits of BS such as early detection, reduced mortality and improved survival.

Several researchers have used standardized measures of HBM constructs, such as Champion's HBM scales for mammography screening (CHBMS-MS) [35, 40, 41] in order to determine the relationships between health beliefs and health behaviours. These scales have been translated and tested for reliability and validity in diverse populations such as Iranian [40], Lithuanian [42], Malaysian [43], Arabic [44], Korean [45], Chinese-Australian [46], African-American [47], Spanish-speaking American women [48] and Spanish women [41]. However, the variation in BS behaviours is limitedly explained through HBM, since the impact of emotions (such as fear) [49] is not considered, nor does it accommodate social and environmental influences of past behaviour [50]. This is why other models, such as the Common-Sense Model (CSM) of self-regulation, have been utilised to understand BS uptake [51] and to explain the variations in physical and psychological adjustment to BC and disease outcomes [52, 53].

Illness perceptions

According to the Common-Sense Model (CSM), illness perceptions are related to the cognitive (i.e. beliefs, thoughts, ideas) and emotional (i.e. feelings) representations derived from the experience of an illness or illness-related symptoms [54]. Each individual is known to have his/her own beliefs about health / illness due to similar but unique experiences [55]. Hence, an individual's behaviour can be affected by the assessment of symptoms and knowledge, beliefs and risk perceptions [56]. In regard to healthy people, illness perceptions can serve as guides for behaviour in relation to prevention [57] and appear to be precursors of screening behaviour [56].

The utility of the CSM has been extensively investigated quantitatively following the development of a questionnaire, the Illness Perception Questionnaire (IPQ) [58], which addresses the following five key dimensions: symptoms and names (identity), severity of pain and impact on life functions (consequences), expected duration or expected age of onset (timeline), whether the disease was perceived as preventable, curable, or controllable (control/cure) and infection or genetics (internal and external causes), in Leventhal's self-regulatory model [59]. Following advancement in theory and measurement of the constructs related to the CSM, the IPQ has been revised, expanded and renamed as IPQ-R [60] with the inclusion of new dimensions, such as the illness coherence scale in order to better evaluate the overall meaning of the illness for the patient. In addition, the content of the original cure/control component from the IPQ was treated separately in the IPQ-R as the 'personal control' scale i.e. about personal abilities to control the illness and 'treatment control' scale i.e. the efficacy of treatment to cure or manage the illness [61]. Also, the timeline dimension was differentiated into two: (a) timeline (acute/chronic) i.e. beliefs about the relative chronicity of the illness and (b) timeline (cyclical) i.e. beliefs about the fluctuation in symptoms and temporal illness changeability [57]. An important inclusion in IPQ-R was the measure of emotional representations (related to the cognitive components of illness representations) [57, 60].

Methods

The full details of the methods are described in detail elsewhere [13]. In brief, a cross-sectional survey was undertaken in Malta in 2015 and data were drawn retrospectively from a nationally representative sample of eligible women ($n = 404$ with 95% confidence level and a 5% significance level), aged 50–60 years at the time of their first invitation at the MBSP with no personal history of BC. From our total sample, 60% were attendees ($n = 243$) to breast screening and 40% were non-attendees ($n = 161$) to the first call. This is an actual representation of the uptake to the first screening invitation. From every sub-population, the sample was selected by stratified random sampling, i.e. stratified based on district and age to give a true representation based on the demographics of attendance and non-attendance to the first screening round. Hence, all individuals were selected at random based on the above percentages and stratification.

Screening mammography uptake in the past three years was self-reported for women who opted to go privately but for those who had attended the MBSP, attendance or non-attendance was verified through screening records. Participation was voluntary and verbal informed consent was obtained by telephone by a research assistant. Full recruitment details are described in our prior paper [13]. In order to carry out the study according to our methods and consent procedure, formal ethical approval was sought and obtained from the School Research Ethics Committee at the University of Stirling (SREC14/15-Paper No.18v4) and from the Maltese Health Ethics Committee (HEC 02/2015).

Measures

Based on previously validated questionnaires (CHBMS-MS and IPQ-R) [35, 60], our study instrument, a 121-item questionnaire was initially translated from English into the Maltese language, adapted and pilot-tested among Maltese women [62] after securing written permission from the respective authors. A full description of the measures has been published in a previous article [13].

Classification of variables

Women were asked with a yes/no response if they had a mammogram within the past three years (ADHERENT) or whether they had exceeded the three-year frequency (NON-ADHERENT). Furthermore, they were asked to identify the location of their mammogram if they had undergone the screening test recently.

Statistical analysis

Throughout the analyses, basic statistics were presented through the use of mean values or percentages. A Chi-square test was used to test for any significant associations between two categorical variables. The Shapiro-Wilk test was applied on all 14 constructs to determine whether these variables are normally distributed. Since only the variable (Causes of BC) was normally distributed, the Independent Samples t-test (parametic test) was used for the latter construct to compare two independent samples, while the Mann-Whitney test was used for the non-normal distributed variables (non-parametric test) i.e. for all the other 13 constructs which were not normally distributed ($p < 0.001$). Missing data was minimal and reported in our previous paper [13]. Statistical significance was established at $p < 0.05$ for all analyses.

Results

Sample characteristics

The mean age was 54.6 years ±2.8 years (SD). A table presenting the sample characteristics for the total sample (n = 404) is available in our previous published paper [13]).

Mammography screening practices

Figure 1 presents the mammography screening practices by Maltese women. From the total sample of 404 women, 80.2% (n = 324) had a recent mammogram (ADHERENT), 5.9% (n = 24) had exceeded the three-year frequency (NON-ADHERENT) and 13.9% (n = 56) never had a mammogram.

Out of the 404 women, 60.1% (n = 243) attended the MBSP and 39.9% (n = 161) did not. Out of 39.9% (n = 161) of women who did not undergo a mammogram at the MBSP, there were 65.2% (n = 105) who underwent mammography elsewhere (at a private practice), of which 82.9% (n = 87) had a mammogram within three years (ADHERENT) while 17.1% (n = 18) had a mammogram that exceeded the recommended regular three-year frequency (NON-ADHERENT).

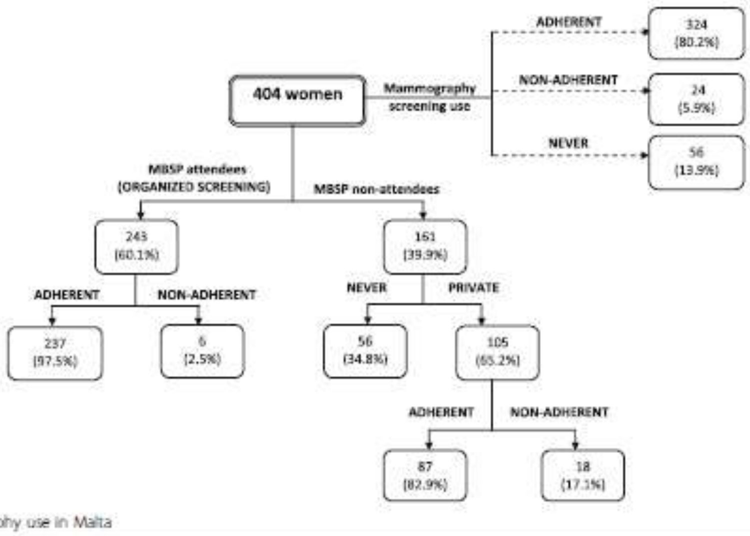

Fig. 1 Mammography use in Malta

Out of the 60.1% ($n = 243$) of women who underwent a mammogram at the MBSP, 97.5% ($n = 237$) had a recent screening mammography at the MBSP (ADHERENT), while 2.5% ($n = 6$) exceeded the three-year frequency (NON-ADHERENT). When applying a Chi-square test to compare NON-ADHERENCE to private practice versus NON-ADHERENCE to MBSP (17.1% versus 2.5%), this result was found to be significantly associated ($\chi 2 = 24.6$, $p = 0.000$).

Those who never attended for mammography anywhere ($n = 56$) were excluded from this analysis as this group was already analysed in further detail in our previous published paper on lifetime mammography use [63].

ADHERENT versus NON-ADHERENT subgroup analyses

Chi-square tests were performed to explore associations between ADHERENT and NON-ADHERENT attenders and the following variables: sociodemographic factors, health status, knowledge, health beliefs and illness perceptions.

Sociodemographic characteristics and health status

No significant associations were found between ADHERENT or NON-ADHERENT women in relation to sociodemographic or health status variables ($p > 0.05$).

Knowledge of breast screening frequency

Knowledge of BS frequency was significantly associated with women's adherence to mammography screening ($\chi 2 = 5.5$, $p = 0.020$). The main difference arises from those who said they were 'unsure' about the recommended frequency, where 12.5% of the non-adherent group were unsure about the recommended BS frequency while only 3.1% of the adherent group were unsure of the recommended time interval.

Health beliefs

Some sub-scale items for perceived barriers and cues to action were found to be statistically significant ($p < 0.05$) when comparing adherent versus non-adherent women (Table 1). Non-adherent women were undecided on the following items when compared to adherent women: 'having a routine mammogram would make you anxious about BC' ($p = 0.040$), 'if your GP advises you to attend, you will attend' ($p = 0.038$), 'hearing about BC and BS in the media or news makes you think about getting a mammogram' ($p = 0.030$), or 'reminder letters', 'reminder phone calls or text messages' would help you to get a mammogram' ($p = 0.000$ respectively). Women who fear or distrust the medical team ($p = 0.003$) or who feel they have too many other problems in life ($p = 0.001$) tend to attend less frequently. Women who do not agree that reminder letters, reminder phone calls or text messages would help them to get a mammogram ($p = 0.000$ respectively) also tend to attend less frequently to mammography.

Illness perceptions

Women who are undecided on the following subscale items attend less frequently for mammography: 'your mental attitude' ($p = 0.008$), 'family problems or worries' ($p = 0.035$), your emotional state' ($p = 0.000$), 'your personality' ($p = 0.006$), and 'you get anxious when you think about BC' ($p = 0.044$) (Table 2). Mann Whitney test and Independent Samples t-test were applied to compare 'ADHERENT' and 'NON-ADHERENT' mammography use against all 14 constructs, showing a statistically significant difference in perceived barriers and cues to action ($p = 0.000$, $p = 0.039$ respectively) between adherent and non-adherent women (Table 3).

The findings show that for women who were NON-ADHERENT to the three-year time frequency for mammography use perceive higher barriers and lower cues to action than ADHERENT women.

Discussion

This study made possible an understanding of the determinants of timely BS behaviour in Malta which may aid the development of evidence-based and culturally-sensitive interventions for the Maltese population. Our findings show that women who have previously participated in BS practices may already understand the screening benefits for BC, have come to terms with barriers to undergo mammography, and have confidence in their abilities to get screened [2] and thus attend for mammography at the recommended time intervals. Similarly, findings by Moodi et al. [64] suggest that women who previously had at least one mammogram in their lifetime had higher levels of health motivation, perceived benefits, and perceived self-efficacy to mammography screening and fewer perceived barriers to having a mammogram. This further proves that previous mammography use strongly predicts subsequent screening [2, 14, 64].

Our study showed that there were some Maltese women who did not attend for mammography in a timely manner. In terms of (self-initiated) behaviour with mammography, this could be due to the fact that not all women may view this as a positive action to improving health outcomes. Identifying attributes of non-attending women to regular time intervals entails going beyond demographic differences to reveal complex interactions among personality attributes. Consistent with Champion's Health Belief Model and Leventhal's Common-Sense Model of self-regulation, it was the 'perceived barriers' and 'cues to action' constructs that emerged as the strongest predictors to describe the variance between the ADHERENT and NON-ADHERENT groups. Hence, women who attend at longer intervals may need to

Table 1 Health Belief items

	ADHERENT versus NON-ADHERENT	
Health Beliefs	χ2	*p*-value
There is no possibility of getting breast cancer *(r)*	5.5	0.239
Your chances of getting breast cancer are high	0.3	0.960
There may be the possibility of developing breast cancer in your lifetime	7.8	0.055
When you get a mammogram, you feel good about yourself	5.9	0.115
When you get a mammogram, you do not worry as much about breast cancer	3.6	0.302
Having a mammogram will help you find lumps early in your breasts	0.9	0.819
If you find a lump through a mammogram, the treatment for breast cancer may not be as bad	0.7	0.863
Having a mammogram will decrease your chances of dying from breast cancer	1.2	0.744
Having a mammogram will help you find a lump before it can be felt by yourself or a health professional	1.5	0.676
Having a routine mammogram would make you anxious about breast cancer	8.3	0.040*
Having a routine mammogram would make you worry	3.2	0.522
You fear having a mammogram because you might find out that something is wrong	5.3	0.257
You fear having a mammogram because you do not know the procedure or what to expect	2.8	0.418
You fear having a mammogram because you know someone (family or friend) with breast cancer	7.0	0.136
It is embarrassing for you to have a mammogram	6.0	0.055
Undergoing mammography will be painful or uncomfortable	3.8	0.284
Having a mammogram is time consuming	2.7	0.258
You are discontent with Breast Screening personnel as they have been rude to you	n/a	n/a
You have fear or distrust in the medical team	13.9	0.003*
Having a mammogram would expose you to unnecessary radiation	4.7	0.197
You have too many other problems in your life than to get a mammogram done	14.9	0.001*
You are not old enough to have a mammogram periodically	0.4	0.823
If your GP advises you to attend for a mammogram, you will attend	8.4	0.038*
If your relatives or friends advise you to attend for a mammogram, you will attend	1.3	0.741
If someone close to you has been diagnosed with breast cancer, you will attend for a mammogram	3.2	0.362
Hearing about breast cancer and breast screening in the media or news makes you think about getting a mammogram	8.9	0.030*
Reminder letters would help you to get a mammogram	20.9	0.000*
Reminder phone calls or text messages would help you to get a mammogram	20.9	0.000*
Routine educational talks regarding breast cancer awareness would help you to get a mammogram	6.7	0.820
You feel confident that if you had a mammogram done, any abnormalities in your breasts will be detected	4.7	0.318
You can arrange other things in your life to get a mammogram	1.5	0.821
In case you need a mammogram, you will find a place to get it done	1.8	0.752
You can make an appointment for a mammogram	1.7	0.800
You can arrange transportation to get a mammogram	1.6	0.812
You can talk to people at the breast screening centre about your concerns	n/a	n/a
You can find a way to pay for a mammogram if you need to	2.3	0.511

(r) = reverse scored
*Significant at $\alpha = 0.05$
Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1 and 5, where 1 = strongly disagree and 5 = strongly agree. For certain items, responses were re-grouped to ensure the feasibility of the Chi-square test

overcome barriers to seeking mammography and follow tailored cues to action in order to attend at recommended time intervals.

A plausible explanation for the disappearance of an effect of socio-demographic factors in our subgroup analyses on adherence in this study is that they represent 'carriers', as described by Lagerlund [65], of already established health-related behaviours. This is evidence in all our studies on first invitation to MBSP [13], re-attendance [14] and lifetime mammography use [63], where different socio-demographic and health status variables were non-significant predictors of uptake to mammography screening.

Literature suggests that having a breast condition or symptoms increase the use of mammography [66, 67] but this factor has not been found consistently in all studies [27, 68] and similarly, not in this study on timely mammography adherence. These results can indicate trust in the health care system and positive cancer experiences such as family members or close friends surviving cancer, but this issue needs further attention, preferable in qualitative research.

In all our data analyses, knowledge of the BS frequency was found to be significantly associated with MBSP attendance [13], re-attendance [14], lifetime screening [63]

Table 2 Illness Perception items

Illness Perceptions	ADHERENT versus NON-ADHERENT $\chi2$	p-value
The presence of a lump or thickening in the breast	3.2	0.361
Nipple discharge	4.1	0.254
Sudden nipple retraction	7.0	0.072
Change in shape or appearance of the nipple	7.9	0.052
Breast swelling, dimpling, redness or soreness of the skin	3.6	0.305
Skin changes of the breast	4.7	0.193
A sudden change in breast size	1.5	0.682
Aching breasts	6.2	0.185
Stress or worry	2.8	0.250
Your mental attitude (e.g. thinking about life negatively)	12.0	0.008*
Family problems or worries	6.7	0.035*
Overwork	7.5	0.057
Your emotional state (e.g. feeling down, lonely, anxious, empty)	22.0	0.000*
Your personality	12.3	0.006*
Hereditary - it runs in the family	3.2	0.360
Diet or eating habits	1.9	0.590
Poor medical care in the past	1.4	0.699
Your own behaviour	3.8	0.282
Ageing	0.8	0.663
Smoking	0.5	0.927
Alcohol	0.0	0.979
A germ or virus	2.9	0.234
Pollution in the environment	2.8	0.428
Altered immunity	0.4	0.933
Chance or bad luck	1.0	0.908
Accident or injury	1.2	0.875
Breast cancer will last a short time	0.6	0.904
Breast cancer is likely to be permanent rather than temporary	4.8	0.089
A patient with breast cancer goes through cycles in which her illness gets better and worse	1.6	0.800
Breast cancer has major consequences on a patient's life	2.1	0.559
Breast cancer will not have much effect on your life	2.4	0.662
Breast cancer would strongly affect the way others see you	4.4	0.351
Breast cancer has serious economic and financial consequences	0.8	0.840
Breast cancer would strongly affect the way you see yourself as a person	2.7	0.446
Breast cancer would threaten a relationship with your husband or partner	3.6	0.461
If you had breast cancer, your whole life would change	0.6	0.902
If you developed breast cancer, the chances of living a long life would decrease	0.8	0.844
There is a lot which you can do to control the symptoms if Breast Cancer occurs	1.3	0.869
The course of Breast Cancer will depend on your actions	1.7	0.646
Your actions will have an effect on the outcome of Breast Cancer	1.1	0.787
There is no treatment that will help to improve Breast Cancer	4.0	0.406
The treatment provided will be effective in controlling or curing Breast Cancer	0.5	0.926
The negative effects of Breast Cancer can be prevented or avoided by the treatment given	1.0	0.914
You have a clear picture and understanding of Breast Cancer	2.6	0.455
Breast Cancer is a mystery to you	1.7	0.786
You get anxious when you think about Breast Cancer	8.1	0.044*
Breast Cancer makes you feel afraid	0.7	0.875
You get worried when you think about Breast Cancer	0.7	0.871

*Significant at $\alpha = 0.05$

Chi-square test was applied for all health beliefs; hence the categorical answers were used to apply this test for association. For each question, respondents were asked to select a number between 1to 5, where 1 = strongly disagree and 5 = strongly agree. For certain items, responses were re-grouped to ensure the feasibility of the Chi-square test

and likewise in this study on timely mammography adherence, showing that women who were unsure were less likely to attend for a mammogram at recommended intervals. Ritvo et al. [19] expands on such data, showing that it becomes more consequential with findings that the belief about recommended screening intervals predicts screening adherence in women with a family history of BC. Our findings are consistent with studies that examined the relationship in average risk women over 50 years where women who reported screening according to the respective national guidelines were significantly more likely to adhere than women who reported less frequent time intervals [19, 69, 70]. Our results underscore the significance of communicating and reiterating a screening interval recommendation to women such that they develop strong beliefs about the need to screen at that recommended time interval.

Table 3 Comparisons between the frequency of mammography use and health beliefs/illness perception constructs

	ADHERENT (n = 324)	NON-ADHERENT (n = 24)	Test Statistic	p-value
Perceived Susceptibility	M = 9.6, SD = 1.0	M = 9.4, SD = 0.9	3641.0[a]	0.577
Perceived Benefits	M = 24.0, SD = 1.8	M = 23.9, SD = 1.3	3515.0[a]	0.387
Perceived Barriers	M = 27.2, SD = 4.7	M = 31.1, SD = 5.0	5540.5[a]	0.000*
Cues to action	M = 27.4, SD = 3.2	M = 26.0, SD = 3.5	2919.0[a]	0.039*
Self-Efficacy	M = 24.8, SD = 2.7	M = 24.5, SD = 2.1	3666.5[a]	0.615
Breast Cancer Identity	M = 30.6, SD = 2.1	M = 30.3, SD = 3.4	4136.5[a]	0.582
Causes of Breast Cancer	M = 55.9, SD = 7.2	M = 57.0, SD = 6.9	-0.7[b]	0.467
Cancer Timeline: Acute/Chronic	M = 6.1, SD = 0.9	M = 5.9, SD = 1.0	3515.5[a]	0.402
Cancer Timeline: Cyclical	M = 3.6, SD = 0.7	M = 3.7, SD = 0.6	4271.0[a]	0.327
Consequences	M = 28.2, SD = 2.5	M = 28.5, SD = 2.7	4247.5[a]	0.446
Personal Control	M = 11.8, SD = 0.8	M = 11.9, SD = 0.6	3905.5[a]	0.951
Treatment Control	M = 9.9, SD = 0.7	M = 10.0, SD = 0.5	4166.5[a]	0.397
Illness Coherence	M = 6.9, SD = 1.2	M = 7.3, SD = 0.9	4538.0[a]	0.139
Emotional Representations	M = 12.2, SD = 2.1	M = 12.7, SD = 1.8	4348.0[a]	0.320

*Significant at $\alpha = 0.05$
[a]Mann Whitney test
[b]Independent Samples t-test

In some countries with dual public and private screening programmes, there is only partial understanding of adherence. Women who were active in opportunistic screening, for instance, are considered non-compliant to the screening programme [27]. Moreover, varying patterns of opportunistic screening exist (differing age groups, sometimes single view mammography) [71], including varying screening intervals such that women's last mammography may have been longer than the recommended screening guidelines [9, 72].

The reasons why women chose to opt for private mammography rather than to the organized programme are not yet fully understood. This may be due to women seeking BS at a younger age (30–49) as a precautionary measure [20] and continue to sustain early detection practices in this way. Evidence from the U.S. National Health Interview Survey revealed that 29% of women aged 30–39 have undergone mammography [73] while data from the 2010 Behavioural Risk Factor Surveillance Study showed that 83% of women aged 40–49 have had BS [74]. Hence, public health strategies and wide media coverage directed at convincing older women to engage in BS may arouse a positive attitude among younger age groups towards early detection practices [75, 76] or may induce anxiety and fear of BC and mortality, motivating younger women, particular those aged 40–49, to engage in mammography screening [20].

The balance of benefits and harms remains to date a strongly debated topic in the field of population-based BS [77]. Although the usually considered benefits from BS include avoiding deaths from BC, achieving less invasive treatments and improving quality of life, there is growing concern that mammography may be overused (overscreening) [78], or screening may result in the detection by screening of BCs that would never have come to clinical attention (overdiagnosis) [79] and thus women receiving treatment for a slow growing or non-invasive cancer which would have unlikely caused any problems if left untreated [80]. Given the lack of reliable evidence, an independent expert panel estimated that around 1 in 4 women (or 4000 out of around 15,500 women) are overdiagnosed in the UK [81]. This is coupled with the side-effects and anxiety that anyone having cancer treatment goes through. Moreover, experts estimate that for every 10,000 women who have regular three-year screening between 47 and 73 years in the UK, there will be between 3 to 6 extra BCs caused by radiation [81]. Notwithstanding, the recent IARC Working Group [79] found sufficient evidence of a reduction in BC mortality through mammography screening in women aged 50–74 years, to the extent that the benefits substantially outweigh the risk of radiation-induced cancer and of overdiagnosis. Moreover, the survival rate of patients with early-detected BC through routine screening is approximately double that from detected cancers through other methods [81]. Unlike consistent mortality reductions reported through organised screening programmes [82], there is yet no direct evidence to support the effectiveness of opportunistic screening [83, 84].

Our results suggest that those attending an organised screening programme such as, the MBSP, are more likely to adhere to recommended time intervals when compared with those attending the private sector for screening. In order to reach greater adherence to recommended time intervals, women should receive further information on the recommended screening frequency and the benefits of being part of an organised programme [31, 85]. For example, in Malta, private screening does not have the same quality controls as the MBSP such as higher quality of mammographic interpretation through special training of the readers and mammographers, double-reading and consensus reads [71]. For instance, a mammogram in organised screening is read by two radiologists, who interpret at least 5000 screening mammograms a year. This is the recommended volume set by the European Guidelines for Quality Assurance in Breast Cancer Screening [30, 82, 84–86] and the desirable individual level of experience set in the United Kingdom [87]. Moreover, based on a similar screening context as our local system, other studies raise awareness that organized screening leads to inequality reductions, higher quality assurance, and more timely screens than opportunistic screening [27, 71, 83, 88].

While private screening remains unregulated, quality cannot be guaranteed which is why national screening programmes are recommended [71, 89]. Therefore, a key benefit of a national screening programme is that women can be individually monitored to ensure that they are conformant with screening guidelines and that they are adequately monitored in terms of robust quality assurance measures.

Strengths and limitations

Although this study was limited to the Maltese setting, much of the developed world has organised breast screening programs and access to the same body of scientific evidence, and thus the findings are likely to be broadly applicable across these countries. However, we found no study that has similarly and simultaneously assessed sociodemographic and psychological variables as predictors of timely attendance and specifically attendance at organized or opportunistic screening. We also found none which utilised HBM and CSM as the theoretical framework. The major strength of this study is the rich dataset which allowed us to analyse diverse subgroups. However, this is not without possible response bias as a source of possible weakness. Since this study was cross-sectional, it precludes looking at cause-and-effect relationships over time. While a Chi-square test showed that women who attend private screening were less likely to be regulated in their attendance when compared to MBSP attendees, it cannot be ruled out that women attending private screening would be less likely to attend screening regularly even if they attended MBSP. This could be due to the characteristics of the women attending private screening. Although screening attendance was confirmed through screening records, our records of private mammography were self-reported and hence, subject to bias. Self-reported data could also have affected the observed difference between women attending private screening and the MBSP. Objective measurement would require data from private clinics, which was not possible to obtain, since no data records from private screening in Malta are nationally available to date. As a first step, it would be necessary to identify reliable and validated measures for regular mammography use that can be used simultaneously in government organised and private screening programmes. While limited studies to date have been of sufficient dimension to provide results on irregular attendance [16], qualitative studies would contribute towards understanding why health beliefs influence adherence.

Conclusions

Our results suggest that attendance at an organised BS programme improves adherence to recommended time intervals when compared with those attending the private sector for screening. In order to reach greater adherence to recommended time intervals, women should be made more aware of the recommended screening frequency and on the benefits of being part of an organised programme. Women can be individually monitored through the national screening programme to ensure that they are conformant with screening guidelines. Screening programmes should target women's health beliefs, in particular perceived barriers and cues to action, which have emerged as the most important factors to distinguish between adherent and non-adherent women to improve adherence to recommended time intervals. Further qualitative research is required to understand in more depth why women choose opportunistic screening over an organised programme.

Additional file

Additional file 1: STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*. (DOCX 22 kb)

Abbreviations

B: Unstandardized coefficients; *BC*: Breast cancer; BS: Breast screening; CHBMS-MS: Champion's Health Belief Model Scale for Mammography Screening; CI: Confidence interval; CSM: Common-sense model; DNA: Did not attend; GP: General practitioner; *HBM*: Health belief model; IPQ: Illness perception questionnaire; IPQ-R: Revised illness perception questionnaire; M: mean score; MBSP: Maltese Breast Screening Programme; OR: Odds ratio; SD: Standard deviation; SE: Standard error; WHO: World Health Organization

Acknowledgements

The authors would like to forward their gratitude to Prof. Victoria Champion and Prof. Rona Moss-Morris for developing the CHBMS-MS and IPQ-R scales respectively and for providing the opportunity to translate and adapt it into the Maltese culture and language. This study was developed as part of the activities of the PhD in Health offered by the University of Stirling, Scotland.

We thank the National Screening Programme in Malta for providing access to the data.

Funding
The PhD program is part-financed by the Malta Government Scholarship Scheme (MGSS), Government of Malta. The main author would like to thank the MGSS for the financial support offered to DM. DM is supported by a grant (MGSS Contract MEDE 96/2012/25) that covers the University of Stirling fees. The rest of the studentship and running costs of this study were self-funded by DM.

Availability of data and materials
Data supporting the conclusions of this study are included within the manuscript. The raw datasets analysed during the current study are available from the corresponding author on reasonable request.

Authors' contributions
DM conceived the study, supervised all aspects of its conduction and wrote the manuscript. VM assisted with data analysis and interpretation of data and revised the manuscript. GH assisted with the study design, and critically reviewed and revised the manuscript. All authors helped to conceptualise ideas, interpret findings and review drafts of the manuscript. All authors read and approved the final manuscript.

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Ethics approval and consent to participate
Ethics approval was obtained via an application to the School Research Ethics Committee at the University of Stirling (SREC14/15-Paper No.18v4) and from the Maltese Health Ethics Committee (HEC 02/2015). The research assistant documented consent, which was provided by the participants over the telephone. The research assistant carried this out manually, using paper format to record verbal consent by ticking Yes/No according to the participant's response. Explaining the study and obtaining consent by telephone facilitated comprehension and reduced the unnecessary burden entailed in a written consent form.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests regarding the publication of this paper.

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Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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Received: 10 September 2017 Accepted: 21 March 2018
Published online: 27 March 2018

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Appendix 4.4.2 - STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cross-sectional studies

Section/Topic	Item #	Recommendation	Reported on page # (of published Study 5)
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2-3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-6
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	9
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	9
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	9
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	10
Bias	9	Describe any efforts to address potential sources of bias	19-20
Study size	10	Explain how the study size was arrived at	9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	10
		(*b*) Describe any methods used to examine subgroups and interactions	10
		(*c*) Explain how missing data were addressed	10
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	11
		(b) Give reasons for non-participation at each stage	11
		(c) Consider use of a flow diagram	11
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11

		(b) Indicate number of participants with missing data for each variable of interest	11
Outcome data	15*	Report numbers of outcome events or summary measures	12-14
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	12-14
Discussion			
Key results	18	Summarise key results with reference to study objectives	15-19
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19-20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20-21
Generalisability	21	Discuss the generalisability (external validity) of the study results	19
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix 5.1 – Primary searches across electronic databases

Ovid MEDLINE(R)

#	Searches	Results	Type
1	exp Breast Neoplasms/	264303	Advanced
2	exp Mammography/	27798	Advanced
3	(breast screen* or mammog*).af.	38816	Advanced
4	(breast cancer* or breast tum?r* or breast neoplasm*).af.	334972	Advanced
5	1 or 2 or 3 or 4	343970	Advanced
6	exp Mass Screening/	116495	Advanced
7	(health screen* or mass screen* or cancer screen*).af.	115973	Advanced
8	6 or 7	137995	Advanced
9	5 and 8	15115	Advanced
10	(campaign* or educat* or interven* or program* or promot* or outreach* or navigat*).af.	3694287	Advanced
11	9 and 10	7450	Advanced
12	(attitud* to health or health* attitud*).af.	263632	Advanced
13	exp Attitude to Health/	371943	Advanced
14	exp health promotion/ or exp health educattion/	68934	Advanced
15	(patient ed* or health ed* or health promot* or health navigat* or patient navigat*).af.	280271	Advanced
16	(audiovisual* or audio-visual*).af.	11868	Advanced
17	12 or 13 or 14 or 15 or 16	692104	Advanced
18	11 and 17	2974	Advanced
19	limit 18 to (english language and yr="2000 - 2015")	1802	Advanced
20	(1 or 2 or 3) and 4	266776	Advanced
21	8 and 20	13191	Advanced
22	10 and 21	6355	Advanced
23	17 and 22	2548	Advanced
24	limit 23 to (english language and yr="2000 - 2015")	1556	Advanced

PUBMED

Search	Query	Items found
#33	Search (#19 and #30) Filters: Publication date from 2000/01/01 to 2015/12/31; English	1832
#32	Search (#19 and #30) Filters: Publication date from 2000/01/01 to 2015/12/31	1937
#31	Search (#19 and #30)	3018
#30	Search (#29 or #28 or #27 or #25 or #23 or #21)	744992
#29	Search (audiovisual* or audio-visual*)	11269
#28	Search (patient ed* or health ed* or health promot* or health navigat* or patient navigat*)	270476
#27	Search "Health Education"[Mesh]	225911
#25	Search "Health Promotion"[Mesh]	69216
#23	Search "Attitude to Health"[Mesh]	373827
#21	Search (attitud* to health or health* attitud*)	315880
#19	Search (#17 and #18)	7412
#18	Search (campaign* or educat* or interven* or program* or promot* or outreach* or navigat*)	3657767
#17	Search (#12 and #16)	15105
#16	Search (#14 or #15)	138321
#15	Search (health screen* or mass screen* or cancer screen*)	116206
#14	Search "Mass Screening"[Mesh]	116906
#12	Search ((#3 or #5 or #7 or #8))	342789
#8	Search (breast cancer* or breast tum?r* or breast neoplasm*)	333669
#7	Search (breast screen* or mammog*)	38915
#5	Search "Mammography"[Mesh]	27881
#3	Search "Breast Neoplasms"[Mesh]	265381

WEB of Science

Search History: All Databases

Set	Results	Save History / Open Saved History	Combine Sets (AND / OR, Combine)	Delete Sets (Select All, Delete)
# 12	548	#9 AND #6 **Refined by: PUBLICATION YEARS:** (2011 OR 2007 OR 2002 OR 2008 OR 2012 OR 2006 OR 2013 OR 2003 OR 2005 OR 2004 OR 2001 OR 2014 OR 2010 OR 2009 OR 2000 OR 2015) AND **LANGUAGES:** (ENGLISH) *Timespan=2000-2015* *Search language=Auto*	Select to combine sets.	Select to delete this set.
# 11	586	#9 AND #6 **Refined by: PUBLICATION YEARS:** (2011 OR 2007 OR 2002 OR 2008 OR 2012 OR 2006 OR 2013 OR 2003 OR 2005 OR 2004 OR 2001 OR 2014 OR 2010 OR 2009 OR 2000 OR 2015) *Timespan=2000-2015* *Search language=Auto*	Select to combine sets.	Select to delete this set.
# 10	586	#9 AND #6 *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 9	Approximately 241,513	#8 OR #7 *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 8	Approximately 203,946	**TOPIC:** (("patient ed*" or "health ed*" or "health promot*")) *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 7	Approximately 45,449	**TOPIC:** (("attitud* to health" or "health* attitud*")) *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 6	Approximately 6,287	#5 AND #4 *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 5	Approximately 8,302,550	**TOPIC:** (campaign* or educat* or intervent* or program* or promot* or outreach* or navig*) *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 4	Approximately 10,926	#3 AND #2 AND #1 *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 3	Approximately 107,324	**TOPIC:** (("health screen*" or "mass screen*" or "cancer screen*")) *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 2	Approximately 829,112	**TOPIC:** (("breast cancer*" or "breast tum?r*" or "breast neoplasm*")) *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.
# 1	Approximately 72,421	**TOPIC:** (("breast screen*" or mammog*) *Timespan=2000-2015* *Search language=English*	Select to combine sets.	Select to delete this set.

PsycINFO

S5	S3 AND S4	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - PsycINFO	221
S4	audio-visual aid* or audiovisual aid* or health educat* or patient educat* or attitud* to health	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - PsycINFO	27,517
S3	S1 AND S2	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - PsycINFO	1,461
S2	campaign* or educat* or interven* or program* or promot* or outreach*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - PsycINFO	1,167,204
S1	breast screen* or mammog*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - PsycINFO	1,850

Scopus

- 10

History Search Terms(((TITLE-ABS-KEY (**"breast screen*"** OR **mammogra***)) OR (TITLE-ABS-KEY ((**"breast cancer*"** OR **"breast tum?r*"** OR **"breast neoplasm*"**) AND **screen***))) AND (TITLE-ABS-KEY (**uptak*** OR **up-tak*** OR **increas*** OR **facilitat*** OR **comply** OR **complianc*** OR **attend*** OR **adher*** OR **predict*** OR **determin*** OR **understand***)) AND (TITLE-ABS-KEY (**metaanal*** OR **meta-anal***))) AND (TITLE (**metaanal*** OR **meta-anal***)) AND (LIMIT-TO (PUBYEAR , **2014**) OR LIMIT-TO (PUBYEAR , **2013**) OR LIMIT-TO (PUBYEAR , **2012**) OR LIMIT-TO (PUBYEAR , **2011**) OR LIMIT-TO (PUBYEAR , **2010**) OR LIMIT-TO (PUBYEAR , **2009**) OR LIMIT-TO (PUBYEAR , **2008**) OR LIMIT-TO (PUBYEAR , **2007**) OR LIMIT-TO (PUBYEAR , **2006**) OR LIMIT-TO (PUBYEAR , **2005**) OR LIMIT-TO (PUBYEAR , **2014**) OR LIMIT-TO (PUBYEAR , **2013**) OR LIMIT-TO (PUBYEAR , **2012**) OR LIMIT-TO (PUBYEAR , **2011**) OR LIMIT-TO (PUBYEAR , **2010**) OR LIMIT-TO (PUBYEAR , **2009**) OR LIMIT-TO (PUBYEAR , **2008**) OR LIMIT-TO (PUBYEAR , **2007**) OR LIMIT-TO (PUBYEAR , **2006**) OR LIMIT-TO (PUBYEAR , **2005**) OR LIMIT-TO (PUBYEAR , **2004**) OR LIMIT-TO (PUBYEAR , **2003**) OR LIMIT-TO (PUBYEAR , **2002**) OR LIMIT-TO (PUBYEAR , **2001**) OR LIMIT-TO (PUBYEAR , **2000**)) AND (LIMIT-TO (LANGUAGE , **"English"**))

78 document results

- History Search Identifier9

History Search TermsTITLE (**metaanal*** OR **meta-anal***)

45,288 document results

- History Search Identifier8

History Search Terms(((TITLE-ABS-KEY (**"breast screen*"** OR **mammogra***)) OR (TITLE-ABS-KEY ((**"breast cancer*"** OR **"breast tum?r*"** OR **"breast neoplasm*"**) AND **screen***))) AND (TITLE-ABS-KEY (**uptak*** OR **up-tak*** OR **increas*** OR **facilitat*** OR **comply** OR **complianc*** OR **attend*** OR **adher*** OR **predict*** OR **determin*** OR **understand***)) AND (TITLE-ABS-KEY (**metaanal*** OR **meta-anal***))) AND (TITLE (**metaanal*** OR **meta-anal***)) AND (LIMIT-TO (PUBYEAR , **2014**) OR LIMIT-TO (PUBYEAR , **2013**) OR LIMIT-TO (PUBYEAR , **2012**) OR LIMIT-TO (PUBYEAR , **2011**) OR LIMIT-TO (PUBYEAR , **2010**) OR LIMIT-TO (PUBYEAR , **2009**) OR LIMIT-TO (PUBYEAR , **2008**) OR LIMIT-TO (PUBYEAR , **2007**) OR LIMIT-TO (PUBYEAR , **2006**) OR LIMIT-TO (PUBYEAR , **2005**) OR LIMIT-TO (PUBYEAR , **2014**) OR LIMIT-TO (PUBYEAR , **2013**) OR LIMIT-TO (PUBYEAR , **2012**) OR LIMIT-TO (PUBYEAR , **2011**) OR LIMIT-TO (PUBYEAR , **2010**) OR LIMIT-TO (PUBYEAR , **2009**) OR LIMIT-TO (PUBYEAR , **2008**) OR LIMIT-TO (PUBYEAR , **2007**) OR LIMIT-TO (PUBYEAR , **2006**) OR LIMIT-TO (PUBYEAR , **2005**) OR LIMIT-TO (PUBYEAR , **2004**) OR LIMIT-TO (PUBYEAR , **2003**) OR LIMIT-TO (PUBYEAR , **2002**) OR LIMIT-TO (PUBYEAR , **2001**) OR LIMIT-TO (PUBYEAR , **2000**)) AND (LIMIT-TO (LANGUAGE , **"English"**))

326 document results

- History Search Identifier7

History Search Terms(((TITLE-ABS-KEY (**"breast screen*"** OR **mammogra***)) OR (TITLE-ABS-KEY ((**"breast cancer*"** OR **"breast tum?r*"** OR **"breast neoplasm*"**) AND **screen***))) AND (TITLE-ABS-KEY (**uptak*** OR **up-tak*** OR **increas*** OR **facilitat*** OR **comply** OR **complianc*** OR **attend*** OR **adher*** OR **predict*** OR **determin*** OR **understand***)) AND (TITLE-ABS-KEY (**metaanal*** OR **meta-anal***))) AND (TITLE (**metaanal*** OR **meta-anal***)) AND (LIMIT-TO (PUBYEAR , **2014**) OR LIMIT-TO (PUBYEAR , **2013**) OR LIMIT-TO (PUBYEAR , **2012**) OR LIMIT-TO (PUBYEAR , **2011**) OR LIMIT-TO (PUBYEAR , **2010**) OR LIMIT-TO (PUBYEAR , **2009**) OR LIMIT-TO (PUBYEAR , **2008**) OR LIMIT-TO (PUBYEAR , **2007**) OR LIMIT-TO (PUBYEAR , **2006**) OR LIMIT-TO (PUBYEAR , **2005**) OR LIMIT-TO (PUBYEAR , **2014**) OR LIMIT-TO (PUBYEAR , **2013**) OR LIMIT-TO (PUBYEAR , **2012**) OR LIMIT-

TO (PUBYEAR , **2011**) OR LIMIT-TO (PUBYEAR , **2010**) OR LIMIT-TO (PUBYEAR , **2009**) OR LIMIT-TO (PUBYEAR , **2008**) OR LIMIT-TO (PUBYEAR , **2007**) OR LIMIT-TO (PUBYEAR , **2006**) OR LIMIT-TO (PUBYEAR , **2005**) OR LIMIT-TO (PUBYEAR , **2004**) OR LIMIT-TO (PUBYEAR , **2003**) OR LIMIT-TO (PUBYEAR , **2002**) OR LIMIT-TO (PUBYEAR , **2001**) OR LIMIT-TO (PUBYEAR , **2000**))

354 document results

- History Search Identifier6

History Search Terms(((TITLE-ABS-KEY (**"breast screen*"** OR **mammogra***)) OR (TITLE-ABS-KEY ((**"breast cancer*"** OR **"breast tum?r*"** OR **"breast neoplasm*"**) AND **screen***))) AND (TITLE-ABS-KEY (**uptak*** OR **up-tak*** OR **increas*** OR **facilitat*** OR **comply** OR **complianc*** OR **attend*** OR **adher*** OR **predict*** OR **determin*** OR **understand***)) AND (TITLE-ABS-KEY (**metaanal*** OR **meta-anal***))) AND (TITLE (**metaanal*** OR **meta-anal***))

406 document results

- 5

TITLE-ABS-KEY(**metaanal* or meta-anal***)

130,986 document results

- 4

TITLE-ABS-KEY(**uptak* or up-tak* or increas* or facilitat* or comply or complianc* or attend* or adher* or predict* or determin* or understand***)

16,182,422 document results

- 3

(((**TITLE-ABS-KEY("breast screen*" or mammogra***)) or (**TITLE-ABS-KEY(("breast cancer*" or "breast tum?r*" or "breast neoplasm*"**) and screen*))) and (**TITLE-ABS-KEY(uptak* or up-tak* or increas* or facilitat* or comply or complianc* or attend* or adher* or predict* or determin* or understand***)) and (**TITLE-ABS-KEY(metaanal* or meta-anal***))) and (**TITLE(metaanal* or meta-anal***))

74,305 document results

- 2

TITLE-ABS-KEY(**("breast cancer*" or "breast tum?r*" or "breast neoplasm*"**) and screen*)

40,461 document results

- 1

TITLE-ABS-KEY(**"breast screen*" or mammogra***)

51,523 document results

EMBASE

Search Strategy:

----

1 exp Breast Neoplasms/ (374237)

2 exp Mammography/ (42361)

3 (breast screen* or mammog*).af. (46072)

4 (breast cancer* or breast tum?r* or breast neoplasm*).af. (369330)

5 1 or 2 or 3 or 4 (414880)

6 exp Mass Screening/ (163736)

7 (health screen* or mass screen* or cancer screen*).af. (108549)

8 6 or 7 (173530)

9 5 and 8 (24283)

10 (campaign* or educat* or interven* or program* or promot* or outreach* or navigat*).af. (3641264)

11 9 and 10 (9999)

12 (attitud* to health or health* attitud*).af. (135535)

13 exp Attitude to Health/ (81358)

14 exp health promotion/ or exp health educattion/ (71434)

15 (patient ed* or health ed* or health promot* or health navigat* or patient navigat*).af. (284138)

16 (audiovisual* or audio-visual*).af. (31708)

17 12 or 13 or 14 or 15 or 16 (428295)

18 11 and 17 (2526)

19 limit 18 to (english language and yr="2000 - 2015") (1829)

COCHRANE

Date Run: 14/01/15 10:14:40.787

ID	Search	Hits
#1	"breast neoplasm*" or "breast cancer*"	18491
#2	mammogra* or "breast screen*"	1839
#3	#1 and #2	1426
#4	campaign* or educat* or intervent* or program* or promot* or outreach* or navig*	180948
#5	#3 and #4	816
#6	"attitud* to health" or "health* attitud*"	3088
#7	"patient ed*" or "health ed*" or "health promot*"	19266
#8	#6 or #7	21194
#9	#5 and #8	224

JOANNA BRIGGS INSTITUTE

Search Strategy:

1 breast screening or mammography {Including Limited Related Terms} (13)

2 limit 1 to yr="2000 - 2015" (13)

PROSPERO

Search strategy: breast screen* OR mammogram* (all fields)
Review Status: Published
Date registered: 01/01/2000 – 31/12/2015

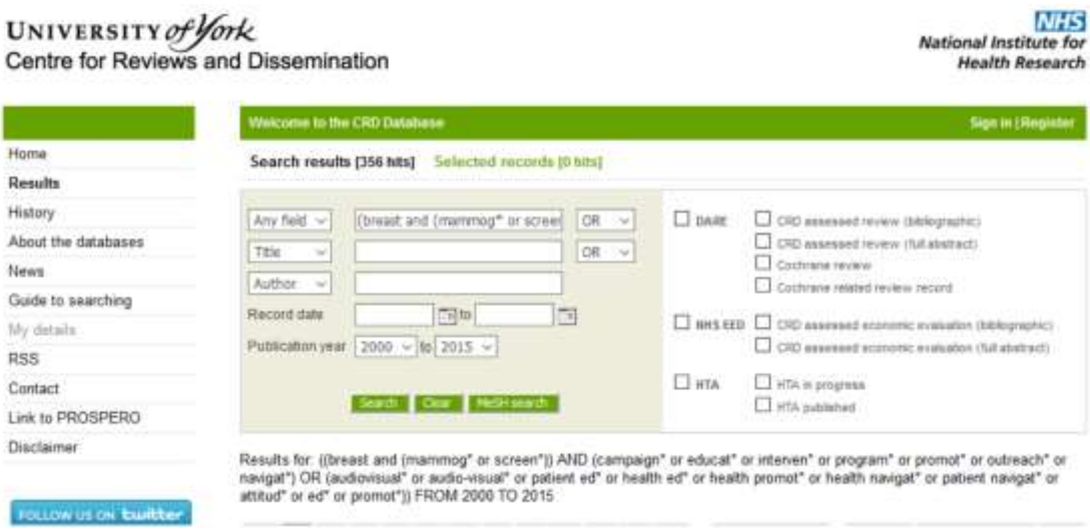
Search Results (1 records)

Registration no.	Title	Status
CRD42012002247	Shift work and the development of breast cancer: protocol for a systematic review	Published

Centre for Reviews and Dissemination | Legal statements

York databases

Search strategy: (breast and (mammog* or screen*)) AND (campaign* or educat* or interven* or program* or promot* or outreach* or navigat*) OR (audiovisual* or audio-visual* or patient ed* or health ed* or health promot* or health navigat* or patient navigat* or attitud* or ed* or promot*) FROM 2000 TO 2015



Appendix 5.2 – Supplementary searches for HBM and/or CSM

CINAHL

EBSCOhost

Friday, August 19, 2016 11:02:43 AM

#	Query	Limiters/Expanders	Last Run Via	Results
S10	S7 OR S9	Limiters - English Language Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	6
S9	S5 AND S6 AND S8	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	6
S8	random* control* trial*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	80,719
S7	S5 AND S6	Limiters - English Language; Publication Type: Randomized Controlled Trial Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	4
S6	champion* health belief OR health belief model OR common sense model OR self regul* model OR illness perception*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	3,011
S5	S1 OR S4	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	11,758
S4	S2 AND S3	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	5,500
S3	(MH "Health Screening+")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	62,543
S2	(MH "Breast Neoplasms+")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	56,636
S1	(MH "Mammography")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Basic Search Database - CINAHL Plus with Full Text	8,712

Medline search

Ovid® Wolters Kluwer

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Search | Journals | Books | Multimedia | My Workspace

Ovid MEDLINE(R) 1946 to Present with Daily Update

#	Searches	Results	Type
1	exp breast neoplasms/	248027	Advanced
2	exp mass screening/	110992	Advanced
3	exp mammography/	26483	Advanced
4	1 and 2	9386	Advanced
5	3 or 4	29751	Advanced
6	champion* health belief.af.	56	Advanced
7	health belief model.af.	1471	Advanced
8	common sense model.af.	160	Advanced
9	self regul* model.af.	188	Advanced
10	illness perception*.af.	970	Advanced
11	or/6-10	2882	Advanced
12	5 and 11	142	Advanced
13	limit 12 to english language	141	Advanced
14	limit 13 to randomized controlled trial	14	Advanced
15	random* control* trial*.af.	560155	Advanced
16	13 and 15	16	Advanced
17	14 or 16	16	Advanced

Embase search

Ovid

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Search | Journals | Books | Multimedia | My Workspace

Embase 1974 to 2016 August 18

#	Searches	Results	Type
1	exp breast cancer/	353852	Advanced
2	exp breast carcinoma/	59888	Advanced
3	exp breast tumor/	424288	Advanced
4	1 or 2 or 3	424288	Advanced
5	exp mass screening/	187088	Advanced
6	4 and 5	22985	Advanced
7	exp mammography/	46670	Advanced
8	6 or 7	59005	Advanced
9	champion* health belief.af.	74	Advanced
10	health belief model.af.	2114	Advanced
11	common sense model.af.	245	Advanced
12	self regul* model.af.	406	Advanced
13	illness perception*.af.	1756	Advanced
14	or/9-13	4275	Advanced
15	8 and 14	198	Advanced
16	limit 15 to english language	192	Advanced
17	limit 16 to randomized controlled trial	12	Advanced
18	random* control* trial*.af.	583524	Advanced
19	16 and 18	13	Advanced
20	17 or 19	13	Advanced

Scopus and Web of Science (same strategy used in each database)

(TITLE-ABS-KEY ((**breast*** AND **screen***) OR **mammog***)) AND (TITLE-ABS-KEY (**"champion* health belief"** OR **"health belief model"** OR **"common sense model"** OR **"self regul* model"** OR **"illness perception*"**))) AND (TITLE-ABS-KEY (**"random* control* trial*"**)) AND (LIMIT-TO (LANGUAGE , **"English"**))

Web of Science

5

23

#2 AND #1
Refined by: LANGUAGES: (ENGLISH) AND PUBLICATION YEARS: (2014 OR 2006 OR 1999 OR 2013 OR 2003 OR 1998 OR 2016 OR 2012 OR 2000 OR 1995 OR 2015 OR 2011)
Databases= WOS, BCI, CCC, DRCI, DIIDW, KJD, MEDLINE, RSCI, SCIELO, ZOOREC Timespan=All years
Search language=Auto

4

30

#2 AND #1
Refined by: LANGUAGES: (ENGLISH)
Databases= WOS, BCI, CCC, DRCI, DIIDW, KJD, MEDLINE, RSCI, SCIELO, ZOOREC Timespan=All years
Search language=Auto

3

30

#2 AND #1
Databases= WOS, BCI, CCC, DRCI, DIIDW, KJD, MEDLINE, RSCI, SCIELO, ZOOREC Timespan=All years
Search language=Auto

2

117,596

TOPIC: (((breast* AND screen*) OR mammog*))
Databases= WOS, BCI, CCC, DRCI, DIIDW, KJD, MEDLINE, RSCI, SCIELO, ZOOREC Timespan=All years
Search language=Auto

1

557

TOPIC: ((("champion* health belief" OR "health belief model" OR "common sense model" OR "self regul* model" OR "illness perception*") AND ("random* control* trial*")))
Databases= WOS, BCI, CCC, DRCI, DIIDW, KJD, MEDLINE, RSCI, SCIELO, ZOOREC Timespan=All years
Search language=Auto

SCOPUS

(TITLE-ABS-KEY (((("champion* health belief" OR "health belief model" OR "common sense model" OR "self regul* model" OR "illness perception*") AND ("random* control* trial*"))))) AND (TITLE-ABS-KEY ((((breast* AND screen*) OR mammog*)))) AND (LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2003) OR LIMIT-TO (PUBYEAR , 2002) OR LIMIT-TO (PUBYEAR , 1999) OR LIMIT-TO (PUBYEAR , 1994) OR LIMIT-TO (PUBYEAR , 1993))
17 document results
3
(TITLE-ABS-KEY (((("champion* health belief" OR "health belief model" OR "common sense model" OR "self regul* model" OR "illness perception*") AND ("random* control* trial*"))))) AND (TITLE-ABS-KEY ((((breast* AND screen*) OR mammog*))))
18 document results
2
TITLE-ABS-KEY ((((breast* AND screen*) OR mammog*)))
103,003 document results
1
TITLE-ABS-KEY (((("champion* health belief" OR "health belief model" OR "common sense model" OR "self regul* model" OR "illness perception*") AND ("random* control* trial*"))))
370 document results

University of York CDR/PROPERO databases (same strategy used in each database)
("champion* health belief" or "health belief model" or "common sense model" or "self regul* model" or "illness perception*") AND breast*

Cochrane

Date Run: 19/08/16 14:46:55.281
ID Search Hits
#1 MeSH descriptor: (Breast Neoplasms) explode all trees 9715
#2 MeSH descriptor: (Mass Screening) explode all trees 5450
#3 MeSH descriptor: (Mammography) explode all trees 1006
#4 #1 and #2 500
#5 #3 or #4 1158
#6 "champion* health belief" or "health belief model" or "common sense model" or "self regul* model" or "illness perception*" 380
#7 #5 and #6 16

Appendix 6.1a – Information sheet for Scottish expert steering group

UNIVERSITY of STIRLING

School of Health Sciences
University of Stirling

Mob: + 356 7777 3313
Email: attard.danika@gmail.com

04 September 2016

Health Beliefs, Illness Perceptions and Determinants of Breast Screening Uptake in Malta

---

Dear Colleagues,

During the past year, I have carried out a Nation-wide survey entitled "**Health beliefs, illness perceptions and the determinants to breast screening uptake in Malta**" as part of my doctoral research work at the University of Stirling. The aim of the study was to determine if health beliefs, illness representations, socio-demographic and medical factors are associated with uptake to attend the Malta Breast Screening Programme (MBSP). The findings of this study are of particular importance to the National Breast Screening Programme, to policy makers and other relevant key stakeholders in Malta.

Following the completion of this survey, expert steering groups are being set up in Malta and in Scotland to bring together local and international expertise in the field of research, screening and intervention development. These steering groups shall provide an opportunity to discuss with experts the appropriate strategies in developing an intervention for the Maltese population.

The objectives of this steering group are:

1. To discuss the findings of the literature review on non-attendance for mammography screening, as well as women's health beliefs, illness perceptions and other determinants to breast screening uptake in Malta;

2. To conceptualise key theoretical components of an intervention that could be used to overcome modifiable barriers to breast screening and that has the potential to increase uptake in Malta;
3. To develop a logic model of change; and
4. To create a "short list" of potential interventions.

Once the above objectives are fulfilled, another future phase of this project will be conducted to develop the intervention material.

You have been nominated as a member of this Expert group as you are considered to be of great value to this steering group. Your contribution shall be acknowledged in future publications. I would appreciate if you could save the following date: **10th November**

The steering group meeting will take place at the University of Stirling, **Pathfoot** building, conference room **E26**. I shall be circulating details of a confirmed date and time in due course.

Meanwhile, I thank you for your interest and for taking the time to collaborate in this project. I look forward to see you all.

Best regards,

Danika Marmarà
Doctoral Researcher
University of Stirling

Appendix 6.1b - Information Sheet for Maltese Expert Steering Group

UNIVERSITY of STIRLING

School of Health Sciences
University of Stirling

Mob: + 356 7777 3313
E: d.m.attard@stir.ac.uk
E: attard.danika@gmail.com

07 March 2017

Health Beliefs, Illness Perceptions and Determinants of Breast Screening Uptake in Malta

---

Dear Colleagues,

During the past two years, I have carried out a Nation-wide survey entitled "**Health beliefs, illness perceptions and the determinants to breast screening uptake in Malta**" as part of my doctoral research work at the University of Stirling. The aim of the study was to determine if health beliefs, illness representations, socio-demographic and medical factors are associated with uptake to attend the Malta Breast Screening Programme (MBSP). The findings of this study are of particular importance to the Chief Executive Officer heading the Primary Health Care Department, the National Breast Screening Programme, policy makers and other relevant key stakeholders in Malta.

Following the completion of this survey, expert steering groups are being set up in Malta and in Scotland to bring together local and international expertise in the field of research, screening and intervention development. These steering groups shall provide an opportunity to discuss the results with academic experts in the field, experts heading the local healthcare community and policy makers in order to explore the way forward in developing appropriate strategies and culturally-appropriate interventions for the Maltese population.

The objectives of this steering group are:

1. To discuss the findings of the literature review on non-attendance for mammography screening, as well as women's health beliefs, illness perceptions and other determinants to breast screening uptake in Malta;
2. To develop a logic model of the problem.

3. To judge basic fit based on priority population and organizational capacity.

Once the above objectives are fulfilled, another future phase of this project will be conducted to carry out further research work.

You have been nominated as a member of this Expert steering group as you bring great value to this steering group. Your contribution shall be acknowledged in future publications.

The steering group meeting will take place at the Office of the Cancer Care Pathways Directorate on **23rd March 2017 at 08:30 – 10:30**.

Meanwhile, I thank you for your interest and for taking the time to collaborate in this project. I look forward to see you all.

Best regards,

Danika Marmarà
Doctoral Researcher
University of Stirling, UK

Appendix 6.2 - Consent Form

UNIVERSITY of STIRLING

School of Health Sciences
University of Stirling

Mob: + 356 7777 3313
E: d.m.attard@stir.ac.uk
E: attard.danika@gmail.com

Consent for Use of Audio Recording

In participating in this study, I have given my consent to participate as an expert member of this Expert steering group as part of Ms. Danika Marmarà's doctoral research study. The researcher has explained to me the purpose and objectives of the steering group and has provided further detail through an information letter. I understand that the results obtained for this study in which I am participating may be used or published for scientific research purposes.

Please read the following and, if you are in agreement, sign where indicated.

1. I consent to the audio-recordings being made of the session/s and to these tapes being used to aid the work.

Signed.. Dated..

2. I consent to the excerpts from these recordings, or descriptions of them, being used by Danika Marmarà (the researcher) for the purposes of her PhD research study.

Signed.. Dated..

3. I understand that every effort will be made to ensure professional confidentiality and anonymity and that any use of audio tapes will be used for research purposes only.

Signed.. Dated..

Name...

Appendix 7.1a: Information Sheet (English version)

School of Health Sciences
University of Stirling
Work contact: + 356 79005111
E: d.m.attard@stir.ac.uk
E: attard.danika@gmail.com

30th August 2017

Health Beliefs, Illness Perceptions and Determinants of Breast Screening Uptake in Malta

---

I am a female researcher at the University of Stirling with experience in mammography screening and cancer care, and trained in performing similar research in Malta. During the past two years, I have carried out a Nation-wide survey entitled "**Health beliefs, illness perceptions and the determinants to breast screening uptake in Malta**" as part of my doctoral research work at the University of Stirling. The aim of the study was to determine if health beliefs, illness representations, knowledge, socio-demographic and health status are associated with uptake of the first invitation to attend the Maltese Breast Screening Programme (MBSP). This study was followed by further analyses of the main predictors for re-attendance, the exploration of women being screened within or in excess of the recommended time intervals, and examining the determinants for lifetime mammography utilization and non-use in Malta. The findings are of particular importance to the Ministry for Health and policy makers and other key stakeholders in Malta.

Today's *Science Espresso* shall provide an opportunity to understand and discuss breast cancer and screening beliefs, attitudes and behaviours among the general public and explore your perceptions, knowledge, barriers and motivators to mammography screening. This will aid the development of appropriate strategies and culturally-appropriate interventions to increase mammography utilization among Maltese women.

As a member of the general public, you bring great value to this research work as your contribution shall form the basis of intervention development in the Maltese context. All information shall be reported as collaborative feedback. Meanwhile, I thank you for your interest and for taking the time to participate in this project.

Danika Marmarà, M.Sc., B.Sc. (Hons.)
Doctoral Researcher
University of Stirling (UK)

Appendix 7.1b: Information Sheet (Maltese version)

UNIVERSITY of STIRLING
Skola tax-Xjenzi tas-Saħħa
L-Università ta' Stirling
Nru tat-telefown: + 356 25452467/8
Posta elettroknika: d.m.attard@stir.ac.uk
Posta elettronika: attard.danika@gmail.com

30 ta' Awwissu 2017

Il-Konvinzjonijiet dwar is-Saħħa, il-Perċezzjonijiet ta' Mard u Determinanti għat-Teħid ta' Skrining tas-Sider f'Malta

---

Jiena riċerkatriċi fl-Università ta' Stirling b'esperjenza fl-Iskrining tas-Sider u l-kura tal-kanċer, u b'taħriġ fit-twettiq ta' ricerki simili. Matul dawn l-aħħar sentejn, għamilt stħarriġ fuq livell nazzjonali intitolat **"Il-Konvinzjonijiet dwar is-Saħħa, il-Perċezzjonijiet ta' Mard u Determinanti għat-Teħid ta' Skrining tas-Sider f'Malta"** bħala parti mir-riċerka tiegħi fil-livell ta' dottorat mal-Università ta' Stirling. L-għan tal-istudju kien li jiddetermina jekk il-konvinzjonijiet dwar is-saħħa, ir-rappreżentazzjonijiet tal-mard, l-għarfien, l-istat soċjodemografiku u tas-saħħa humiex marbutin mal-attendenza tal-Programm Nazzzjonali tal-Iskrining tas-Sider f'Malta (MBSP) mal-ewwel stedina. Dan l-istudju kien segwit b'iktar analiżi f'Malta tal-fatturi ewlenin li jwasslu għal attendenza mill-ġdid, studju dwar nisa li qed jiġu skrinjati f'intervalli ta' żmien kif rakkommandat, u eżaminazzjoni tad-determinanti li jwasslu lil dak li jkun li jirrikorri għall-mammografija matul il-ħajja jew li ma jmur qatt. Is-sejbiet jinteressaw b'mod partikolari lill-Ministeru tas-Saħħa u lil dawk li jfasslu l-politika u msieħba interessati oħra f'Malta.

Il-preżentazzjoni fis-*Science Espresso* tal-lum joffru l-opportunità lil dak li jkun li jifhem u jiddiskuti l-kanċer tas-sider u l-konvinzjonijiet u l-attitudnjiiet dwar l-iskrining fost il-pubbliku ġenerali u jesplora l-perċezzjonijiet, l-għarfien, l-ostakoli u dak li jħeġġeġ lill-mara tmur tagħmel skrining tas-sider. Dan jgħin fl-iżvilupp ta' strateġija xierqa u interventi li jkunu adattati skont il-kultura biex tiżdied l-attendenza tan-nisa Maltin li jagħmlu mammogram.

Bħala membru tal-pubbliku ġenerali, il-kontribut tiegħek hu siewi ħafna f'din il-ħidma ta' riċerka minħabba li jservi bħala l-bażi biex jiġu żviluppati azzjonijiet fil-kuntest Malti. L-informazzjoni ser tiġi rrapurtata bħala rispons kollaborattiv. Għaldaqstant, nirringrazzjakom tal-interess li wrejtu u għall-ħin li tajtu biex tieħdu sehem f'dan il-proġett.

Danika Marmarà M.Sc., B.Sc. (Hons.)
Riċerkatriċi fil-livell ta' dottorat,
L-Università ta' Stirling (ir-Renju Unit)

Appendix 7.2a: Baseline recruitment screener (English version)

Sociodemographics and health status (English version)

Unique Identifier Number: ___________ *30th August 2017*

Q1. Female ❑ Male ❑

Q2. How old are you? ____________________

Q3. Where do you live? ____________________

Q4. What is the highest level of education you have completed?

(1) No schooling ❑
(2) Primary level ❑
(3) Secondary level ❑
(4) Diploma ❑
(5) Bachelor Degree ❑
(6) Post-Graduate Degree (Masters or above) ❑
(7) Other (Specify) ____________________ ❑

Q5. What is your current employment status? Are you..

a. Employed full-time ❑
b. Employed part-time ❑
c. Unemployed ❑
d. Retired or on a pension ❑
e. Full-time student ❑
f. Engaged in home duties ❑
g. Other (Specify) __________________ ❑

Q6. What best describes your current marital status?

a. Single/Never been married ❑
b. Married ❑
c. Cohabitating ❑
d. Separated/Divorced ❑
e. Widowed ❑

Q7. What is your annual household income?

(1) Less than €10,737 ❑
(2) €10,737 – €16,113 ❑
(3) €16,114 – €23,563 ❑
(4) €23,564 – €33,966 ❑
(5) Greater than €33,966 ❑
(6) Don’t know/Prefer not to say ❑

Q8. a) Do you own a car? Yes ❑ No ❑
b) Do you drive? Yes ❑ No ❑

Q9. (a) Have you had a breast cancer diagnosis in the last 5 years?
Yes ❑ No ❑

(b) Have you had any other cancer diagnosis in the last 5 years?
Yes ❑ *Which cancer?* ____________________ No ❑

Q10. Have your relatives had cancer?
Yes ❑ Who? ___________________ Define which cancer _______________
No ❑

Q11. Has a close friend been diagnosed with cancer?
Yes ❑ Define which cancer _________________________
No ❑

Q12. Which best describes the last time you had any of the following? (circle number below)

Health services utilization	Within the past 12 months	1 to 2 years ago	More than 2 years ago	Never
Visit to a primary care physician / GP	1	2	3	4
Pap smear for Cervical cancer screening	1	2	3	4
Faecal Occult Blood test (FOBT) (through a stool sample) for Colorectal cancer screening	1	2	3	4
Blood pressure check for high blood pressure	1	2	3	4
Bone density screening for Osteoporosis	1	2	3	4
Mammogram for Breast cancer	1	2	3	4
Clinical Breast Examination by a specialist	1	2	3	4
Blood test for diabetes	1	2	3	4

Q13. Religion

a. Catholic affiliation ❑

b. Christian affiliation ❑

c. Other religion (specify) ❑ _________________________

d. Somewhat religious (rate on 1-10 scale) 1 2 3 4 5 6 7 8 9 10

e. Atheist (non-believer in the existence of God or gods) ❑

Appendix 7.2b: Baseline recruitment screener (Maltese version)

Numru tal-identifikatur uniku: ___________ *30 ta' Awwissu 2017*

Q1. Mara ❑ Raġel ❑

Q2. Kemm għandek żmien? ____________________

Q3. Fejn toqgħod? ____________________

Q4. X'inhu l-ogħla livell ta' edukazzjoni li temmejt?
- (1) Qatt ma mort skola ❑
- (2) Livell primarju ❑
- (3) Livell sekondarju ❑
- (4) Diploma ❑
- (5) Grad ta' Baċellerat ❑
- (6) Grad post Gradwatorju (Masters jew iktar) ❑
- (7) Ieħor (Speċifika) ____________________ ❑

Q5. X'taħdem? Int...
- a. Impjegat/a full-time ❑
- b. Impjegat/a part-time ❑
- c. Bla xogħol ❑
- d. Irtirat/a jew pensjonat/a ❑
- e. Student/a full-time ❑
- f. Tagħmel xogħol fid-dar ❑
- g. Taghmel Ħaġ'oħra (Speċifika) _______________ ❑

Q6. Kif l-aqwa tiddeskrivi l-istat ċivili tiegħek bħalissa?
- a. Xebba/Ġuvni ❑
- b. Miżżeweġ/Miżżewġa ❑
- c. Nikkoabita ❑
- d. Separat/a/Divorzjat/a ❑
- e. Armel/Armla ❑

Q7. X'inhu d-dħul tal-familja tiegħek?
- (1) Inqas minn €10,737 ❑
- (2) €10,737 – €16,113 ❑
- (3) €16,114 – €23,563 ❑
- (4) €23,564 – €33,966 ❑
- (5) Iktar minn €33,966 ❑
- (6) Ma nafx/Nippreferi ma ngħidx ❑

Q8. a) Għandek karozza? Iva ❑ Le ❑
b) Issuq? Iva ❑ Le ❑

Q9. (a) Fl-aħħar 5 snin kellek dijanjożi ta' kanċer tas-sider?
Iva ❑ Le ❑

(b) Kellek xi dijanjożi ta' xi kanċer ieħor fl-aħħar 5 snin?
Iva ❑ *X'kanċer?* ____________________ Le ❑

Q10. Kellek xi qraba li ħarġilhom kanċer?

Iva ❑ Min? ____________________ *X'kanċer*? ____________________

Le ❑

Q11. Kellek xi ħabib/a tal-qalb bil-kanċer?

Iva ❑ *X'kanċer*? ___________________________

Le ❑

Q12. Liema minn dawn jiddeskrivu bl-aqwa mod l-aħħar darba li għamilt xi użu minn xi wieħed mis-servizzi tas-saħħa li ġejjin? (agħmel ċirku man-numru t'hawn taħt)

Użu minn servizz tas-saħħa	Fl-aħħar 12-il xahar	Minn sena sa sentejn ilu	Iktar minn sentejn ilu	Qatt
Vista għand it-tabib tiegħek	1	2	3	4
Skrining għall-kanċer tal-għonq tal-utru (Pap smear)	1	2	3	4
Skrining għall-kanċer tal-musrana permezz ta' test guaiac tad-demm okkult fir-rawt (FOBT) (permezz ta' kampjun tal-ippurgar)	1	2	3	4
Test tad-demm għall-pressjoni għolja	1	2	3	4
Skrining tad-densità tal-għadam għall-Osteoporożi	1	2	3	4
Mammogram għall-kanċer tas-sider	1	2	3	4
Eżami kliniku tas-sider minn speċjalista	1	2	3	4
Test tad-demm għad-dijabete	1	2	3	4

Q13. Reliġjon

a. Affiljazzjoni kattolika ❑

b. Affiljazzjoni kristjana ❑

c. Reliġjon ieħor (speċifika) ❑ ___________________________

d. Reliġjuż/a b'mod moderat (minn grad 1 sa 10) 1 2 3 4 5 6 7 8 9 10

e. Ateist/a (ma nemminx fl-eżistenza ta' Alla jew tal-allat) ❑

Appendix 8.1: Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews

No. Item	Guide questions/description	Reported on Page / Section #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Section 8.3.2
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Appendix, Participant Information Sheet
3. Occupation	What was their occupation at the time of the study?	n/a
4. Gender	Was the researcher male or female?	Appendix, Participant Information Sheet
5. Experience and training	What experience or training did the researcher have?	Appendix, Participant Information Sheet
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Study 2 .
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Appendix, Participant Information Sheet
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Appendix, Participant Information Sheet, reasons and interests in the research topic
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Section 8.3
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Section 8.3.4

11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Section 8.3.5
12. Sample size	How many participants were in the study?	Section 8.3.4
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Figure 8.1
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Section 8.3.2 .
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Section 8.3.2 Inferred as one-to-one interviews
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Section 8.3.3 – 8.3.4
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Appendix and Section 8.3.7.2
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Yes, Section 8.3.6
20. Field notes	Were field notes made during and/or after the interview or focus group?	Section 8.3.6
21. Duration	What was the duration of the interviews or focus group?	Section 8.3.6
22. Data saturation	Was data saturation discussed?	Sections 8.3.4
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Section 8.3.9.5
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Section 8.3.9.3
25. Description of the coding tree	Did authors provide a description of the coding tree?	Section 8.3.9.3
26. Derivation of themes	Were themes identified in advance or derived from the data?	In advance, Section 8.3.9.4
27. Software	What software, if applicable, was used to manage the data?	Manually, Section 8.3.9.3

28. Participant checking	Did participants provide feedback on the findings?	Yes, Section 8.3.9.5
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, Sections 8.4.3 – 8.4.6
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, there was. Section 8.4, Results
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, Sections 8.4.3 – 8.4.6
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Discussion of major and minor sub-themes in Section 8.5

Appendix 8.2a: Participant information sheet for Maltese women (English version)

Study Title: Non-attendance to mammography screening: a Qualitative Study among non-screeners in Malta

You are invited to take part in this study.

This sheet is to provide you with the information you need to see if you would like to take part in the study.

Please ask if you have more questions or need more information.

What is the purpose of the Study?

I am a female researcher at the University of Stirling with experience in mammography screening and cancer care, and trained in performing similar research in Malta. I am interested in understanding why women do not undergo mammography. This will help to develop a future intervention to promote breast cancer prevention and screening among Maltese women living in Malta. Therefore, we need to collect some data to understand the Maltese women's knowledge and beliefs about breast cancer, barriers to mammography, and motivating and inhibiting factors related to the uptake of mammography.

Why you?

You have been asked to join the study as you have never attended for mammography screening. This study is an extension to the previous telephone survey where we had explored your health beliefs, illness perceptions and determinants of Breast Screening Uptake in Malta, and you had agreed to be contacted further.

What will it involve?

You will be interviewed by the main researcher of this study at a convenient location and time for you. At first, you will be asked to complete a questionnaire regarding some demographic information such as your age. After that, you will be encouraged to discuss your views and experiences about breast cancer prevention and other life experiences. This conversation will be audio recorded for the purpose of data analyses. A debrief will be provided once the conversation has finished. In this, you will get detailed information about this study and the breast cancer screening programme.

How long will participation take?

This conversation will last approximately one to one and a half hours.

Will I encounter any risk or discomfort?

Usually, you will have no risks or discomfort in participation in this study. In rare cases, the questions could be distressing. You will be given details of counselling services that are available to help you.

What are the benefits in taking part in this study?

By taking part in this study, you can help us to understand factors associated with screening decisions among Maltese women, thus to design and implement effective services to improve breast health among Maltese women. In addition, you will be provided some useful information about breast cancer and the effective ways to prevent it. You will be awarded 20 euros at the end of the interview as a token of thanks for participation in this study.

What will happen to the results of the study?

The results will be used to better understand the beliefs, perceptions, attitudes and knowledge about breast screening among women who do not attend for mammography, to better understand potential barriers to participation and to determine which interventions, cues to actions, key messages and channels are most appropriate for communicating with women about breast cancer screening. Research papers may be published and presented at conferences. In this way, more people are aware of the factors related to non-attendance to mammography screening. These results will aid the future development of interventions to increase breast screening uptake in Malta.

What about Confidentiality?

All information will be confidential and anonymous. You will NOT be named in any results or reports written on the study. Data will be kept in a locked filing cabinet and in password protected folders on computers at the School of Health Sciences and Sport, University of Stirling. The audio recording will not be destroyed for at least five years.

Ethical Approval

The NHS, Invasive or Clinical Research (NICR) Committee at the University of Stirling and the Maltese Health Ethics Committee has reviewed the study. There will be monitoring from the University of Stirling that this research project is being properly conducted.

What happens next?

A research assistant shall contact you by telephone to confirm that they have NEVER been screened, to explain the research objectives and to confirm if you are willing and able to participate. If you agree to take part in this research study, you shall receive the information sheet by post and a suitable time and location for the interview shall be arranged according to your preferences and availability. The interview shall be conducted face-to-face between yourself and the researcher, based on your preferences. You will be asked by the researcher to complete a consent form to confirm your willingness to participate in the study. The interview will be conducted in the Maltese or English language (as preferred by yourself) and is envisaged to last between 60 - 90 minutes. The researcher shall take field notes during the interview to facilitate the interview process.

What about Voluntary Participation and Withdrawal?

You have the right to withdraw at any stage without having to give an explanation and without loss of payment. If you do stop you may wish to give a reason as this may help plan future studies. You are free to ask any questions at any time.

Where will the study take place?

This study will be carried out at a convenient location and time as defined by yourself.

Please keep a copy of this information sheet.

What if I wish to complain about the study?

You can submit a written complaint about any part of the study to:
Ministry for Health
Director General (Health Care Services)

Office of the Director General,
15, Palazzo Castellania,
Merchants Street,
Valletta, Malta.

Who do I contact for further information about the study?

If you have any questions about this research project or concerns about your rights as a research participant in this study, please call the Principal Investigator (researcher) for this study. Details of the researcher can be found hereunder.

Researcher

Danika Marmarà, M.Sc., B.Sc. (Hons.)
School of Health Sciences and Sport,
University of Stirling
Stirling
FK9 4LA
Tel: +356 77773313
Email: d.m.attard@stir.ac.uk
attard.danika@gmail.com

Independent contact

Should you have any concerns, or wish to speak to someone independent of the study, please contact ________________, Faculty of Health Sciences and Sports at: __________@stir.ac.uk

Thank you for taking the time to read this and to consider taking part in the study.

Appendix 8.2b: Participant information sheet for Maltese women (Maltese version)

Nota ta' informazzjoni għall-parteċipanti Maltin (verżjoni bil-Malti)

Titlu tal-Istudju: Nuqqas ta' attendenza għall-iskrining tas-sider: Studju Kwalitattiv fost dawk li ma jmorrux għall-iskrining f'Malta

Int mistiedna tieħu sehem f'dan l-istudju.

L-għan ta' din in-nota hu li tagħtik l-informazzjoni li teħtieġ jekk tixtieq tieħu sehem fl-istudju.

F'każ li għandek iktar mistoqsijiet jew tixtieq iktar informazzjoni, staqsi.

X'inhu l-għan tal-Istudju?

Jiena riċerkatriċi fl-Università ta' Stirling b'esperjenza fl-Iskrining tas-Sider u l-kura tal-kanċer, u b'taħriġ fit-twettiq ta' ricerki simili. Qiegħda nistħarreġ għalfejn in-nisa jiddeċiedu li ma jmorrux għall-mammogram. Dan jgħin sabiex tiġi żviluppata strateġija li tippromwovi l-prevenzjoni tal-kanċer tas-sider u l-iskrining fost in-nisa Maltin li jgħixu Malta. Għaldaqstant, irridu niġbru xi data biex nifhmu l-għarfien tan-nisa Maltin u l-konvinzjonijiet dwar il-kanċer tas-sider, l-ostakoli għall-mammografija, u l-fatturi li jħeġġu u li jwaqqfu lil dak li jkun milli jmur għal skrining tas-sider.

Għalfejn qed nikkuntattjaw lilek?

Qed tintalab tieħu sehem fl-istudju minħabba li qatt ma mort tagħmel skrining tas-sider. Dan l-istudju hu estensjoni tal-istħarriġ li kien sar bit-telefown fejn konna stħarriġna il-konvinzjonijiet tiegħek dwar is-saħħa, il-perċezzjonijiet ta' mard u determinanti għat-Teħid ta' Skrining tas-Sider f'Malta, u kont qbilt li terġa' tiġi kkuntattjata.

X'jinvolvi?

Se tiġi intervistata mir-riċerkatriċi ewlenija ta' dan l-istudju f'post u ħin konvenjenti għalik. Fil-bidu, se tintalab timla kwestjonarju li fih tagħti informazzjoni demografika dwarek, pereżempju l-età. Wara, se tiddiskuti l-ideat u l-esperjenzi tiegħek dwar il-prevenzjoni tal-kanċer tas-sider u xi esperjenzi oħra li kellek tul ħajtek. Il-vuċi tul il-konverżazzjoni se tiġi rrekordjata sabiex tkun tista' tiġi analizzata d-data li tingabar. Fi tmiem il-konverżazzjoni, jingħata rendikont ġenerali. Hawn, tingħata informazzjoni dettaljata dwar dan l-istudju u l-programm ta' skrining għall-kanċer tas-sider.

Kemm idum dan il-proċess?

Din il-konverżazzjoni mistennija ddum bejn siegħa u siegħa u nofs.

Hemm xi riskju jew ċans li nħossni skomda?

Normalment, ma jkunx hemm lok għal riskji jew li tħossok skomda meta tipparteċipa f'dan l-istudju. F'każijiet rari, il-mistoqsijiet jistgħu jqanqlu ansjetà. F'dak il-każ tingħata dettalji ta' min jista' jgħinek.

X'inhuma l-benefiċċji li tieħu sehem f'dan l-istudju?

Is-sehem tiegħek f'dan l-istudju jista' jgħinna nifhmu l-fatturi assoċjati mad-deċiżjoni li jieħdu n-nisa f'Malta biex imorru għall-iskrining jew le, biex infasslu u nattwaw servizzi effettivi li jtejbu s-saħħa tas-sider fost in-nisa f'Malta. Barra minn hekk, tingħata informazzjoni utli dwar il-kanċer tas-sider u modi effettivi ta' prevenzjoni. Tingħata 20 ewro fl-aħħar tal-intervista bħala turija ta' ringrazzjament talli tkun ħadt sehem f'dan l-istudju.

Xi jsir mir-riżultati tal-istudju?

Ir-riżultati jintużaw biex nifhmu aħjar il-konvinzjonijiet, perċezzjonijiet, attitudnijiet u għarfien dwar l-iskrining tas-sider fost in-nisa li ma jmorrux għall-mammogram, nifhmu x'inhuma l-ostakoli li jista' jkun qed jiffaċċjaw biex jipparteċipaw u niddeterminaw x'tip ta' azzjonijiet u messaġġi ewlenin imissna nużaw biex nikkomunikaw man-nisa dwar l-iskrining għall-kanċer tas-sider. Jista' jkun li riċerka abbinata ma' dan tiġi ppubblikata u ppreżentata f'konferenzi. B'dan il-mod, iktar nies isiru konxji tal-fatturi relatati man-nuqqas ta' attendenza għall-iskrining tas-sider. Dawn ir-riżultati jgħinu biex ikun hemm żvilupp fil-ġejjieni ta' azzjonijiet biex tiżdied l-attendenza ta' dawk li jmorru għall-iskrining f'Malta.

L-informazzjoni li tinġabar tinżamm kunfidenzjali?

L-informazzjoni kollha tinżamm kunfidenzjali u anonima. Ismek mhu se jitniżżel fl-ebda riżultat jew rapport li jinħareġ ta' dan l-istudju. Id-data tinżamm f'armarju msakkar u f'folders protetti b'password fuq kompjuters tal-Iskola tax-Xjenzi tas-Saħħa u l-Isport, l-Università ta' Stirling. Ir-rekording tal-vuċi tinżamm għallanqas ħames snin.

Approvazzjoni etika

Il-Kumitat tal-Iskola tar-Riċerka (NICR) fl-Università ta' Stirling u l-Kumitat ta' Etika dwar is-Saħħa ta' Malta analizzaw l-istudju. L-Università ta' Stirling se timmonitorja dan il-proġett ta' riċerka biex tiżgura li jitwettaq sew.

X'inhuma l-passi li jmiss?

L-assistenta tar-riċerkatrici għandha tikkuntattjak bit-telefown biex tikkonferma li int QATT ma mort għal skrining, tispjegalek l-għanijiet tar-riċerka u tikkonferma miegħek li tixtieq tieħu sehem. Jekk taqbel li tieħu sehem f'dan l-istudju ta' riċerka, tirċievi n-nota ta' informazzjoni bil-posta u jiġi miftiehem ħin u post tajjeb għalik biex issir l-intervista skont il-preferenzi u d-disponibbiltà tiegħek. L-intervista ssir wiċċ'imb wiċċ bejnek u r-riċerkatriċi, abbażi tal-preferenzi tiegħek rigward il-ħin. Ir-riċerkatriċi titolbok timla formola tal-kunsens biex tikkonferma li int tixtieq tieħu sehem f'dan l-istudju. L-intervista ssir bil-Malti jew bl-Ingliż (skont kif tippreferi) u mistenni li ddum minn 60 sa 90 minuta. Ir-riċerkatriċi tieħu n-noti waqt l-intervista biex tiffaċilita l-proċess tal-intervista.

Is-sehem tiegħi hu voluntarju u nista' nirtira mill-proċess?

Għandek dritt tirtira fi kwalunkwe stadju tal-proċess mingħajr ma tagħti spjegazzjoni u mingħajr ma titlef il-ħlas. Jekk tiddeċiedi li tieqaf ikun apprezzat jekk tagħti raġuni għalfejn għamilt dan peress li hekk tkun qed tgħin lil min se jkun qed jippjana studji simili fil-futur. Tista' tistaqsi kwalunkwe mistoqsija fi kwalunkwe mument.

Fejn isir l-istudju?

Dan l-istudju se jsir f'post u ħin konvenjenti skont kif indikat minnek.

Jekk jogħġbok żomm kopja ta' din in-nota ta' informazzjoni.

X'jiġri jekk inkun irrid inressaq ilment dwar l-istudju?

Tista' tibgħat l-ilment bil-miktub dwar kwalunkwe parti ta' dan l-istudju f'dan l-indirizz:
Il-Ministeru tas-Saħħa

Id-Direttur Ġenerali (Servizzi għall-Kura tas-Saħħa)
Uffiċċju tad-Direttur Ġenerali,
15, Palazzo Castellania,
Triq il-Merkanti,
Il-Belt Valletta, Malta.

Lil min nikkuntattja għal iktar informazzjoni dwar l-istudju?

Jekk għandek xi mistoqsijiet dwar dan il-proġett ta' riċerka jew xi tħassib dwar id-drittijiet tiegħek bħala parteċipanta f'dan l-istudju, tista' ċċempel lill-Investigatur Prinċipali (ir-riċerkatriċi) ta' dan l-istudju. Id-dettalji tar-riċerkatriċi jinsabu hawn taħt.

Ir-Riċerkatriċi

Danika Marmarà M.Sc., B.Sc. (Hons.)
L-Iskola tax-Xjenzi tas-Saħħa u l-Isport,
L-Università ta' Stirling
Stirling, Ir-Renju Unit
FK9 4LA
Nru tat-telefown: +356 77773313
Posta elettronika: d.m.attard@stir.ac.uk
attard.danika@gmail.com

Kuntatt indipendenti

F'każ li għandek xi problema, jew tixtieq titkellem ma' xi ħadd indipendenti dwar dan l-istudju, tista' tikkuntattja lill-______________, il-Fakultà tax-Xjenzi tas-Saħħa u l-Isport permezz tal-posta elettronika: _____________@stir.ac.uk

Nirringrazzjak tal-ħin li sibt biex taqra din in-nota u talli kkunsidrajt tieħu sehem fl-istudju.

Appendix 8.3a - Informed consent form (English version)

		PLEASE INITIAL BOX IF YOU AGREE
1.	I confirm that I have read and understand the information sheet (version 2 160917) for this study and have had the opportunity to ask questions	
2.	I understand that if I participate in an interview it may be audio-recorded	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason	
4.	I understand that the research team will hold the information I give confidentially and my name will not be mentioned in any reports	
5.	I understand that all information from this study will be kept in a locked filing cabinet at the University of Stirling and stored in a password protected folder on the University computer hard drive	
6.	I understand that if consent to participate in the study is declined or terminated at any stage, I will enter normal follow up care	
7.	I agree to participate in this study	

Name of participant______________________________

Signature ______________________________________
Date____

Name of witness (Researcher)______________________

Signature ______________________________________
Date____

Participant consent form V2 16.09.17

Appendix 8.3b - Informed consent form (Maltese version)

Formola tal-kunsens infurmat

Titlu tal-Istudju: Nuqqas ta’ attendenza għall-iskrining tas-sider: Studju Kwalitattiv fost dawk li ma jmorrux għall-iskrining f’Malta

		JEKK JOGĦĠBOK DAĦĦAL L-INIZJALI TIEGĦEK JEKK TAQBEL
1.	Nikkonferma li qrajt u fhimt in-nota ta' informazzjoni (verżjoni 2 160917) għal dan l-istudju u kelli ċ-ċans insaqsi l-mistoqsijiet	
2.	Nifhem li jekk nieħu sehem, l-intervista se tiġi rekordjata	
3.	Nifhem li l-parteċipazzjoni tiegħi hija volontarja u li nista’ nirtira fi kwalunkwe stadju, mingħajr ma nagħti raġuni	
4.	Nifhem li t-tim ta' riċerka se jżomm l-informazzjoni li nagħti b'mod kunfidenzjali u ismi mhu se jidher fl-ebda rapport	
5.	Nifhem li l-informazzjoni kollha minn dan l-istudju se tinżamm imsakkra f’armarju fl-Università ta’ Stirling u f'folders protetti b'password fuq il-hard drive tal-kompjuters tal-Università	
6.	Nifhem li jekk inwaqqa' jew nittermina l-kunsens biex nieħu sehem fi kwalunkwe stadju tal-istudju, jien inkun nista’ nirrikorri għall-kura tas-saħħa mingħajr xkiel	
7.	Naqbel li nieħu sehem f’dan l-istudju	

Isem il-parteċipanta ______________________________

Firma ____
Data____

Isem ix-xhud (Ir-Riċerkatriċi)______________________

Firma ____
Data____

Formola tal-kunsens għall-parteċipanti V2 16.09.17

Appendix 8.4a – Socio-demographic questionnaire (English version)

Code Number: ______________________

Date of Interview (MM/DD/YY): ______________________

Location of Interview: ______________________

Start time of Interview: ______________________

Has participant signed the Informed Consent? Yes ❑ No ❑

End time of Interview: ______________________

Table 1: **Individual characteristics**

Sociodemographic and Health Status variables	
Age (years)	______________________
District	______________________
Marital status	Married ❑ Single ❑ Separated / Divorced ❑ Widowed ❑
Education	Primary school ❑ Secondary school ❑ Tertiary level (Diploma) ❑ Tertiary level (Degree) ❑ Tertiary level (Masters or above) ❑
Occupation	Government employee ❑ Private employee ❑ Housewife ❑ Unemployed ❑ Pensioner ❑
Income	Less than €10,737 ❑ Between €10,737 – €16,113 ❑ Between €16,114 – €23,563 ❑ Between €23,564 – €33,966 ❑ Greater than €33,966 ❑ Unable/unwilling to say ❑
Do you own a car? *Do you drive?*	Yes ❑ No ❑ Yes ❑ No ❑
Illness or Disability If Yes, what is it?	Yes ❑ No ❑ ______________________________
Do you have a family physician (GP) who provides medical care and advice to you?	Yes ❑ No ❑

Have you ever had any type of breast condition or disease? *What type of breast condition or disease?*	Yes ❑ No ❑ Fibrocystic 'Lumpy Breasts' ❑ Cysts ❑ Other ❑ ___________________
Have you ever been diagnosed with cancer? *Do you have a family history or close friends with cancer?* *If Yes, who?*	Yes ❑ No ❑ Yes ❑ No ❑ _____________________
Perceived health status	Excellent ❑ Very good ❑ Good ❑ Fair ❑ Poor ❑
Cancer Screening behaviours Ever had a clinical breast exam? Ever performed breast self-examination? Ever had a mammogram? Ever had a Pap-smear test (cervical Papanicolaou's smear)? Ever had a faecal occult blood test (FOBT)?	 Yes ❑ No ❑ Yes ❑ No ❑ Yes ❑ No ❑ Yes ❑ No ❑ Yes ❑ No ❑

Appendix 8.4b – Socio-demographic questionnaire (Maltese version)

Numru tal-kodiċi: ______________________

Data tal-Intervista (XX/DD/SS): ______________________

Post fejn saret l-Intervista: ______________________

X'ħin bdiet l-Intervista: ______________________

Il-parteċipanta ffirmat il-Formola tal-Kunsens Infurmat? Iva ❑ Le ❑

X'ħin spiċċat l-Intervista: ______________________

Tabella 1: **Karatteristiċi individwali**

Varjabbli soċjodemografiċi u Stat ta' Saħħa	
Età (fi snin)	______________________
Distrett	______________________
Stat	Miżżewġa ❑ Xebba ❑ Separata / Divorzjata ❑ Armla ❑
Edukazzjoni	Skola primarja ❑ Skola sekondarja ❑ Livell terzjarju (Diploma) ❑ Livell terzjarju (Lawrja) ❑ Livell terzjarju (Masters jew iktar) ❑
Impjieg	Impjegata mal-Gvern ❑ Impjegata mal-Privat ❑ Mara tad-dar ❑ Qiegħda ❑ Pensjonanta ❑
Dħul	Inqas minn €10,737 ❑ Bejn €10,737 – €16,113 ❑ Bejn €16,114 – €23,563 ❑ Bejn €23,564 – €33,966 ❑ Iktar minn €33,966 ❑ Ma nistax jew nippreferi ma ngħidx ❑
Għandek karozza? *Issuq?*	Iva ❑ Le ❑ Iva ❑ Le ❑
Mard jew diżabbiltà Jekk iva, speċifika?	Iva ❑ Le ❑ ______________________________
Għandek tabib tal-familja (GP) li jipprovdilek saħħa medika u jtik pariri?	Iva ❑ Le ❑
Qatt kellek xi tip ta' kundizzjoni jew marda f'sidrek? *X'tip ta' kundizzjoni jew marda?*	Iva ❑ Le ❑ "Boċoċ fis-Sider"(fibrocystic) ❑

	Ċesti ❑ Ħaġ'oħra ❑ ________________
Qatt kellek xi tip ta' kanċer? *Għandek lil xiħadd fil-familja jew ħbieb qrib li ntlaqtu mill-kanċer?* *Jekk iva, min?*	Iva ❑ Le ❑ Iva ❑ Le ❑ ______________________
Perċezzjoni tal-istat ta' saħħa	Eċċellenti ❑ Tajba ħafna ❑ Tajba ❑ Passabbli ❑ Ħażina ❑
Skrining għal kanċer Qatt għamilt eżami kliniku ta' sidrek? Qatt eżaminajt sidrek int stess? Qatt għamilt mammogram? Qatt għamilt test tal-għonq tal-utru? (cervical Papanicolaou's smear) Qatt għamilt test tad-demm kontra l-kanċer tal-musrana (magħruf bħala FOBT - test guaiac tad-demm okkult fir-rawt)?	 Iva ❑ Le ❑ Iva ❑ Le ❑ Iva ❑ Le ❑ Iva ❑ Le ❑ Iva ❑ Le ❑

Appendix 8.5a - Debrief (English version)

Thank you very much for taking part in the study. The aim of this study is to understand factors related to mammographic decisions among Maltese women in order to design and implement effective services to improve your participant rates.

Breast cancer accounts for 28.8% of all female cancer incidences in Europe with 425,000 new cases diagnosed yearly. In Malta, BC accounts for 21% of all female cancer incidences with an average of 280 women diagnosed each year, over the last decade. Breast cancer is more common in women who are over 50 years of age and in post-menopausal women and the risk continues to increase with age. Therefore, it is necessary to uptake of mammography in order to detect the early cancer.

Mammography can detect breast cancer early and women who take part in breast screening reduce their personal risk of dying from breast cancer. The mammography procedure is a low dose x-ray and during the procedure, each breast is placed in turn on the x-ray machine and gently but firmly compressed with a clear plate. Compression is needed to keep the breast still and to get the clearest picture with the lowest amount of radiation possible. Most women find this uncomfortable and some feel short-lived pain. Most women find it slightly uncomfortable and some may find it painful. All women will have two views of the breast taken at every screen - one from above (cranio-caudal) and one into the armpit diagonally across the breast (medio-lateral oblique).

In this study, you will not be identified at any time in the write up. Information given by you will not be disclosed to any third parties. No records will be kept which could identify any individual as being linked to any information disclosed in this study. The information you have provided will be only used to design and implement effective services to improve the prevention of breast cancer among Maltese women.

For more information about breast screening programme, please call on 21227470/1. A video of the mammography procedure is available at http://www.nhs.uk/video/Pages/Breastcancerscreening.aspx

If you have any queries or concerns regarding the study please contact the researcher, Danika Marmarà, at d.m.attard@stir.ac.uk or 77773313. If you feel that you have experienced any feelings of distress as a result of this study and want to discuss these feelings please contact the nursing team at the National Breast Screening Programme on 21227470/1 for counselling.

Participant debrief V2 16.09.17

Appendix 8.5b - Debrief (Maltese version)

<u>Rendikont ġenerali</u>

Grazzi talli ħadt sehem fl-istudju. L-għan ta' dan l-istudju hu li nifhmu il-fatturi marbutin mad-deċiżjonijiet li jieħdu nisa Maltin dwar jekk imorrux jagħmlu mammogram jew le sabiex inkunu nistgħu nfasslu u nattwaw servizzi effettivi biex intejbu l-attendenza.

Il-kanċer tas-sider jammonta għal 28.8% tal-każijiet kollha ta' kanċer fost in-nisa madwar l-Ewropa b'425,000 każ ġdid fis-sena. F'Malta, il-kanċer tas-sider jammonta għal 21% tal-każijiet kollha ta' kanċer fis-sena, b'medja ta' 280 każ ġdid fis-sena, fuq l-aħħar medda ta' għaxar snin. Il-kanċer tas-sider hu iktar komuni fin-nisa 'il fuq minn 50 sena u li jkunu fil-fażi ta' wara l-menopawsa u r-riskju jkompli jiżdied mal-età. Għalhekk, hu neċessarju li jsir mammogram sabiex il-kanċer ikun jista' jinqabad fi stadju bikri.

Il-mammografija tista' taqbad kanċer tas-sider fi stadju bikri u n-nisa li jmorru għall-iskrining tas-sider inaqqsu r-riskju li jmutu bil-kanċer tas-sider. Il-proċedura tal-mammografija hija doża baxxa ta' raġġi X u matul il-proċedura, is-sider jitpoġġa fuq il-magna li titfa' r-raġġi X u tiġi kompressata bil-galbu biex ma jiċċaqlax. Il-kompressjoni hi meħtieġa sabiex is-sider ma jiċċaqlaqx u jkun jista' jittieħed l-iktar ritratt ċar bl-inqas ammont possibbli ta' radjazzjoni. Bosta jħossuhom skomdi u wħud iħossu uġigħ li ma jdumx. Oħrajn iħossuhom ftit skomdi u wħud iweġġagħhom sew il-proċess. Kull mara jitteħdulha żewġ ritratti ta' kull sider – wieħed minn fuq (cranio-caudal) u ieħor b'mod dijagonali minn taħt l-abt san-naħa l-oħra tas-sider (medio-lateral oblique).

F'dan l-istudju, fl-ebda ħin ma int se tiġi identifikata fil-ktiba li ssir wara. L-informazzjoni li tagħti mhux se tiġi żvelata ma' terzi persuni. Mhu se jinżamm l-ebda reġistru li b'xi mod jista' jidentifika l-individwu li jkun abbinat ma' kwalunkwe informazzjoni li tkun ġiet żvelata matul l-istudju. L-informazzjoni li tagħti tista' tintuża biss biex jiġu mfassla u attwati servizzi effettivi biex titjieb il-prevenzjoni kontra l-kanċer tas-sider fost in-nisa Maltin.

Għal iktar informazzjoni dwar il-programm ta' skrining tas-sider, ċempel fuq 21227470/1. Wieħed jista' jara vidjo dwar il-proċedura tal-mammografija fuq http://www.nhs.uk/video/Pages/Breastcancerscreening.aspx

Jekk għandek xi mistoqsijiet jew tħassib dwar l-istudju, jekk jogħġbok ikkuntattja lir-riċerkatriċi, Danika Marmara' permezz tal-posta elettronika d.m.attard@stir.ac.uk jew fuq 77773313. Jekk tħoss li kien hemm xi mumenti li kkawżawlek l-ansjetà minħabba dan l-istudju u tixtieq tiddiskuti ma' xiħadd, ikkuntattja lit-tim ta' infermiera tal-Programm Nazzjonali tal-Iskrining tas-Sider fuq 21227470/1 għal għajnuna psikoloġika.

Rendikont ġenerali għall-parteċipanti V2 16.09.17

Appendix 8.6a: Interview guide with Maltese women (English version)

- How do you take care of your health in general?
- How do you remember to schedule your health appointments?
- What is the meaning of 'cancer' in your view?
- And the words 'breast cancer'?
- Have you ever thought about the possibility of developing breast cancer? What are your related fears?
- Do you think breast cancer can be prevented? What effective ways do you think about preventing breast cancer?
- Do you have any intentions to prevent breast cancer? What do you usually do?
- What do you know about breast health practices?
- What can you tell me about breast screening in Malta?
- What is your perception about a Breast Screening mammogram at the National Breast Screening Programme as opposed to a private mammogram? *Do you think that the quality of the mammogram differs?*
- Why did you not attend to a mammogram in your life? *Are there any environmental barrier, social barriers or intrapersonal barriers you would like to mention that really discourage you from having a mammogram?*
- Did any earlier experience in your life influence your decision to reject the screening invitation? *Explain some of your experiences in which you have made decisions which you think were risky.*
- In your opinion, what set of circumstances would encourage you to go for a mammogram?
- Where and how do you get health-related information? What sources of advice or information do you look to?
- Which kind of educational modality would you prefer to get information about breast health?
- We are trying to figure out how we can encourage women like you to get checked for breast cancer. What things would encourage you to screen regularly? What can we do from our end to help you attend?
- Is there anything else you would like to share?

Interview guide V2 16.09.17

Appendix 8.6b: Interview guide with Maltese women (Maltese version)

Gwida għall-Intervista: **Sett ta' mistoqsijiet għal waqt l-Intervista ma' nisa Maltin**

- Kif tieħu ħsieb saħħtek b'mod ġenerali?
- Kif tagħmel biex tiftakar tagħmel l-appuntamenti mediċi?
- Fil-fehma tiegħek, x'inhi t-tifsira ta' "kanċer"?
- U l-kliem "kanċer tas-sider"?
- Qatt ħsibt dwar il-possibbiltà li joħroġlek kanċer tas-sider? X'inhuma l-biżgħat tiegħek?
- Taħseb li l-kanċer tas-sider jista' jiġi evitat? X'taħseb li huma l-modi effettivi biex tevita l-kanċer tas-sider?
- Għandek intenzjonijiet biex tevita milli joħroġlok kanċer tas-sider? X'tagħmel normalment?
- X'taf dwar il-prattiki għas-saħħa tas-sider?
- X'taf tgħidli dwar l-iskrining tas-sider f'Malta?
- X'inhi l-perċezzjoni tiegħek tal-Iskrining tas-Sider bil-mammogram li jsir fil-Programm Nazzjonali tal-Iskrining tas-Sider li mhux bħall-mammogram li jsir privat? Taħseb li l-kwalità tal-mammograms tvarja?
- Għalfejn qatt ma mort tagħmel mammogram? Hemm xi ostakolu ambjentali, soċjali jew intrapersonali li tixtieq tindika li qed iwaqqfek milli tagħmel mammogram?
- Għaddejt minn xi esperjenza fil-ħajja li jista' jkun li qed tinfluwenzalek id-deċiżjoni li tirrifjuta li tilqa' l-istedina għall-iskrining? Spjegali xi esperjenzi li minħabba fihom ħadt deċiżjonijiet li taħseb li setgħu kienu ta' riskju.
- Fl-opinjoni tiegħek, x'inhuma ċ-ċirkostanzi li jistgħu jħeġġuk tmur tagħmel mammogram?
- Minn fejn u kif iġġib l-informazzjoni dwar is-saħħa? Minn fejn tieħu l-pariri tiegħek u x'sorsi ta' informazzjoni tfittex?
- B'liema mezz tippreferi teduka lilek innifsek biex iġġib informazzjoni dwar is-saħħa tas-sider?
- Qed nippruvaw nistħarrġu kif nistgħu nħeġġu nisa bħalek biex jagħmlu testijiet għall-kanċer tas-sider. X'taħseb li jħeġġek biex tagħmel skrining regolari? X'nistghu naghmlu iktar biex nhegguk tmur ghal breast screening?
- Hemm xiħaġa oħra li tixtieq taqsam miegħi?

Appendix 8.7 – NICR Approval

UNIVERSITY of STIRLING

NHS, Invasive or Clinical Research (NICR) Committee

Room G10
Pathfoot Building
University of Stirling
Stirling FK9 4LA

Tel: +44 (0) 1786 467390
Email: nicr@stir.ac.uk

JE/SF

26 September 2017

Ms D Marmara
13, Sinfonija
Triq L-Anglu
Zebbug ZBG2273
Malta

Dear Danika

Request for Approval of Project Amendment:
- **Non-attendance to mammography screening: A qualitative study among non-screeners in Malta**
  SREC 14/15 – Paper No.18 – Version 4

Thank you for your email of 16 September 2017, attaching the following items:

- Covering letter, 16-09-17;
- Notice of Amendment Form, 16-09-17;
- PhD Protocol Qualitative, 16-09-17.

I am pleased to advise that your study has been granted approval, and wish you and your team all the best.

May I remind you of the need to inform NICR (nicr@stir.ac.uk) prior to making any amendments to this protocol, or any changes to the duration of the project and provide notification of study completion. A site file of all documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the NICR webpage at:
http://www.stir.ac.uk/research/integritygovernanceethics/researchethics/formsandguidance/

Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

SREC 14/15 – Paper No.18 – Version 4
Please quote this number on all correspondence

Yours sincerely

Dr Josie Evans
(Depute Chair)

Appendix 8.8 – HEC Approval

DIRETTORAT TA' L-INFORMAZZJONI
FUQ IS-SAHHA U RIČERKA

Indirizz postali:
95, Telghet Gwardamanġa, Gwardamanġa, PTA 1313
MALTA

DIRECTORATE FOR
HEALTH INFORMATION &
RESEARCH

Postal address:
95, Guardamangia Hill, Guardamangia PTA 1313
MALTA

Tel: (+356) 25599000
Fax: (+356) 25599385

Our Ref: **HEC 11/2014**
Your Ref:

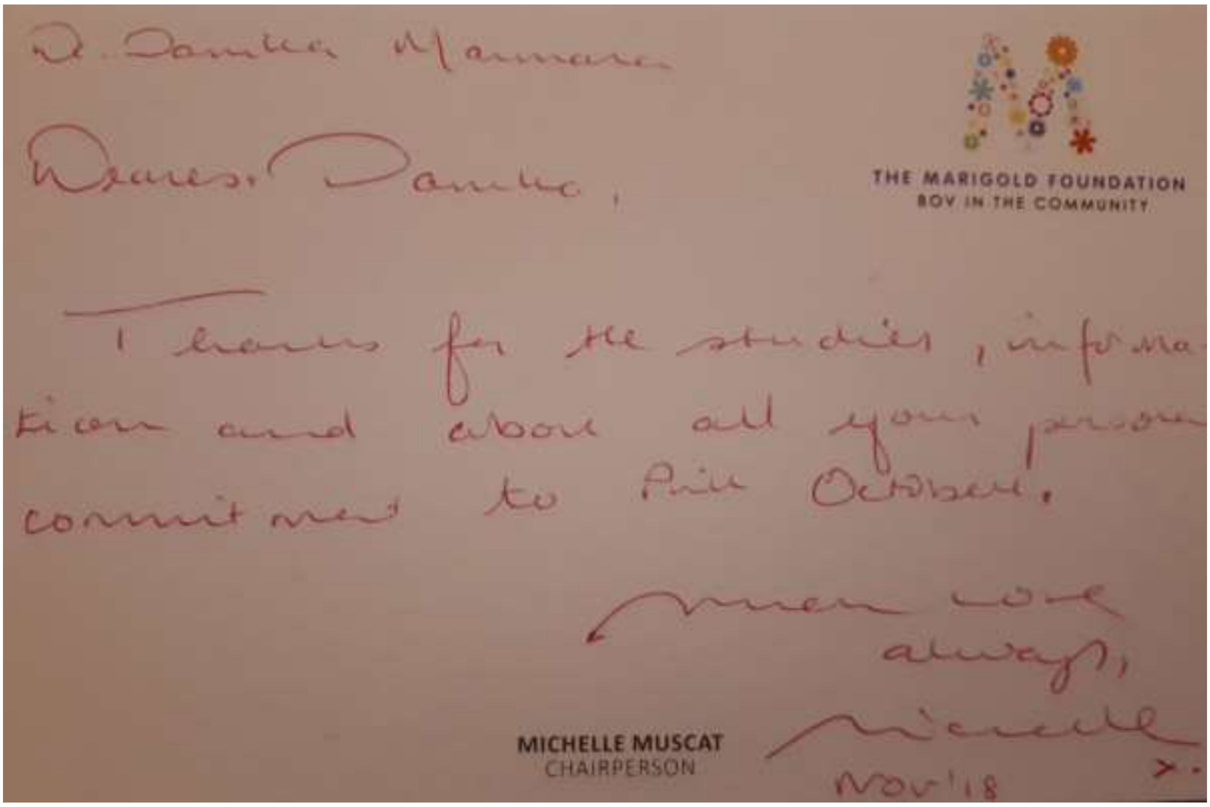
29th November, 2017

Ms Danika Marmara
Cancer Care Researcher
Director
Cancer Care Pathways
Sir Paul Boffa Hospital
Floriana

Request for Approval of Project Amendment:
NON-ATTENDANCE TO MAMMOGRAPHY SCREENING: A QUALITATIVE STUDY AMONG NON-SCREENERS IN MALTA

The Health Ethics Committee would like to inform you that the above mentioned application has been reviewed and assessed, and is giving its approval to carry out the study.

Appendix 9 – A recognition note from the Maltese Prime Minister’s wife



Dr. Daniela Mamara

Dearest Daniela,

Thanks for the studies, information and above all your personal commitment to Pink October!

Much love always,

Michelle x.

Nov'18

THE MARIGOLD FOUNDATION
BOV IN THE COMMUNITY

MICHELLE MUSCAT
CHAIRPERSON