Department of Nursing and Healthcare

Waterford Institute of Technology

Doctoral Thesis Volume I

TITLE:

Promoting Cancer and Screening Awareness in Women with Intellectual Disabilities: A Mixed Methods Study.

BY

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Submitted as partial fulfilment of the

Requirements for the Doctor of Philosophy Degree

June 2016

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Abstract

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Background: People with intellectual disabilities are living longer which has led to increasing cancer rates among this demographic. Women with intellectual disabilities are more likely to have poorer cancer awareness and lower screening participation than women in the general population. They also present at later stages of cancer despite similar cancer rates in both populations.

Aim: This two phase mixed methods study tested the feasibility and acceptability of a targeted educational intervention for women with ID and their carers. EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities) aimed to raise the awareness of warning signs, risk factors, screening programmes, and promote early help-seeking on symptom discovery.

Methods: In line with the MRC's Guidance for Complex Interventions this work was based on empirical evidence and was theoretically underpinned by Bandura's Social Cognitive Theory. Phase I involved a survey of carers (n= 125) and women with mild to moderate ID (n = 45), as well as semi- structured interviews with 25 carers. Phase II involved the feasibility and acceptability testing of EMBRACES- ID among 25 women with mild to moderate ID and 9 carers. A pre-test/post-test design incorporating a 12 week evaluation survey and interview was utilised. Ethical approval for the study was received from the relevant Research Ethics Committees**.**

Findings: In Phase I, gaps in cancer and screening awareness were found. These results formed the basis for the development of the EMBRACES-ID intervention. In Phase II, testing of EMBRACES-ID identified changes in cancer and screening awareness for women with ID and their carers, the majority of changes were retained over the 12 week post intervention time frame.

Conclusions: EMBRACES-ID raised cancer and screening awareness for women with ID and their carers. This may lead to earlier diagnosis and treatment of cancers with better survival outcomes.

Declaration

I, Mary Reidy, declare that this thesis is submitted in partial fulfilment of the requirement for the degree of Doctor of Philosophy (PhD) and is entirely my own work except where otherwise accredited. It has not at any time either in whole or in part been submitted for any other educational award.

Signed: Mary Reidy (Candidate)

Mary Reidy

Date: 7th June 2016

List of Publications

REIDY, M., DENIEFFE, S. & FORAN, S. 2014. Cancer screening in women with intellectual disabilities: an Irish perspective. *J Intellect Disabil,* 18**,** 51-60.

REIDY, M., DENIEFFE, S. & FORAN, S. 2015. Conference Abstracts. *Journal of Applied Research in Intellectual Disabilities,* 28**,** 57.

REIDY, M., DENIEFFE, S. & FORAN, S. 2015. Cancer Awareness among Women with Intellectual Disabilities. *Research Matters.* Waterford: Waterford Institute of Technology.

Dedication

This thesis is dedicated to my wonderful family who encouraged and supported me to follow my dream.

To my husband Chris, I love you more with each passing day. You have been my rock since we first met in 1988 when we were sweet sixteen.

To my sons Chris, Andy and Jason, my daughter Sarah and future daughter in law Ciara, thanks for everything over the last four years to help 'make it happen'.

To my beautiful grandaughter Caitlin, you make me smile with all your hugs and kisses.

To my brother Michael, for being my sounding board during endless phone calls.

To my parents in law Marie and Paddy, for hours of baby sitting and hundreds of school runs.

And lastly, to my late parents Kathleen and Thomas, who lost their lives to cancers which were detected too late to be treated. I know you are with me every day, and my love for you is endless.

Acknowledgement

I would like to express my sincere thanks to my supervisors at the Department of Nursing and Health Care at Waterford Institute of Technology, Dr Suzanne Denieffe, Ms Sinéad Foran and Dr. Martina Gooney. I am grateful for all their support and academic direction over the last four years. Without their support I might have faltered and given up on this PhD thesis.

To the members of the WIT/ HSE Steering Committee, thank you for the opportunity to undertake this project, and for your guidance throughout the lifetime of the project.

Thank you to the intellectual disabilities service providers who helped to get the project up and running, and all the staff and family carers who took part in the study. In particular, I would like to thank the liaison persons for the services: Ms Aileen Moynihan, Ms Hilary Deeley, Ms Claire O' Brien and Ms Liz O'Rourke, Brothers of Charity Services South East; Dr Nick Blitz and Ms Aine Taylor, Camphill Communities of Ireland; Ms Catherine Casey Farrell, Carriglea Cairde Services; Ms Fran Parsons, Waterford Intellectual Disability Association; Ms Elma White, CWCWE; Ms Anne McClean and her team at Wexford Intellectual Disabilities Services, and Mr Liam Quinn, SOS Kilkenny for all their assistance.

Finally, I would like to express my utmost gratitude to the all women with intellectual disabilities who participated in the study. It was a privilege to work with you. It is important to let your voices be heard and I hope you agree that my work made this happen.

Definition of Key Terms

Intellectual disability

Mild intellectual disability: F70: Approximate IQ range of 50-69 (in adults, mental age from 9 to under 12 years. Likely to result in some learning difficulties in school. Many adults will be able to work and maintain good social relationships and contribute to society. *Adapted from* ICD-10 Version:2016 (World Health Organisation, 2016).

Moderate intellectual disability: F71: Approximate IQ range of 35 to 49 (in adults, mental age from 6 to under 9 years). Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community. *Adapted from* ICD-10 Version:2016 (World Health Organisation, 2016).

Severe intellectual disability: F72: Approximate IQ range of 20 to 34 (in adults, mental age from 3 to under 6 years). Likely to result in continuous need of support. *Adapted from* ICD-10 Version:2016 (World Health Organisation, 2016).

Profound intellectual disability: F73: IQ under 20 (in adults, mental age below 3 years). Results in severe limitation in self-care, continence, communication and mobility. *Adapted from* ICD-10 Version:2016 (World Health Organisation, 2016).

Carer

Family carer: Care given for a period of at least three months, by a non-paid carer, from the individual’s direct social environment, springing from the social link between the individual and the family carer, not coming from an organised setting and not provided within the framework of professional nursing or social care. *Adapted from* Kolmer (2007).

Non-professional paid carer: This individual is an employee of an intellectual disability service provider who provides direct care to an adult with an intellectual disability in a residential or day service. Health care assistants, social care workers and students were included in this classification.

Health Care Assistant: This individual supports people with intellectual disabilities to continue to exercise independence and autonomy in leading a full life no matter what their level of dependency and assist with the provision of health and social care (Health Service Executive, 2016).

Social Care Worker**:** This individual works in partnership with those who experience marginalisation or disadvantage, including people with intellectual or physical disabilities. *Adapted from* CORU (2010).

Student Carer*:* This individual is an undergraduate student from a third level institution who provides direct care to an adult with an intellectual disability in a residential or day service as part of their academic studies.

Registered Nurse: A nurse whose name is entered in the nurses division of the register of nurses and midwives (Government of Ireland, 2011).

Key terms used

Consent: giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication in which the service user has received sufficient information to enable him/her to understand the nature, potential risks and benefits of the proposed intervention or service (Health Service Executive, 2013).

Opt- off by a medical practitioner: In the following circumstances a woman may be opted off the cervical screening programme by the Medical Practitioner. These may include women for whom the Medical Practitioner deems the smear test to be inappropriate:

- Women who are patients in psychiatric hospitals
- Women with severe physical disabilities in care/ at home
- Women with intellectual disabilities in care/ at home

(National Cancer Screening Service, 2011).

Protectionism: Staff, families or guardians control opportunities for sexuality based decision making for women with intellectual disabilities. *Adapted from* Hingsburger (1995).

Age classifications for statistical analysis

Carers

Older group: 50 years of age and older as per the Irish Longitudinal Study on Ageing (TILDA) (Barrett et al., 2011).

Younger group: Aged 18 years to 49 years for comparative purposes.

Women with intellectual disabilities

Older group: 40 years of age and older as per the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) (Mc Carron et al., 2011).

Younger group: Aged 18 years to 39 years for comparative purposes.

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Chapter 1: Introduction and Organisation of Thesis

1.0. Introduction

This chapter begins with a brief background to the study presented in section 1.1. Following this section 1.2. explores cancer prevention in the context of breast and cervical cancer risk factors. A brief analysis of the goals of the early detection of cancer including warning signs and screening programmes are presented in section 1.3. Subsequently, the rationale for the current study is presented in section 1.4. Section 1.5. describes the structure of the thesis chapters. Finally, Chapter 1 concludes with a summary in section 1.6.

1.1. Background to the study

Section 1.1.1. introduces the definition for intellectual disabilities adopted throughout this study. Section 1.1.2. explores cancer incidence among the general population in an international and national context, and then focuses on cancer incidence in the intellectual disabilities population.

1.1.1. Intellectual disability

Intellectual disability is characterised by significant limitations both intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. which originates before 18 years of age (Schalock et al., 2010). There have been significant improvements in life expectancy in people with intellectual disability resulting from technological advancements, improved medical care and environmental conditions (Sullivan et al., 2004, Wilkinson and Cerreto, 2008).

It is estimated that there are almost 60 million people worldwide with an intellectual disability (IASSID, 2002). The National Intellectual Disabilities Database (NIDD) provides a demographic profile of people with intellectual disabilities who are known to access intellectual disability services in Ireland. Currently, over 27,000 people with intellectual disabilities are registered on the NIDD (Kelly and O' Donoghue, 2014).

1.1.2. Cancer incidence and people with intellectual disabilities

Almost 1.67 million new cases of breast cancer were diagnosed worldwide in 2012 (Ferlay et al., 2013). It is the most common invasive cancer diagnosed in Irish women and accounts for almost 16% of female cancer related deaths with a median age of 59 years at diagnosis

(National Cancer Registry, 2012a). Ductal carcinoma accounts for 70% to 80% of all breast cancers diagnosed and the remainder are invasive lobular carcinoma (Cancer Research UK, 2012a, Cancer Research UK, 2012b).

Cervical cancer is the fourth most common cancer in women, representing 7.5% of all female deaths internationally (Ferlay et al., 2013). In Ireland, cervical cancer is the eighth most common cancer and 60% of invasive tumours and almost all in situ tumours are diagnosed in women under 50 years of age (National Cancer Registry/ Northern Ireland Cancer Registry, 2011, National Cancer Registry, 2012b). The normal cells of the cervix first gradually develop dysplasia that may turn into cancer. About 80% to 90% of cervical cancers are squamous cell carcinomas (American Cancer Society Inc., 2014a).

Gastrointestinal and oesophageal cancer are more common in people with intellectual disabilities which may be attributable to higher incidences of Helicobacter Pylori infection (Cooke, 1997, Taggart and Proulx, 2014). Women with Down syndrome are reported to have lower than expected incidences of breast cancer (Hasle et al., 2000, Patja et al., 2001, Satge et al., 2001).

Cervical cancer incidence appears to be lower among women with intellectual disabilities than the general population (Patja et al., 2001, Jaffe et al., 2002, Sullivan et al., 2004). Despite this it seems that the age standardised incidence of cancer in people with intellectual disabilities is not significantly different to that of the general population (Patja et al., 2001, Sullivan et al., 2004).

1.2. Cancer risk factors

Cancer prevention is focused on reducing individual risk through the implementation of lifestyle changes and interventions to modify risk (Alberts and Hess, 2008, World Health Organisation, 2014). Sections 1.2.1. and 1.2.2. examine risk factors for breast and cervical cancer in the general population and among the population of women with intellectual disabilities.

1.2.1. Breast cancer risk factors

Advancing age is the strongest risk factor for breast cancer (Lacey et al., 2009, Newcomb and Wernli, 2010). Alcohol use, being overweight and obesity and physical inactivity account for over one fifth of female breast cancer deaths (Danaei et al., 2005). A positive family history of breast cancer, nulliparity, first time mothers over 35 years, early menses and late menopause are associated with increased breast cancer risk (Lacey et al., 2009, Newcomb and Wernli, 2010, Gierach et al., 2013). The contraceptive pill and hormone replacement therapy (HRT) after menopause may also increase risk. Reduced duration of breastfeeding lessens the protective factor provided by breastfeeding (Lacey et al., 2009, Newcomb and Wernli, 2010, American Cancer Society Inc., 2014b, Cancer Research UK, 2014a).

These risk factors are also important considerations in the development of breast cancer in the intellectual disabilities population (Davies and Duff, 2001, Emerson and Turnbull, 2005, Rimmer and Yamaki, 2006, Willis et al., 2008, Begley et al., 2009, van Schrojenstein Lantman-de Valk et al., 2011).

1.2.2. Cervical cancer risk factors

There is a well- established link between Human Papilloma Virus (HPV) infection and cervical cancer (WHO/ICO Information Centre on HPV and Cervical Cancer, 2010). An accumulative incidence of 15% of cervical HPV has been reported among virgins before penetrative sexual intercourse (Harper, 2012). Smoking, parity, oral contraceptive use, and co-infection with HIV have been identified as established cofactors necessary for the progression from cervical HPV infection to cancer (WHO/ICO Information Centre on HPV and Cervical Cancer, 2010).

The evidence suggests that smoking rates are increasing among those with mild to moderate intellectual disabilities (Taggart and Temple, 2014). More people with mild to moderate intellectual disabilities are becoming parents (Willems et al., 2007, Hoglund et al., 2012). A significant proportion of women with intellectual disabilities continue to be prescribed oral contraception (Begley et al., 2009, van Schrojenstein Lantman-de Valk et al., 2011).

There is a paucity of evidence regarding the rates of sexually transmitted infection (STI) and STI testing among adults with intellectual disabilities (Greenwood and Wilkinson, 2013). Likewise, there is limited understanding of the rates of sexual abuse and sexual activity within this population (Drummond, 2006, Carlson and Diedrich, 2009, McConkey and Leavey, 2013).

1.3. Early detection of cancer

Education to increase awareness of the early warning signs of cancer and seeking medical attention, and cancer screening tests leads to earlier cancer detection with more effective treatment and improved prognosis (World Health Organisation, 2014).

1.3.1. Breast cancer warning signs

Early breast cancer does not have any symptoms. The warning signs for breast cancer include lumps or thickening in the breast or armpit; change in the size of the breast or nipple; dimpling of the skin; blood stained nipple discharge; a rash on the nipple and breast pain (Irish Cancer Society, 2012, Cancer Research UK, 2014b).

1.3.2. Cervical cancer warning signs

Symptoms of cervical cancer often do not begin until the cancer grows into nearby tissue. The most common symptom is abnormal vaginal bleeding. Other symptoms include unusual vaginal discharge, pelvic discomfort or pain, and painful intercourse (American Cancer Society Inc., 2014a, Irish Cancer Society, 2014, National Cancer Institute, 2014).

1.3.3. Screening

Population based screening programmes endeavour to provide a sensitive and specific screening tests to >70% of the age eligible women to detect early forms of disease. The programmes monitor and evaluate measurable reduction in disease burden and mortality rates, and cost effectiveness (Seballos, 2010, International Agency for Research on Cancer, 2012, Gotzsche and Jorgensen, 2013, Marmot et al., 2013).

1.3.3.1. Breast screening

A mammogram is designed to detect changes in breast tissue that may indicate that cancer is present (Marmot et al., 2013). A number of international reviews presented conflicting results on the breast cancer mortality rates and estimates of overdiagnosis (Nelson et al., 2009, Duffy et al., 2010, Gotzsche and Jorgensen, 2013, Marmot et al., 2013, Mukhtar et al., 2013). Mammography screening at any age is a trade-off between the benefits and harms of screening (Nelson et al., 2009, Marmot et al., 2013, Mukhtar et al., 2013).

1.3.3.2. Cervical screening

Cervical screening can prevent at least 75% of cervical cancers in women aged 60 and over and at least 45% of cervical cancers in women in their 30’s (Cancer Research UK, 2012). The principal cervical screening tests are pap tests, acetic acid visual inspection of the cervix and HPV testing (United Nations Population Fund, 2011, National Cancer Institute, 2012). Cervical screening methods in conjunction with the HPV vaccination have the potential to improvement cervical cancer control internationally (World Health Organisation, 2011a).

The vaccination of girls before sexual activity commences protects against HPV high risk types 16 and 18 which are responsible for almost 70% of cervical cancer cases (WHO/ICO Information Centre on HPV and Cervical Cancer, 2010, Health Service Executive, 2012, National Cancer Institute, 2012). There has been a paucity of research investigating the HPV vaccine uptake in girls with intellectual disabilities, although a preliminary study indicates lower uptake levels than in the general population (MacLeod and Tuffrey, 2014) .

1.4. Rationale for the study

In the Ottowa Charter health promotion is defined as 'the process of enabling people to increase control over, and to improve, their health' (World Health Organisation, 1986). Effective health promotion can lead to health and economic gains for health services and the individual through improved health behaviours (Health Service Executive, 2011). However, it seems that health promotion policies currently exclude people with intellectual disabilities (Hanna-Trainor, 2013), as evidenced in mainstream Health Promotion Policy and Strategies in the Republic of Ireland which had limited or no reference to people with intellectual disabilities (Department of Health and Children, 2006a, Department of Health and Children, 2006b, Department of Health and Children, 2008, Department of Health and Children, 2010, Department of Health, 2013).

Although it seems this trend may be amenable to change. Marginalised groups to be targeted for health promotion interventions include people with disabilities, mental health issues, disadvantaged communities and minority groups (Irish Cancer Society, 2013, Department of Health, 2013). It is important to consider how people understand and process information in the design of targeted health promotion interventions (Doyle et al., 2012). Recent international reviews indicate a movement towards theoretically driven tailored health promotion interventions which take into account the perspectives of people with intellectual disabilities (Kerr et al., 2013, Naaldenberg et al., 2013, Heller et al., 2014). It is therefore an opportune time to address the development of a theoretically driven tailored cancer and screening awareness education intervention taking into account the perspectives of Irish women with intellectual disabilities.

1.5. Structure of the work

This PhD dissertation is composed of eight chapters. Chapter 1 introduces the background and study rationale in the context of the movement towards tailored health promotion interventions for marginalised groups such as women with intellectual disabilities. Chapter 2 presents the comprehensive search strategy used to explore the current national and international knowledge base in the area of health promotion, and cancer and screening awareness for women with intellectual disabilities and their carers. Chapter 3 describes the conceptual framework for this exploratory study. It examines the links between health inequalities and models of disabilities, and explores the potential of mixed methods transformative feminist research as a tool to promote social justice. Next it examines key factors involved in the development, feasibility and acceptability testing of tailored health promotion interventions for women with intellectual disabilities. Chapter 4 explains the two phase research design including the questionnaire and interview data collection and analysis techniques and ethical considerations when working with a vulnerable population. Chapter 5 presents key findings from Phase I, the Comprehensive Needs Assessment, to inform the development of the EMBRACES-ID cancer screening and awareness education programme. Chapter 6 presents the key findings of the single arm mixed methods feasibility testing of the intervention using pretest-posttest design to monitor for changes in primary and secondary outcome measures among participants. Chapter 7 first describes the mixed methods integration of the quantitative and qualitative data in Phase I and Phase II of the study to get a broader perspective on key issues. Next it details the acceptability testing of the EMBRACES- ID intervention and presents key participant reflections on the programme. The thesis concludes with Chapter 8 which considers the clinical and theoretical implications of the study in the context of the current body of evidence. It also addresses key strengths and limitations of the study and makes clear recommendations for clinical practice and future research directions.

1.6. Chapter summary

This chapter explored the relationship between an ageing profile of women with intellectual disabilities and future increases in cancer incidence. It is evident that cancer prevention and early detection for women with intellectual disabilities is an ongoing challenge which may lead to later diagnosis of cancer with poorer outcomes. The rationale for the need to explore the cancer and screening awareness and participation in screening programmes among Irish women with intellectual disabilities and their carers was introduced The chapter concludes with a description of the structure of the thesis.

Chapter 2: Literature Review

2.0 Introduction

As identified in Chapter 1 breast and cervical cancer are a worldwide problem. While there are known risk factors and screening programmes developed there is a clear need for education about cancer awareness and screening programmes to enhance earlier detection of cancer with better prognosis and outcomes particularly in women with intellectual disabilities, an identified marginalised group. The overall aim of this review is to provide a summary of the current understanding about cancer and screening awareness among women with intellectual disabilities and their carers.

Section 2.1. describes the search strategy used to screen and identify relevant literature and the rationale for selecting a narrative approach to frame to review. Section 2.2. examines cancer and screening awareness in the general population nationally and internationally. Next, section 2.3. explores evidence about cancer incidence in women with intellectual disabilities. Section 2.4. first looks the perspectives of women with intellectual disabilities to develop an understanding of their cancer awareness and their screening experiences. Then, the cancer awareness and knowledge of preventative screening programmes among paid and family carers is examined. Following this section 2.5. explores determinants for the participation of women with intellectual disabilities in screening programmes and explores participation disparities among these women in screening programmes. Section 2.6. focuses on ‘what’s out there’ in terms of accessible information about cancer awareness and screening programmes for women with intellectual disabilities and their carers. Subsequently, section 2.7. addresses the methodological limitations of the studies included in the review. Section 2.8. considers the gaps identified in the literature and how this study could bridge these gaps. Finally, section 2.9. summarises the key elements discussed in Chapter 2 and concludes the literature review.

2.1. Search strategy and themes identified

The literature concerning cancer and screening awareness, screening uptake and health promotion interventions for women with intellectual disabilities and their carers consisted mainly of peer reviewed articles found in the electronic databases CINAHL with Full Text; Science Direct; Wiley Online Library; Pubmed and Scopus. Search terms and keywords used to locate the relevant literature included a combination of the terms: women; intellectual disabilities; developmental disabilities; learning disabilities; cancer screening; breast cancer; cervical cancer; awareness; carers (care*); general population; health promotion; health behaviour theory; cancer screening inequalities; delayed presentation; beliefs; Ireland. The inclusion and exclusion criteria for the literature review are presented in Table 2.1.

Table 2.1. Inclusion and exclusion criteria for review

Inclusion criteria	
Study focus	Breast and cervical cancer and screening awareness; screening uptake levels; Beliefs about cancer; Cancer screening inequalities for women with intellectual disabilities; Cancer awareness information for adults with intellectual disabilities.
Method	Primary research using quantitative and qualitative methodologies; Published reports from national and international agencies.
Publication dates	2005-2015
Language	English
Exclusion criteria	Non peer reviewed studies Non English language studies

First, literature focused on cancer and screening awareness for women with intellectual disabilities and their carers was investigated. Next, Irish literature focusing on population based cancer and screening awareness was explored. Subsequently, Irish reports looking at healthcare inequalities in people with intellectual disabilities were examined. Following this international literature where an Irish focus could readily be identified, and the input of Irish women with intellectual disabilities could be discerned clearly were also accessed. Finally, institutional websites with links to online resources were accessed for publications of interest especially in relation to the design of the health promotion interventions for adults with intellectual disabilities.

Among the key approaches to conducting a literature review are systematic review, meta-analysis, meta-synthesis or narrative review. Systematic reviews involve a comprehensive search strategy, which aims to reduce bias by identifying, appraising, and synthesizing all relevant studies on a particular topic and are reported according to the PRISMA Statement (Moher et al., 2009, Higgins and Green, 2011). Meta-analysis is a quantitative synthesis of study findings as a part of a systematic review (Petticrew and Roberts, 2008). Meta-synthesis is a systematic qualitative synthesis of a set of reports resulting in a complete description of the experience (Sandelowski and Barroso, 2007, Reidy and Denieffe, 2014). Narrative reviews are comprehensive narrative syntheses of previously published studies and are useful to present a broad perspective on a topic (Green et al., 2006). A scoping study review tends to address broader topics where a broader range of study designs might be applicable and is useful to identify all relevant literature regardless of study design (Arksey and O'Malley, 2005).

The initial step involved comprehensively identifying the relevant studies using the defined inclusion criteria. Initial searches identified 1671 articles and removal of duplicates resulted in 1570 articles for preliminary screening. The titles and abstracts these identified articles were screened and those not meeting the inclusion and exclusion criteria were excluded. The Fulltext of each of the relevant articles was retrieved from the electronic databases, via inter-library loan or directly from the authors via Researchgate.

Critical appraisal of the literature was initially guided by the framework of Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011) and the PRISMA Statement for Reporting Systematic Reviews (Moher et al., 2009). During the appraisal of the abstracts online further articles of interest were identified either through related citations or author searching. The citations were uploaded into Endnote®, citation reference manager to organise and keep track of the articles retrieved. A second screening of the articles involved reading the full-text and checking its eligibility with the inclusion criteria. Articles not adhering to the inclusion and exclusion criteria were then excluded. A total of 49 publications were deemed to be relevant in the context of the research objectives and met the inclusion and exclusion criteria, see Figure 2.1.

The MMAT and PRISMA guidelines were initially used in the critical appraisal of the literature to guide the appraisal. As the appraisal progressed it became clear that meta-analysis or meta-synthesis was not possible due to the wide variety of methodologies and designs found in the literature on cancer and screening awareness. As it was considered important to present a broad perspective on the topic, regardless of the study design or issues related to the quality of the research, the scoping study review approach was selected to frame the literature review (Arskey and O' Malley, 2005).

The first stage involved charting the key data from each of the included studies, government reports and accessible cancer publications for people with intellectual disabilities. The process involved extracting the authors, year of publication, geographical locations, aim of the study, method and sample and the key findings of each of the included studies examined. The fundamental components of each of the included accessible cancer publications and government reports were examined. Key elements from the evidence were collated and synthesised descriptively to explore emerging themes in the literature.

During the analysis of the literature five themes emerged which were crucial in developing this insight. Table 2.2. identifies these emerging themes and the studies/ reports from which they arose. Table 2.3.- 2.6. present the extracted data for the included studies/ reports based on the emergent themes.

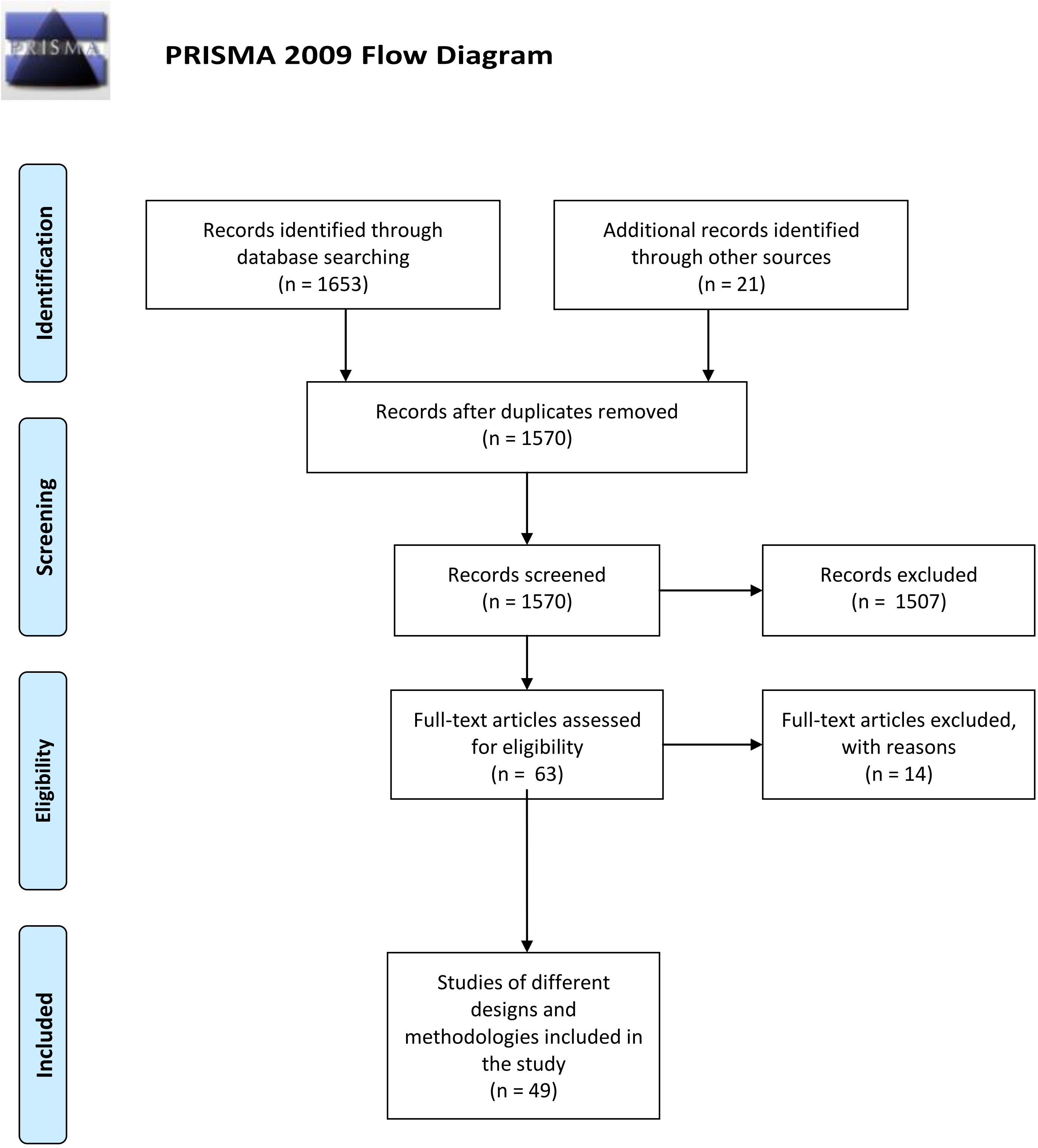
2.2. Exploring cancer and screening awareness in the general population

This section explores cancer, including breast and cervical cancer, awareness, screening knowledge of screening programmes and factors causing delays in medical help seeking upon self-discovery of a cancer symptom among the general population in international and national studies. Many gaps in public knowledge about these important issues have been identified in these studies. The key information charted from the studies in this discussion can be seen in Table 2.3.

2.2.1. Cancer and screening awareness – international perspectives

The International Cancer Benchmarking Partnership (ICBP) was set up to examine and explain survival difference between Australia, Canada, Denmark, Norway, Sweden and the United Kingdom for cancers of the lung, breast, bowel and ovary from 1995-2007. The ICBP undertook a population based study (n=19,079) to assess differences in cancer awareness and beliefs in the ICBP countries (Forbes et al., 2013).

The Awareness and Beliefs about Cancer questionnaire was used to identify key items that could differ between countries. The sample selected was representative of the general



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For more information, visit www.prisma-statement.org.

Figure 2.1. PRISMA 2009 Flow Diagram for study selection

Table 2.2: Emerging themes from the literature review and the studies from which they arose

Theme 1 Exploring cancer and screening awareness in the general population	Mc Menamin et al. (2005) Scanlon et al. (2006) Linsell et al. (2008) O' Mahoney and Hegarty (2009) Robb et al. (2009)	Keeney et al. (2010) Walsh et al. (2010) Forbes et al. (2011) Low et al. (2012) O' Connor et al. (2012)	Forbes et al. (2013) Ekechi et al. (2014) Tazhibi and Feizi (2014) Ryan et al. (2015)
Theme 2 Cancer and women with intellectual disabilities	Mc Carron et al. (2011) Satgé et al. (2014)		
Theme 3 Perspectives of women with intellectual disabilities, family and paid carers about cancer and screening	D'eath et al. (2005) Lalor and Redmond (2009) Kirby and Hegarty (2010) Lin et al. (2010) Tyler et al. (2010) Hanna et al. (2011)	Taggart et al. (2011) Truesdale-Kennedy et al. (2011) Wilkinson et al. (2011a) Wilkinson et al. (2011b) Parish et al. (2012)	Parish et al. (2013) Swaine et al. (2013) Wyatt and Talbot (2013) Lloyd and Coulson (2014) Willis et al. (2015)
Theme 4 Investigating disparities and barriers to screening for women with intellectual disabilities	Noonan- Walsh et al. (2008) Lalor and Redmond (2009) Dowling et al. (2010) Lin et al. (2010) Walsh et al. (2010)	Department of Health (2011) Wilkinson et al. (2011b) Osborn et al. (2012) NCSS (2012a) Cobigo et al. (2013)	NCCS, 2013 Parish et al. (2013) Horner- Johnson et al. (2014) Lai et al. (2014)
Theme 5 Accessible cancer and screening information for women with intellectual disabilities	Hollins and Downer (2000) Hollins and Perez (2000) NHS Cancer Screening Programmes 2006 (a,b,c)	Booth et al. (2010) Taggart and McKendry (2010) National Cancer Screening Service (2012)	

population in each of the countries in terms of sex, age and education level. Almost one third of the sample was aged 70 years or over, 79-86% had personal experience of cancer, more women than men took part and participants had higher levels of education. It was suggested that women with higher levels of education are more likely to participate in health surveys.

The findings indicate that the mean number of symptoms recognised was 7-8 out of the eleven warning signs for cancer across the ICBP. However, just 14% of the UK sample demonstrated awareness of the risk that cancer risk increases with age. Awareness of the age related risk was considerably higher (38%) in the Swedish population. The poor awareness of age related cancer risk is of interest in the context of a growing and ageing population in Ireland, both in the general and intellectual disability populations.

In the UK, Robb et al. (2009) undertook a population based study to assess awareness of cancer warning signs, anticipated delay and barriers to seeking help for symptomatic presentation for the British population. The sample (n=2208) approximated the British population. Similar to Forbes et al. (2013) the sample trended toward higher levels of education and socioeconomic status (SES). The majority of respondents (94%) recognised a change in the appearance of a mole and a lump/ swelling as warning signs for cancer. The mean number of cancer warning signs recognised from the list of nine warning signs presented ranged from 7.6 for the highest socioeconomic group to 6.9 for the lowest socioeconomic group which is broadly similar to Forbes et al., (2013). The lower awareness in the lower SES is noteworthy, given the likelihood of lower educational attainment and reliance on social welfare as a means of income for women with intellectual disabilities in the Republic of Ireland.

2.2.1.1. Breast cancer and screening awareness

The previous section looked at general cancer and screening awareness in the general population internationally. This section considers breast cancer and screening awareness in the general population as evidenced in larger population based studies.

Within the UK Forbes et al. (2011) undertook a population based study to assess the breast cancer awareness among women (n=1515), aged 30 years and over, from different ethnic groups in East London. The variables of interest were measured using a population validated survey. These variables were the knowledge of breast cancer symptoms, increasing risk of breast cancer with age and breast self-examination.

The results indicate low levels of awareness of non-lump breast cancer symptoms as less than one fifth of participants recognised five or more of the warning signs including discharges, rashes, changes in shape or size of breast and nipple and changes in breast skin such as puckering. The awareness levels were particularly low among Bangladeshi women (9%). This was lower than the mean number (7-8) cancer warning signs reported in the International Cancer Benchmarking Partnership. Similar to Forbes et al. (2013), just 14% of the women recognised that a 70 year old woman was most likely to develop breast cancer which is alarming in the light of population growth and increased longevity.

In relation to the NHS Breast Cancer Screening Programme, just over half of the women responded that they were aware of the programme. Over half the women indicated that they were confident that they would notice a change in their breast, while just under a quarter of the women reported monthly breast self-examination. In all, three quarters of the women reported that they would seek medical help within one week of noticing a change in their breast.

Likewise within the UK, Linsell et al. (2008) assessed the knowledge of breast cancer symptoms and risk, and the confidence to detect breast changes in older women aged 67- 73 years of age (n=712) using a survey. Similar to Forbes et al. (2011) the results indicate that older women are less knowledgeable about non-lump breast cancer symptoms. Less than one fifth of participants recognised a nipple rash (13.9%) and redness of the skin (19.4%) as warning signs for breast cancer. The awareness levels were higher in more affluent and educated women in the sample.

The median number of cancer warning signs recognised by the older women was six (range 4-9), and again was higher in more educated women. Nevertheless, this was lower than the mean number (7-8) cancer warning signs reported in the International Cancer Benchmarking Partnership research (Forbes et al., 2013). However, it was broadly similar to the five or more warning signs recognised by ethnically different women in East London (Forbes et al., 2011).

Unlike Forbes et al. (2011) over a quarter of the women reported that a 70 year old woman is most likely to develop breast cancer. However, this remains an area of concern given the age profile of the sample that three quarters of the sample were not aware of the increased risk of breast cancer with advancing age, even though they had participated in the NHS Breast Cancer Screening Programme.

Around two thirds of the older women reported that they checked their breasts at least once a month, and felt confident that they would notice a change in their breast. The rate of monthly self- examination and confidence in detecting breast changes was much higher than that reported by Forbes et al. (2011). However, it is interesting to note that Linsell and colleagues (2008) found that more highly educated women reported that they were least likely to check their breasts.

More recently, Tazhibi and Feizi (2014) undertook a population based survey (n=2250) to evaluate the baseline awareness levels about breast cancer risk factors, early warning signs, screening approaches and breast cancer treatments among women participating in a public education programme in Iran. The research was contextualised in relation to the disagreement in the literature about the best ways to measure cancer awareness.

Although data was collected by Tazhibi and Feizi (2014) using a newly validated measurement tool, the results are broadly related to international findings. In agreement with Linsell et al. (2008) and Forbes et al. (2011) almost three quarters of the participants had poor awareness of the non -lump symptoms of breast cancer such as rashes. There was broadly similar awareness of breast cancer screening methods. Higher awareness levels trended toward higher educational levels, in additional to a personal history of cancer and attendance at educational or screening programmes (Linsell et al., 2008).

Although certain breast cancer symptoms are well recognised, such as breast lumps, awareness of other non- lump symptoms is much lower. Despite the availability of breast cancer education and information from international sources such as the World Health Organisation there is widespread evidence of gaps in cancer and screening awareness in the general population.

2.2.1.2. Cervical cancer and screening awareness

This section explores cervical cancer and screening awareness in women in large population based studies using a validated measure to identify important gaps in awareness levels.

In the UK, Low et al. (2012) carried out a population based study in women aged 16 years and older (n=1392) to assess cervical cancer and screening awareness using a validated tool to systematically measure awareness of symptoms and risk factors for cervical cancer. The majority of the sample was of white ethnic origin (91%) and over half the sample had no formal or low educational attainment.

The link between sexual activity and cervical cancer was poorly understood in this population, only 20% of respondents recalled having many sexual partners as a risk factor. None of the respondents recalled HPV as a risk factor for cervical cancer, which is concerning given the link between HPV and cervical cancer. Alarmingly, 65% of the respondents could not recall any risk factor for cervical cancer. Additionally, over half the respondents could not recall a target symptom for cervical cancer, while just under one third of the respondents recalled unusual vaginal bleeding as a symptom. Furthermore, almost one quarter of the respondents did not recognise that not attending regular smear tests to promote early detection of cervical cancer was a risk factor for cervical cancer even when prompted by the interviewer.

More recently, Ekechi et al. (2014) explored the sociodemographic and ethnicity related factors associated with cervical cancer knowledge and non-attendance at screening among Black women (n=876) in London. Consistent with Low et al. (2012) the majority (96%) of women did not cite HPV as a risk factor for cervical cancer. Although when the factors related to sexual activity, for example, many sexual partners were combined this figure rose to 29%. Vaginal bleeding was cited by the 32% women as a symptom of cervical cancer which was broadly similar to Low et al. (2012). Alarmingly, 90% of the women did not mention not having regular smear tests to check for abnormal cells risk factor for cervical cancer, which was considerably lower than Low et al. 2012. Low et al. (2012) and Ekechi et al. (2014) agreed that advancing age and a higher education level predict higher awareness levels.

2.2.1.3. Delays in medical help seeking on the self-discovery of a cancer symptom-international perspective

Delayed help seeking of the self-discovery of a breast cancer symptom is problematic for women in terms of delayed symptom presentation leading to later diagnosis with poorer prognosis.

Emotional barriers may be a key factor in early medical help seeking on discovery of a cancer warning sign (Forbes et al., 2013). The UK had the highest mean barriers to symptomatic presentation (8.29/ 50) in the ICBP. The key barriers to presentation endorsed among the UK participants that would delay medical help seeking for a symptom they thought might be serious included worry about wasting the doctor's time (34%); worry about what the doctor might find (28%) and embarrassment (15%). Although in Sweden just 9% of participants would delay symptomatic presentation based on worry about wasting the doctor's time. While in Canadian participants, over one quarter of participants (29%) reported that being too busy would be a barrier to symptomatic presentation (Forbes et al., 2013).

Forbes et al., (2011) reported that participants in the lower SES were most likely to endorse emotional barriers to medical help seeking. For example, just over one third of the female participants (41%) reported that worry about wasting the doctor's time would delay medical help seeking for a symptomatic presentation. This was comparable to the findings of Forbes et al. (2013) in that the women do not feel confident that the symptom needs medical attention and so delay medical help seeking.

Almost half of the women reported that worry about what the doctor would find would delay their medical help seeking for a symptom they thought might be serious. White women (52.7%) were more likely to report that worry about wasting the doctor's time would be a barrier to symptomatic presentation (Forbes et al., 2011). This is much higher than reported by Robb et al. (2009) and Forbes et al. (2013). This is of interest on the context of this study given the high prevalence of white women in the Irish population.

2.2.2. Cancer and screening awareness in Ireland

It is important to contextualise awareness and beliefs about cancer and knowledge of screening programmes in Ireland compared to international perspectives. This section explores and compares awareness of cancer risk factors, beliefs about cancer, and factors related to participation in cancer screening programmes in the general population with international findings.

2.2.2.1. Awareness of cancer risk factors

Recently in Ireland, Ryan et al. (2015) undertook an online survey (n=748 including 126 healthcare practitioners) to assess public perceptions of the risk factors of cancer and to assess myths and misconceptions surrounding cancer risk. Similar to international studies the sample was educated and comprised more women than men (Robb et al., 2009, Forbes et al., 2013).

The top five risk factors reported for cancer in the Irish Republic were smoking (87%); diet (76%); genetics (47%); alcohol (42%) and obesity (32%). The awareness of smoking as a risk factor for cancer is well established in the Irish population given that 99% of respondents agree that smoking is a risk factor for cancer. A higher proportion of healthcare practitioners (41%) than the general population (32%) noted that obesity was a risk factor for cancer. This awareness deficit is interesting given the level of obesity among the intellectual disability population and its association with cancer.

Conflicting findings were observed among respondents' opinions about the link between cancer and age. When asked whether it was true or false that cancer increases with age 80% of the general population and 90% of healthcare practitioners agreed. However, in the open ended question about opinions about risk factors for cancer just 6% of respondents mentioned age as a risk factor. This is much lower than awareness levels noted internationally by Forbes et al. (2013). Given that the population of the Republic of Ireland is ageing and growing with expected increases in cancer incidence this knowledge deficit about age as a risk factor for cancer is worrying.

2.2.2.2. Breast cancer and screening awareness

With regard to assessing the breast cancer awareness and knowledge in the general population in Ireland, McMenamin et al. (2005) undertook a national population based study. The purposive sample was geographically representative based on census derived quotas and was as follows 53% female (n=1250) and 47% male (n= 1105). The demographic profile indicates that almost 50 % of the participants were under the age of 30 and nearly 70% had an educational attainment of Leaving Certificate or higher. The survey data was collected via questionnaires administered in urban and rural sites.

The findings showed that Irish women demonstrated a good awareness of breast cancer screening and a reasonable knowledge of heredity and lifestyle related breast cancer risk factors. Breast lumps were widely recognised as a symptom of breast cancer. However, similar to Linsell et al. (2008) and Forbes et al. (2011) the knowledge of other non- lump symptoms such as nipple and skin changes was substantially lower.

Like the findings of Linsell et al. (2008) and Forbes et al. (2011, 2013) awareness of the most common age for developing breast cancer was low. Just 2% of Irish women correctly identified the most common age for developing breast cancer which was substantially lower than international awareness. Over 80% of the women reported that they were aware of BreastCheck, the National Breast Screening Programme in Ireland, this figure was substantially higher than the screening programme awareness levels reported in the UK (Forbes et al., 2011).

2.2.2.3. Cervical cancer and screening awareness

In an Irish context O' Connor et al. (2012) carried out a national population survey which investigated the factors associated with never having a cervical smear. An age stratified random sample of women age 20-64 years (n=3,470) was selected from a number of primary care settings nationwide. The findings indicated that in excess of 200 women reported never having had a smear test and embarrassment and anxiety were cited as contributing factors. Key health behaviours associated with not having a smear test included being a current smoker and never having asked a GP for a breast examination. Key socio demographic factors associated with never having a smear test included being single, nulliparity, never living abroad, and no health insurance (O' Connor et al., 2012).

Similar to Low et al. (2012) the majority of Irish women agreed that smear tests have to be carried out regularly to be effective. Unlike the findings in the UK where the understanding of the link between sexual activity and cervical cancer was low (Low et al., 2012, Ekechi et al., 2014) the majority Irish of women believed that you should commence smears following the onset of sexual activity (O' Connor et al., 2012). Another key finding was that over one quarter of the participants reported that they did not know enough about smear tests to make a decision about having one (Adjusted OR 7.96%: 95% CI 5.30-11.9) (O' Connor et al., 2012).

2.2.2.4. Factors affecting screening participation

Walsh et al. (2010) examined data from the SLÁN 2007, the Survey of Lifestyle, Attitudes and Nutrition in Ireland (Morgan et al., 2008) to assess uptake of breast and cervical screening in the preceding 12 months. Similar to O'Connor et al. (2012), the sample of interest were women between the age of 20 and 64 years who were age eligible for breast and cervical screening in the Republic of Ireland. In this sample 1256 women were eligible for breast screening and 4402 women were eligible for cervical screening. The analysis of the breast cancer screening rates offered clear evidence of lower breast screening uptake levels amongst women with lower levels of educational attainment. Similar analysis of the cervical screening rates found that those in lowest socio- economic group were less likely to have had a cervical screen compared to the most affluent group.

2.2.2.5. Delays in symptom presentation on the self- discovery of a symptom

O'Mahony and Hegarty (2009) explored the extent of delay in symptom presentation and factors influencing medical help seeking on the discovery of a breast cancer symptom. It was evident that over one third of Irish women with a breast lump chose to delay seeking help on the discovery of a symptom citing fear, anxiety and being scared as the main factors causing delay. Similar to Forbes (2011, 2013) the key issue related to delayed medical help seek was the woman's knowledge and beliefs about breast cancer that is considering the symptom as harmless or temporary leading to a decision to wait a while before making an appointment. This presents a major challenge as lower breast cancer awareness is associated with poorer breast cancer survival through the mechanism of delayed symptom presentation (Forbes et al., 2011).

2.2.2.6. Irish attitudes and beliefs about cancer

Scanlon et al. (2006) explored lay models of cancer awareness among Irish migrants (n=58) living in Britain. A comparison with British born participants of non- Irish descent (n=57) illustrated a number of unique attitudes and beliefs about cancer among Irish migrants. Older Irish adults, in particular men, had the poorest cancer knowledge in the sample. This was thought to be a consequence of poor education and literacy and a general reluctance or fear to talk about cancer.

Traditionally, in Irish Catholic families speaking about death and dying was a subject to be avoided for as long as possible. Fear and fatalism about cancer seemed to be closely linked to late detection and the deaths of family and friends among first generation Irish migrants living in Britain. The delay in presentation may be linked to a failure to display weakness, preference not to know if they had cancer or poor engagement with the health service. Fear and fatalism about cancer were also considered to be associated with the failure to engage in health promotion interventions (Scanlon et al., 2006). This was a broadly similar finding to that of O' Connor et al. (2012) in that women cited that the fear and embarrassment associated with cervical screening would deter their attendance.

Younger second and third generation Irish migrants in Britain were also found to display a combination of attitudes and beliefs about cancer, based on traditional Irish beliefs about cancer especially in relation to hereditary cancers, but also biomedical knowledge about cancer (Scanlon et al., 2006). Likewise, O' Connor et al. (2012) found that a key predictor for never having a smear test amongst women in the Republic of Ireland was never having lived abroad. It seems reasonable then to consider that adult caregivers in the Republic of Ireland might also share these attitudes and beliefs about cancer and health promotion interventions.

In a similar vein in Northern Ireland Keeney et al. (2010) explored the attitudes and knowledge about cancer in a representative sample of adults aged between 35-54 years of age (n=1065).

Women were found to be more likely to hold positive attitudes towards cancer prevention. However, similar to international studies more negative attitudes were encountered among men, those with a lower level of education, those with poor knowledge about cancer and those from lower socio-economic backgrounds (e.g. Forbes et al., 2013).

In agreement with international research there was apparent confusion in relation to the level of risk associated with age in regard to cancer (McMenamin et al., 2005, Linsell et al., 2008, Forbes et al., 2011, Forbes et al., 2013, Ryan et al., 2015). Participants reported that they believed they were too young to be concerned about cancer and cancer prevention (Keeney et al., 2010). It appears plausible that the population of women with intellectual disabilities may also be concerned that they are too young to be worried about cancer and cancer prevention.

Similar to Scanlon (2006) and O' Connor et al (2012) fear and fatalism about cancer and cancer prevention was apparent among the participants (Keeney et al., 2010). There was a widespread belief that cancer would not happen to them and they simply did not want to know anything about it. The belief that cancer was a matter of luck especially among people with family history was similar to that found among Irish migrants in Britain (Scanlon et al., 2006, Keeney et al., 2010). More recently Ryan and colleagues (2015) found that 15% of their respondents, the majority of whom were aged 50 years and younger, still held fatalistic views about cancer. Given that Irish women with intellectual disabilities may be dependent on family members for access to healthcare, these prevailing attitudes and beliefs about cancer and disengagement with health promotion interventions are concerning.

While this section explored cancer and screening awareness in the general population, the next section examines cancer among the population of women with intellectual disabilities.

2.3. Cancer and women with intellectual disabilities

It is often difficult to detect cancers early in women with intellectual disabilities due to communication difficulties, issues related to performing clinical exams and under- recognised pain in this population. The key data charted from the studies used in this section are available in Table 2.4.

To address the limited clinical knowledge based regarding invasive breast cancer incidence in women with intellectual disabilities, Satge et al. (2014) undertook an exploration of 11 women with intellectual disabilities with invasive breast cancer presentation at a French

Table 2.3. Exploring cancer and screening awareness in the general population

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Mc Menamin *et al*. (2005) Republic of Ireland	To determine awareness and knowledge of breast cancer in the Irish population	Written questionnaire n= 2355 Logistic regression analysis	Majority of participants aware of breast cancer: screening, symptoms, diagnosis and treatment. Little knowledge about risk factors apart from positive family history Poor knowledge of non- lump symptoms Poor knowledge of survival rates
Scanlon *et al*. (2006) Britain	To identify and explore explanatory models of cancer among Irish and white British people living in Britain.	Qualitative, focus groups and individual interview. Miles and Huberman thematic analysis n=58 Irish and n=57 British for comparative purposes	Women had better awareness of cancer signs and symptoms than men Older Irish people had the poorest cancer knowledge- attributed to poorer education and literacy, and reluctance to talk about cancer Fear about cancer closely linked to late detection and death of family/ friends among the Irish participants Irish men reluctant to talk about cancer Irish people greater emphasis on smoking and drinking Interaction with health service – long waiting times to see a GP and rushed appointments People may prefer not to know if they had cancer Delay linked to reluctance to show weakness
Linsell *et al*. (2008) United Kingdom	Describe the levels of knowledge of breast cancer symptoms and risk in older women Assess their confidence to detect a breast change Determine which older women are more at risk of delayed presentation Inform interventions that promote early help seeking	Questionnaire relating to breast cancer warning signs and sociodemographic characteristics n= 712 women, age range 67-73 years of age Descriptive statistical analysis	Non lump symptoms less than half the sample knowledgeable; Median number symptoms recognised =6; Most women not aware of the increased risk of breast cancer with age; One fifth of the women did not check their breasts for changes; Poorer awareness among those who were less educated especially non lump symptom and a poor understanding about risk
O' Mahony and Hegarty (2009) Republic of Ireland	To identify the extent of the delay and factors influencing women who live in the ROI in seeking help from a health care practitioner on self- discovery of a breast symptom	Descriptive, cross sectional correlational design Adapted questionnaire 'Women's help seeking for breast symptoms' n=99 Age range 18-75 years Majority of delay group age 20-40 years	93.9% discovered the symptom themselves. 72.3% of women attended their GP within one month (non-delayers) 41.4% of non-delayers - Breast lump primary symptom discovered 31% non-delayers- a combination of symptoms Personal risk rated 4.6 (SD 2.68) out of ten 65% of women regularly perform BSE 82.8% never had a mammogram 43.4%, 32.9%, 30.1% reported being anxious, afraid and scared (non- delayers) Key facilitators of help seeking- the earlier it was seen the better Key barrier- symptom considered temporary

Table 2.3. Exploring cancer and screening awareness in the general population

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Robb *et al*. (2009) United Kingdom	To assess public awareness of cancer warning signs; anticipated delay and perceived barriers to seeking medical advice in the British population	Validated measure- Cancer Awareness Measure (Stubbings et al., 2009) Face to face computer assisted interview n= 2208	Awareness of cancer warning signs was lower in younger males form lower socioeconomic groups or ethnic minorities; Emotional barriers were endorsed for medical help seeking for lower socioeconomic groups in comparison to practical barriers for higher socioeconomic groups.
Keeney *et al*. (2010) Northern Ireland	To explore the attitudes, knowledge and behaviours of members of the public aged between 35-54 years of age.	Cross sectional survey n=1065 Theoretical framework- Theory of planned behaviour Non parametric statistics	Men; lower level of education; lower level of knowledge; and lower SES more likely to hold negative attitudes about cancer and cancer prevention; Women more likely to hold attitudes that are positive towards cancer prevention.
Walsh *et al*. (2010) Ireland	To examine the differences in cancer screening related to socio-economic characteristics and educational attainment between Ireland and Northern Ireland	Data from health being surveys- SLAN 2007 in the Republic of Ireland n=1256 women eligible for breast screening (50-64 years of age) n= 4402 women aged 20-64 years of age accessing cervical screening Descriptive statistics; multivariate analysis	Higher breast screening uptake in women with higher educational attainment; Women with lowest socio economic group less likely to have a cervical screen.
Forbes *et al*. (2011) United Kingdom	To measure breast cancer and screening awareness and barriers to symptomatic presentation in women with ethnic differences in inner East London.	Face to face interview with Cancer Research UK Breast Cancer Awareness Measure. n=1515: >=30 years of age; Descriptive statistical analysis- Logistic Regression	South Asian women's breast cancer awareness lower than white women; Black women had lower knowledge of breast cancer warning signs and lower levels of breast self-examination than white women; South Asian women more like to report emotional barriers to attending the doctor; White women more likely to worry about wasting the doctors time.
Low *et al*. (2012) United Kingdom	To identify levels of cervical risk factor and symptom awareness Identify predictors of higher awareness in the UK female population	Cervical Cancer Awareness measure – self completed computer assisted survey Descriptive statistical analysis: Linear regression analysis n= 1392; age 16 years of age and older	65% of women could not recall any risk factors; 75% of women unable to recall any symptoms; Symptom recognition associated with older age, white ethnicity, higher education and having personal experience of cervical cancer.

Table 2.3. Exploring cancer and screening awareness in the general population

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
O' Connor *et al.* (2012) Republic of Ireland	To explore factors associated with never having had a cervical smear To explores differences in behaviours, attitudes and beliefs of women who had ever, or never had a smear test	Newly developed questionnaire- postal n=3470 (age stratified random sample) Age range 20-64 years of age Logistic regression	7% of sample had never had a smear test; Key health behaviours associated with never having a smear: current smoker and never asked GP for breast exam; Women who had a smear views and beliefs about smears- 95% -smear tests have to be done regularly to be effective 87% - women should have smears soon after they become sexually active; Views and beliefs associated with never having a smear- Anxious -11.8%; Feel embarrassed- 13.4% Don't know enough about smears to make a decision about having one -28.1%.
Forbes *et al*. (2013) Australia, Canada, Denmark, Norway, Sweden and the UK	To examine whether people living in countries with lower cancer survival (UK, Denmark) had lower cancer awareness, more negative beliefs about cancer or more barriers to symptomatic presentation than people in countries with higher cancer survival (Australia, Canada and Sweden)	Validated culturally appropriate questionnaire n=19, 079 Age range >= 50 years of age Logistic or linear regressions	Cancer awareness – mean number of symptoms recognised out of 11: range 7.71 (Sweden)- 8.70 (Canada); Age related risk of cancer- range 13.3% (Canada)- 37.8% (Sweden); Beliefs about barriers to symptom presentation: embarrassment (15% UK); worry about wasting the doctors time (34% UK); worry about what the doctor would find (28% UK); too busy (29% Canada); UK highest mean barriers to symptom presentation (8.29/50) Beliefs about cancer- Cancer can be cured- agree Range: 88.3 % (Canada) to 92.8% (UK); Cancer is a death sentence – disagree Range: 65.5% Northern Ireland- 77.2% (Sweden); People with cancer can expect to continue with normal activities and responsibilities- agree Range: 87.6% (Denmark) to 94.4% (Norway).
Ekechi *et al.* (2014) United Kingdom	To explore socio demographic and ethnicity related factors associated with cervical cancer knowledge and non-attendance at cervical screening Consider self-reported reasons for non -attendance at screening	Community based survey n=876 Age range 18 years and over Logistic regression	28% did not cite a symptom or risk factor for cervical cancer; 29% cited at least one factor related to sexual activity; (4% cited HPV as a risk factor); 12% cited smoking; 10% cited not going for a smear test; High level education more likely to cite a risk factor; Vaginal bleeding/ unusual discharge cited by 32% and 29% respectively; Less than 1% cited heavier/ longer periods/ bleeding after the menopause; Age most important predictor in citing a symptom; 75% of eligible population screened within the last 3 years; Reasons for being overdue at screening: 28% didn't get around to it; 18% fear of the procedure; 18% low risk perception.

Table 2.3. Exploring cancer and screening awareness in the general population

Author/ year/ location	Aim of study	Method/ sample	Key findings
Tazhibi and Feizi (2014) Iran	To evaluate the levels of knowledge about risk factors, early warning signs , screening approaches and therapeutic methods of breast cancer and to determine which women are less knowledgeable.	Cross sectional study N=2250 women participating in a community based and public education programme. Summary statistics- Latent class analysis/ latent class regression	Breast cancer risk factors – limited awareness of non-lifestyle related risk factors e.g. age at menarche and infertility; Early warning signs- 73% of sample had poor awareness of non-lump symptoms; Breast cancer screening methods-in high awareness group over 80% aware of mammography and breast examination; High awareness related to level of education, personal history of cancer and attending educational or screening programmes- 33.2% of total sample.
Ryan *et al*. (2015) Ireland	To assess public perception of the risk factors for cancer and to assess myths and misconceptions surrounding cancer risk	Online survey(48 question) n=748 (648 women and 100 men) Mean age 37 years (range 18-74 years SD 19 years) Healthcare practitioners: n=126	Top five risk factors by all respondents Smoking- 87%; Diet- 76%; Genetics- 47%; Alcohol- 42%; Obesity- 32% of public and 41% HCP (Note: older age- 6%); 15% of respondent held a fatalistic view of cancer related to family risk; 99% of respondents agreed that smoking increased risk; 69% of respondents agreed that moderate physical active means 30 mins per day.

hospital. Variables of interest included age, tumour stage/ size and breast cancer stage at diagnosis during the time frame 1989-2006. The results of the conditional logistic regression highlighted that 7 of the 11 women with intellectual disabilities lived with their families; 5 of the 11 tumours were found during mammography and 9 of the 11 women had lymph node metastases. The mean age at diagnosis was 55.64 years of age and a mean tumour diameter of 3.35cm in comparison with a mean age of diagnosis of 62.35 years of age and a mean tumour diameter of 1.80cm in the control group. Furthermore, lymph node involvement was 11 times more frequent, blood metastases were 12 times more frequent than in the control group and 10.2 times higher risk of AJCC3 with respect to AJCC1 than the control group. It was clear that prolonged delayed in diagnosis are associated with increase tumour size, increased likelihood of nodal involvement and metastases resulting in advanced tumour stages. Moreover, women with intellectual disabilities were diagnosed with breast cancer at an earlier age, which may indicate the need for adapted breast screening guidelines in this population (Satge et al., 2014).

Satgé and colleagues (2014) established that these women accounted of 2.23% of the women treated for invasive breast cancer. Given that the frequency of intellectual disabilities is estimated to be almost 2.5% of Western populations, breast cancer seems to be as frequent in women with intellectual disabilities as in the general population. This added credence to the fact that the self- reported incidence (29%) of breast cancer in Irish women with intellectual disabilities was found to be comparable to the incidence (30%) in women in the general population (Mc Carron et al., 2011).

2.4. Perspectives of women with intellectual disabilities, family and paid caregivers about cancer and screening

Section 2.4.1. examines the perspectives of women with intellectual disabilities about issues related to cancer and screening awareness Women with intellectual disabilities are often reliant on paid and family carers for healthcare advice. Section 2.4.2.examines the perspectives of family carers Finally section 2.4.3. concludes with the views of paid (professional and non-professional) carers, with an emphasis on the role of the nurse. The key data extracted from the relevant studies are shown in Table 2.5.

Table 2.4. Cancer and women with intellectual disabilities

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Mc Carron *et. al* (2011) Ireland	To explore issues for people with an ID in areas such as their ageing profile, health and health service needs. To potentially compare the ageing of people with ID directly with the general ageing population.	Descriptive statistical analysis of interviews. n= 753 people with ID representing 8.9% of the Irish ID population >40 years.	Access to health checks was high overall; Concerns regarding access to screening; Lower screening access for people with severe to profound ID; Prevalence of cancer diagnosis was slightly lower among people with ID than for the general Irish adult population; Breast cancer being the most commonly reported cancer in women with ID.
Satgé *et al*. (2014) France	To investigate a clinically detailed series of women with intellectual disabilities with breast cancer to identify histology, tumour grade, age, tumour size and disease stage at diagnosis	Retrospective investigation of hospital records for women treated with invasive breast cancer at a French hospital during the 18 year period 1989-2006. n=484 inclusive of 11 women with intellectual disabilities n=11 women with intellectual disabilities matched with n=44 controls women with invasive breast cancer from the general population Conditional logistic regression	Women with intellectual disabilities had tumours with greater volumes at diagnosis compared to control group; Lymph node involvement was 11 times more frequent; Blood metastases was 12 times more frequent; More likely to have a higher AJCC stage-10.2 times higher risk of AJCC3 with respect to AJCC1

2.4.1. Perspectives of women with intellectual disabilities

Women with intellectual disabilities are best placed to discuss their own understanding of cancer and experience of screening programmes and this section explores what the women had to say.

In Northern Ireland, Truesdale-Kennedy et al. (2011) explored the understanding of breast cancer and experience of mammography among 19 women with mild to moderate intellectual disabilities who had undergone mammography in the last 12 months. The researchers used focus groups, which have proven usefulness in engaging low usage mammography groups, to explore the breast cancer knowledge and mammography experience of the women.

The findings explicitly highlighted the low levels of breast cancer knowledge among the women. It is interesting to note that there was a general consensus among the women that breast cancer was a ‘lump’ in the breast. The risk factors for breast cancer identified by a small number of women related to lifestyle factors such as smoking, lack of exercise, drinking and diet. It is concerning that the women’s knowledge of non- lifestyle related risk factors for breast cancer was so limited. Furthermore, the findings indicated that a lack of understanding of the breast screening process exacerbated stress and anxiety amongst the women. Of interest is the role played by information and explanation of the process in reducing these anxiety levels (Truesdale-Kennedy et al., 2011).

In the United States, Parish et al. (2012b) assessed the baseline breast and cervical cancer awareness and knowledge of screening programmes of community-dwelling women with intellectual disabilities (n=202) as part of a larger randomised control trial. The summed composite measure of the nine items relating to cancer and screening awareness ranged from 3.3 correct responses out of nine for women living with family to 5.5 correct responses out of nine for women living alone or with a spouse. Although the women had a markedly better understanding of breast cancer screening when compared to cervical screening, it could still be considered poor and similar to awareness levels identified by Truesdale- Kennedy et al (2011).

Likewise in the United States, Wilkinson et al. (2011a) explored perspectives about the reasons which influence decisions to participate in mammography via interview with 27 women with intellectual disabilities who had participated in the breast screening programme. Over half the women were aged between 51-60 years: and similarly over half the women lived independently. There were clear indications of a deficit in understanding about the relationship between mammography and cancer detection amongst the women.

In fact the women seemed unsure as to whether the mammogram actually prevented cancer or was an early detection system for cancer (Wilkinson et al., 2011a). This is problematic given that some of the women had actually participated in the programme without understanding the process, which raises contentious issues for informed consent and decision making. Similarly, Parish et al. (2012b) found that the women in their study demonstrated poor knowledge about the definition (39%) and frequency (18%) of mammography.

Many women felt ill-prepared for the impact of the feelings of undue stress and anxiety associated with mammography. The women primarily associated these feelings with the challenges posed by the unfamiliar surroundings and lack of knowledge about the mammography procedure (D'Eath et al., 2005, Truesdale-Kennedy et al., 2011, Wilkinson et al., 2011a, Parish et al., 2012b). It is noteworthy that this anxiety may be related to the women's desire to be perceived as competent and not disabled in unfamiliar situations (Wilkinson et al., 2011a).

Moreover, many women highlighted the necessity for carer engagement in order to alleviate the stress and anxiety that the women associate with mammography (Truesdale-Kennedy et al., 2011, Wilkinson et al., 2011a). It seems then that women were aware of the important role of their caregivers in facilitating them to become more familiar with the process, and the key role this played in reducing their anxiety levels during screening appointments.

With regard to cervical cancer awareness and screening knowledge of women with intellectual disabilities in their analysis of the findings, (Parish et al., 2012b) identified considerable gaps in the women's knowledge. In particular almost two-thirds of the women had no knowledge of the Pap smear test used for cervical cancer screening. Furthermore, less than one fifth of the women had any knowledge of the frequency of the Pap smear test. Once again, the women mentioned the use of relaxation techniques to reduce the anxieties encountered during pelvic examinations. Parish and colleagues (2012) found that the most limited awareness levels were for cervical screening awareness for women with intellectual disabilities living in paid residential facilities and with family caregivers ($\bar{x}$= 1.7 and $\bar{x}$= 1.2 on pap knowledge composite respectively).

D'Eath et al. (2005) undertook interviews with people with a range of disabilities including intellectual disabilities, parents and advocates in one health service area in Ireland (n=32). Irish women with intellectual disabilities who had accessed screening perceived a number of barriers. Among these barriers were a lack of awareness among the personnel carrying out the procedure about people with intellectual disabilities; and abandonment of the test when the person found it difficult to cooperate during the procedure. There is international agreement concerning these perceived barriers to screening for Irish women with intellectual disabilities in the literature reviewed.

Concerns have been expressed about physical disabilities and stature (Tyler et al., 2010, Wilkinson et al., 2011a); medical personal interactions with women with intellectual disabilities (Tyler et al., 2010, Wilkinson et al., 2011a, Lloyd and Coulson, 2014); painful experiences of procedure (Truesdale-Kennedy et al., 2011, Wilkinson et al., 2011a, Lloyd and Coulson, 2014); lack of understanding about the procedure resulting in stress and anxiety (Truesdale-Kennedy et al., 2011, Wilkinson et al., 2011a, Parish et al., 2012b, Lloyd and Coulson, 2014); fear or embarrassment about being touched (Tyler et al., 2010, Swaine et al., 2013); poor provision of accessible information (Truesdale-Kennedy et al., 2011, Wilkinson et al., 2011a, Lloyd and Coulson, 2014).

2.4.2. Perspectives of families of women with intellectual disabilities

Exploring the perspectives of caregivers about cancer and screening for their daughters/ siblings is crucial given that a large majority of women with intellectual disabilities live with family caregivers. The views of family caregivers about cancer screening for women with intellectual disabilities are limited in the research.

Swaine et al. (2013) carried out 32 semi-structured interviews in the United States to elicit the perspectives of female familial care givers, mainly mothers, about the barriers related to screening uptake in women with intellectual disabilities. The majority of the women with intellectual disabilities (94%) had mild to moderate intellectual disabilities. Among the most common reasons given by caregivers for a woman’s poor participation in screening programmes was caregiver beliefs that the screening procedure was not essential; doctors’ advice that cervical screening was not necessary due to sexual inactivity; and the woman’s own attitudes towards the screening (Swaine et al., 2013).

More recently, Willis et al. (2015) examined the views of paid and family carers about factors which influence women with intellectual disabilities to participate in breast screening. Similar to the findings of Swaine et al. (2013) the main barriers to breast screening were identified as the women's attitude towards screening namely pain and fear of the unknown and attitudes of professionals towards the women. Conversely, Willis et al. (2015) found that the carers believed that all women should be offered breast screening. Carers reported that it should be the woman's choice to participate for those with capacity and a collaborative decision with the team for those who lack capacity. Willis et al. (2015) contended that women with intellectual disabilities were being left down at all stages of the breast screening process.

Furthermore, an exploration of the factors regarding the uptake of cervical screening in Taiwan from the caregivers perspective found that just over one fifth of the women with intellectual disabilities had ever had a smear test (Lin et al., 2010). Caregiver attributes such as the relationship with the woman with intellectual disabilities, age, religious beliefs and household income were likely to affect whether the woman accepted the screening invitation. Interestingly, 77.8% of the women who lived with family did not participate in the screening programme (Lin et al., 2010).

Lalor and Redmond (2009) concurred that although to the majority of women with intellectual disabilities in their study were invited to breast cancer screening, five families made a decision to refuse the test on the woman's behalf. Two families declined the invitation, and three families declined future invitations based on an unsuccessful procedure. However, these decisions are a legal minefield as family caregivers cannot legally consent to or withhold consent on behalf of adult with intellectual disabilities. Giving the changing landscape of residential status for women with intellectual disabilities in Ireland, with a strong emphasis on living with family caregivers this issue is particularly contentious.

Furthermore, Lin et al. (2010) and Wilkinson et al. (2011b) found that caregiver attributes such as religious beliefs, age and relationship to the woman such as guardianship were barriers to the women participating in screening programmes, although Parish et al. (2013) found that guardianship status had no effect on participation. It seems that cultural and nationwide differences in caregiver attributes have a major impact on the women's participation in screening programmes.

Compared with women with intellectual disabilities who lived alone or with a spouse, women with intellectual disabilities who lived with family caregivers demonstrated the most limited understanding of cancer awareness and screening programmes, were less likely to access preventative healthcare, and relied on family members to provide healthcare advice. It appeared that family members were most likely not as well informed or lack understanding about preventative healthcare (Wilkinson et al., 2011b, Parish et al., 2012, Willis et al., 2015). This presents a major challenge in an Irish context as almost 70% of Irish women with intellectual disabilities live at home with family caregivers.

2.4.3. Perspectives of paid carers of women with intellectual disabilities

However, a large number of women with intellectual disabilities continue to live in residential setting, so it is also prudent to examine the perspectives of paid carers (professional and non-professional) regarding cancer awareness and screening for women with intellectual disabilities. In conjunction with professional carers, people with intellectual disabilities are often reliant on non-professional paid carers to encourage a healthy lifestyle and identify health risks. The cancer awareness, knowledge of preventative screening programmes and health promotion activities of paid carers is the focus of this section.

In the United States Tyler et al. (2010) surveyed nurses working in the area of intellectual disabilities (n=93), to gain an understanding of barriers and opportunities to improve cancer screening participation for adults with intellectual disabilities. Over half the respondents (54%) identified three or more barriers to the receipt of recommended cancer screening for adults with intellectual disabilities. The key barriers endorsed by the nurses were as follows: the need for additional intervention such as sedation (76%); attempted tests not successfully completed (58%); cancer screening tests not ordered (48%) and individual fearfulness (47%).

The most frequently endorsed nurse identified intervention (62%) to improve cancer screening in adults with intellectual disabilities was education and training for adults with intellectual disabilities, caregivers and service providers. Further evidence of preventative healthcare disparities for people with intellectual disabilities was identified: over half the nurses surveyed knew a person with intellectual disabilities who had received a cancer diagnosis but had never received screening prior to diagnosis (Tyler et al., 2010).

Meanwhile, in the United Kingdom Lloyd and Coulson (2014) examined the experiences and clinical practices of learning disability nurses who had direct experience in supporting women with intellectual disabilities to access cervical screening (n=10). The key objective was to identify barriers and facilitators to screening utilisation by women with intellectual disabilities, and the role of the nurse in promoting uptake. Among the key issues identified were the influence individual psychological factors and limited health literacy on the woman’s attitude towards screening and moreso the woman’s ability to tolerate the procedure. There were frequent references towards the invasive and unpleasant nature of cervical screening for women with intellectual disabilities.

Looking at the knowledge base of paid carers in Northern Ireland, Taggart et al. (2011) explored ,using focus groups, how Community Intellectual Disability Nurses (n=16) and residential workers in intellectual disability settings (n=13) supported women with intellectual disabilities to access breast screening services. Deficits in knowledge of risk factors identified included reproductive risk factors, for example, nulliparity and early menarche, previous history of breast cancer and the increasing cancer risk with age. However, nurses reported more signs and symptoms of breast cancer than residential staff. Nevertheless, neither group recognised key warning signs related to swelling or pain in armpit, swelling in the collarbone or changes in the nipple such as shape, position and rash.

Wyatt and Talbot (2013) explored the knowledge and attitudes about cancer (n=324) of paid carers working directly with people with intellectual disabilities in Britain. The majority of staff (81%) believed that the prevalence of cancer among people with intellectual disabilities was similar to that of the general population. Similar to Taggart et al. (2011) the majority of the staff appeared unaware that the risk of cancer increases with age. Over 80% of the staff reported that they did not know enough about the signs and symptoms of cancer to facilitate cancer health promotion activities with people with intellectual disabilities.

In another study, Hanna et al. (2011) examined staff engagement (n=40) in cancer prevention and health promotion activities for people with intellectual disabilities (n=90); and the staffs' personal awareness of cancer in Northern Ireland. Staff included intellectual disability nurses (n=10) and non–qualified staff, for example support assistant, support worker and residential workers (n=30). Like the work of Taggart et al. (2011) significant gaps in staff knowledge about the early warning signs of breast and cervical cancer; risk factors such as family histories of women with intellectual disabilities, and reproductive risk factors; and preventative factors were apparent. However, unlike Taggart et al. (2011) Hanna et al. (2011) found no significant difference between the cancer risk factor knowledge levels of qualified and unqualified staff. Similar to Wyatt and Talbot (2013) social care staff reported offering information to reduce the risk of cancer such as lifestyle modification and encourage earlier cancer detection such as screening.

Focusing solely on nurses in the Republic of Ireland working within intellectual disability settings (n= 106), Kirby and Hegarty (2010) investigated personal and professional breast awareness practices. In agreement with the finding of Wyatt and Talbot (2013), Hanna et al. (2011) and Taggart et al. (2011) there was evidence of poor awareness of reproductive risk factors and the relationship of advancing age to an increased risk of cancer. This is alarming as a lack of carer knowledge could be an obstruction to an ageing population of women with intellectual disabilities accessing appropriate preventative healthcare such as cancer screening programmes.

Hanna et al. (2011) reported that just 7.5% of the staff received training related to cancer awareness and cancer health promoting activities targeted for people with intellectual disabilities. This is comparable to the findings of Wyatt and Talbot (2013) as just 11% of the staff reported that they had received training related to cancer awareness. Likewise in Kirby and Hegarty's (2010) study just 8.5% of the intellectual disability nurses had received instruction in the area of breast care in the preceding 12 month period.

Kirby and Hegarty (2010) also found evidence that intellectual disability nurses rarely promote breast awareness and screening for women with intellectual disabilities in their professional practice. In fact 14.2% of the nurses surveyed were not aware of the breast screening guidelines in the Republic of Ireland. Likewise, Hanna et al. (2011) reported that few staff offered women with intellectual disabilities advice on the benefits of regular breast screening. Conversely, Taggart et al. (2011) report that many intellectual disability nurses in their study supported women with intellectual disabilities about breast awareness and breast screening using accessible information. However, a conflicting view is heard from non- nursing staff many of whom were unaware of the accessible information (Taggart et al., 2011).

It seems therefore that even within the health care professions there are gaps in cancer awareness knowledge. It might have seemed that the advice of health care professionals in supporting women with intellectual disabilities to adapt healthy lifestyles, such as participating in cancer screening programmes, could be relied upon. However, this does not appear to be an accurate reflection of the situation.

2.4.3.1. The role of the nurse

Irish nurses reported that the absence of clear policy and guidelines in relation to breast examination, compounded by challenges due to communication difficulties, consent and tolerance of the procedure by women with intellectual disabilities made the area of breast and screening awareness a very difficult area to manage (Lalor and Redmond, 2009, Kirby and Hegarty, 2010).

However, international evidence clearly emphasised the value of the interventions to prepare the woman psychologically for screening, in particular nurse-led interventions (Tyler et al., 2010; Lloyd and Coulson 2014). The key objectives of these interventions involved familiarising the woman with the procedure and encouraging the women to take an active role in their preventative healthcare. Likewise, Taggart et al. (2011) suggested that emotional support given by community intellectual disability nurses to women with intellectual disabilities about breast examination and screening participation was vital to ease negative emotions and attitudes related to breast surveillance. In a similar vein women labelled as uncooperative or requiring a limited wait were more likely to complete mammography if health coordination was provided by a registered nurse (Wilkinson et al., 2011b). The next section looks at both the determinants associated with participation in screening programmes and screening disparities for women with intellectual disabilities.

2.5. Investigating the determinants associated with screening and screening disparities for women with intellectual disabilities

It is acknowledged in the literature that screening disparities exist for women with intellectual disabilities when compared to women in the general population. The focus of this theme is to initially examine determinants for screening participation for women with intellectual disabilities. Following this the extent of the disparities they encounter when accessing screening is explored. Table 2.6. details the key data extracted from each of the relevant studies.

2.5.1. Determinants for the participation of women with intellectual disabilities in cervical and breast cancer screening

Walsh et al. (2010) argued that socioeconomic classification and lower levels of educational attainment may offer insight into the individual’s ability to acquire and process health related information and screening uptake may depend on the women’s ability to organise a screening appointment. This is of interest as Irish women with intellectual disabilities traditionally have low educational attainment and rely on a social welfare payment as the main source of income.

Table 2.5. Perspectives of women with intellectual disabilities, family and paid carers about cancer and screening

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
D'Eath *et al.* (2005) Ireland	To explore the experience of Irish people with disabilities in accessing mainstream health services; To consider this in the context of international findings and; To present findings to relevant parties to inform practice, policy or further research.	Thematic analysis of interviews using Miles and Huberman's framework. n=32; 27 people with disabilities including ID; and 5 advocates and parents.	Evidence of health service inequalities in the following areas: Inequality of access to health services; Preventative and screening services, specific groups are particularly disadvantaged such as women with ID; Financial barriers to accessing services; Communication, attitudinal and physical barriers.
Lalor and Redmond (2009) Ireland	To identify practices in relation to breast surveillance for post menopausal women with ID. To identify challenges that affect mammography screening services attendance. To explore the practices related to clinical breast examinations.	Statistical and content analysis of a newly developed questionnaire- n=90: primary carers of post-menopausal women with ID; women with ID participated in questionnaire completion based on ability.	67% of women had successfully completed mammogram; 14% of eligible women had not received an invitation to attend; 16% unable to complete the procedure due to difficulties such as fear, distress and inability to cooperate; 24% of women had no breast surveillance at all.
Kirby and Hegarty (2010) Ireland	To examine personal and professional breast awareness practices of nurses within an ID setting and to investigate nurses' knowledge, motivation and proficiency regarding breast cancer awareness and screening.	Quantitative descriptive design Convenience sampling strategy 200 female nurses working in an ID setting. Response rate 54% where n=106 Modified Toronto Breast Self – Examination Inventory (MTBSEI)	54.9% confident they would detect a lump; 58% confident they would detect a change in their breast; 47.9% confident that they were performing BSE accurately; 97.1% consider BSE important to detect changes; 69.8% unaware late childbearing; 69.8% unaware early menses/late menopause and 55.6% unaware nulliparity; 19.8% not aware that risk of breast cancer increases with age; 14.2% were not aware of current mammography age and frequency guidelines; 71.1% never taught BSE to women with ID; 74.5% didn't encourage breast awareness in female clients; 30% observe and document breast changes for female clients; 50% never or rarely engage in these practices; 22% have facilitated clients to access CBE at GP at regular intervals; 82% have never or rarely supported women with ID to access mammography services; 92.5% suggest they require additional support in the area of breast care; 42.5% acquired their knowledge and skills indiscriminately through random sources.

Table 2.5. Perspectives of women with intellectual disabilities, family and paid carers about cancer and screening

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Lin *et al*. (2010) Taiwan	Identify and evaluate the factors regarding the utilisation of the Pap smears in women with ID seen in the preventative health screening programme in Taiwan	Cross sectional survey n=508 (age 15 years and over registered as having an intellectual disability.	69.7% of the women had mild to moderate intellectual disabilities; 22.1% had ever used pap smear; Mean age of screening was 39.75+- 14.30 years; 46.4% of women received a screening letter; 44.4% of women use smear test regularly; 77.8% who lived with family did not have a smear test.
Tyler *et al*. (2010) United States	To develop an understanding of barriers and potential opportunities to improve cancer screening in adults with intellectual and developmental disabilities	Survey of nurses working in developmental disabilities; n=93; Open ended questions categorised thematically; Descriptive statistics for demographic and closed ended responses.	The individual's behaviour/ lack of cooperation does not allow screening to be completed without additional interventions (e.g. sedation) – 76% of nurses; The individual is fearful- 47% of nurses; The individual/ family does not understand the benefit of screening- 38% of nurses; Educational interventions required- 62% of nurses.
Hanna ***et a**l*. (2011) Northern Ireland	To examine how care staff engaged in cancer prevention and health promotion activities on behalf of adults with intellectual disabilities.	Postal survey Exploratory descriptive study n=40 personal questionnaire n=90 on behalf of people with intellectual disabilities	No significant differences found between unqualified (75%) and qualified ID nurses (25%), or whether participants had personal knowledge of cancer in terms of risk factor knowledge; 7.5% had completed minimal training in cancer awareness; About half the adults with ID were offered regular lifestyle advice to reduce cancer risk; Just 10% of women with intellectual disabilities were offered advice regular breast screening; High rate of obesity among women with intellectual disability.
Taggart *et al*. (2011) Northern Ireland	To examine how community intellectual disability nurses and residential staff support women with intellectual disabilities to access breast screening services	Focus group, semi-structured interview guide n=29 (n=13 residential staff; n=16 CIDN) Thematic Analysis Newell and Burnard (2006) framework	Importance of breast screening Risk factors for breast cancer in women with intellectual disabilities- obesity, poor diet and lack of exercise; Gaps in awareness of risk factors for breast cancer; Identification of barriers and facilitators to women accessing screening; Need for accessible information and education for women, carers and families.
Truesdale-Kennedy *et al*. (2011) Northern Ireland	To describe understanding of breast cancer and experiences of breast mammography among women with intellectual disabilities.	Purposeful sampling Focus groups n=19 women had undergone mammography in the last 12 months. Borderline to moderate intellectual disabilities. Newell and Burnard's framework	Limited knowledge of about cancer and the signs and symptoms of breast cancer; Main risk factors reported by the women associated with lifestyle; Lack of understanding about breast screening process associated with increased anxiety and stress; Main barriers for non-attendance at breast screening- fear and embarrassment; Solutions to barriers- informational and emotional support.

Table 2.5. Perspectives of women with intellectual disabilities, family and paid carers about cancer and screening

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Wilkinson *et al*. (2011a) United States	To understand decisions about mammography from the perspective of women with intellectual disabilities and to explore aspects of their knowledge, experiences and expectations leading to a decision to have or not to have a mammogram.	Purposive Sample n=27 Age range 27-69 years of age Semi-structured interview guide Grounded theory	Lack of accurate information about breast cancer or mammography; Uninformed about what happens during the mammography; Motivations to have at least one mammogram e.g. fitting in with others in the age group; Poor experience at mammography – little guidance from staff, feeling singled out.
Wilkinson *et al.* (2011b) United States	To determine characteristics associated with mammography related to domains of the ecological model Make preliminary recommendations for interventions to improve screening and prevention of breast cancer in women with intellectual disabilities in the patient centered medical home	Women with intellectual disabilities age range 42- 74 years of age (mean 54.7 years of age) n=2907 Bivariate analyses to identify variables associated with mammography	Overall mammography rate is 53% - lower than the rate of 84.9% found in the general population in Massachusetts; Interpersonal domain – categories reflecting higher needs for supports – needing special positioning, uncooperative with exams and higher adl needs associated with lower odds of mammography (OR 0.69- 0.84); Residential setting (OR 1.32) and health coordination by an RN (OR 1.40) are most strongly associated with mammography; Family history of breast cancer positively associated with mammography; Ability to communicate strongly associated with mammography; Assignment of a guardian negatively associated with mammography.
Parish *et al*. (2012) United States	To assess the level of knowledge about cervical and breast cancer screening of women with developmental disabilities who live in the community To see if there are differences in knowledge among women with developmental disabilities who live in different types of settings (residential, alone or with family members)	Computer assisted face to face interviews (n=202) Univariate and bivariate statistical analysis	Evidence of limited knowledge about cervical and breast cancer screening- mean number of correct responses across the sample =3.9 out of nine items; Greater knowledge among women living alone or with spouse 5.5 out of nine items; Better knowledge about breast cancer than cervical cancer; More limited accurate knowledge about cervical and breast cancer screening for women living with family caregivers.

Table 2.5. Perspectives of women with intellectual disabilities, family and paid carers about cancer and screening

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Parish *et al.* (2013) United States	To determine rates of Pap test receipt for women with intellectual disabilities from women's medical records To identify the determinants of Pap test receipt	n=163 women age 18 years or older, with an intellectual disability, and able to participate in an interview Medical records from health care providers via the Health Insurance Portability and Accountability Act 1996 Multivariate logistic regression models	3 year pap test rate of 55% compared with actual three year screening rate of 85% Women who lived at home with family caregivers less likely to receive a pap smear than women living in residential settings; Women living in rural settings greater likelihood than women living in urban settings; Women with GP less likely to receive screening that women with an OB/GYN as their physician.
Swaine *et al.* (2013) United States	What are family caregivers perspectives on why women with intellectual disabilities don't receive breast and cervical cancer screening and their own knowledge of screening; the comfort of the women have with respect to screening; the best ways to facilitate screening for the women; do the women receive adequate healthcare.	Random assignment for black and white participants n=32 female familial caregivers 20-60 minute telephone interview Descriptive statistics	83% women with intellectual disabilities received clinical breast exams from healthcare professional/ 80% in the past year; 75% of age eligible women with intellectual disabilities received mammography; 77% women with intellectual disabilities received pap/ pelvic exam/ 38.5% in the past year; 87% reported family member with intellectual disability received adequate healthcare; 50% of caregivers correctly answered that a clinical breast exam was annual; 75% correctly answered that women age 40 and over should have annual mammography; 64% correctly answered pap tests every one to three years depending on age and health history.
Wyatt and Talbot (2013) United Kingdom	An exploration of the knowledge and attitudes that paid carers of people with a learning disability have about cancer.	Survey approach- newly designed questionnaire n=324 social care workers	18% correctly identified cancer is more common in elderly people; 81% believed the incidence of cancer as common as in the general population; 89% no training in cancer awareness; 80% did not feel the know enough about cancer risk reduction in people with learning disabilities.

Table 2.5. Perspectives of women with intellectual disabilities, family and paid carers about cancer and screening

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Lloyd and Coulson (2014) United Kingdom	To explore the experiences, perceptions and clinical practices of learning disability nurses in order to identify specific barriers and facilitators influencing cervical screening utilization by women with learning disabilities and the role of learning disability nurses in promoting uptake	Semi-structured interview n=10 RNLD Age: 36-52 Data analysis framework: Braun and Clarke (2013)	The role of individual factors . Psychological impact of cervical screening . Limited health literacy and competing demands on attitudes towards screening The role of the learning disability nurse . Preparing women psychological for screening . Managing the challenges of supporting women with complex needs The role of the healthcare professional . Managing the women's experiences of cervical screening .Maximising flexibility within the constraints of the primary care system
Willis *et al.* (2015) Scotland	To examine the views of paid and family carers on what influences women with intellectual disability to participate in breast screening.	Ethnographic study 10 paid carers; 3 family carers interviews Two observations at mammography with paid carers Purposive sampling method	Carers could monitor breast changes in less able women; More able an independent women disadvantaged in this regard; Pictures and plain language are useful; The word cancer invokes fear, but may be difficult for women with intellectual disability to understand; Carers believed all women should be offered breast screening; It should be the woman's choice for those with capacity; Experiences at the breast screening appointment; Main barriers to breast screening; limited time for appointments, pain and fear of the unknown; Attitudes of professionals.

In the United States, Wilkinson and colleagues (2011b) explored the characteristics associated with mammography use among women with intellectual disabilities. A sample highly representative of women living in supported settings in the Massachusetts area was derived from administrative health records which are used to track health outcomes (n=2907). The findings indicated that women presenting with higher support needs in activities of daily living, women requiring special positioning for exams and women who were uncooperative with the exam were less likely (OR 0.69-0.84) to have received mammography (Wilkinson et al., 2011b). Similarly, in Ireland, Lalor and Redmond (2009) found that none of the women with severe to profound intellectual disabilities living in the residential settings in their study had successfully completed mammography.

More recently in Taiwan, Lai et al. (2014) analysed mammography use of women with intellectual disabilities aged 50-69 years (n=4370) using databases held by the Ministry of the Interior in Taiwan and the National Health Administration database. Overall mammography use was dismally low (4.32%) among these women. In broad agreement with Lalor and Redmond (2009) and Wilkinson et al. (2011b) the highest mammography rates were found among women with mild intellectual disabilities (6.07%) and lowest among women with profound intellectual disabilities (2.65%). Women with higher education levels were 4.56 times more likely to have higher participation in the breast screening programme (95% CI 1.2-14.87). In addition, women who participated in cervical screening were 11.45 times more likely to participate in the mammography programme (95% CI= 7.66-17.12) (Lai et al., 2014).

It seems then that the system is failing women with higher support needs or more complex limitations. National and international evidence clearly signals that these women are losing out on vital screening opportunities and early detection for possible cancers (Lalor and Redmond, 2009, Wilkinson et al., 2011b, Horner-Johnson et al., 2014).

In relation to participation in cervical screening for women with intellectual disabilities, in the United States, Parish et al. (2013) examined the medical records of 163 women with intellectual disabilities to determine both the rate of cervical screening and determinants of receipt of screening. The use of objective medical records circumvents the recall bias and social desirability related to self-report data. The findings indicates a 3 year pap test rate of 55% compared with an actual 3 year screening rate of 85% for women in the general population in the geographical area. It seems that the rates of preventative screening for women with intellectual disabilities are generally worse for women living with family caregivers (OR=0.21)

Table 2.6. Investigating the determinants associated with screening and screening disparities for women with intellectual disabilities

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Noonan- Walsh *et al.* (2008) Europe	To promote the quality of life and health of people with ID in Europe. To test the validity and utility of the POMONA health indicators for people with ID. To establish ways to sustain the flow of information about the health of people with ID nationally, at European level and internationally.	Descriptive statistical analysis of the health interview survey. n= 1253 people with ID in 14 European countries.	Evidence of less common gender-specific screening checks for breast cancer and cervical cancer in women with intellectual disabilities.
Lalor and Redmond (2009) Ireland	To identify practices in relation to breast surveillance for post-menopausal women with ID. To identify challenges that affect mammography screening services attendance. To explore the practices related to clinical breast examinations.	Statistical and content analysis of a newly developed questionnaire- n=90: primary carers of post-menopausal women with ID; women with ID participated in questionnaire completion based on ability.	67% of women had successfully completed mammogram; 14% of eligible women had not received an invitation to attend; 16% unable to complete the procedure due to difficulties such as fear, distress and inability to cooperate; 24% of women had no breast surveillance at all.
Dowling *et al*. (2010) United States	A programme assessment from ISCN to understand characteristics of cervical cancer screening programmes within countries with population based breast screening programmes	US National Cancer Institute administered web based survey Descriptive statistical analysis n=16	In over half the countries the breast and cervical cancer screening programmes had similar organisation; Wide international variation in participation rates in both programmes; HPV vaccination approval on the increase.
Lin *et al.* (2010) Taiwan	Identify and evaluate the factors regarding the utilisation of the Pap smears in women with ID seen in the preventative health screening programme in Taiwan	Cross sectional survey n=508 (age 15 years and over registered as having an intellectual disability.	69.7% of the women had mild to moderate intellectual disabilities; 22.1% had ever used pap smear; Mean age of screening was 39.75+- 14.30 years; 46.4% of women received a screening letter; 44.4% of women use smear test regularly; 77.8% who lived with family did not have a smear test.

Table 2.6. Investigating the determinants associated with screening and screening disparities for women with intellectual disabilities

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Walsh *et al*. (2010) Ireland	To examine the differences in cancer screening related to socio-economic characteristics and educational attainment between Ireland and Northern Ireland	Data from health being surveys-SLAN 2007 in the Republic of Ireland n=1256 women eligible for breast screening (50-64 years of age) n= 4402 women aged 20-64 years of age accessing cervical screening Descriptive statistics; multivariate analysis	Higher breast screening uptake in women with higher educational attainment; Women with lowest socio economic group less likely to have a cervical screen.
Department of Health (2011) Australia	To describe and explore the health and wellbeing of Victorians with an intellectual disability and to compare this to the health and wellbeing of the general Victorian population.	CATI administered survey for proxy respondents. n=897 proxy respondents on behalf of people with intellectual disabilities over 18 years of age Descriptive statistical analysis	14.8% of women with intellectual disabilities aged 20-69 years reported to have pap smear in the last two years compared with 71.1% of the general Victorian population; 55.2% of women with intellectual disabilities were reported to have a mammogram in the last two years compared with 75.9% of the general Victorian population.
Wilkinson *et al.* (2011b) United States	To determine characteristics associated with mammography related to domains of the ecological model Make preliminary recommendations for interventions to improve screening and prevention of breast cancer in women with intellectual disabilities in the patient centered medical home	Women with intellectual disabilities age range 42- 74 years of age (mean 54.7 years of age) n=2907 Bivariate analyses to identify variables associated with mammography	Overall mammography rate is 53% - lower than the rate of 84.9% found in the general population in Massachusetts; Interpersonal domain – categories reflecting higher needs for supports – needing special positioning, uncooperative with exams and higher adl needs associated with lower odds of mammography (OR 0.69- 0.84); Residential setting (OR 1.32) and health coordination by an RN (OR 1.40) are most strongly associated with mammography; Family history of breast cancer positively associated with mammography; Ability to communicate strongly associated with mammography; Assignment of a guardian negatively associated with mammography.
Osborn *et al.* (2012) United Kingdom	To explore whether rates of cancer screening differ in people with learning disability (LD) compared to people without a learning disability (No LD) in primary care.	A cohort study using data from the Health Improvement Network (THIN), research database compiled from 450 general practices across the UK. *Cervical screening cohort* (age eligible women) n= 6254 (LD); n= 33425 (No LD). *Breast screening cohort* (age eligible women) n=2956 (LD); n= 17354 (No LD).	Relative rates of screening were significantly lower for people with learning disability; Disparities in cervical screening rates were 45% lower in 2008/9: IRR = 0.76 (0.72–0.81) (95% CI); Disparities in breast screening rates were 35% lower in 2008/9: IRR = 0.54 (0.52–0.56) (95% CI).

Table 2.6. Investigating the determinants associated with screening and screening disparities for women with intellectual disabilities

Author/ year/ location	Aim of study	Method/ sample	Key findings
Parish *et al.* (2013) United States	To determine rates of Pap test receipt for women with intellectual disabilities from women's medical records To identify the determinants of Pap test receipt	n=163 women age 18 years or older, with an intellectual disability, and able to participate in an interview Medical records from health care providers via the Health Insurance Portability and Accountability Act 1996 Multivariate logistic regression models	3 year pap test rate of 55% compared with actual three year screening rate of 85%; Women who lived at home with family caregivers less likely to receive a pap smear than women living in residential settings; Women living in rural settings greater likelihood than women living in urban settings; Women with GP less likely to receive screening that women with an OB/GYN as their physician.
Horner-Johnson *et al*. (2014) United States	Examine the relationship of disability severity to receipt of mammography and Pap smears in a nationally representative sample, and to assess the extent to which other variables account for any differences between disability groups	Analysis of Medical Expenditure Panel Survey- 2002-2008: nationally representative data on healthcare and expenditure Logistic regression- severity of disability (dependent variable) Pap smear: n=120,147 (age range 18-64 years of age as per USPSTF Guidelines) Mammogram: n= 34,738 (age range 40-64 years of age as per USPSTF Guidelines)	Women with disabilities were less like to be up to date with mammograms and pap tests compared to women with no disabilities; The magnitude of disparities was greater for women with complex limitations; Higher educational achievement: greater odds of recommended cancer screening; Not married or uninsured – less likely to achieve compliance with recommended screening 14.4% of women aged 18-64 years had gone longer than 3 years without a pap test n=10636; 25.6% of women aged 40-64 years had gone longer than two year without a mammograms n=9821.
Lai *et al.* (2014) Taiwan	To draw the attention of public health policy makers, increase the mammography utilisation rate among women with intellectual disability and decrease the incidence and mortality rate of breast cancer.	Analysis of public records to identify mammography utilisation rate of women aged 50-69 years Univariate and bivariate analysis n=4370	50.27% mild to moderate ID; 69.20% aged 50-59 years; 47.19% married; 82.27% illiterate / or elementary education; 84.46% minimum monthly salary/ or dependant; 75.57% lived in urban areas; 28.54% underwent pap smears; Mammography utilisation 4.32%.

compared to those living in residential settings (reference group in the multiple logistic regression model), and also for women with intellectual disabilities who have a General Practitioner as a primary physician (OR=0.13) (Parish et al., 2013).

2.5.2. Examining screening disparities for women with intellectual disabilities

It is acknowledged in the literature that screening disparities exist for women with intellectual disabilities when compared to women in the general population. The focus of this section is to examine the extent of the disparities encountered by women with intellectual disabilities when accessing screening.

The International Cancer Screening Network (ICSN) represents a voluntary confederate of countries that have active population based cancer screening programmes. The ICSN compares data from international screening programmes to identify efficient and effective approaches to cancer control. An international assessment of breast and cervical cancer screening programme implementation was undertaken in 16 ISCN countries in the time period 2007-2008 (Dowling et al., 2010).

Equality in access to breast and cervical screening programmes is increasingly recognised as an important health concern in women with intellectual disabilities. A European Commission funded health project (2005-2008) POMONA II Health Indicators for People with Intellectual Disabilities developed a set of health indicators specific to people with intellectual disabilities across the European Union to promote inclusion in future health surveys. The mean age of the participants from 14 EU member states was 41 years (range 19-90 years), 1269 adults with intellectual disabilities participated in the study and 49% of participants were female (Noonan Walsh et al., 2008).

An examination of both of these reports facilitated a comparison of the screening participation rates in breast and cervical screening for women in the general population (GP) taken from Dowling et al. (2010) and women with intellectual disabilities (WWID) in Ireland, Finland, France, Norway and the United Kingdom as reported in Noonan Walsh et al. (2008). Table 2.7. presents the comparative data adapted from Noonan Walsh et al. (2008) and Dowling et al. (2010), and the comparative data is then discussed in the national context of the above mentioned countries.

Table 2.7. Comparison of breast and cervical screening: Adapted from Noonan Walsh et al. (2008) and Dowling et al. (2010)

Country	**Breast screening rate (GP) (Dowling et al., 2010)**	**Breast screening rate (WWID) (Noonan Walsh et al., 2008)**	**Cervical screening rate (GP) (Dowling et al., 2010)**	**Cervical screening rate (WWID) (Noonan Walsh et al., 2008)**
Ireland	74.1%	<50%	60.9%	<5%
Finland	87%	<50%	~ 70%	<50%
France	<50%	>50%	70%	<50%
Norway	76%	<33%	77%	<33%
UK	75%	<20%	80%	<20%

Ireland

BreastCheck, the national cancer screening service invites women aged 50-64 years to have a free mammogram biennially. In 2011 the screening rate was 72.2%, over 125,000 women participated in the screening programme and 832 women had cancers detected (National Cancer Screening Service, 2013).

CervicalCheck, the national cervical screening programme invites women for a free cervical smear test every three years for women aged 25-44 years and every five years for women aged 45-60 years. In the first three years of the programme 60.9% of the eligible population were screened. Pre-cancerous abnormalities were detected in just over 8000 women, and 104 women were diagnosed with cervical cancer (National Cancer Screening Service, 2012a).

The ISCN assessment for the Irish breast and cervical screening programmes indicated that 74.1% of age eligible Irish women participated in the breast screening programme while the participation rate for Irish women in cervical screening was 60.9% (Dowling et al., 2010). A slight drop in the participation in the breast screening programme is evident as the ISCN data refers to participation rates in 2007-2008 (Dowling et al., 2010), while the NCSS data refers participation rates to 2011 (National Cancer Screening Service, 2013).

In comparison it was disconcerting that so few Irish women in the POMONA II study had received a cervical screen in the last three years. Furthermore, less than half the Irish sample had received a mammogram in the last two years, which was substantially lower than the uptake in the general population.

Finland

Finland implements an organised population based breast and cervical screening programme. The ICSN data for screening uptake for Finnish women shows that over 87% of the target population received breast screening and almost 70% of the target population received cervical screening. The rates for women with intellectual disabilities were noticeably lower; less than half of the POMONA II Finnish sample received a mammogram in the previous two years or a cervical screen in the last three years.

France

In France, the national breast cancer screening programme was launched in 2004. The ICSN data which refers to the 2005 time period indicates that just under half of the target population participated in breast screening. A regional based population cervical cancer screening programme was operational at the time of the ICSN assessment (Dowling et al., 2010). The

POMONA II data indicates that the majority of the French sample with intellectual disabilities had received a mammogram in the last two years and may be attributable to regional variations in screening uptake. In excess of half of the sample had a cervical screen in the last three years, which was lower than the uptake in the general French population.

Norway

Norway operates a population based breast and cervical screening programme as part of the public health care system. In the ICSN data participation rates of 76% and 77% were recorded for the breast and cervical screening programmes respectively. These are amongst the highest participation rates recorded for international breast and cervical screening programmes in the ICSN assessment. The POMONA II data for the Norwegian sample demonstrated that less than one third of the participants had received a mammogram in the last two years or a cervical smear in the last three years. The sample size for Norwegian women in the project was relatively small as in the Irish case. Nevertheless, these participation rates were considerably lower than the uptake levels in the general population.

United Kingdom

The NHS in the UK provides population based breast and cervical cancer screening programme. The ICSN assessment reported participation rates of 75% and 80% in the breast and cervical cancer screening programmes. Similar to Norway these were amongst the highest recorded participation rates in the ICSN assessment. The POMONA II data for the British sample indicated that less than a fifth of the participants had received a mammogram in the last two years or a cervical screen in the last three years. The sample size was similar to the Irish and Norwegian sample sizes. It appears that women with intellectual disabilities in the UK experienced inequalities in participating in population based breast and cervical screening programmes.

It is acknowledged that the comparison of convenience samples with national norms and the comparison of findings from methodologically different studies is not empirically sound. However, the objective of the comparison was to offer insight into the level of international and national inequalities in screening uptake levels for women with intellectual disabilities.

In a small scale Irish study in the Republic of Ireland in 2009, Lalor and Redmond undertook a survey to explore the extent of breast screening among post- menopausal women with intellectual disabilities living in three residential care settings (n=90). Further evidence of inequalities of access for Irish women with intellectual disabilities was presented as 14% of the age eligible women surveyed were not included on the BreastCheck register for invitation to participate in the breast screening programme. Given that the BreastCheck database register is compiled from information supplied by the Department of Social Protection and General Medical Services, it would have been expected that all age eligible woman would be registered (Lalor and Redmond, 2009).

In Taiwan, Lin et al. (2010) used the results to the ‘2009 National Survey on Preventative Health Use and Determinants among People with Disabilities’ to identify and evaluate the use of cervical screening among women with intellectual disabilities (n= 508). Over 70% of the respondents had mild to moderate intellectual disabilities, which was similar to the demographic profile of people with intellectual disabilities in the Republic of Ireland as discussed earlier in section 1.1.1.

Just over one fifth (22.1%) of the respondents had taken part in the cervical screening programme, although the mean age at the commencement was almost 40 years of age. Although it was encouraging to see that women were participating in cervical screening programmes, particularly where they are likely to be sexually active, the uptake level for cervical screening for Taiwanese women with intellectual disabilities remained very poor.

In an Australian context, the Department of Health undertook two major population based health surveys. The Victorian Population Health Survey of People with an Intellectual Disability 2009 explored the health and wellbeing of people with intellectual disabilities (n=897). These findings were compared with the results of the Victorian Population Health Survey 2008 which explored the health and wellbeing of the general population (n= 34,169). The comparative data indicated disparities in participation rates in cancer screening programmes for people with intellectual disabilities when compared with the general population. Proxy respondents completed that questionnaire on behalf of women with intellectual disabilities.

More than half (55.2%) of the women with intellectual disabilities were reported to have had a mammogram in the two years prior to the survey. However, the participation rate is much lower than that of women in the general population. Over three quarters of women in the general population (75.9%) reported that they had participated in breast screening in the previous two years (Department of Health, 2011).

In Victoria, all women on the electoral register aged between 50 and 69 years of aged are offered a free mammogram. It seems then women with intellectual disabilities who were not on the electoral register lost out on this invitation to participate. This was similar to the findings of Lalor and Redmond (2009) in the Irish context, in that some women with intellectual disabilities were omitted from the registers used to offer breast screening appointments.

In relation to cervical screening just 14.8% of women with intellectual disabilities aged 20-69 years were reported to have had a cervical screening in the two years before the survey was carried out. Once again, a significantly higher participation rate in cervical screening was reported by women in the general population. The participation rate in cervical screening for these women was 71.1% (Department of Health, 2011).

In a major United Kingdom based study, Osborn and colleagues (2012) undertook a retrospective cohort study to assess whether people with intellectual disabilities have poorer access to cancer screening using the Health Improvement Network (THIN) primary care research database. The active participants in THIN represented almost 6% of the UK population at the time of the study. The two cohort groups of interest were people with intellectual disability and a demographically similar group without intellectual disabilities.

Women with intellectual disabilities (n= 6254) were compared with women without intellectual disabilities (n=33,425) in the Cervical Cohort in the time period 2008-9. The key finding in this cohort was that age eligible women with intellectual disabilities were almost half as likely to have had cervical cancer screening than women without intellectual disabilities (Osborn et al., 2012).

With regard to breast screening in the UK, women with intellectual disabilities (n= 2,956) were compared with women without intellectual disabilities (n= 17,354) in the Mammogram Cohort in 2009. The key finding in this cohort was that age eligible women with intellectual disabilities were still 35% less likely to have a mammogram than women without intellectual disabilities (Osborn et al. 2012).

In a Canadian context, Cobigo et al. (2013) investigated whether cervical and breast cancer screening programmes were equitable for Canadian women with intellectual disabilities. Two cohorts of adult women with and without intellectual disabilities who were eligible for health coverage in a twelve month period living in Ontario in 2009-2010 were created. All women with intellectual disabilities (n=16,663) and a random sample of 20% of the women without intellectual disabilities (n=1,352,366) were included in the cohorts.

The key findings in this study were that in Ontario the proportion of age eligible women with intellectual disabilities who were not screened for cervical cancer over a three year period from 2007-2010 was almost twice that of age eligible women without intellectual disabilities. Likewise the proportion of age eligible women with intellectual disabilities who did not receive a mammogram over a two year period from 2008-2010 was one and a half times that of age eligible women without intellectual disabilities (Cobigo et al., 2013).

More recently in the United States, in an analysis of the self-reported screening data of a nationally representative sample, Horner- Johnson and colleagues (2014) found that women with disabilities were less likely to be up to date with cancer screening compared to women with no disabilities. The magnitude of disparities were more pronounced for women presenting with both basic and complex limitations: these women were 48% less likely to have had a pap smear in the preceding 3 years and 23% less likely to have had a mammogram in the prior two year period (Horner-Johnson et al., 2014).

It is disconcerting that in both the national and international arena women with intellectual disabilities experience inequalities in participating in breast and cervical cancer screening programmes. The evidence base clearly signposts to much lower screening uptake rates than in women who do not have intellectual disabilities. It is crucial to increase participation of women with intellectual disabilities in cancer screening programmes to reduce the risk of cancer incidence and premature mortality among these women. As a growing population of women with intellectual disabilities will live at home with family caregivers and attend intellectual disability services it seems there is a need for targeted education for family and paid caregivers as well as women with intellectual disabilities about the value of preventative screening.

2.6. Accessible cancer and screening information for women with intellectual disabilities

Women with intellectual disabilities often have literacy difficulties which have a major impact on decision making about a healthy lifestyle or accessing screening. Popular interventions used in health promotion interventions for women with intellectual disabilities include providing health promotion information in multiple formats and targeted health promotion. Furthermore women with intellectual disabilities or their carers may not actually be aware of the existence of this health promotion information. This section presents a review of a number of breast and cervical educational interventions available for women with intellectual disabilities and their carers nationally and internationally.

In Ireland, the National Cancer Screening Services developed two accessible documents, approved by the National Adult Literacy Agency, to facilitate the education of women with intellectual disabilities about screening. A brief two page pamphlet has been produced for the cervical programme ‘Your Smear Test’ using text and illustration. However, the information page appeared overly complicated with quite an amount of text and illustration on one page which may be difficult for a woman with intellectual disabilities to comprehend. ‘A Guide to Breast Screening’ targets women with intellectual disabilities, carers, family, friends and medical guardians of care. While it provided valuable health and screening related information for the woman with intellectual disabilities, it contained 84 pages which may be difficult to navigate for women with comprehension difficulties (National Cancer Screening Service, 2012b).

It seems that less precedence is given to the importance of the cervical screening based on limited information provided to women with intellectual disabilities. It is concerning that the breast screening guidance appears to suggest that women with intellectual disabilities must attend their breast screening appointment when they get the letter; while in the cervical screening pamphlet no reference is made to the woman deciding whether she wants to have a smear test. This raises concerns about decision making for women with intellectual disabilities related to attending screening.

In the UK the NHS Cancer Screening Programmes produced the key guidance documents on breast and cervical screening which can be supplemented with two further publications all of which are freely available to download from the internet. This guidance was designed with the input of women with intellectual disabilities and professionals. ‘Equal Access to Breast and Cervical Screening for Disabled Women’ provides useful screening related information for carers. The supplementary eight page booklets ‘An Easy Guide to Breast Screening’ and ‘An Easy Guide to Cervical Screening’ addressed the screening procedure using pictures and text (NHS Cancer Screening Programmes, 2006a, NHS Cancer Screening Programmes, 2006b, NHS Cancer Screening Programmes, 2006c). Moreover, it seems that decision making for women with intellectual disabilities has on whether or not to participate in screening had been addressed. In this regard further supplementary publications were suggested by the NHS to assist this decision making process.

‘Looking after my breasts’ (Hollins and Perez, 2000) and ‘Keeping Healthy Down Below’(Hollins and Downer, 2000) are companion books to the NHS guidance, and were also developed with the input of women with intellectual disabilities and professionals. ‘Looking after my breasts’ also has a section on breast awareness and how to look for changes in the breast. These books use illustrations to help women with intellectual disabilities to consider feelings they have about screening and address issues such as decision making and giving consent.

‘My Boobs and Me! How Are My Boobs Today?’ was designed to promote breast health in women with intellectual disabilities (Taggart and Mc Kendry, 2010). Unlike the previous publications discussed this book had easy to read text with photographic images rather than illustrations. Similar to the NHS guidance the content had been designed by women with intellectual disabilities and professionals. The content included information about breast cancer awareness, risk and protective factors, and attending a mammogram. Although like the Irish guidance, attendance at breast screening appears to be promoted. Women with intellectual disabilities are encouraged to become more involved their own breast care for instance by keeping contact details for carers and healthcare professionals. The excellent quality of the images provide good guidance to carers in how to approach the subject of breast screening in women with intellectual disabilities especially in the breast self-examination section.

Women with intellectual disabilities may depend on family and non- nursing staff for health care advice it is also crucial to educate the carers about cancer awareness and screening. In the UK the CHANGE Cancer Project in collaboration with Macmillan Cancer Support, developed the accessible guide ‘Symptoms, Screening and Staying Healthy’ for people with intellectual disabilities and a companion book for carers (Booth et al., 2010). The accessible book explains in easy to read format with illustrations what cancer is; early recognition of symptoms; breast awareness, screening and preventative factors. The carers guide follows an identical format providing additional information for the carers to encourage people with intellectual disabilities to become more active participants in their own health care.

However, the books are not designed specifically for women with intellectual disabilities and so do not focus solely on breast and cervical cancer awareness and screening. Men and women were depicted in the illustrations. For example, on page 63 of the accessible guide the illustration for pain in the back, hips or pelvis showed a man with no corresponding picture of a woman available (Booth et al., 2010). So with regard to explaining back or pelvic pain as symptoms of cervical cancer to women with intellectual disabilities this picture may cause confusion.

There is a wide range of health promoting information to encourage women with intellectual disabilities to decide whether to participate in breast and cervical screening programmes. However many of these interventions have not been evaluated. There is a need to develop and evaluate theoretically driven targeted health promotion interventions for the intellectual disabilities population.

2.7. Methodological limitations of the literature

It is acknowledged that there are a number of methodological limitations in the studies included in the review that warrant consideration as they may affect the generalisability of their results. Among the key methodological limitations are issues with non-responders, self-selected samples, the age of the study participants, low response rate, small sample size. The context and settings in which the data is gathered cancer can introduce bias in the findings, for example, the geographical location and a sample which are only known to the intellectual disabilities service providers. The study design and instruments used to gather data can also affect the rigour of the study.

Although Robb et al. (2009) and Mc Menamin et al. (2005) undertook large scale studies with samples which were representative of the general population in the United Kingdom and the Republic of Ireland no data was kept on non-responders. For instance Robb et al. (2009) commented that although the response rate could be considered acceptable at 61%, they could not make an assessment on how the remaining 39% of the British population would score on cancer awareness. Other studies which exclusively study nurses such as Lloyd and Coulson (2014) and Tyler et al. (2010) reported that self- selected samples or captive audiences attending a conference may not be representative of intellectual disability nurses.

The use of the electoral register allowed access to 60% of the Northern Ireland population, however, it was reported that identifying specific age groups in the general population was extremely difficult (Keeney et al., 2010). For instance many people may consider themselves to be at lower risk of cancer due to their relatively younger age, as cancer is so strongly associated with increasing age, for example Ryan et al. (2015). It was also noteworthy that more women than men participate in health based studies, for example Forbes et al. (2013) and Ryan et al. (2015). Many younger participants also had high educational attainment, for example Mc Menamin et al. (2005). Although it is very concerning that awareness of cancer risk factors and warning signs is relatively poor across the lifespan and geographical borders.

Other researchers considered the effect of selection bias in their studies. For example, Tazhibi and Feizi (2014) suggested that people who had an expressed interest in attending public screening and educational programmes were more likely to participate in the study.

A low response rate reflects the representativeness of the sample to the target population, as non-responders may have different characteristics than those who did participate (Parahoo, 2006). Wide variations in response rate were observed in a number of studies in the review. Among the poorest response rates recorded among caregivers of people with intellectual disabilities in the international literature were 16.9% (Lin et al., 2010); 25.7% (Hanna et al., 2011); 32.4% (Wyatt and Talbot, 2013) and 54.4% (Lalor and Redmond, 2009). Comparably, Willis et al. (2015) acknowledged that the small number of interviews and observations involved in their study limited the generalisability of their findings. Although these response rates could be considered acceptable for the exploratory nature of the studies, Taggart et al. (2011) postulated that low response rates to participate in research studies among caregivers may be related to scheduling difficulties due to sick leave, work commitments and annual leave.

Similarly in studies of cancer awareness in general populations or population subgroups low response rates were also observed. Forbes and colleagues (2013) noted a variation in estimated response rates ranging from 23% in Norway to 47% in Australia in the exploration of cancer awareness in the over 50 years age group in the ICBP countries. Likewise, Eckechi and colleagues (2014) documented a low response rate on 25.5% in their exploration of cervical cancer awareness among Black women in London. In an Irish context, O’ Connor et al. (2012) noted that the response rate (62%) could be considered satisfactory in their exploration of cervical cancer awareness. However, each of these studies recognised that the findings may not be generalizable to the general population (O’ Connor et al., 2012; Forbes et al., 2013) or the entire population of Black women living in London (Ekechi et al., 2014).

The context and settings in which data are collected can also introduce bias into the findings (Parahoo, 2006). A number of studies were conducted in a single geographical location. For example, Lalor and Redmond (2009) examined the perspectives of registered nurses intellectual disabilities in one intellectual disability service provider in the Republic of Ireland; Wyatt and Talbot (2013) examined carer perspectives in three organisations in one geographical area in the United Kingdom and Hanna et al. (2011) undertook their exploration of staff knowledge in one Health and Social Care Trust in Northern Ireland.

A key influence affecting the generalisability of results was that research studies are likely not to include women with intellectual disabilities who are unknown to the service system (Parish et al. 2012) or women who live with families or in the community without state supports (Wilkinson et al., 2011b). In an Irish context there was a limited body of research undertaken with women with intellectual disabilities in relation to cancer awareness or cancer screening (Trusdale- Kennedy et al., 2011, Lalor and Redmond, 2009). It is noteworthy that a number of studies relied on proxy reports from caregivers mainly due to literacy difficulties experienced by women with intellectual disabilities, for example Lalor and Redmond (2009) and Lin et al. (2010). It seems that in this emerging research area women who are known to the service system remain more likely to be invited to participate in research studies with an acknowledgement that the generalisability of the results to the entire population of women with intellectual disabilities is not possible.

A small body of recent research into mammography and pap smear uptake was also undertaken in Taiwan (Lin et al., 2010, Lai et al., 2014). The provision of intellectual disability services, caregiver perspectives and access to cancer screening programmes vary between different countries thus the results from the American and Taiwanese studies were not generalizable beyond those populations studied. However, they did offer a comparative basis for studies conducted in an Irish context.

Another factor affecting the generalisability of the results is small sample sizes. For example, O’ Mahony and Hegarty (2009) in their exploration of women’s help seeking on discovery of a breast symptom acknowledged that the findings cannot be generalised beyond the sample due to its small size. Similarly, Parish et al. (2013) asserted that their examination of the determinants of cervical screening among women with intellectual disabilities was limited by a combination of a small sample size and a single geographical location. Satge and colleagues studied the breast cancer staging of just eleven women with intellectual disabilities which limited the statistical analysis possible on the data.

An additional methodological concern is the use of appropriate instrument to collect data. Newly developed instruments, for example Mc Menamin et al. (2005) and Ryan et al. (2015) have been used to collect data on cancer risk factors and symptom awareness. Parish and colleagues (2012) used a straightforward set of questions to evaluate women’s knowledge about breast and cervical cancer screening. Elsewhere in the literature it is suggested that the use of validated and reliable instruments to assess cancer and screening awareness in different populations could lead to more rigourous studies. The Cancer Research UK Cancer Awareness Measures, for example Robb (2009) and internationally validated measure of cancer awareness and beliefs i.e. the awareness and beliefs about cancer (ABC) measure (Forbes et al., 2013) are examples of such instruments which may enhance the rigour of a cancer and screening awareness study.

A large volume of the studies had a cross sectional design which measured the constructs of interest at baseline assessment and may be susceptible to social desirability and over estimates of knowledge levels, for example Tazhibi and Feizi (2014). Retrospective studies, for example O' Mahony and Hegarty (2009) and Scanlon et al. (2006) have potential validity threats due to recall bias which influences the accuracy of recall of events. Related to this was a reliance on self- report data which is susceptible to the bias of over reporting, for example the receipt of breast and cervical cancer screening (Horner- Johnson et al., 2014). Furthermore, Robb et al. (2009) commented that recall of cancer warning signs or risk factors underestimates awareness levels because it is limited by memory, whereas recognition overestimates awareness levels because it is easier for the participant to guess.

2.8. Gaps in the literature

A small body of evidence indicates poorer breast and cervical cancer and screening awareness among women with mild to moderate intellectual disabilities living with family caregivers. This is concerning in an Irish context given that a large majority of women with mild to moderate intellectual disabilities live with family carers, and family caregivers may be less aware of the cancer risk for women with intellectual disabilities. This novel study will consult with women with mild to moderate intellectual disabilities and their family carers regarding the warning signs for breast and cervical cancer, risk factors and screening awareness to see how the awareness levels compare internationally.

Global evidence identifies disparities in screening access for women with intellectual disabilities. However, there is a distinct lack of knowledge in the Republic of Ireland on the participation of women with intellectual disabilities in breast and cervical cancer screening programmes. This study will address this issue through an examination of the self-reported screening participation of women with mild to moderate intellectual disabilities. A particular focus will be to elicit the perspectives of Irish women with intellectual disabilities and their carers to understand factors which impact upon the uptake of breast and cervical cancer screening especially for women with more significant intellectual disabilities.

The evidence base indicates a need for health promotion and cancer initiatives targeted at carers and people with intellectual disabilities to address the poor knowledge base related to cancer and screening awareness. This study will make a contribution to this body of knowledge in three key areas.

First, a baseline assessment of breast and cervical cancer and screening awareness will be undertaken with women with intellectual disabilities and their paid and family carers. Second, a theoretically underpinned cancer awareness intervention will be developed by the research team to address gaps in awareness levels identified in the baseline assessment. Finally, a mixed methods approach will be used to assess the feasibility of the intervention.

2.9. Chapter summary

This chapter provided an overview of the contemporary literature about cancer and screening awareness and screening participation uptake for women with and without intellectual disabilities in a national and international arena. There is not a vast evidence base relating to cancer awareness and screening for women with intellectual disabilities from the perspectives of the women themselves or their family caregivers. Knowledge deficits in cancer and screening awareness have been found among women with intellectual disabilities, their family and paid carers as well as among women in the general population. Clear evidence of the determinants which impact on the participation of women with intellectual disabilities and of extent of the inequalities in access to cancer screening programmes experienced by this group has been identified. There has also been a call for research to address the advancement and evaluation of targeted health promotion interventions for women with intellectual disabilities, and to evaluate their impact in improving cancer and screening awareness. In summary, a gap exists in the evidence base regarding cancer and screening awareness, and the provision of evaluated education initiatives for women with intellectual disabilities and their carers to improve breast and cervical cancer awareness and screening participation for women with intellectual disabilities. In Chapter 3 the conceptual framework of the study will be discussed.

Chapter 3: Conceptual Framework

3.0. Introduction

Inequalities have been documented in all major institutions in society especially for marginalised groups including women with intellectual disabilities. Sections 3.1. and 3.2. look at inequality, particularly healthcare inequalities, in the context of how health inequalities are dealt with within the various constructions of intellectual disabilities. Section 3.3. explores the relationship between social justice and the transformative paradigm and its focus on reducing health inequalities in marginalised groups using mixed methods for healthcare interventions to effect social change. Next section 3.4. examines the evidence base in the development of health promotion interventions for adults with intellectual disabilities to identify common theoretical underpinnings and study designs for complex interventions in health. Section 3.5. describes the stages involved in the processes of development and feasibility testing of EMBRACES- ID a cancer awareness programme for women with mild to moderate intellectual disabilities and their carers. The key intervention stages discussed are the two phase mixed methods design, the comprehensive needs assessment, the selection of a theoretical framework and the educational materials, and the feasibility testing of the intervention. Figure 3.3. represents the conceptual framework of the study. Finally the chapter concludes with Section 3.6.

3.1. Exploring inequalities

The major institutions of society (political, economic and social) define people's rights and duties, influencing their life prospects, the expectations of what they can be and how well they can hope to do. Rawls (p.7) argues that deep inequalities arise when institutions 'favour certain starting places over others' (Rawls, 1971) Society favours certain social groups; such is the nature of human diversity (Young, 1990, Sen, 1992). An analysis of inequality finds that differences between groups lead to marginalisation (Young, 1990, Sen, 1992).

Throughout history people with intellectual disabilities have been marginalised by society (Carlson and Diedrich, 2009, Sheerin, 2013), with limited access to education, employment and financial resources (Davis et al., 2014, Reidy et al., 2014). Sociodemographic characteristics have been linked to both health status and health behaviour. People in lower socio-economic groups experience healthcare inequalities leading to higher morbidity and mortality (Glanz et al., 2008, Irish Cancer Society, 2013, Hayden, 2014). Research shows that in the Republic of Ireland people with intellectual disabilities have lower employment levels, 6.5 % in regular paid/ self-employed compared to 54% in regular paid/ self- employed in the general population (Burke et al., 2014, Hudson et al., 2014).

As people with intellectual disabilities also experience more health problems than other members of society they are more prone to deficits in knowledge and means because of the negative biases of social systems (Bandura, 1997, Taggart and Cousins, 2014). Support models for people with intellectual disabilities which focus on health, well-being and social outcomes are key features of an inclusive and fair society (World Health Organisation, 2011b). The next section introduces the various constructions of intellectual disabilities and how health inequalities are dealt with within these constructions of intellectual disabilities.

3.2. Models of disability and health inequalities

There are a number of different models used in the construction of intellectual disabilities. This section explores the medical model, the social model, the ICF classification, the AAIDD definition and the Capabilities Framework and the relationship of health inequalities to each of these.

In the medical model intellectual disabilities are constructed as a series of functional deficits caused by physical causal agents. Reducing health inequalities for people with intellectual disabilities is not an objective of the medical model, it contends that they will always have poorer health than the general population (Emerson and Hatton, 2013). The social model of disability evolved to counteract the medical model and views health inequalities as an outcome of the oppressive ways in which society treats people with intellectual disabilities. The political action required is to eliminate health inequalities to achieve civil rights and empowerment (Emerson and Hatton, 2013).

In the International Classification of Functioning, Disability and Health (ICF) framework the approach to disability is conceptualised as involving the individual, their environment and a biopsychosocial approach (World Health Organisation, 2001, Buntinx and Schalock, 2010). Emerson and Hatton (2013) argue that the ICF framework does not set clear priorities for identifying and eliminating health inequalities experienced by people with intellectual disabilities.

The American Association of Intellectual and Developmental Disabilities (AAIDD) model involves a reciprocal relationship between the intellectual disability, adaptive behaviours, participation, context and individual supports (Buntinx and Schalock, 2010). Emerson and Hatton (2013) argue that this model does not identify clear goals to eliminate health inequalities for people with intellectual disabilities.

The Capabilities Framework is concerned with inequalities entrenched in marginalisation and oppression (Nussbaum, 2011, Emerson and Hatton, 2013), and is compatible with the social model of disability and the human rights approach used in this study. It is concerned with social justice and societal responsibilities to ensure every person is in a position to achieve substantial freedoms (Emerson and Hatton, 2013). The next section looks closely at the relationship between social justice and the transformative paradigm in the context of reducing health inequalities in marginalised groups.

3.3. Social justice, health inequalities and the mixed methods transformative paradigm

Healthcare is a social right that every person should enjoy (Social Justice Ireland, 2016). The Strategic Review of Health Inequalities in England Post 2010 argues that reducing health inequalities is a matter of social justice and fairness: a perspective reiterated in the Capabilities Framework for Disabilities and the transformative paradigm (Marmot Review, 2010, Mertens, 2010c, Emerson and Hatton, 2013). ‘Social justice is a matter of life and death, affecting how people live, their chances of illness and their risk of premature death’ (Marmot Review, 2010, p. 34). In this context it is crucial to undertake research to investigate how health inequalities impact on the lives of women with intellectual disabilities.

3.3.1. The Transformative Paradigm

The transformative paradigm emerged in response to individuals who have been pushed to the margins of society historically as a means to have their voices heard in research (Mertens, 2010c) The transformative paradigm is firmly rooted in a human rights agenda much as it is reflected in the United Nations Universal Declaration of Human Rights (United Nations General Assembly, 1948, Mertens, 2010c). It provides a philosophical framework in addition to methodological guidance to researchers on how to directly engage members of marginalised groups in order to challenge the status quo and further social justice in a similar vein to the Capabilities Framework approach.

The aim of transformative research is to foster real world community partnerships between the researcher and the many types of expert stakeholders (Mertens, 2009a). Transformative researchers position themselves side by side with the less powerful in society in a joint effort to bring about social transformation (Mertens, 2010b). These partnerships need to be developed in an ethos of trust and cultural sensitivity and this joint enterprise leads to the application of rigourous research methods by the researcher and meaningful connections to real world issues (Jensen et al., 1999, Mertens et al., 2009). Only from the unique contributions of the researcher and the stakeholders can what is feasible, durable and sustainable be decided (Jensen et al., 1999, Mertens, 2010c, Natasi et al., 2010).

The axiological assumption of the transformative paradigm re-examines the regulatory principles of respect, beneficence and justice. Respect is examined in terms of the cultural norms of interaction between diverse groups such as the non- disabled researcher and the women with intellectual disabilities. Informed consent is obtained with full cognisance of the power differentials between women with intellectual disabilities and the researcher with particular emphasis on the role of acquiescence in this relationship. The key axiological focus of beneficence is firmly rooted in a human rights agenda with a connection between the research process and the use of the findings to further human rights and social justice (Mertens, 2010a). The disability community is a heterogenous and culturally complex community. The transformative paradigm promotes ethical disability research in terms of the way it positions people with intellectual disabilities and the importance placed on listening to what they have to say (Sullivan, 2009).

Ontologically, the transformative researcher is acutely aware that reality is a socially constructed entity. This is influenced by their belief in the importance of respectfully addressing cultural diversity, the conscious awareness that certain individuals occupy a position of greater power and that specific characteristics associated with power differentials determine which version of reality is accepted as real (Mertens, 2009b, Mertens, 2010c). Combined with a feminist approach the transformative paradigm provides the opportunity for the women's voices to be brought into conversation with the carers thus allowing different perspectives to be heard in a balanced way with the goal of promoting social justice (Hesse-Biber, 2012, Mertens and Hesse-Biber, 2012).

The underlying epistemological assumption is that the focus, planning, implementation and use of the research is culturally sensitive and cognisant of power relationships This is operationalised by close collaboration between researcher and study participants by building trust and the researcher’s moral imperative to challenge the status quo for the purpose of contributing to a more just society (Mertens et al., 2009).

The epistemological assumptions have a logical connection to the transformative methodological assumption including mixed methods research (Hesse-Biber, 2010, Mertens, 2010c). Methodologically choices go beyond quantitative, qualitative or mixed methods approaches to how to collect data about the reality of a concept in such a way that the researcher can be confident that reality is captured in an ethical way. The kernel of the transformative paradigm is to collect data by paying close attention to the avoidance of bias and giving voice to the marginalised (Mertens et al., 2009).

Complex interventions, such as health promotion interventions, aim to improve the well-being of people with health and/ or social care needs and research questions need to be answered with methods capable of dealing with this complexity. Key resources involved in complex intervention implementation in healthcare settings are the organisational culture, norms and values as they structure the participants capacity for intervention engagement (Craig et al., 2008, Borglin, 2015, May, 2015, Richards, 2015).

The Medical Research Council Framework for the design and evaluation of complex interventions in healthcare settings supports a process of ‘development- testing- evaluation-implementation. The aim of mixed methods research is to achieve optimum answer to the research question and the integration of the results from both strands provides explanation as to what extent the different types of data explain each other. The MRC Guidelines support the use of a mixed methods research design to establish the feasibility, acceptability and effectiveness of the intervention (Mertens, 2010c, Creswell and Plano Clark, 2011, Richards, 2015).

3.4. Health promotion interventions for adults with intellectual disabilities

Kerr et al. (2013), Naaldenberg et al. (2013) and Heller et al. (2014) highlighted the necessity to develop and evaluate empirically based and theoretically driven health promotion interventions targeted to the needs of people with intellectual disabilities. However, few theoretically based lifestyle interventions for people with intellectual disabilities have been published.

An exploration of health promotion interventions with a sound theoretical base for adults with intellectual disabilities was used to inform the development of this study. Thirteen relevant interventions were identified Bazzano et al. (2009); Elinder et al. (2010); Bodde et al. (2012); Parish et al. (2012a); McDermott et al. (2012); Beeken et al. (2013); Marks et al. (2013);Mitchell et al. (2013);van Schijndel-Speet et al. (2013); Greenwood et al. (2014); Swaine et al. (2014); Kouimtsidis et al. (2015) and Taggart et al. (2015). These interventions included those which were evaluated through the use of randomised control trials and protocols developed to test the feasibility of the intervention prior to undertaking a randomised control trial.

The key data charted from completed studies and study protocols such as author, year, geographical location, aim of the study, method and sample, key findings (completed studies) and key outcome measures (trial protocols).

The SPIRIT (Standard Protocol Items- Recommendations for Interventional Trials) 2013 Statement (Chan et al., 2013) is an international initiative that aims to improve the quality of clinical trial protocols by defining an evidence-based set of items to address in a protocol. The focus of the TIDiER (Template for Intervention Description and Replication) Checklist (Hoffmann et al., 2014) is on reporting details of the intervention elements of a study.

It was decided that following these guidelines was essential to ensure the relevant elements of the included studied were reported to inform the development of the EMBRACES-ID intervention. The key elements of the SPIRIT Statement and the TIDiER Checklist which were used to report the key elements of interest in the interventions are shown in Table 3.3.

The next sections describe the key elements of the randomised controlled trials and the trial protocols as described in Table 3.3. It begins by exploring the principal foci of current theoretically based health promotion interventions for adults with intellectual disabilities.

3.4.1. Focus of the intervention including theoretical background

Current research in the area of theoretically driven health promotion for adults with intellectual disabilities is primarily concentrated in the area of lifestyle changes. The key areas targeted in health promotion programme included weight management (Bazzano et al., 2009, Beeken et al., 2013), diet and physical activity (Elinder et al., 2010), physical activity knowledge (Bodde et al., 2012, Marks et al., 2013), promoting physical activity (McDermott et al., 2012, Mitchell et al., 2013, van Schijndel-Speet et al., 2013), self-management of diabetes (Taggart et al., 2015) and alcohol misuse (Kouimtsidis et al., 2015).

It was immediately obvious that empirically and theoretically based health promotion interventions about breast and cervical cancer awareness and screening for women with intellectual disabilities were sparse (Parish et al., 2012a, Greenwood et al., 2014, Swaine et al., 2014). The majority of the research activity was concentrated in the United States.

There were some examples of randomised controlled trials carried out on health promotion interventions among the intellectual disabilities population in the literature such as McDermott et al. (2012) which promoted physical activity; Parish et al., (2012a) and Swaine et al. (2014) which promoted cancer and screening awareness; and Marks et al., (2013) which promoted knowledge about physical activity. Another design utilised for the evaluation of health promotion interventions in the intellectual disabilities field included small scale single group pretest/postest designs (Bazzano et al., 2009).

There is a move toward adapting health promotion initiatives designed for the general population for use in the intellectual disabilities population. For example Beeken and colleagues (2013) adapted a healthy lifestyle programme while Taggart and colleagues (2015) adapted a UK national diabetes management.

It has become more common in recent years to test the feasibility of health promotions to determine whether it is worthwhile to undertake randomised controlled trials. Important issues to be considered in feasibility studies are the appropriateness and acceptability of programme and outcome measures for participant, compliance of the facilitator, estimate treatment effects and the time needed to collect and analyse data.

An analysis of the studies reviewed identified that the Medical Research Council’s (MRC) Guidance for the development and evaluation of complex interventions Craig et al. (2013) is gaining popularity in the United Kingdom for the development of feasibility studies. The MRC Guidance for the development of trial protocol was used by Beeken et al. (2013), Mitchell et al. (2013), Kouimtsidis et al. (2015) and Taggart et al. (2015).

Intervention planning/ mapping seems to be the preferred method used for the development of study protocols in the Netherlands (van Schijndel- Speet et al., 2013) and in Sweden

Table 3.1. Evaluated health promotion interventions for adults with intellectual disabilities

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Bazzano *et al.* (2009) United States	To examine whether the Healthy Lifestyle Change Program (HCLP) could result in weightloss; improved dietary habits; increased exercise; increased self-efficacy; improved access to healthcare; improved life satisfaction and increased community capacity	Pre-test/Post-test design (no control group) n=44 completed the intervention (35% attrition rate) Bivariate analysis	Outcomes measured at baseline and after 7 months; -Two thirds of participants who completed the intervention lost or maintained weight; -Physical activity increased in 61% of participants; -improved eating habits; -83% of participants totally sure they could make a doctor's appointment; -59% of participants showed improvement in overall life satisfaction; - Peer mentors and community care providers equipped with tools to continue the programme in the community.
Bodde *et al*. (2012) United States	Formative and process evaluation of the Promoting Health through Physical Activity and Skills (PHPAKS) curriculum	Pre-test/ post-test n=42 adults with mild to moderate intellectual disabilities Ajzen's Theory of Planned Behaviour Descriptive Statistics	Evaluation of process measures at the end of the session for the ability to independently perform the relevant knowledge or skills and 7- 10 days later to monitor retention; 87.7% (mean) met learning objectives of the session; 89.8% (mean) retained knowledge after 7-10 days.
Mc Dermott *et al*. (2012) United States	To test the efficacy of Steps to Your Health to prevent increase in BMI and to increase physical activity in adults with intellectual disabilities.	Randomised Controlled Trial Logistic and linear regression n=443 adults with intellectual disabilities for baseline assessment Intervention group n=216 Control group n=216 Participatory model Social cognitive approaches to learning	Moderate to vigourous activity was not significantly increased from baseline to one year fir participants in the intervention group compared to the control group; Almost half of the participants decreased their BMI from baseline to one year, but no significant difference between intervention and control group.
Parish *et al.* (2012) United States	Will women with intellectual disabilities demonstrate knowledge gains from participating in Women be Healthy, a targeted educational intervention designed to improve women's knowledge about cervical and breast screening,	Randomised control trial n=91 women with intellectual disabilities in intervention group n=84 women with intellectual disabilities in control group Newly designed questionnaire Bivariate analysis Regression analysis	Intervention group post test n=50 attended 8 sessions, n=19 attended 7 sessions, n=12 attended 6 sessions n=10 attended fewer than 6 sessions; Correctly define mammography (OR 2.33, $p < 0.05$;) Frequency of mammography (OR 3.09, $p<0.05$); Overall knowledge composite ($\beta=0.38$, $p=0.05$); Non-significant gains in cervical cancer knowledge.

Table 3.1. Evaluated health promotion interventions for adults with intellectual disabilities

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Marks *et al*. (2013) United States	To evaluate the efficacy of a HealthMatters Program- Train-the-Trainer Workshop on promoting and maintaining healthy behaviours of adults with intellectual disabilities	Randomised pre-test/ post-test comparison (control) group design Social Cognitive Theory Transtheoretical Model n=35 staff n=32 adults with intellectual disabilities in intervention group n=35 adults with intellectual disabilities in control group	Intervention group - demonstrated significant improvements in psychosocial measures - Over 81.2% reported good or excellent health; -increased number of healthy behaviours; - improvements in nutrition and activity knowledge and skills; - improvement in flexibility.
Greenwood *et al*. (2014) United States	Evaluate the acceptability, demand and limited efficacy of a mammography preparedness DVD as a health education intervention for women with intellectual disabilities.	Convenience sample n=46 (watched the DVD and completed pre-post DVD Mammography preparedness measure) Age range 37-82 (average age 56 years (SD 11.6 years)	Limited efficacy- moderate increase in mammography knowledge post DVD, especially in women who had previously had mammograms (92.45% of the sample); Demand- n=42 participants kept the DVD; Acceptability: participants expressed satisfaction with the DVD overall- learned about mammography, found it interesting and appreciated the story based format.
Swaine *et al*. (2014) United States	Is Women be Healthy 2 effective in increasing cervical and breast screening knowledge among women with intellectual disabilities in comparison to Women be Healthy or no treatment	3 arm randomised control trial n=98 Women be Healthy n=35Women be Healthy 2 n=65 no intervention Descriptive and bivariate analysis statistics	Women be Healthy: Knowledge gains on the nine item composite and six individual measures definition and frequency of mammography and pap test; pap test picture identification, ways to decrease anxiety during exams; Outcomes measured 11 days after intervention; Women be Healthy 2: Knowledge gains on the nine item composite 3.7-5.4; Outcomes measured 5 days after intervention.

Table 3.2. Trial protocols for health promotion interventions for adults with intellectual disabilities

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Elinder *et al*. (2010) Sweden	To describe and explain the design and evaluation of a health intervention targeting people with intellectual disabilities.	Fraser 2009 (step-by-step approach) Cluster randomised trial- waiting list control group Social Cognitive Theory Cluster size n=5 and 32 community residences needed to detect significant change between intervention and control group.	Increase in physical activity; Changes in dietary quality, quality of life, weight and waist circumference; Intervention outcomes measured at baseline, following the intervention and after 6 months.
Beeken *et al*. (2013) United Kingdom	Is Shape UP LD more effective than usual care in helping overweight and obese service users with mild to moderate intellectual disabilities reduce body weight.	Phase 2 MRC Guidelines Two arm individually randomised controlled pilot trial Social Cognitive Theory and Control Theory n=60 in feasibility trial	5% reduction in weight; Changes in biomedical measures, quality of life and health behaviours and knowledge; Follow up at end of treatment period and at 6 months to assess maintenance.
Mitchell *et al*. (2013) Scotland	To examine whether a walking intervention can improve physical activity levels, health and wellbeing in people with intellectual disabilities.	Phase 2 MRC Guidelines Cluster randomisation Active intervention- waiting list control group n=50 per group	Measurement of moderate to vigourous physical activity; Well-being, self-efficacy for activity for adults with intellectual disabilities; Weight and waist circumference; Outcome measures at baseline, at end of 12 week intervention and after a further 12 weeks.
van Schijndel- Speet *et al*. (2013) Netherlands	Development and evaluation of a structured programme (HA-PAP) for promoting physical activity among seniors with intellectual disabilities.	Intervention planning Cluster randomised RCT n=80 per group Theory of planned behaviour; Social cognitive theory ; Control theory; Operant conditioning	Physical activity- steps per day; Motor fitness, biomedical data; Outcome measures at baseline and after the 8 month intervention.
Kouimtsidis *et al*. (2015) United Kingdom	Can a large scale randomised controlled trial that will answer whether EBI is more effective than usual care in helping adults with mild to moderate intellectual disability to reduce their alcohol intake.	Phase 2 MRC Guidelines Single bling RCT protocol Motivational Interviewing Readiness to change n=50 adults with mild to moderate intellectual disabilities (25 in each arm	Reduction in alcohol intake; Willingness to change; Health status and quality of life; Outcomes measured at baseline, at two months and at three months.

Table 3.2. Trial protocols for health promotion interventions for adults with intellectual disabilities

Author/ year/ location	**Aim of study**	**Method/ sample**	**Key findings**
Taggart *et al*. (2015) United Kingdom	Is DESMOND-ID more effective than usual routine care in helping adults with intellectual disabilities manage their Type 2 Diabetes and reduce their HB1ac levels	Phase 2 MRC Guidelines Two arm individually randomised pilot trial n=36 (n=18 intervention, n=18 control) Self-regulation theory, social learning theory, dual process theory.	HB1ac measure; Biomedical data, psychosocial and behaviour measures; Outcomes measure at baseline and 3 month follow up.

Table 3.3. Key elements used: Adapted from SPIRIT Statement and TIDiER Checklist

SPIRIT- Standard Protocol Items: Recommendations for Interventional Trials (Chan et al., 2013)	**The TIDieR (Template for Intervention Description and Replication) Checklist (Hoffmann et al., 2014)**
Specific objectives or hypotheses	Theory essential to the intervention
Trial design	Materials used and each of the procedures used in the intervention.
Study setting	How the intervention was delivered
Eligibility criteria	The number of times the intervention was delivered.
Interventions	Discuss any tailoring or modification of the intervention.
Outcomes	Adherence or fidelity testing if relevant
Sample size	
Recruitment	
Data collection, management, and analysis	
Ethical consideration	

(Elinder et al., 2010). A further method of interest was the Feasibility Method developed by Bowen et al. (2009) used by Greenwood and colleagues (2014) in the United States.

The theoretical background relevant to the intervention is extremely important in the development of health promotion interventions. It appears that Social Cognitive Theory (Bandura, 1986) is the most popular theoretical background for intervention development for adults with intellectual disabilities. SCT can improve health behaviours through personal factors – knowledge, skill, preferences self-efficacy and improvements in social and physical environment. Eight studies used SCT as part of the theoretical framework for the intervention development (Bazzano et al., 2009, Elinder et al., 2010, Mc Dermott et al., 2012, Beeken et al., 2013, Marks et al., 2013, Mitchell et al., 2013, van Schijndel- Speet et al., 2013, Taggart et al., 2015).

Other theories and models used in intervention development included the Theory of Planned Behaviour (Ajzen, 1991) as reported by Bodde et al. (2012) and van Schijndel- Speet et al. (2013) and the Transtheoretical Model (Prochaska and DiClemente, 1984) as used by Marks et al. (2013) and Mitchell et al. (2013), and Motivational Interviewing (Kouimtsidis et al., 2015).

However, it was much more difficult to ascertain theoretical backgrounds in the area of cancer and screening awareness interventions. For example, in Greenwood et al. (2014) social cognitive approaches such as modelling were eluded to but not explicitly mentioned.

3.4.2. Study setting

The studies were sited in a diverse range of intellectual disability day services, communities and community residences. The principal countries where data was collected were the United States: Mc Dermott et al. (2012), Bazzano et al. (2009), Bodde et al. (2012), Parish et al. (2012a), Marks et al. (2013), Greenwood et al. (2014) and Swaine et al (2014); the United Kingdom: Beeken et al. (2013), Mitchell et al. (2013), Kouimtsidis et al. (2015) and Taggart et al. (2015); Sweden: Elinder et al. (2010) and the Netherlands: van Schijndel-Speet et al. (2013).

3.4.3. Eligibility criteria

There was a wide range of eligibility criteria for participants in the interventions, however, the samples included mainly adults with mild to moderate intellectual disabilities with the ability to provide informed consent or assent and the ability to verbally communicate. Mitchell et al. (2013) was a notable exception where adults with all levels of intellectual disability were invited to participate in the intervention. A small number of studies also specified that paid or informal carers must have been willing to participate in the intervention (Beeken et al, 2013, Taggart et al., 2015).

3.4.4. Outcomes of interest

The primary outcomes of interest in eight of the studies related to weight reduction, physical activity or knowledge about physical activity (Bazzano et al., 2009, Elinder et al., 2010, Bodde et al., 2012, Mc Dermott, 2012, Beeken et al., 2013, Marks et al. (2013), Mitchell et al. (2013) and van Schijndel-Speet et al. (2013).

HB1ac measurement was the primary outcome measure of interest for Taggart and colleagues (2015), while Kouimtsidis et al. (2015) were interested in the primary reduction in alcohol intake. In the three cancer awareness interventions the primary outcome of interest related to changes in cancer and screening awareness levels (Parish et al., 2012a, Swaine et al. 2014) and preparedness for mammography (Greenwood et al., 2014).

Secondary outcomes of interest frequently referred to included health knowledge or behaviours (Bodde et al., 2012, Beeken et al., 2013, Marks et al., 2013); quality of life (Elinder et al., 2010, Beeken et al., 2013, Kouimtsidis et al. (2015); self-esteem /self-efficacy (Beeken et al., 2013, Marks et al., 2013, Mitchell et al., 2013); biomedical data such as body fat and waist circumference (Bazzano et al., 2009, Elinder et al., 2010, Beeken et al., 2013, Marks et al., 2013, Mitchell et al., 2013, van Schijndel-Speet et al., (2013) and physical activity (Taggart et al., 2015).

In addition the timescales for measure of intervention outcomes were much longer for the majority of the lifestyle health promotion programmes. Although a low follow up time of 7-10 days for the measurement of outcomes was recorded by Bodde et al. (2012), it appears intervention outcomes were more likely to be measured at baseline and at periodic intervals to monitor changes. For example, Elinder et al. (2010) reported that outcomes of interest were to be measured at baseline, at the end of the intervention and after 6 months. However, in the cancer and screening awareness interventions the changes in knowledge levels compared to baseline levels were measured between 5-11 days post intervention (Swaine et al., 2014). Similarly, Parish et al. (2012a) recorded that post-test interviews took place on average 13 days after the end of the intervention. Greenwood et al. (2014) undertook acceptability interviews on average 3-6 weeks post the intervention. It seems there is a need to measure to outcomes over a longer time frame to explore the retention of changes in knowledge levels post intervention.

3.4.5. Materials used

Various types of media were used to develop or adapt health promotion programmes to the limited cognitive abilities of people with intellectual disabilities. By far the most common media used was easy to read information supplemented with pictorial illustration, using face to face instruction for example Elinder et al. (2010); Beeken et al. (2013); van Schijndel-Speet et al. (2013) and Taggart et al. (2015).

Among the other techniques used to engage adults with intellectual disabilities were group discussion, role play and interactive materials across a wide range of interventions Bodde et al. (2012); McDermott et al. (2012); Parish et al. (2012a) and van Schijndel-Speet et al. (2013). Information provision in DVD format and the repetition of information was also considered particularly useful due to the cognitive difficulties of the target audience, Parish et al. (2012a); Mitchell et al. (2013); Greenwood et al. (2014) and Swaine et al. (2014). Information for carers was suggested by Bazzano et al. (2009); Elinder et al. (2010); Mitchell et al. (2013) and Taggart et al. (2015) to foster the link between carers and people with intellectual disabilities becoming more active participants in their own health care.

Of particular interest in the cancer health promotion programmes group were techniques to build advocacy skills about personal decisions such as talking to healthcare professionals and how to report symptoms (Parish et al. 2012a, Swaine et al., 2014). Similar to Greenwood et al. (2014) modelling the behaviours through role play or by the use of an actress to demonstrate the skills was important to encourage advocacy skills development for women with intellectual disabilities.

3.4.6. When and how much intervention

In order to facilitate the development of future health promotion activities or the replication of current programmes for adults with intellectual disabilities information such as the number of times the intervention was delivered, over what period of time including the number of sessions, their schedule and their duration was given in each of the studies.

The number and duration of sessions varied between the outcomes measured in the interventions. For example, Beeken et al. (2013) ran the intervention over a 12 week time frame, comprising a 90 minute session every week where groups of four to six service users or pairs of service users/ carers attended the sessions to monitor for reduction in weight. Van Schijndel-Speet et al. (2013) ran a group based physical activity programme, with three sessions per week over an eight month time frame to monitor changes in physical activity.

Whereas Kouimtsidis et al. (2015) ran an intervention which was comprised of five half hour weekly classes with a final session after eight weeks to assess changes in alcohol consumption.

In terms of the cancer awareness interventions, the Women be Healthy programme ran for 8 weeks with the aim of improving knowledge levels and increasing screening rates whereas the Women be Healthy 2 programmes ran over an 11 week timeframe, with twice weekly classes with a similar aim (Swaine et al., 2014). Recently, Wilkinson and colleagues (2014) developed a DVD based intervention to improve mammography preparedness for women with intellectual disabilities.

There was broad agreement with Parish et al. (2012a) in that repetitions of the information in the DVD may increase knowledge and comfort about the mammography process, in particular, amongst the women. However, unlike the time and resource intensive Women be Healthy curricula which required specially trained facilitators, the DVD seemed to be an effective and efficient means to provide accessible information within a reasonable time frame and cost to a population with limited literacy (Greenwood et al., 2014).

3.4.7. Sample size

In the evaluation of the revised Women be Healthy 2 programme (Swaine et al., 2014) the total sample size in the 3 arm RCT was 198 women (n=65 control group; n= 98 Women be Healthy Group; n=35 Women be Healthy 2 group). While in the original two arm RCT of the Women be Healthy Programme, 91 women were in the intervention group and 88 women were in the control group (Parish et al., 2012a). Thus it seems in this emerging area of study there is a wide range of sample sizes referred to in the literature.

Another approach adopted by Bazzano et al. (2009) in the evaluation of an intervention to see if it could result in weight loss, was to use pre- test post-test design with no control group. Of the 431 eligible participants, 85 signed up for the intervention, 68 attended the initial session. The study had a 35% attrition rate over the 7 month timeframe, 44 completed the weight loss intervention. So it seems attrition is an important factor to consider in the design of health promotion studies.

Feasibility studies are considered useful to estimate the sample size needed to achieve study objectives and detect significant changes. One method used to estimate sample size for feasibility studies is to calculate the sample and 80% power at 5% significance level to detect change, and allow for an attrition rate of 20% based on the knowledge base in the area, for example, Mitchell et al. (2013) and van Schijndel-Speet et al. (2013). Another method involves selecting a sample size based on MRC guidance. For example, Beeken et al. (2013) used a sample size of 60 in their study as there was no RCT in the area to allow an estimation of the likely effect size of the intervention.

3.4.8. Recruitment

A variety of techniques were utilised to recruit adults with intellectual disabilities and their carers to participate in health promotion interventions. A popular strategy was to provide on-site sessions at the intellectual disability service providers' premises in which information and consent forms were distributed for discussion with the women and their families, for example, Parish et al. (2012a). Other strategies included self-referral in response to posters (Beeken et al., 2013, Taggart et al., 2015) and return of an expression of interest to the researcher (Mitchell et al., 2013).

3.4.9. Data collection methods

The majority of the studies reviewed related to weight loss or increases in physical activity thus commonly used data collection instruments included body fat analysers, blood pressure monitors, accelerometer, pedometers and survey instruments such as quality of life questionnaires.

In the cancer and screening awareness interventions Parish et al. (2012a) and Swaine et al. (2014) used a nine item validated survey to assess baseline and post intervention knowledge changes. The questions were taken from the National Core Indicators and the Socio- Sexual Knowledge and Assessment Tool Revised (Griffiths and Lunsky, 2003). Greenwood and colleagues used the newly validated Mammography Preparedness Measure (Wang et al., 2015) to measure knowledge of mammography purpose and process in women with intellectual disabilities.

3.4.10. Statistical methods used

The feasibility studies of the lifestyle interventions used exploratory statistical analysis to estimate effect sizes and sample sizes for a randomised controlled trial (Beeken et al., 2013), and process evaluation to measure factors such as facilitators and barriers to attendance at the health promotion classes (van Schijndel-Speet et al., 2013, Taggart et al., 2015). Completed interventions used a range of statistical tests such as bivariate analysis Chi squared and Fisher test for categorical variable and paired t tests for continuous variables, for example, Marks et al. 2013).

In the evaluation of completed interventions in the cancer and screening awareness interventions, descriptive and bivariate analysis were used such as McNemars test for the knowledge indicators and paired samples t test for the knowledge composite and regression models for other variables of interest such as baseline knowledge (Parish et al., 2012a, Swaine et al., 2014). Greenwood and colleagues (2014) tested three aspects of feasibility in their evaluation of the Mammography Preparedness DVD. These were the efficacy and acceptability of the DVD to promote mammography preparedness and the demand for copies of the DVD by women who participated in the study.

3.4.11. Consent

Many different strategies were used to gain the informed consent/ assent of adults with intellectual disabilities to participate in the studies. It was most common that written or verbal consent was required from adults with intellectual disabilities, or assent and legal guardian consent. It was suggested that time is given to discuss the consent with carers or guardians. Offering incentives such as $5 wear accelerometer (Mc Dermott et al., 2012), $15 per interview (Parish et al., 2012a, Swaine et al., 2014) or cinema tickets (Beeken et al., 2013) could be considered contentious amongst a population that trend towards social desirability and acquiescence.

Sections 3.4.1.- 3.4.11. explored the crucial elements needed to design, test the feasibility of, or evaluate the effect of theoretically based health promotion interventions. Figure 3.1. details the key elements that are needed to undertake feasibility testing of health promotion interventions for adults with intellectual disabilities. In the context of this study the MRC guidelines and their link mixed methods research were particularly interesting. In addition the MRC Framework recommended the use of feasibility studies to address key uncertainties in intervention, design and procedural strategies which could undermine a thorough evaluation of the study (Thabane et al., 2010, Richards, 2015). The following section describes the stages involved in the processes of development and feasibility testing of EMBRACES- ID.

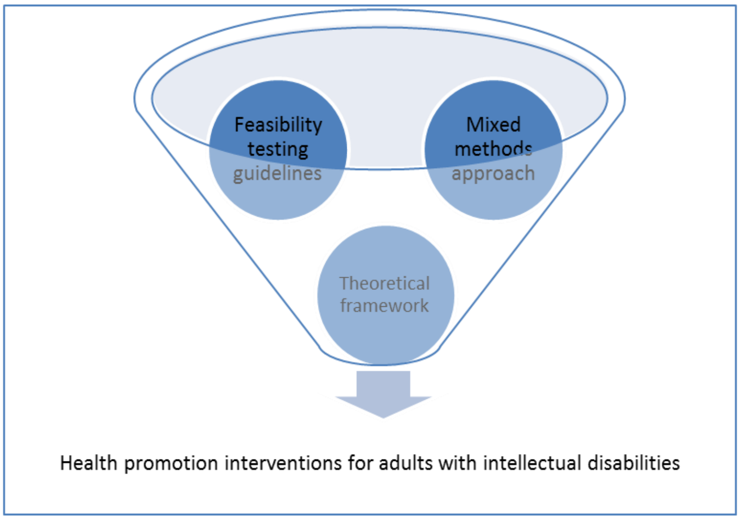


Figure 3.1. Key elements required to design health promotion interventions for adults with intellectual disabilities.

3.5. EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities)

This intervention to promote cancer and screening awareness is designed for women with mild to moderate intellectual disabilities and their carers. Important phases in the intervention planning stage involve selecting a mixed methods design for the study, undertaking a comprehensive needs assessment to ascertain the extent of the deficits in cancer and screening awareness, and to select a relevant theory to underpin the intervention. The following section considers these issues in further detail.

3.5.1. Mixed methods design

In the early 1980’s mixed method scholars or the third methodological community emerged which advocated methodological mixing (Niglas, 2010). The need for mixed methods research is crucial in the exploration of public health issues encompassing the persistent inequalities that exist in this area for marginalised groups (Creswell et al., 2011, Mertens, 2011). There exists the potential to contribute to the social change in a more defined way if mixed methods are viewed as a tool for such change (Mertens, 2011).

Mixed methods studies with a transformative aim address issues of social justice and the needs of under-represented or marginalised populations. This approach provides richer, more meaningful answers to the research questions with a view to achieving social justice (Johnson et al., 2007). The inclusion of both quantitative and qualitative data is to facilitate responsiveness for different stakeholders and issues (Hesse-Biber, 2010, Mertens, 2011). This approach ensures all voices are heard, confronts power differentials and produces results that are viewed both as useful and credible to the needs of the different stakeholders involved and provide clear recommendations for future research (Hesse-Biber, 2010, Mertens et al., 2010, O'Cathain et al., 2010, Creswell and Plano Clark, 2011). Hesse-Biber (2010; 2012) argues that a feminist approach privileges the lived experience of women at the centre of research inquiry through concern for the women's voices and experiences.

A strong mixed methods research design addresses the decisions about the level of integration; priority; timing and mixing. An important decision in mixed methods studies is the level of interaction between the quantitative and qualitative strands of the study (Creswell and Plano Clark, 2011). The study design was informed by the literature, devised to meet the objectives of this study and represents the cornerstone of moving through the transformative research cycle (Figure 3.2).

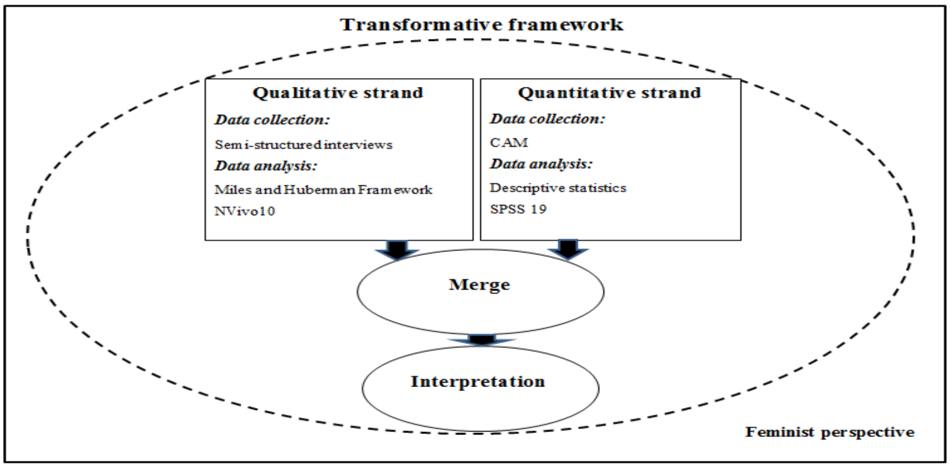


Figure 3.2. Transformative feminist convergent mixed method design

A transformative feminist convergent mixed method research design is an efficient design where quantitative and qualitative data are collected at approximately the same time using methods that are predetermined at the start of the study (Creswell et al., 2011, Creswell and Plano Clark, 2011). Both the quantitative and qualitative strands are determined to have equal priority in addressing the research objectives in both phases of the study. During interpretation the result of the quantitative data will be compared with the themes which emerge from the qualitative data to give a more complete understanding of cancer awareness and screening in women with intellectual disabilities and their carers.

The central focus the transformative paradigm places on the experiences of marginalised groups might constrain its application to a small subset of social research and limits its use as a paradigm for mixed methods (Hall, 2012). Despite these misgiving the transformative stance has been used to effect social change about healthcare for marginalised groups such as HIV/AIDS prevention in Botswana (Chilisa, 2005) and appropriate breast cancer screening services for women from multiple ethnic groups (Chiu, 2003). This section explored the research design for the study, the next section explores planning the intervention including a comprehensive needs assessment in Phase I and feasibility testing of the intervention in Phase II.

3.5.2. Comprehensive needs assessment

In the first instance a comprehensive needs assessment of the population and the situation in which the health problem occurs is a key feature of intervention planning (Abraham et al., 2015). To inform the needs assessment a literature review first examined the cancer and screening awareness of the general population, and women with intellectual disabilities and their carers. It also looked at the extent of screening disparities for women with intellectual disabilities when compared with women in the general population. Second, the intervention would be based on the existing knowledge base supplemented by the clinical and educational expertise of the research group. Findings from the baseline cancer and screening awareness assessment of women with intellectual disabilities and their carers in the South East region would further inform the intervention development.

3.5.3. Selecting a theoretical approach

The next phase of the intervention development involved a review of health promotion information and interventions designed for adults with intellectual disabilities. Successful theoretically driven health promotion interventions can be used as an instrument of social change which is compatible with the transformative paradigm. They are founded on a clear understanding of targeted health behaviours and the process of changing them, and the social and physical environmental context in which they occur (Glanz et al., 2008). Among the various approaches used were the Health Belief Model (Rosenstock, 1974), the Transtheoretical Model (Prochaska and DiClemente, 1984), Social Cognitive Theory (Bandura, 1986, Bandura, 1989), and the Theory of Planned Behaviour (Ajzen, 1991).

As discussed in section 3.4.1. the Social Cognitive Theory (Bandura 1986), which explores reciprocal exchanges between individuals and their environments, is favourable to health promotion programme design for adults with intellectual disabilities. As seen in Bandura (1997) people work together to improve the quality of their lives with their shared beliefs in their collective efficacy to accomplish social change.

3.5.3.1. Social Cognitive Theory

SCT is based on a triadic reciprocal model where behaviour, personal and environmental factors influence each other in a bidirectional manner (Bandura, 1986). SCT was chosen as the theoretical base to frame the intervention based on the strong evidence base on the suitability of SCT to theoretically underpin targeted health promotion programmes for adults with intellectual disabilities.

Cognitive characteristics of adults with intellectual disabilities which need to be considered in the development of health promotion programmes include smaller memory capacity which impacts on the ability to recall relevant knowledge; limited ability to generalise; and a shorter attention span (Snowman et al., 2012). In 1954, Piaget suggested those with a mental age of 9-12 years may be able to deal with a concrete situation but find it difficult to grasp abstract concepts and generalise from one situation to another (Piaget, 1999, Mc Leod, 2010). EMBRACES-ID would be developed to take into account the limited cognitive abilities of people with intellectual disabilities.

The six key concepts involved in SCT reciprocal determinism, behavioural capability, expectation, self-efficacy, observational learning and reinforcements. Key elements of effective SCT health promotion programmes include matching programmes to the audience, using accessible information, encouraging active learning, including elements that build skills and reinforce behaviour change (Rimer and Glanz, 2005). These key concepts were defined by McAlister et al. (2008) and were adapted to facilitate the design of key elements of the EMBRACES-ID intervention, see Table 3.4.

People are influenced by what they observe. It is important to remember that people will not be very influenced by modelled events if they do not remember them. Motivational processes also play a major role in learning as people will do what they find interesting and self-satisfying.

'Perceived self-efficacy refers to beliefs in one's capabilities to organise and execute the courses of action required to produce given attainments' (Bandura, 1997 p3). The very essence

of confidence is the belief in our ability to succeed (Valiante and Stachura, 2005). Self-efficacy beliefs are constructed from the following four primary sources of information: enactive mastery experiences; vicarious experiences; verbal persuasion and physiological states. Each of these sources can help individuals to develop a sense of efficacy needed to override difficulties that arise from time to time (Bandura, 1997).

A key design issue involves modelling how the EMBRACES- ID would be operationalised in practice looking at factors such as what participants will need to do as part of the intervention (Hoffmann et al., 2014, Richards, 2015). The more resources that are needed and the more the intervention requires the participants to do the more difficult it will be to recruit and retain people (Bandura, 1997, Treweek, 2015).

Intervention planning involves comprehensive needs assessment which explores the need and resources of the population and learns how to design effective materials and strategies for the target group. Firstly, the information would be gathered directly from the women with mild to moderate intellectual disabilities and carers themselves, and through proxy interviews with carers of women with severe to profound intellectual disabilities. Secondly, there would be a key emphasis on reading research literature about women who share the characteristics of the target population.

Modelling the intervention is particularly important for women with intellectual disabilities as the burden of repeated visits and classes may be enough to cause a woman or her carer to decide against participation (Treweek, 2015). There is no point in designing a programme that is so specialised that it has no chance of being used by intellectual disability services or women with intellectual disabilities (Richards, 2015). The intervention will comprise an eight hour programme which runs over four two hour weekly sessions to reduce the burden on women and their carers in the vein of comparable health promotion programmes to raise knowledge levels, for example Bodde et al. (2012) and Taggart et al. (2015).

Information sheets, consent forms and informational materials for the study will be provided in an easy to read format with simple spoken and written communications used throughout similar to other health promotion programmes critiqued in section 3.4. Each participant would be given an EMBRACES- ID programme folder containing the written materials needed for the classes and weekly activity sheets. Each participant would be asked to bring the folder to each of the four classes in the intervention.

Table 3.4. Application of SCT concepts to EMBRACES-ID (Adapted from Mc Allister 2008)

SCT Concept	Definition	Key EMBRACES- ID programme elements
Reciprocal Determinism	The dynamic interaction of the person, behaviour and the environment in which the behaviour is performed.	Influencing personal attitudes about cancer screening; Making adjustments to the environment
Behavioural capability	Knowledge and skills to perform a given behaviour i.e a person must know what to do and how to do it	Promoting mastery learning through skills training: For example providing the skills to perform breast self-examination through the use of various types of breast models
Outcome expectations	Outcomes expectations is a judgement of the likely consequences such performances will produce.	Model positive outcomes of a healthful behaviour- if you notice a cancer warning sign do not delay medical help seeking; attending screening may diagnose a cancer /precancer and more successful treatment.
Perceived self-efficacy	Perceived self-efficacy is a judgement of one's ability to organise and execute given types of performances	Approach behaviour change in small steps to ensure success. For example fear and embarrassment in attending doctor about issues with breast or 'down below'. Teaching relaxation strategies should help women to overcome this barrier to early help seeking, in tandem with building self-advocacy skills to talk to the doctor.
Observational learning (modelling)	Behavioural acquisition that occurs by watching the actions and outcomes of other's behaviour.	Offer credible role models who perform the targeted behaviour. For example, showing a DVD about women discussing embarrassment and fear prior having a smear test, and their experiences of the test.
Reinforcements	Responses to a person's behaviour that increase or decrease the likelihood of reoccurrence.	Promote self-initiated rewards and incentives. For example, providing positive reinforcement when using the breast models to identify the lumps.

Key areas where knowledge deficits arose as identified in the needs assessment undertaken in Phase I would be combined with the key themes from the CHANGE Cancer Series Accessible Book: Symptoms, screening and staying healthy (Booth et al., 2010) in the development of the EMBRACES-ID intervention. These CHANGE themes were: ‘What is cancer?’; spotting cancer early; staying healthy; breast and cervical cancer risks and screening; and changes to look out for. The cervical cancer risk factors were based on the three main risk factors in the Irish Cancer Society© information booklets.

A Licence Agreement for the CHANGE UK Specialist Image Collection© was purchased to allow the use of the images to make information accessible and easy to understand. The services of CHANGE UK were also employed to design intervention specific pictures to support communication about the themes and to make the screening information nationally representative. The accessible language would be used to make the key concepts of each theme easy to understand. The illustrations with people with intellectual disabilities would demonstrate certain skills and signs and symptoms of breast and cervical cancer.

It was anticipated at the programme design stage that the participants would have diverse cognitive abilities and thus reliance on written materials was not a viable option. The written class materials would be supplemented with group discussion topics, creative activities, and building advocacy skills primarily based on curriculum materials used in the Women Be Healthy© intervention and clinical expertise of the research group. The Women Be Healthy group gave permission to use the information on the WBH website.

For example to supplement the information about the theme ‘What is cancer?’ the information in the programme booklet would be supplemented with a group discussion about the types of cancer the participants had heard of prior to enrolling in the programme. Next, the cell growth group learning activity would be used to help the participants to visualise the growth pattern of a cancer cell.

Observational learning can have significant advantages for people with intellectual disabilities especially those with limited verbal skills (Monfils and Menolascino, 1984). The most effective way for the development of skill competencies is through guided mastery and proficient modelling (Bandura, 1986, Bandura, 1997). The Health Edco© breast self-examination model, the Breastology Bag© and the Health Edco© lump awareness necklace would be useful to teach the participants about being breast aware. The Health Edco© cervical models, a speculum, cytobrush and liquid cytology bottle would be used to explain to the participants what happens during a cervical screening.

Also included in the programme would be a number of short interactive video clips which demonstrated the mammography procedure (NHS Screening Programme©); breast self-examination (Embarrassing Bodies Series Channel Four©); examining cervical screening attitudes among women (Jo’s Cervical Cancer Trust©). Permission was granted to use this information in the programme by the relevant organisations, see Appendix III, Volume II.

Key information needed for developing skills can be modelled by physical demonstration, pictorial portrayal and verbal information. The intervention facilitator would model appropriate responses to the participants, for example how to perform Breast Self- Examination (BSE) using the various types of breast models. The participants would benefit from practicing the skill in front of their peers in group situations. Immediate feedback from the facilitator in the form of verbal praise, correction and redirection would be useful to help the women further refine and master the skill (Monfils and Menolascino, 1984).

Perceived self-efficacy is a good predictor of how well people adhere to behaviours that enable them to manage their own health (Bandura, 1997). Increasing self-efficacy to perform a behaviour through learning and positive reinforcement is critical to improving cancer and screening awareness (Bandura, 1989). For example in the case of BSE, the degree to which a woman feels self-efficious in performing BSE and has positive outcome expectations about the value of performing BSE results in an acceptable frequency of BSE (Konicki Dilorio, 2005).

Distal and proximal goal setting should be structured in ways to build a sense of personal efficacy as well as continuous gains in skills performance (Bandura, 1997). The women would be encouraged to look over the class materials with their family and paid carers, to encourage goal setting and improvements in skills development.

The lesson plans for the four sessions detail the pages referred to in the programme booklet, the materials needed, the timing needed for each activity, and the scripts to be used during the session. This is considered important to ensure the intervention would be delivered as planned. The weekly lesson plans for the facilitator and the equipment schedule needed for the implementation are found in Appendix VI, Volume II.

3.5.4. Assessing the feasibility of complex interventions

The MRC framework recommends the use of feasibility studies to address uncertainties which could undermine a thorough evaluation of the intervention (Thabane et al., 2010, Richards, 2015). Performing a feasibility study is indicated when previous interventions had positive outcomes but in different settings than the one of interest (Parish et al., 2012a, Greenwood et al., 2014, Swaine et al., 2014).

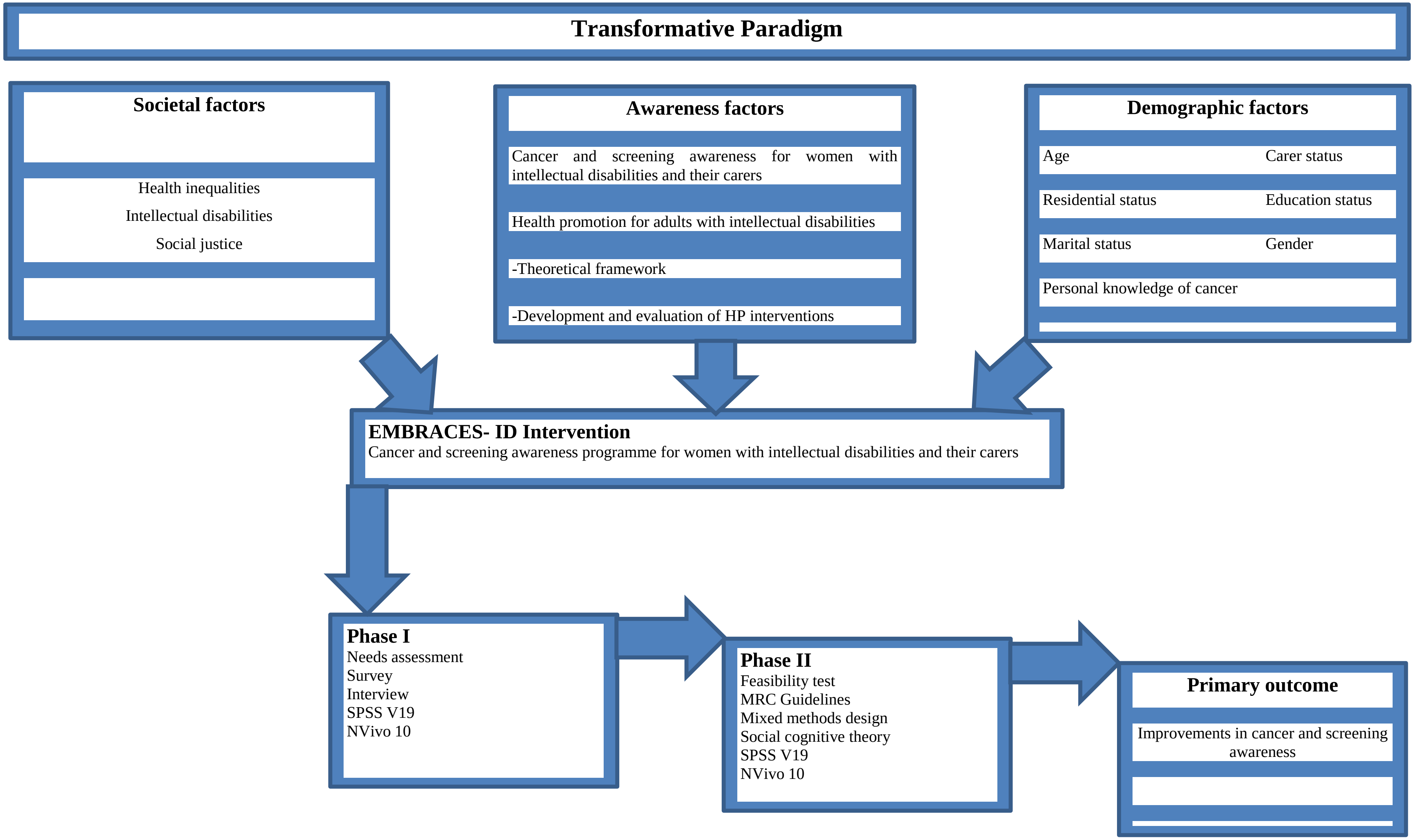
In the spirit of the transformative approach it is important to test the fit of interventions in real-world settings, by engaging participants early in the process to increase the likelihood of informing a change in cancer awareness and screening practices (Bowen et al., 2009, Mertens, 2010, Giangregorio and Thabane, 2015). The EMBRACES-ID intervention would be a single arm study which facilitates a more detailed assessment of intervention acceptability as all participants would receive the intervention (Taylor et al., 2015).

Primary and secondary outcome measures would be defined for the EMBRACES-ID intervention based on the empirical data, clinical expertise and the findings of the Phase I comprehensive needs assessment (Abraham et al., 2015, Lancaster, 2015). Key areas to be addressed include assessing outcomes such as satisfaction with the intervention (Giangregorio and Thabane, 2015, Lancaster, 2015). Figure 3.3. represents the conceptual framework used to design and implement this study.

3.6. Chapter Summary

This chapter looked at health inequalities for women with intellectual disabilities and how the transformative paradigm can be used to design mixed methods study to address social change. An exploration of current designs and theoretical frameworks used to develop and evaluate complex interventions in health for women with intellectual disabilities helped to frame the current study. An overview of the EMBRACES- ID intervention was provided, this will be further discussed in the methods and methodology chapter.

Figure 3.3. Conceptual Framework for the study



Chapter 4: Methods and Methodology

4.0. Introduction

The evidence signals a critical need to improve the education of women with intellectual disabilities and their carers about breast and cervical cancer and screening awareness. This is strengthened by the human rights approaches to service provision in intellectual disability services (UN General Assembly, 2007), and the goal of the Irish Cancer Society‘s Strategy Statement 2013-2017 to close the gap on cancer care inequalities in marginalised groups (Irish Cancer Society, 2013).

Within this chapter an overview of the mixed methods research procedures used to assess baseline cancer and screening of women with intellectual disabilities and their carers, and monitor changes in awareness levels following an educational intervention in this study will be discussed. Section 4.1. provides a brief synopsis of the rationale for the study and the research objectives and study outcomes. Section 4.2. reviews the mixed method research design used in the study. Next, section 4.3. describes the population estimates for the target populations for the study and the sampling method used throughout in Phase I of the study, the comprehensive needs assessment to identify gaps in cancer and screening awareness. Section 4.3. also examines the eligibility requirements for the target population, how the populations of interest to the study were accessed to draw relevant samples and the recruitment procedure to. Subsequently sections 4.4. and 4.5. describe the approaches to quantitative and qualitative data collection including the selection and development of the research instruments and pilot testing of the survey and interview protocol. Section 4.6. then explores the data analysis procedures in this phase of the study, section 4.6.1. details the data analysis procedures for the CAM surveys including the statistical tests used in the exploration of the data. Then section 4.6.2. takes a closer look at data analysis procedures for the carer interviews in the context of Miles and Huberman’s framework for qualitative data analysis (Miles and Huberman, 1994) introducing the approach to thematic data integration that will be used in the analysis.

Next the key elements involved in Phase II the feasibility and acceptability testing of the EMBRACES- ID cancer and screening awareness intervention are examined. Section 4.7. presents the eligibility requirements for the target populations of interest, the sample size justification for the feasibility study, and the recruitment procedure for this phase of the study. Section 4.8. reviews the approach to data collection in this phase of the study. Section 4.8.1.

describes quantitative data collection including modifications made to the CAM since Phase I. Subsequently section 4.8.2. explores the qualitative approach to data collection including the development and administration of the interview protocols for this phase. Then section 4.9. details the pilot testing of the interview protocols for the EMBRACES- ID intervention. Section 4.10. examines the implementation procedure for the intervention including the pilot testing and the modifications made to the original programme.

Section 4.11. presents the data analysis procedures for the quantitative and qualitative elements of this phase. In section 4.12. attention shifts to the mixed methods interpretation of the findings and how these will be addressed within the study. Section 4.13. explores issues of validity in quantitative and qualitative research and how these are addressed in the context of this study. Strategies to reduce potential threats to validity when connecting the quantitative and qualitative analysis are also a focus of section 4.13. After this, section 4.14. describes the ethical considerations used to frame this study. Finally, the chapter concludes in section 4.15. with the chapter summary.

4.1 The aim of the study

The principal aim of the mixed method study was to test the feasibility and acceptability of **EMBRACES-ID** (**E**arly **M**onitoring of **Br**east **a**nd **Ce**rvical **C**ancer **S**igns & **S**creening in **I**ntellectual **D**isabilities). This was an educational intervention designed for women with mild to moderate intellectual disabilities and their carers. EMBRACES-ID aimed to raise the awareness of: cancer warning signs; risk factors; screening programmes and promote early medical help-seeking on discovery of a symptom of breast or cervical cancer.

4.1.1. Research objectives

In order to achieve this aim a number of objectives were developed over two phases

Phase I:

- To assess the baseline breast and cervical cancer and screening awareness of women with mild to moderate intellectual disabilities, family and paid carers using cancer awareness measure survey;
- To gather information from carers using semi-structured interviews on their views of the needs of women with severe to profound intellectual disabilities about breast and cervical cancer awareness and screening.

Phase II:

- To develop a theoretically based cancer and screening awareness health promotion intervention for women with mild to moderate intellectual disabilities and their family and paid carers;
- To assess changes in outcome measures from baseline to post intervention and at 12 week follow up using a cancer awareness measure survey;
- To assess changes in outcome measures from baseline to post intervention and at 12 week follow up using a semi-structured interview;
- To assess the rates of recruitment and retention of participants;
- To test the acceptability of the intervention for participants using a semi-structured interview post intervention and at 12 week follow-up.

4.1.2. Study outcomes

Phase I assessed the baseline breast and cervical cancer and screening awareness of women with intellectual disabilities and their carers in the South East region using a cross sectional survey and semi- structured interview. The information obtained informed the development of the intervention and Phase II tested the feasibility of the intervention. This included testing the intervention for acceptability as well as the rates of recruitment and retention of participants. The primary outcome measure was changes in cancer awareness levels. A pre-test/posttest with a 12 week follow up design tested this. Secondary outcomes included examining participants sense of self-efficacy to perform breast self-examination, exploring perspectives on screening and medical help-seeking, and checking the understanding of the reasons behind cancer screening.

4.2. Research design

The core characteristics of a mixed methods study involve gathering quantitative and qualitative data and incorporating a plan to integrate the dataset. Key issues addressed in selecting the appropriate research design include whether either dataset will be prioritised or have equal priority in answering the research question, whether the data collection takes place simultaneously or in a sequential, phased manner, and when in the study will the datasets be combined. The research design guides the decisions made during the study, reflects on the philosophical and theoretical basis of the study, and set the logic for the enquiry (Creswell and Plano Clark, 2011, Parahoo, 2006).

The convergent parallel mixed methods design is the most common approach used in mixed methods research (Kettles et al., 2011). The context of this research study leaned toward the selection of an adaptation of this design, the transformative convergent design (Creswell and Plano- Clark, 2011). This design was considered the most appropriate means to get wider perspectives from the key stakeholders about cancer and screening awareness as well as views about the acceptability of the intervention. In this research design interview and questionnaire data were collected concurrently and with equal priority. The datasets were analysed separately using descriptive statistics and qualitative data analysis and then merged in the interpretation stage (O'Cathain et al., 2010, Borglin, 2015, Miles and Huberman, 1994).

The case for combining both approaches was to achieve a wider understanding of the issues investigated (Barbour, 2001, O'Cathain et al., 2010). The mixed methods triangulation process challenges researchers to think about meta-themes that cut across the findings from different methods (Farmer et al., 2006). The process of triangulating findings from different methods took place at the interpretation stage of this study and was used to check for convergence or dissonance among the quantitative and qualitative research findings (O' Cathain et al., 2010, Creswell and Plano Clark, 2011, Fetters et al., 2013). It is important to acknowledge that merging two different sets of data can be very challenging in mixed methods research (Mertens, 2010c), but was feasible.

In order to overcome this challenge the CAM and semi-structured interviews addressed the same concepts to facilitate the merging and interpretation of the data sets. During interpretation quantitative findings were compared with qualitative themes to give a more complete understanding of cancer awareness and screening in women with intellectual disabilities and their carers following participation in the EMBRACES- ID intervention.

PHASE I of the study: The comprehensive needs assessment

A comprehensive needs assessment is crucial to the development of complex interventions in healthcare (Abraham et al., 2015). Two key steps were to identify the knowledge gaps in cancer and screening awareness for women with intellectual disabilities and their carers through systematic review of the literature see Chapter 2 and via survey and interview of these target populations. Sections 4.3.1. and 4.3.2. describe the population of women with intellectual disabilities, and their paid and family carers living in the South East Region of Ireland, and establishes population estimates for the comprehensive needs assessment. Next, section 4.3.3.

describes the rationale for the sampling method used. Subsequently, section 4.3.4. describes the inclusion and exclusion criteria for women with intellectual disabilities and their carers to participate in the study. Following this section 4.3.5 discuss the procedures used to access to the sample including the estimated sample size, the characteristics of the participants and their recruitment procedures

4.3. Population and sample

The most recent census in Ireland, Census 2011 reported that the population in the South East of Ireland which covers the counties of Carlow, Kilkenny, South Tipperary, Waterford and Wexford was estimated to be 397,000 (Central Statistics Office, 2011). Profile 8- Our Bill of Health, a Census 2011 document, examined health, disability and carers in Ireland and provided data on the persons in each province, county and city, classified by those with a disability and type of disability (Central Statistics Office, 2012). Based on this data an estimated population of 6,560 people with an intellectual disability live in the South East Region. Table 4.1. provides a breakdown of the population with intellectual disabilities residing in each of the counties in the region.

A key objective of the study was to assess the cancer and screening awareness of women with intellectual disabilities and their carers. Therefore, population estimates of women with mild to moderate, women with severe to profound intellectual disabilities, staff profiles and family carers were required.

4.3.1. Population estimates

This section looks at the population estimates for the study. The samples of women with mild to moderate disabilities, family carers, paid carers and carers of women with severe to profound intellectual disabilities were drawn from these populations. First, the population of women with mild to moderate intellectual disabilities in the region is explored.

Women with mild to moderate intellectual disabilities

The Intellectual Disability Database Bulletin 2011 HSE South (Kelly and O' Donoghue, 2012), provided detailed statistical analysis of the population of women with intellectual disabilities living in the HSE South catchment area which incorporates the South East Region. The population of women with mild to moderate intellectual disabilities was estimated by the researcher from an extrapolation of figures from Profile 8- Our Bill of Health Statistical Table 5 and The Intellectual Disability Database Bulletin 2011 HSE South.

Table 4.1. Total population of people with intellectual disability in the South East Region adapted from Statistical Table 5: Profile 8- Our Bill of Health (Central Statistics Office, 2012*)*

County	Number of people with an intellectual disability
Carlow	721
Kilkenny	1,325
South Tipperary	1,198
Waterford (City and County)	1,423
Wexford	1,893
Total	6,560

The estimated population of interest was approximately 1300 women with mild to moderate intellectual disabilities. Figure 4.1 provides a detailed breakdown of the generation of the population size estimate. The next section explores the calculation of the population estimates for family carers of women with mild to moderate intellectual disabilities in the South East Region.

Family carers of women with mild to moderate intellectual disabilities

The National Intellectual Disability Database reported that in 2011 68% of people intellectual disabilities lived at home with family carers, relatives or foster carers (Kelly, 2012). Therefore, a further statistical analysis by the researcher of the data provided by Central Statistics Office (2012) and Kelly and O' Donoghue (2012) found that the estimated population of interest was approximately 900 families providing care to women with mild to moderate intellectual disabilities. Figure 4.2 provides a detailed breakdown of the generation of the population size estimate. The population estimates for paid carers of women with intellectual disabilities is discussed in the next section.

Paid carers of women with mild to moderate intellectual disabilities

The estimated number of carers employed by the seven participating intellectual disability service providers in the South East estimate was compiled from discussions with Human Resource Departments, Nurse Managers and Medical Advisors in each of the participating intellectual disability service providers. The figure was inclusive of Whole Time Equivalent Posts and flexi employees such as job sharers. The population of interest was estimated to be less than 1500 paid carers. The next section looks at the rationale for the interviews with

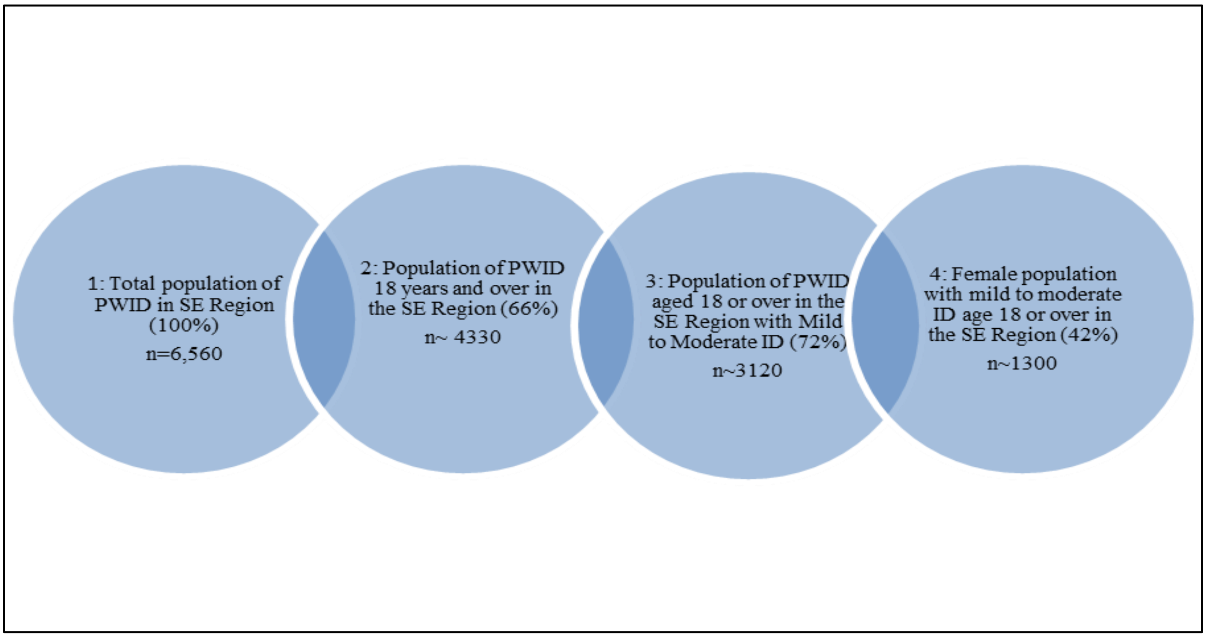


Figure 4.1. Calculation of population size for women with mild to moderate intellectual disabilities. Adapted from Central Statistics Office (2012) and Kelly and O' Donoghue (2012)

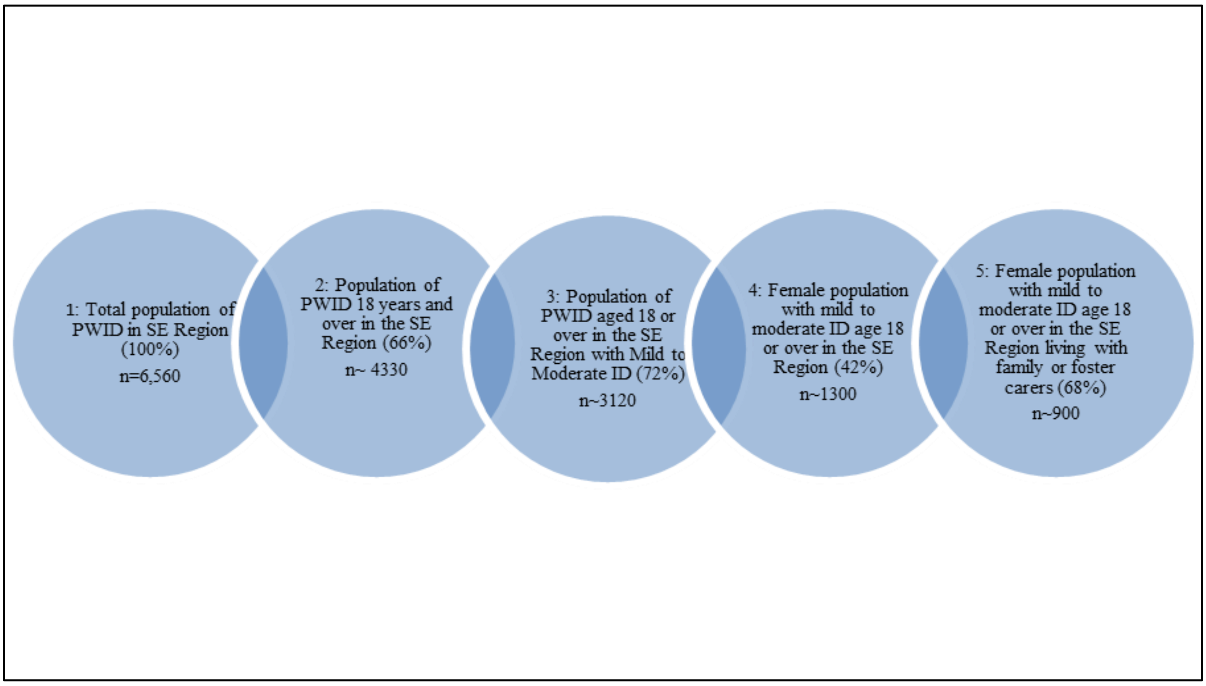


Figure 4.2. Calculation of population size for family carers of women with mild to moderate intellectual disabilities. Adapted from Central Statistics Office (2012) and Kelly and O' Donoghue (2012)

carers of women with severe to profound intellectual disabilities.

Carers of women with severe to profound intellectual disabilities

As women with severe to profound intellectual disabilities have communication and literacy difficulties, the research team decided to collect data regarding the needs of these women about cancer awareness and participation in screening programmes via interviews with their carers. This section discussed the population estimates for the different stakeholder groups involved in the study. The following section looks at the rationale for the sampling method used in the study.

4.3.2. Sampling method

The non- probability sampling method of purposive sampling was selected to enhance the understanding of the phenomenon (Robson, 2002, Polit and Beck, 2010). This sampling method wass aligned both to the researcher's judgement and the evidence that indicates women with intellectual disabilities and their carers were best placed to provide data on their cancer awareness and screening knowledge (Robson, 2002; Parahoo, 2006; Polit and Beck, 2010).

4.3.3. Sample size

It was essential to ensure that there was sufficient time, resources and access to participants through the intellectual disability service providers. The sampling frame and sample boundaries in the quantitative and qualitative strands set the foci for the selection of the sample size to ensure sufficient data was generated to allow the formulation of conclusions and interpretations in each phase of the study which was then integrated and conclusions drawn (Miles and Huberman, 1994, Collins, 2010).

The quantitative strand of the research question was addressed using a sampling frame with a 10% margin of error and a 95% confidence level Conroy (2012). The sample sizes were calculated using the 'Sample Size Calculator' which was available as a public service of Creative Research Systems survey software. It can be used to determine how many people required to survey in order to get results that reflect the target population as precisely as required in the study (Creative Research Systems, 2012). Figure 4.3 details the estimated sample size n=89 for women with mild to moderate intellectual disabilities n=90 for paid carers and n=87 for family carers of women with mild to moderate intellectual disabilities (Creative Research Systems, 2012).

A number of texts offered guidance on sample size for qualitative interviewing which allow you to find out what you need to know, that is the point of saturation, where further interviews reveal no new perspectives (Kvale, 2007). Griffin and Hauser (1993) recommended 20 interviews, while Warren (2002) suggested that the minimum number of interviews falls in the range 20-30 interviews. Kvale (2007) proposed that in common interview studies it is necessary to interview 15 people (±10 people). Adler and Adler (2012) concurred that a medium size sample of loosely around 30 interviews is needed. Based on this guidance it was estimated that a sample size of 20 individual carer interviews was appropriate to identify the needs of the women from the carers perspectives. This information is represented in Figure 4.3 which details the research design of the study.

4.3.4. Inclusion and exclusion criteria

This section describes the inclusion and exclusion criteria for the women with intellectual disabilities and their paid and family carers.

Women with intellectual disabilities

The inclusion criteria for the women with intellectual disabilities w:

- have a known diagnosis of mild to moderate intellectual disabilities;
- be able to provide informed consent;
- be able to communicate verbally;
- be aged 18 years and over.

The exclusion criteria for women with intellectual disabilities were

- have a known diagnosis of severe to profound intellectual disabilities;
- unable to provide informed consent;
- inability to communicate verbally;
- be less than 18 years of age.

Health and social care staff and family carers

The inclusion criteria for health and social care staff and family carers were to be a:

- health and social care staff directly involved in the care of women with intellectual disabilities;
- family carer of a woman with intellectual disabilities;

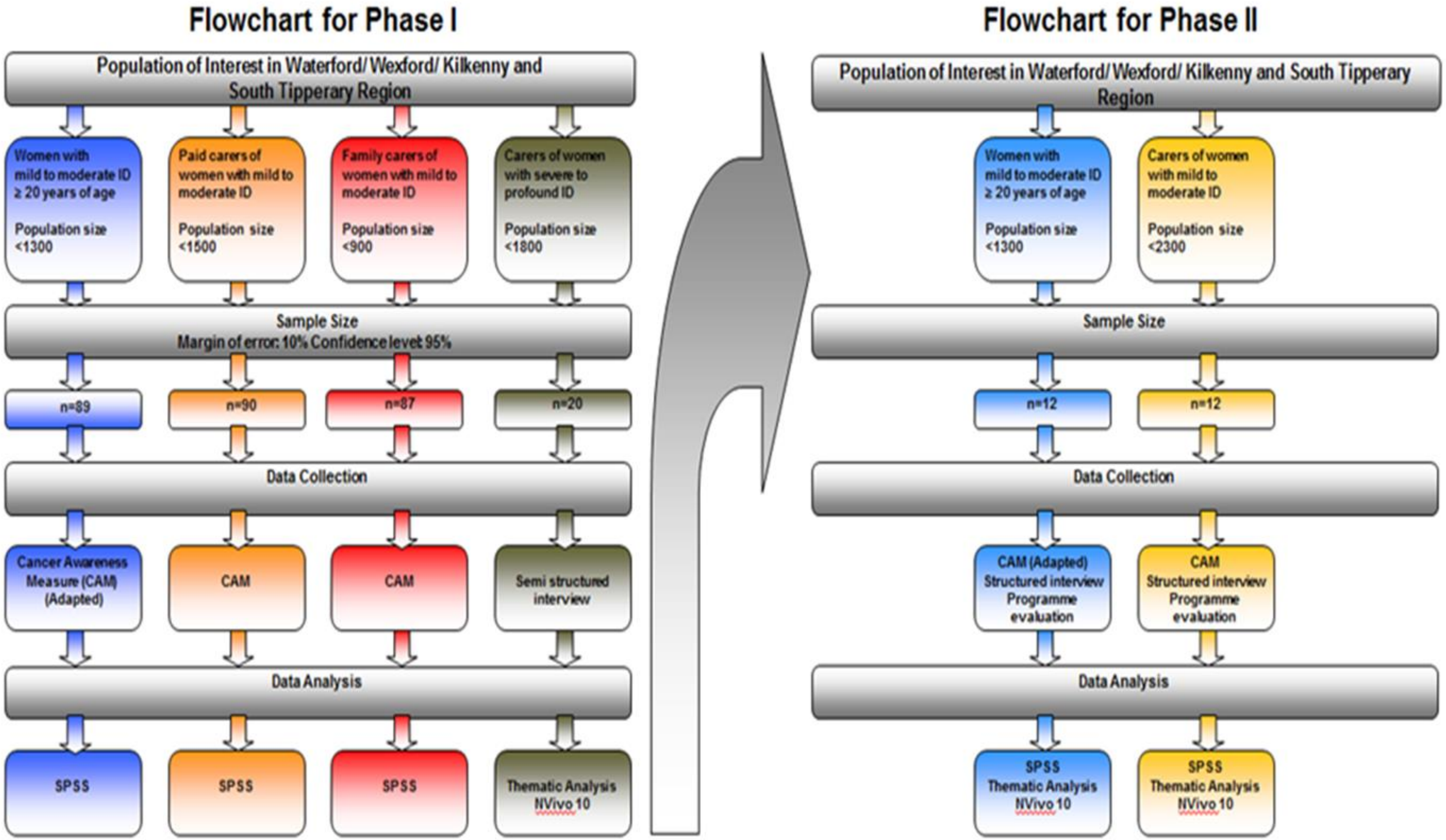


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Figure 4.3. Research design for the study

- Over the age of 18 years of age.

The exclusion criteria for health and social care staff and family carers were to be a:

- health and social care staff not directly involved in the care of women with intellectual disabilities;
- Under the age of 18 years of age.

This section looked at the inclusion and exclusion criteria for study participants, now the discussion turns to the estimation of the sample sizes needed to carry out and exploration of cancer and screening awareness in the target populations.

4.3.5. Participants and recruitment

Women with intellectual disabilities rarely participate in health related research arguing that they don’t understand what is being said, or they are not understood themselves (Ali et al., 2013, Lennox et al., 2012). In this study the research team decided to design information packs and hold a series of information meetings for the intellectual disability services, the women using these services and their families. This section describes the recruitment procedure for the comprehensive needs assessment phase of the study.

The researcher personally contacted the Service Managers at Intellectual Disability Services in the South East Region by way of introduction to the research team and the study. An introductory meeting was organised with the interested service to discuss the study. A follow up e-mail to the Service Manager once relevant ethical approval had been received comprised the study information and consent sheets; clarified the target populations with relevant inclusion criteria; and provided advertisement posters and invitation letters for the study information meeting (see Appendix IV, Volume II). A liaison person was appointed by each service to coordinate the meetings, distribute surveys, to facilitate recruitment and the provision of rooms for meetings.

The information meetings were advertised by posters at the day services of the intellectual disabilities service provider inviting women with intellectual disabilities and their paid carers to the information meetings. The liaison person coordinated the distribution of the information meeting invitation letter for the family carers. The key purpose of the information meeting was to explain the purpose of the study to potential participants using easy to understand language (National Disability Authority, 2009, Swaine et al., 2011).

The women were re-assured that their participation in the study would not involve any medical tests. The women were given one week to consult with families and keyworkers to ensure that they understood the nature of their participation in the study before making a decision to participate. The women were also advised that it was completely their own choice whether or not to participate in the project. The liaison person at the service coordinated the recruitment of the women with intellectual disabilities and contacted the researcher with participant numbers.

The survey information pack was provided to the liaison person in an online or print format and they distributed them to staff in the day services and in the community houses who had not attended the information meetings. They also oversaw the distribution of the survey information packs to families on behalf of the research team. The women with intellectual disabilities were invited to bring the carer survey information packs home to their family.

At the information meetings staff and families supporting women with severe to profound intellectual disabilities were also invited to an individual interview offer their perspectives on issues relating to cancer awareness and screening participation for women with severe to profound intellectual disabilities. A date was arranged with the researcher to meet interested parties for a recorded interview. The next section looks at the approaches to data collection used in the quantitative and qualitative strands of the comprehensive needs assessment.

4.4. Approach to data collection

Section 4.4.1. explores the approach to data collection in the quantitative strand of the needs assessment including the selection of the survey instrument, the modifications made to the survey to meet the study objectives and the administration of the survey to the study participants. Then section 4.4.2. describes the approach to qualitative data collection in this study phase incorporating the development of the carers interview schedule.

4.4.1. Quantitative data collection

Questionnaires are a structured approach data collection and analysis which are suitable for providing factual, descriptive information. In order to improve cost effectiveness, reliability and validity it is advisable to use validated instruments that are well designed and easy to use

(Miles and Huberman, 1994, Fink and Kosecoff, 1998, De Vaus, 2002). The following section explores the decisions made about the selection of the survey instrument for the study.

Selection of the survey instrument

Parish et al. (2012) designed a measure to assess the knowledge of women with intellectual disabilities about breast and cervical cancer. It was designed with questions from the National Core Indicators (National Association of State DD Directors & Human Services Research Institute, 2010) and the Socio- Sexual Knowledge and Assessment Tool- Revised (Griffiths and Lunsky, 2003). The nine variables measured were general knowledge of cancer, knowledge of breast cancer screening and knowledge of cervical cancer screening.

However, the measure was not suitable to collect all the information needed for the current study. The key foci are to assess cancer and screening awareness, knowledge of cancer risk factors and factors affecting early medical help seeking on the self-discovery of a cancer symptom among women with intellectual disabilities and their carers. So, it was necessary to select an established cancer and screening awareness measure which had previously been used in the general population and among people with intellectual disabilities.

In the United Kingdom the NHS Cancer Reform Strategy (Department of Health, 2007) highlighted the importance of raising population based cancer awareness. This led Cancer Research UK in collaboration with a number of UK universities to develop standardised Cancer Awareness Measure Toolkits to measure general and tumour specific cancer and screening awareness, and assess the effectiveness of awareness raising educational programmes. The CAM toolkits contain the survey instruments, interview scripts, answer sheets, recruitment records and guidance on coding and are freely available for use by researchers. The CAM can be administered in a face to face interview with the option to use prompts for people with literacy difficulties, over the telephone or online, or as a self-administered test. The coded CAM data must be deposited to the UK Data Archive to build an understanding of public knowledge about cancer to develop improved communications and services that aim to improve cancer outcomes.

In the validation studies for CAM and cervical CAM internal reliability (Cronbach's $\alpha=0.77$ for CAM and Cronbach's $\alpha=0.84$ for cervical CAM) were both high (Stubbings et al., 2009, Simon et al., 2012). Test-retest reliability was high ($r>0.7$) for CAM and cervical CAM, and moderate to high (0.42-0.70) for breast CAM (Stubbings et al., 2009, Linsell et al., 2010, Simon et al., 2012). Construct validity demonstrated that each CAM can distinguish between groups with differences in cancer and screening awareness levels with cancer experts scoring higher than controls (Stubbings et al., 2009; Linsell et al., 2010; Simon et al., 2012).

Each of the instruments demonstrated sensitivity to increases in awareness levels following educational interventions. They are useful in the development and assessment of the impact of interventions designed to target gaps in public cancer awareness or in specific sub-groups (Stubbings et al., 2009, Linsell et al., 2010, Simon et al., 2012). For instance the CAM population based study carried out by the North London Network – Cancer Awareness Research, included a booster sample of 276 disabled people (17% with intellectual disabilities). The findings identified gaps in cancer and screening awareness levels among people with disabilities and demonstrated the usefulness of the CAM to assess awareness levels among minority groups (Turnill, 2010).

The CAM Toolkits were chosen as the survey instrument for the quantitative phases of current study. The CAM was used to assess baseline awareness levels in Phase I to inform the development to the EMBRACES- ID intervention. In Phase II the CAM was used to monitor changes in awareness in awareness levels post intervention and retention of knowledge gains at 12 week follow up. We believe that this is the first time that the breast and cervical CAM has been used to measure the cancer and screening awareness of women with mild to moderate intellectual disabilities and their carers in the Republic of Ireland.

This section explored the selection of the CAM as the survey instrument for both phases of the study. The next section looks at the selection of the questions from the CAM toolkits and additional questions added to the study CAM to answer the questions in the study.

CAM survey design for the study

The CAM survey designed for this study (Appendix IV, Volume II) used selected questions from each of the three CAM instruments to meet the objectives of the study. The questions selected are detailed below

- Recognition of warning signs for breast and cervical cancer
- Recall/ recognition of breast and cervical cancer risk factors
- Age related risk of breast and cervical cancer
- Confidence to notice and breast or cervical cancer symptom
- Frequency of breast self-examination
- Anticipated delay in medical help seeking on self-discovery of a breast or cervical cancer symptom

- Barriers to seeking medical advice on discovery a breast or cervical cancer warning sign
- Awareness about breast and cervical cancer-screening programmes, attendance at the breast screening programme and the Cervical Cancer vaccination programme
- Personal experience of cancer (self, family or friend)
- Demographic variables of interest such as age, carer status and residential status of women with mild to moderate intellectual disabilities

In order to meet the study objectives two additional questions were added to the Cervical- CAM relating to the receipt of a cervical screen invite, and attendance at the cervical screening programme in the Republic of Ireland. In addition, just one set of the awareness of cancer risk factors questions were included in the CAM, as the inclusion of both could lead to self-prompting of the answer which could lead to a misleading assessment of awareness levels.

Close attention was paid to the power dynamics that can arise between women with intellectual disabilities and those perceived to be in positions of power such as the interviewer in terms of status and privilege (Carlson and Diedrich, 2009). Thus the CAM was adapted to a pictorial format with images from this CHANGE Specialist Cancer Collection for women with mild to moderate intellectual disabilities (Appendix V, Volume II). These images were subject to a licencing agreement with CHANGE which allowed their use only to create accessible information (Appendix III, Volume II).

Survey administration

This section explores the CAM administration for women with mild to moderate intellectual disabilities and their paid and family carers. The CAM data was collected between June and December 2013.

Women with mild to moderate intellectual disabilities

CAM for the women with mild to moderate intellectual disabilities was administered by the researcher as a face-to-face interview as participants literacy levels were acknowledged to be poor (Fink and Kosecoff, 1998, Cancer Research UK, 2011). The researcher made every effort to be flexible to suit the needs of the women with intellectual disabilities. Strategies involved meetings and interviews during working hours, at convenient times such as at home in the evening and on Sunday afternoons.

Prior to the 15-20 minute interview commencing the woman co-signed the accessible information consent form with the researcher and the carer where present, and provided GP details. The woman was reminded that the interview was being recorded and that she could withdraw from the interview at any time. Following the interview the woman's GP was notified via post/fax that the woman was participating in the study just in case the woman had any further queries following participation in the study.

Paid and family carers

The carer CAM was made available in two formats a self-administered postal version and an online version (Cancer Research UK, 2011). A detailed information sheet was provided with the CAM based on CAM toolkit guidance that discussed issues such as confidentiality and the advice to be followed should a cancer symptom be noticed following completion of the CAM. There was no consent form given, implied consent was presumed by self-completion of the CAM. The CAM took about 20 minutes to complete. A limited demographic profile was collected in this exploratory phase of the study. The demographic factors were age, gender, carer status and personal knowledge of knowing somebody with breast cancer. Substantial effort was given to achieving a reasonable response rate from paid and family carers to enhance the reliability of the study.

Approximately 300 surveys were distributed throughout the participating intellectual disability service providers for paid and family carers. In order to obtain a high reliability of response all carers were presented with the same standardised questions (De Vaus, 2002; Robson, 2002). The researcher provided a self- addressed stamped envelope with the print version in an effort to improve the response rate for the survey. The online survey CAM was also provided to the intellectual disabilities liaison person for distribution to staff and family carers.

4.4.2. Qualitative data collection

This study adopts the feminist stance of research by women on women with a desire to make sense of women's experience cancer awareness and screening (Kvale, 1996). Interviews are used widely in the qualitative strand of mixed method research studies (Robson, 2002). A semi-structured interview protocol is a reliable process of obtaining interviewees perspectives (Robson, 2002, Polkinghorne, 2008). A pre-structured design is particularly useful when negotiating access agreements with the intellectual disability service providers in terms of time required by staff to participate in the interviews (Robson, 2002).

Interview guide development

An interview guide with five pre-determined set of open- ended questions was developed for the carers of women with severe to profound intellectual disabilities. Bearing in mind the mixed method approach to the research the interview guide was developed by the research team based on the evidence from the literature, clinical expertise and the questions related to cancer and screening awareness in the CAM. The questions were based on the objectives of the mixed methods approach and contain questions based on the CAM questionnaire in relation to personal cancer awareness, knowledge and participation in cancer screening programmes and questions related to the issues facing women with severe to profound intellectual disabilities in relation to cancer awareness and screening programmes (Appendix IV, Volume II).

4.5. Pilot Testing of research instruments

A pilot test of the adapted CAM was undertaken with four women with mild to moderate intellectual disabilities. There were two main implementation issues identified. In the first instance, the researcher had intended on entering the responses directly into the online version of the CAM for time management purposes. However, this was discovered to be too disruptive in the interview process. This method was discarded in subsequent interviews and all responses were collected on the print version of the CAM. Secondly, the pictorial prompt for the awareness of the Cervical Cancer Vaccination programme appeared to elicit a positive response from the women. It was decided by the research team that this may have an adverse response on the validity of the results of the Adapted CAM thus the prompt was removed from subsequent interviews.

The semi-structured interview guide was pilot tested with the first participant in the carers interview. It was deemed to be an appropriate tool to elicit the carers perspectives of the issues facing women with severe to profound intellectual disabilities about cancer awareness and accessing screening programmes. These sections described the data collection procedures in the comprehensive needs assessment phase of the study. Next, the data analysis procedures for this phase of the study are presented.

4.6. Data Analysis procedures

This section first looks at the coding guidance for the CAM survey and the descriptive statistics used to explore the quantitative data further for the women with mild to moderate intellectual disabilities and their paid and family carers. Subsequently the data analysis procedures for the carers interviews to explore their perspectives of the issues related to cancer awareness and participation in screening programmes for women with severe to profound intellectual disabilities will be described.

4.6.1. Quantitative data analysis procedures

The coding guidance for CAM has been developed to ensure that the CAM data was suitable for depositing to the UK Data Archive. The CAM produced mainly quantitative data and the focus of the analysis was descriptive and exploratory. Data files were prepared in IBM Statistical Package for Social Sciences (SPSS) Version 19 for statistical analysis.

Responses were coded with number and SPSS variable names for each question as per the CAM toolkit guidance. A sample CAM question is shown below relating to barriers to seeking help on the self-discovery of a cancer symptom in Figure 4.4. The complete CAM and Adapted CAM are available in Appendix IV (Volume II). The available participant responses for the barriers to seeking help were ‘Yes Often’, ‘Yes Sometimes’, ‘No’ or ‘Don’t know’ which were coded (1-4) and SPSS variable name is Embarrassed.

Q1. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to see the doctor?

	Yes Often	**Yes sometimes**	**No**	**Don’t know**
I would be too embarrassed Embarrassed (SPSS Variable name)	4	**3**	2	1

Figure 4.4. Sample CAM question

In Phase I the Chi Square test compared the observed frequencies that occur in each of the categories that would be expected if there was no association between the two variables being measured. It was based on a cross tabulation table, with the cases classified according to the categories in each variable (e.g.nurse/ carer) (Pallant, 2013). In this study the $\chi 2$ test was used to test for differences in breast and cervical warning signs recognition; knowledge and participation in screening programmes; the confidence to detect changes and factors affecting medical help seeking on discovery of a symptom. The demographic categories examined in this exploratory needs assessment were carer status; residential status of women with intellectual disabilities; age; personal knowledge of cancer. Risk factor categories such as non-modifiable and lifestyle related risk factors were explored using descriptive statistics in the form of frequencies.

4.6.2. Qualitative data analysis procedures

'Systematic, self-conscious research design, data collection, interpretation, and communication' is the central strategy for ensuring rigour in qualitative research (Mays and Pope, 2000, p.52). Mertens et al. (2010) argue that in qualitative research undertaken using a transformative lens interviews with key informants raise the stakeholders awareness of their right to have a voice in the process. It was important to collect data from the women with intellectual disabilities themselves and their carers. This leads to thick descriptions that were nested in a real context of what is known or felt about cancer and screening awareness among the women and their carers. Connecting people's meanings and connecting these meanings to the social world around them is an aim of transformative research (Ryan, 2006, Mertens et al., 2010).

I was not completely familiar with the dynamics of the intellectual disabilities service providers in this exploratory and descriptive qualitative study. Thus heavy prior instrumentation was inappropriate in this study (Miles and Huberman, 1994). As previously discussed in Section 4.3.5. I developed an early familiarity with the culture of the participating intellectual disabilities service providers through personal telephone contact with service managers, email follow up and the information meetings with interested parties at the services prior to the first data collection interviews (Mays and Pope, 2000, Shenton, 2004). The research team endeavoured to ensure that too many demands were not made on the services or the designated liaison person appointed by the service. In actual fact the liaison person became the gatekeeper with responsibility to allow me access to the sample (Shenton, 2004).

Close attention was played to the cultural dynamics in the study settings in an attempt to co-generate complete and thorough accounts during the interview process thus improving contextual validity of the study (Miles and Huberman, 1994; Mertens, 2009). The contextual validity of qualitative inquiry is enhanced by my knowledge of the literature and theory in the field of cancer awareness and screening in women with intellectual disabilities and their carers.

Broadly related to this is that ethical considerations are of key priority in this study and are discussed in Section 4.14. It is crucial to transformative research that women with intellectual disabilities did not feel that they have to participate in the study either through well intentioned carer coercion or acquiescence. This ensured that only those women and carers who were genuinely willing and prepared to offer data freely take part in the study. The participants were reassured that there were no right or wrong answers to the questions, it was their opinions that were important. This was reiterated by my independent status as a registered nurse and researcher who was not employed by the intellectual disability service provider (Shenton, 2004).

Miles and Huberman Framework

Miles and Huberman (1994) consider qualitative data analysis to be three concurrent flows of data: data reduction; data display and conclusion drawing and verification. Data reduction occurs throughout the study based on the researcher analytic choices. It refers to the process of selecting, focusing, simplifying, abstracting and transforming the data from the interviews. Data display refers to the process used to assemble organised information into a compact form to facilitate data analysis. The final stage is conclusion drawing and verification where the meanings i.e. confirmability is tested. The following sections explore these elements in more detail.

Data reduction

The first level of qualitative data analysis is data reduction which is the systematic condensation and transformation of the data for the sake of manageability and the relevance of the data for answering the questions addressed (Miles and Huberman, 1994, Ryan, 2006). The initial start lists in each of the semi-structured interviews in this study were guided by the conceptual framework, the research objectives and the clinical expertise of the research team. However, I also remained open to inducing new meanings from the data (Miles and Huberman, 1994; Ryan 2006).

The digitally recorded semi-structured individual interview research method was used to promote confidence and ensure that the research accurately captured the relevant issues. The principal ways in which the reliability of the analyses were enhanced was to maintain clear records of the interviews and documenting the process of the analyses in detail throughout the study (Mays and Pope, 2000). The interviews were recorded using the Sony IC Recorder ICD-PX333. In Phase I these were the perspectives of carers about the issues facing women with severe to profound intellectual disabilities about cancer awareness and accessing cancer screening programmes.

In Phase I each digitally recorded individual interview was transcribed using Sony Digital Voice Editor Version 2. This gave me the opportunity to engage in a process of deep listening, analysis and interpretation thus increasing the trustworthiness of my data gathering techniques. The research supervisors regularly reviewed the interview process, the transcriptions and field notes and offered ongoing advice and guidance on the progress and interview techniques used. It was critical to ensure good data management techniques to facilitate data analysis and accurate reporting of the results. Recordings and transcripts offer a highly reliable record to which I could return to as the analysis proceeded (Seale and Silverman, 1997).

Each of the Microsoft Word transcript documents for the digitally recorded interviews was uploaded into NVivo 10 (QSR International Pty Ltd 2014) for analysis and a backup copy of the digital recording was securely stored onto a CD-ROM. A codebook was set up in NVivo 10 for each of the Phase I carers interviews. Initially in the data reduction stage a start list was coded at nodes in the relevant NVivo 10 study codebook for each interview type. In addition emerging codes were subsequently identified and added to the start list. Each node was assigned a descriptive label and related data across the transcripts was coded at these nodes Each node was supplemented with a description of what information the node contained.

Next the summarised segments of meaningful data were coded to these nodes. This was essential to help me follow my thoughts about how the analysis was progressing and prepared the data for subsequent analysis. The development of an audit trail with accompanying memos written and recorded was essential to trace the course of the research including the analytical decisions made and the procedures followed throughout the study to generate a more integrated understanding of the data gathered.

As a reflective researcher it was crucial for me to capture my analytic decisions in the moment which meant writing frequent date and time stamped memos or else recording my analytic thoughts quickly with the digital recorder. As the analysis progressed and I became more familiar with NVivo 10 the development of memos to keep a record of the progress of the data analysis attached to the nodes became easier and much less cumbersome than maintaining a separate memo folder in NVivo 10.

Data display

Data display is the second level in Miles and Huberman's (1994) model of qualitative data analysis. A display allows the analyst to look for systematic patterns, interrelationships and higher order themes in the data using extended text or visual displays such as network matrices. Glaser and Strauss’s (1967) ‘method of constant comparison’ is the ongoing analytic process of comparing and contrasting across instances to establish patterns in the views and experiences of the participants (Barbour, 2001), and then to further question and refine these patterns. The development of the audit trial and the generation of memos continued throughout the phase of data analysis.

Subsequent data analysis involved reading and re-reading the coded data to identify recurring phrases and common threads. The original start codes were subsumed into the codes generated in the data display. Pattern codes are codes that identify an emerging theme in the data, and are considered to be more inferential and explanatory (Miles and Huberman, 1994, Saldana, 2014).

The data was queried using the query function in NVivo for issues that were raised frequently about issues that were salient to the participants. This helped me with the development of the second level coding with the emergent of tentative themes and subthemes. In the codebook the nodes were supplemented with descriptions and colour coding of the nodes made the flow of the analysis clearer.

It is useful to have another person cross check coding strategies and the interpretation of the data (Barbour, 2001). With this in mind there were regular meetings with the academic supervisors to discuss the emerging issues in the data analysis, and the steering group to monitor progress and offer guidance the issues raised in the analysis.

As a result my original ideas about the data analysis were amended to fit more directly with the Miles and Huberman framework where attention is paid to both the generation of themes and subthemes to explain the findings. These meeting offered me opportunities to test developing ideas and interpretations, and recognise my own biases and preferences in my transformative worldview. The need to give voice to marginalised groups in the world of research underpinned my decision to favour the transformative paradigm over other paradigms. The strengths and limitations of this worldview have been discussed in Chapter 3 (Shenton, 2004).

Conclusion Drawing and Verification

This activity is the third level of qualitative analysis. Conclusion drawing involves stepping back to consider what the analyzed data mean and to assess their implications for the questions at hand. Verification takes place when ‘The meanings emerging from the data have to be tested for their plausibility, their sturdiness, their ‘confirmability’ - that is, their validity’ (Miles and Huberman, 1994, p.11).

It was crucial for me to examine previous research findings to see how the study findings related to these findings (Shenton, 2004). A key criterion for evaluating qualitative studies is my ability to relate the findings to the existing body of knowledge. Detailed attention needs to be paid to the quality of qualitative data and the ways in which judgements are made about its content (Seale and Silverman, 1997). This was essential to addressing the gaps in cancer and screening awareness levels identified in the comprehensive needs assessment to facilitate to development of the EMBRACES- ID cancer and screening awareness intervention in Phase II of the study. The discussion now turns to Phase II of the study which involved the development and feasibility testing of the EMBRACES- ID intervention.

Phase II of the study: Feasibility and acceptability testing of the EMBRACES-ID Intervention

4.7. Population and sample

As in the Phase I comprehensive needs assessment the target population of women with mild to moderate intellectual disability from the South East Region was informed by population based data from the Intellectual Disability Database Bulletin 2011 HSE South (Kelly and O' Donoghue, 2012) and the Profile 8- Our Bill of Health Statistical Table 5 (Central Statistics Office, 2012). Similar to Phase I data on the target populations of paid and family carers was compiled from The National Intellectual Disabilities Database (Kelly and O' Donoghue, 2014) and consultation with the Human Resource Departments, Nurse Managers and Medical Advisors in each of the participating intellectual disability services. Figures 4.1 and 4.2 show the population estimates for the target population of interest for the feasibility study of the EMBRACES-ID intervention.

4.7 1. Sampling method

A purposive sampling approach was chosen as this was aligned both to the researcher’s judgement and the evidence that indicated women with intellectual disabilities and their carers were best placed to provide data on their cancer awareness and screening knowledge (Robson, 2002; Parahoo, 2006; Polit and Beck, 2010).

4.7.2. Sample size calculations

Traditionally sample sizes have not played a role in the design of feasibility studies (Treweek 2015, Ukoumunne et al., 2015). The sample sizes for feasibility studies in the literature ranged from 10-300 with a median of 30 (Billingham et al., 2013). Julious (2005) justified a sample size of 12 per group for an exploratory study. The sample sizes for the feasibility study were estimated to be 12 for women with mild to moderate intellectual disabilities and 12 for carers, see Figure 4.3. Failure to meet recruitment and retention targets would mean consideration of whether going to a full scale trial was sensible (Richards, 2015, Treweek, 2015)

4.7.3. Inclusion and exclusion criteria

This section looks at the inclusion and exclusion criteria established for women with mild to moderate intellectual disabilities and their carers who participated in the EMBRACES- ID intervention. These criteria also included the criterion of attending a minimum of 3 classes to be considered a completer in the programme and be eligible to complete the post-test interviews and the programme evaluation for acceptability of the programme. First the eligibility criteria for women with mild to moderate intellectual disabilities are presented followed by those of the carers.

Women with intellectual disabilities

Inclusion criteria for women with mild to moderate intellectual disabilities

- Have a diagnosis of mild to moderate intellectual disabilities;
- Demonstrate an understanding of the purpose of the study;
- Ability to give informed consent;
- Have expressive language skills;
- Aged 18 years or older;
- Attend at least 3 sessions of the intervention.

Exclusion criteria for women with mild to moderate intellectual disabilities

- Have a diagnosis of severe to profound intellectual disabilities;
- Inability to understand the purpose of the study;
- Inability to give informed consent;
- Poor expressive language skills;
- Aged under 18 years of age;
- Attended less than 3 sessions of the intervention.

Health and social care staff and family carers

Inclusion criteria for health and social care staff and family carers

Paid carer of woman with intellectual disabilities;
Family carer of women with intellectual disabilities;
Aged 18 years or older.

Exclusion criteria for health and social care staff and family carers

Aged under 18 years of age.
Not directly involved in care provision to women with intellectual disabilities.

4.7.4 Participants and recruitment

In early August 2014 the researcher sent an initial email to introducing the EMBRACES- ID programme to seven intellectual disability service providers located in the HSE South administrative area from the geographic areas Waterford, Wexford and Tipperary (South Riding) region that had previously taken part in Phase I. Three further intellectual disability services in the region were contacted about participating in the study.

The email provided detail about how and where the intervention would be delivered, the information and consent sheets for the study, carer involvement and advertisement posters. In addition all materials for the intervention were to be provided to the participants and that no medical tests were involved.

Each of the services responded by expressing an interest in participating in the programmes. The researcher then spoke with the liaison person in the service to clarify any questions the service had about the intervention. A preliminary programme schedule was given to the service for the roll out of the intervention including dates for the baseline, post and 12 week follow up data collection.

Seven services confirmed the suitability of preliminary programme and a finalised programme was agreed with the service and the researcher. Despite two further reminder emails three intellectual disability providers failed to the respond and finalise dates for the programme, and hence did not participate in the EMBRACES- ID intervention.

The liaison person at the services facilitated the recruitment of the women and the support staff. In order to meet the objectives of the feasibility study, and following the rule of thumb for a sample size of 12 (Julious, 2005), 12 women with mild to moderate intellectual disabilities and

12 carers were considered adequate to estimate parameters such as recruitment rate to the necessary degree of precision for the single arm study.

The recruitment phase of the EMBRACES-ID intervention went well, and the sample size of twelve was exceeded among both women with intellectual disabilities and their carers. In the spirit of transformative research each participant was facilitated to participate in the EMBRACES- ID programme, as it was important to let the womens voices be heard in the world of research.

A number of services raised concerns about the requirement for one carer accompanying one woman during the intervention. These concerns related to staffing levels and working commitments of family members and services suggested that one carer could support two women to the programme. This was agreed with the research team, but it was expected that the same carer would accompany the women to each of the classes.

A reminder email was sent to the services two weeks before the agreed dates for the baseline data collection meetings with women with intellectual disabilities and carers. Women with intellectual disabilities were asked to discuss their involvement in and consent procedure for the study with their families/ paid carers.

The intellectual disability service provided the meeting room for the EMBRACES- ID programme. Arrangements were made for the allocated times for the 30 minute pretest recorded interviews with the women. The carers also completed their pretest documents at this time. The consent procedure was discussed with each participant prior the interview commencing. Just one participant decided to withdraw from the study at this stage, and did not complete any of the documentation.

4.8. Approach to data collection

This section first explores the approach to quantitative data collection in the feasibility test of the EMBRACES- ID intervention the modifications made to the survey to meet the study objectives and the administration of the survey to the study participants.

4.8.1. Quantitative data collection

This section explores the approach to the quantitative strand of data collection in this phase. A number of changes were made to the carers CAM and the Adapted CAM for women with mild to moderate intellectual disabilities in this phase. First, the changes to the both types of CAM involved collecting a wider range of demographic variables. The additional demographic variables were marital status, economic status and education (Morgan et al., 2008), and carer status to include professional grade.

Modifications to the CAM

A number of changes were made to the illustrations used in the Adapted CAM to blend with the illustrations in the EMBRACES- ID programme folder of accessible materials for the education sessions. As in Phase I these illustrations were developed with the illustrator at CHANGE UK. The Adapted CAM for women with mild to moderate intellectual disabilities was administered as a face to face interview at baseline, post intervention and at 12 week follow up, however, the GP was only contacted at the baseline assessment in this phase.

Administration of the CAM

The carers CAM was self-administered at baseline, post intervention and at 12 week follow up. In the carers CAM the key change from Phase I was that data was collected on the level of agreement about which risk factors increase the chance of getting breast cancer rather than asking the participants to recall the risk factors for breast and cervical cancer. This was based on the limited recall of risk factors evidenced in the Phase I comprehensive needs assessment.

4.8.2. Qualitative data collection

In this phase there were two qualitative interview protocols developed to meet the research objectives. First, a programme evaluation sheet was developed to test the acceptability of the programme for the participants. Second, a semi- structured interview protocol was developed to explore secondary outcomes of interest such as the understanding cancer risk and prevention and the purpose of screening, perspectives about screening for women with intellectual disabilities and perceived self-efficacy about performing breast self-examination.

Development of the Interview guide

For this phase it was decided by the research team to develop a semi-structured interview guide to counteract the dependence on the CAM as the main outcome measure. The questions were developed from the key themes from the literature review about cancer prevention awareness and attitudes to cancer, clinical expertise, and the findings of the Phase I interviews with carers of women with severe to profound intellectual disabilities. The open style questions developed explored perceived knowledge about cancer risk and prevention; checked the understanding of the purpose of cancer screening; looked at the attitudes towards women with intellectual disabilities accessing screening from the perspectives of carers and the women themselves and measured self-efficacy at performing breast self-examination, see Appendix V, Volume II.

Development of the EMBRACES- ID programme evaluation sheet

Participants gave their perspectives on the acceptability of the EMBRACES- ID intervention using an evaluation sheet designed by the research team based on clinical expertise in course evaluation, see Appendix V, Volume II. The women with intellectual disabilities answered the questions on the evaluation sheet as part of the face to face recorded interview with the researcher. The carers self-completed the evaluation sheet with questions with open ended responses and return the completed evaluations to the researcher. The evaluation sheet was only completed at the post intervention stage.

Administration of the instruments

Data collection took place between September 2014 and March 2015. The women with mild to moderate intellectual disabilities participated in the cancer awareness semi-structured individual interview at the same time as the CAM interview at baseline, post intervention and at the 12 week follow up. The women partook in the interview to determine the acceptability of the EMBRACES-ID intervention for women after the intervention was over.

The carers interview protocol was self-administered for both the cancer and screening awareness questions at baseline, post intervention and the 12 week evaluation, and the acceptability of the programme after the intervention was completed. The interview protocol asked each carer the same questions as the women with intellectual disabilities interviews were asked in the face to face recorded interviews.

In both the cancer awareness and programme administration the interview protocol the questions were provided in an open ended format with space left for the carers to give their answers. A self-completion copy of both interview protocols was given to the carers who had met the eligibility requirements as completers of the programme. Both interview protocols and the CAM survey were returned to the researcher via post at each of the three measurement times i.e. baseline, post intervention and at 12 week follow up.

4.9. Pilot testing of the research instruments

The interview guide to assess the secondary outcomes was reduced from nine questions to five questions for women with intellectual disabilities. The questions assessed general cancer and screening awareness rather than separating the topics into cervical and breast questions. This was to decrease the burden on women with intellectual disabilities to provide long narrative answers. The EMBRACES- ID evaluation form was piloted in the first service and wasn't modified in any during the programme. Data from the pilot evaluation is included in the final results. The next section looks at the implementation of the EMBRACES- ID intervention and the pilot testing of the intervention.

4.10. Implementation of the EMBRACES-ID Intervention

This section details the implementation of the EMBRACES- ID intervention. The EMBRACES- ID intervention ran twice between September 2014 and March 2015 to facilitate the needs of the participants and the intellectual disability providers. The intervention was delivered in face to face weekly two hour sessions with group of 2-6 women with mild to moderate intellectual disabilities and 1-3 carers for four weeks in each of the services. Each service was allocated a day per week for the intervention which was suitable for the women and their carers due to issues such as work commitments and doctor’s appointments.

At the first session group rules were established to ensure each participant felt comfortable to discuss the programme material in the class. Throughout the programme participants were encouraged to ask questions and generate group discussions to raise their cancer and screening knowledge base. Breast self-examination techniques were modelled by the facilitator and the women were given constant feedback to help them to build their skills set in this area.

A number of women and carers withdrew from the study and retention issues are discussed in Chapter 6. Following this arrangements were made for the post test data collection for the following two week period to facilitate factors such as illness and work commitments. Two weeks before the 12 week data collection a reminder email was sent to the services to organise the participants and the room for the data collection.

Participants were advised that they could withdraw from the study at any time. The collection of data at post intervention and the 12 week follow up assessment followed the same protocol as at the baseline data collection. In the post test data collection a test of the acceptability of the programme was also undertaken with the women with intellectual disabilities and their carers.

Once all data had been collected at the service an email was sent to each of the liaison persons to thank the service for their involvement in the EMBRACES- ID intervention and to the women and carers who participated in the intervention.

4.10.1. Pilot testing of the EMBRACES- ID Intervention

This section describes the pilot testing of the EMBRACES-ID intervention with the first groups of participants recruited to the study. Minor modifications were made to two aspects of the EMBRACES- ID intervention delivery based on feedback from the carer participants. The women with mild to moderate intellectual disabilities did not make any suggestions for change during the pilot testing of the intervention.

First, a question and answer session was introduced after each of the major topics to ensure repetition and aid understanding. The participants were given yes (green tick), no (red x) and don't know (grey question mark) laminated cards. The researcher put selected programme picture on the flip chart, and the women were asked to raise a card if they agreed of disagreed or didn't really know what the question was about. This generated group discussion, and women appeared comfortable to admit they weren't sure about the topic. This allowed the facilitator to reiterate the topic for the group.

Second, the original weekly home worksheet did not work out. For example, the worksheet was untenable if the primary carer at home was very elderly or there were staff constraints Instead each woman was asked to adopt the relaxation technique for 3-5 minutes each day, to build up their relaxation skills to help decrease anxieties associated with doctors appointments.

4.11. Data Analysis procedures

This section first looks at the descriptive statistics used to explore the quantitative data for the women with mild to moderate intellectual disabilities and their carers who met the eligibility requirements for completion of the EMBRACES- ID intervention. Subsequently the data analysis procedures for the interviews and the programme evaluation sheets for the eligible participants are discussed.

4.11.1. Quantitative data analysis procedure

The analysis of the CAM surveys was broadly similar to Phase I with two key exceptions. First, in the carers CAM the data on risk factor knowledge was collected via levels of agreement rather than recall with verbatim responses as in Phase I. Second, as the data was measured at three distinct time points, the Chi Square test was not appropriate for use in the statistical analysis of this phase.

Cochran's Q test is considered to be similar to the one-way repeated measures ANOVA, but for a dichotomous rather than a continuous dependent variable. Cochran's Q repeated measure technique for related samples was used to determine if there were differences in the dichotomous dependent variable at each measurement. The null hypothesis for the Cochran's Q test is that there are no differences between the variables and it can be concluded that the proportions in at least 2 of the variables are significantly different from each other if a significance level of $p<0.05$ is found (Sheskin, 2004, Pallant, 2013). The test was administered on a sample of women with intellectual disabilities and paid carers and evaluated a dichotomous dependent variable at the three time points (Vonk, 2011).

Table 4.2. Cochran's Q Test assumptions

Assumption	**Study fulfilment**
One dichotomous dependent variable with two groups	Categorical variables
One independent variable with at least three groups	Baseline, post-test and 12 week evaluation
Random sample- not always feasible in practice	Purposive sampling of the target population

The three assumptions of the Cochran's Q test are shown in Table 4.2. First there was one dichotomous dependent variable with two groups (Lund Research Ltd., 2013). Scores on the dependent variable must fall within one of two mutually exclusive categories. For example, in the CAM survey participants were asked if they recognised a warning sign for breast / cervical cancer. The assignation of the dependent variable binary responses for the analysis were as follows '0' to 'No/ Don't know' responses for the warning signs recognition (collapsing the answers into one categorical responses) while '1' was assigned to the 'Yes' response to the warning signs recognition question (Vonk, 2011).

The next assumption was that there is one independent variable with at least three groups, in this study each participant answers questions at baseline, post intervention and twelve week follow up. The final assumption was that the participants are a random sample from the population of interest, although this is not how sampling might take place in practice, and as was the case in this study (Lund Research Ltd., 2013).

Regression analysis was used to test the predictive power of a set of variables to assess the relative contribution of each individual variable (Pallant, 2013). Logistic regression was used as the dependent variable was categorical. Dependent variables analysed included breast cancer risk factor recall; cervical cancer risk factor recall and time taken to seek medical help for a self-discovered symptom of breast or cervical cancer. The independent variable set included age, carer status and personal knowledge of a cancer diagnosis in a close family member. The next section describes the qualitative data analysis procedures for the EMBRACES-ID intervention.

4.11.2. Qualitative data analysis procedures

A codebook was set up in NVivo 10 containing each of the interview transcripts women with mild to moderate intellectual disabilities for the cancer and screening awareness knowledge and the acceptability of the intervention; and the carers cancer and screening awareness knowledge and acceptability of the intervention. The self -administered open ended questions were imported as Microsoft Word documents into NVivo 10 for analysis. The data analysis procedure followed the same procedures as in Phase I in the spirit of the Miles and Huberman framework for qualitative data analysis.

In addition to the supervisory and steering group meetings an external consultant also provided input into the construction of the data analysis codebook, and the themes generated in the data analysis to increase the credibility of the findings and to strengthen the arguments made in the study. Section 4.12 explores the mixed methods interpretation of both the quantitative and qualitative strands of the study.

4.12. Mixed methods interpretation

In this study data were collected and analysed separately for both the quantitative and qualitative strands to produce two sets of findings about cancer and screening awareness presented in Chapters 5 and 6. These findings were combined at the interpretation stage using the process of mixed methods triangulation namely studying a problem using different methods to gain a more complete picture (O' Cathain et al., 2010). The results of the quantitative and qualitative strands were merged based on common themes emerging in the data set and consideration given to whether the findings from each method agree, offer complementary information on the same issue, or appear to contradict each other (O' Cathain et al., 2010). An assessment was then made on how the inferences address the mixed methods objectives to explore the extent of the inequalities faced by women with intellectual disabilities accessing screening programmes and cancer and screening awareness of the women and their carers (Creswell and Plano Clark, 2011).

4.13. Issues of Validity in Mixed Methods Research

The types of validity associated with both the qualitative and quantitative elements of the study needed to be considered in conjunction with any validity issues that arose related to the mixed methods approach (Creswell, 2009). This section first explores validity issues in quantitative research. This is followed by a discussion of validity issues associated with qualitative research. Finally issues of validity related to mixed methods research are discussed.

4.13.1. Quantitative research

In quantitative research validity is broadly defined as 'a quality criterion referring to the degree to which inferences made in a study are accurate and well founded' (Polit and Beck, 2010 p. 571). Shadish et al. (2002) suggested four important aspects a study's validity must be addressed by researcher's regarding research design namely statistical conclusion validity; external validity; internal validity; and construct validity. Each of these aspects are examined in the following sections.

Statistical conclusion validity

Statistical conclusion validity refers to reasonable inferences given a specified significance level and a given power in a study (García-Pérez, 2012). Statistical power is the ability of a design to detect true relationship, and the use of a sufficient sample is the most straight forward way of achieving statistical power (Polit and Beck, 2010). In Phase I the Survey System online calculation was used to determine the sample size based on the population, margin of error and confidence interval for an exploratory study to improve statistical conclusion validity (Central Statistics Office, 2012; Conroy, 2012; Creative Research Systems, 2012).

The feasibility study was designed to test the intervention in a limited way, using a purposive sample with a relatively short follow up period of 12 weeks. The focus of this phase was an assessment of feasibility thus a power calculation was not undertaken and this element of the study had limited statistical power in keeping with a feasibility study (Bowen et al., 2009, Arain et al., 2010, Lancaster, 2015).

Mertens (2009) suggested that advance contact with the stakeholders prior to the survey may increase response rates for the survey. Substantial effort was given to achieving a reasonable response rate to enhance the reliability of the study such as follow up emails to services, follow up letters to families and media advertisement in the comprehensive needs assessment phase of the study.

External Validity

External validity concerns inferences about the extent to the findings observed in a study readily apply across persons, settings and time (Parahoo, 2006; Polit and Beck, 2010; Shadish et al., 2002). In this study the CAM and adapted CAM were administered to similar populations in a number of intellectual disability service providers in the South East of Ireland.

The main threat comes from the selection of participants based on the inclusion criteria, thus there is only external validity for those meeting the researcher's inclusion criteria. The scores and resulting inferences from difference examinee groups are comparably reliable if a parallel version of the same instrument is administered to different groups i.e. CAM and Adapted CAM (Zumbo and Rupp, 2004).

Internal Validity

Internal validity refers to unwanted factors internal to the study which can interfere with the results (Parahoo, 2006). Bias is an influence that can produce estimate or inference errors and can be present at every stage of a study. It is a key concern as it can threaten the study's validity and trustworthiness and warrants the application of rigourous research methods (Parahoo, 2006; Polit and Beck, 2010). A number of threats to internal validity were identified in this study and strategies were implemented to mimimise the effect including the use of a mixed methods research design.

- Historical effects occur when uncontrolled events can alter responses to the CAM such as media exposure to information about breast and cervical cancer and screening. To minimise this effect participants were requested to complete the CAM without referring to literature or the internet for answers.
- Instrumentation effects were minimised by the data collection method most appropriate to the quantitative strand of the study that is the CAM.
- Selection effects are concerned with the researcher's judgement regarding inclusion and exclusion criteria. In order to facilitate completion of the Adapted CAM the women with mild to moderate intellectual disabilities had to demonstrate cognitive ability and understanding of the purpose of the study. The internal consistency of the CAM and Adapted CAM were measured using Cronbach's Alpha, see Tables 5.2 and 5.17.

Construct Validity

Construct validity is a key criterion for assessment of the quality of a study and is most often linked to measurement issues namely what exactly is the CAM measuring and does it validly measure the concept of interest (Polit and Beck, 2010).

The reliability and validity of a quantitative instrument are both major criterion for assessing its quality. Internal consistency is the most widely used reliability approach i.e. the extent that the instrument's items measure the same trait. It is usually evaluated using Cronbach's α, and the higher its value the more reliable the measure is (Polit and Beck, 2010). Assessments of the stability of an instrument are undertaken using test- retest procedures to measure the extent to which similar results are obtained on two different occasions (Polit and Beck, 2010).

In order to establish construct validity 'known-groups' design was used in which the CAM was administered to groups expected to differ on the target attribute and the group scores were compared (Stubbings et al., 2009; Polit and Beck, 2010). Internal reliability and test-retest reliability were demonstrated to be high. Scores for cancer experts were significantly higher than those for non-medical academics. CAM scores were higher among students who received an intervention leaflet than the control leaflet, providing evidence that CAM is sensitive to detecting change following brief educational interventions (Stubbings et al., 2009).

The psychometric properties of the Breast CAM were measured in women attending the NHS Breast Screening Programme. The readability of Breast CAM was high. Breast CAM was sensitive to change: there was an increase in the proportion of women obtaining the full score for breast cancer awareness one month after receiving the intervention promoting breast cancer awareness. Test-retest reliability and construct validity of Breast CAM were deemed to be good (Linsell et al., 2010). The psychometric properties of Cervical CAM were measured in women and ovarian and cervical cancer experts. Internal reliability and test-retest reliability were high. Validity was demonstrated with cancer experts achieving higher scores than controls, and volunteers who were randomised to read a cancer leaflet scored higher than those who received a control leaflet. This section discussed the statistical analysis for the quantitative strand of the study, the next section explore data analysis procedures and rigour in qualitative research.

4.13.2. Qualitative research

It was important for me to interact with all stakeholder groups throughout the lifecycle of the study, including those less powerful to determine local meanings attached to experiences (Greenwood and Levin, 2005, Guba and Lincoln, 2005). Paying close attention to bias when gaining access to the data and being aware of the influence of gatekeepers; and ensuring a good match between the research objectives and the study design enhances the contextual validity of qualitative enquiry. It was my task to weave the various voices and sources together in a narrative that responds to the research objectives. The perspectives of the women with intellectual disabilities and their carers were of interest and not my own personal opinions.

Triangulation addresses the issue of internal validity by using more than one method of data collection to answer a research question and strengthen the credibility and transferability of the findings (Barbour, 2001, Shenton, 2004, Farmer et al., 2006). The two types of triangulation used in this case were methodological and data source triangulation (Farmer et al., 2006). In methodological triangulation results were compared from the CAM and the cancer and screening awareness interviews. The data source triangulation represented the perspectives of women with intellectual disabilities and their carers about cancer and screening awareness and issues faced by women with intellectual disabilities accessing screening.

Validity, credibility and reliability in transformative research are measured by the willingness of the stakeholders to act on the results based on the validity of their ideas and the degree of which the outcomes meet their expectations. A challenge to this is that because knowledge is ingrained deeply in a local context, the creation of generalisations is a challenge (Greenwood and Levin, 2005; Mertens, 2009). Despite this findings that are consistent across multiple data sources and settings provide greater confidence in the credibility of interpretations and the possibility of transferring key learning to similar contexts (Farmer et al., 2006).

4.13.3. Mixed methods research

The validity procedures for mixed methods research must address the specific types of validity checks for the quantitative and qualitative strands as discussed in Section 4.13.1 and 4.13.2. Validity in mixed methods research involves employing strategies that address potential issues in both strands that may impact of the merging of the data and the subsequent conclusions drawn (Creswell and Plano Clark, 2011). Mixed methods validity is enhanced through the legitimation concept of weakness minimisation, where the researcher pays close attention to the extent to which the weakness from the quantitative strand is compensated for by the strengths of the other and vice versa throughout the research process (Onwuegbuzie and Burke Johnson, 2006).

Two principal strategies were used in this study to minimise the threat to the mixed methods validity. First, an interpretation of the quantitative and qualitative data sets was used to answer the mixed methods research questions (Creswell and Plano Clark, 2011). Consideration was given on how to combine the different stakeholders views in making quality inferences (Onwuegbuzie and Burke Johnson, 2006). Second, as this was a transformative study it was crucial to return to the perspective used at the beginning of the study to advance the call for action based on the results (Creswell and Plano Clark, 2011).

4.14. Ethical considerations

The study has received full ethical approval from the HSE South Research Ethics Committee; the WIT Research Ethics Committee and the Brothers of Charity South East Services see Appendix I.

4.14.1. Informed Consent

Women with intellectual disabilities are a vulnerable research population and obtaining informed consent for participation in research is a key issue. As a transformative researcher it was essential to avoid induced acquiescence which is the desire of the women with intellectual disabilities to please those perceived to be in a powerful role, such as the researcher (D'eath et al., 2005; Mertens, 2009). It was critical to ensure the women with intellectual disabilities understood that their participation in the research was voluntary and it was perfectly acceptable for them to refuse to take part (World Medical Association, 2008).

Appropriate methods were used to help the women with mild to moderate intellectual disabilities to understand the purpose of the research and their role as a participant (Cameron and Murphy, 2007, National Disability Authority, 2009, Government of Ireland, 2015):

- Information was presented in an easy to read format with illustrations.
- Sufficient time was taken by the researcher to explain the research to the woman.
- The woman was made aware that it was her choice whether or not to participate in the project.
- The woman was made aware that she could withdraw from the project at any time.
- The woman’s written consent to participate in the research was sought. The carer read the form with the woman to ensure the woman has support to understand the information presented to her about the study. The form was co-signed by the carer and the researcher. Courtesy and autonomy was operationalized through the informed consent process.

Written informed consent was required for carers who decided to participate in the Phase I interviews in about the needs of women with severe to profound intellectual disabilities in relation to cancer awareness and screening. Carers consent was implied by the self-completion and return of the CAM and interview protocol in Phase I and II.

4.14.2. Adverse events

Carers who completed the self-administered CAM were advised in the information sheet to seek medical advice from their GP should they have concerns about breast or cervical cancer symptoms following completion of the CAM. In the event that a woman with intellectual disability raised a concern about a breast or cervical cancer symptom during the interview she would be made aware that there are options available to her to discuss her concerns. This information was provided in the information sheet given to the women who participated in the study. The researcher informed the woman's GP of the woman's participation in the study.

4.14.3. Protection of anonymity

All data collected in this study was coded to protect confidentiality; the only person that was able to convert the coded data to identifiable data was the researcher. No personal data on any of the participants was shared with the UK Data Archive.

4.14.4. Security measures

Appropriate security measures were taken to ensure unauthorised access to, or alteration, disclosure or destruction of data and against accidental loss or destruction was avoided. Data obtained will be retained for as long as it is required for the duration of the study and in accordance with the Institute's Records Retention Policy and the Data Protection Acts. All personal details were omitted and anonymity ensured when writing up the final report and in respective academic papers.

4.15. Chapter summary

This chapter described the methodological structure for this study. It gave a general overview of the aim of the study, and the research objectives designed to meet this aim. It introduced the research design chosen for the study. It described the data collection and data analysis of the quantitative and qualitative elements of the Phase I comprehensive needs assessment which assessed baseline cancer and screening awareness. It explained the development and feasibility testing of the EMBRACES-ID cancer awareness intervention. Finally, it explored the ethical considerations involved in carrying out research with a vulnerable population of women with intellectual disabilities. The next chapter presents the quantitative and qualitative findings of the Phase I comprehensive needs assessment for women with mild to moderate intellectual disabilities, nurses, healthcare assistants, social care workers and family carers.

Chapter 5: Phase I Results

5.0. Introduction

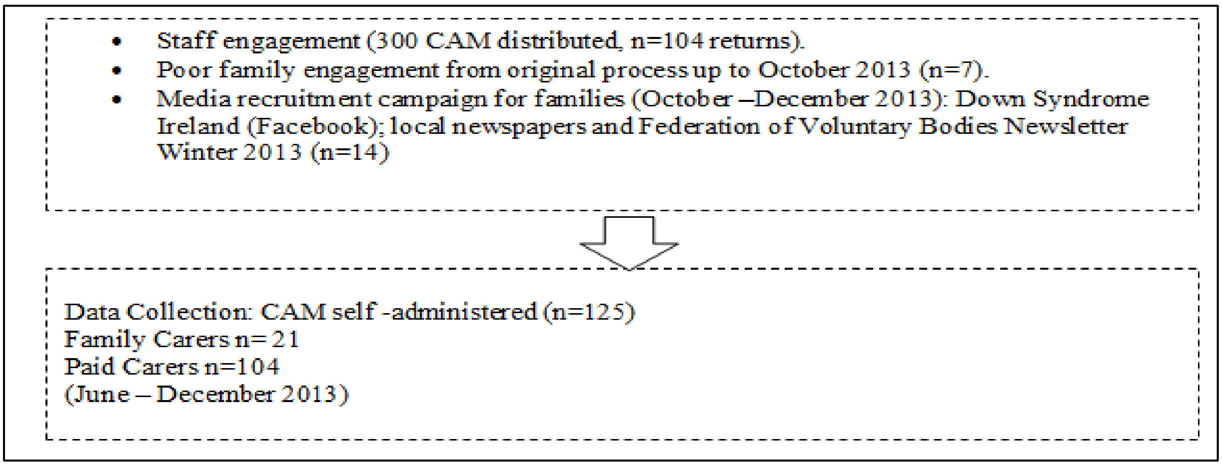
This chapter reports the findings of the comprehensive needs assessment undertaken in Phase I of the study which established the baseline cancer and screening awareness of women with mild to moderate intellectual disabilities and their carers in the South East region. Sections 5.1. -5.9. describe the findings of the Carers CAM. Next, sections 5.10.-5.18. explore the results of the Adapted CAM for women with mild to moderate intellectual disabilities. Then sections 5.19.-5.29. report on the findings of the carers interviews about their views on the key challenges faced by women with severe to profound intellectual disabilities about cancer and screening awareness. Finally, the chapter concludes with a summary in section 5.30.

5.1. Introduction to the results of the Phase I carers CAM

This section reports on the findings of the carers CAM. First the study accrual is described in section 5.2., followed by the demographic profile of the respondents in section 5.3. The reliability statistics of the CAM are then examined and presented in section 5.4. Next, section 5.5. describes the awareness of cancer signs and symptoms among the carers including chi-square tests to examine differences in awareness on the basis of carer status, age and a personal knowledge of cancer in a close family member. Section 5.6. examines the carers skills and confidence to detect a change in their own breast or to notice a cervical cancer symptom in their own body. Next, section 5.7. explores the carers awareness of the risk factors for breast and cervical cancer and include chi square tests and logistic regression analysis based on carer status, age and personal knowledge of cancer. Section 5.8. describes awareness about the breast and cervical screening programme, and the HPV vaccination programme. It also reports on participation rates in the screening programme among carers. Finally, section 5.9. explores the barriers to medical help seeking for a self- discovered symptom for breast cancer including chi-square and logistic regression analysis based on carer status, age and personal knowledge of cancer.

5.2. Study Accrual

Over three hundred printed CAM were distributed by the researcher to the seven intellectual disability service providers for distribution to carers (social care workers; health care assistants and family carers) during the time frame June to December 2013. The online version of CAM was advertised and distributed via a national organisation to the family members of women with Down Syndrome during the time frame October to December 2013. The study was advertised in regional newspapers and the newsletter of the Federation of Voluntary Bodies, see Appendix IV, Volume II. A total of 125 nurses, social care workers, health care assistants and family carers completed a self-administered English language version of the study CAM. Figure 5.1 summarises this pathway.



- Staff engagement (300 CAM distributed, n=104 returns).
- Poor family engagement from original process up to October 2013 (n=7).
- Media recruitment campaign for families (October –December 2013): Down Syndrome Ireland (Facebook); local newspapers and Federation of Voluntary Bodies Newsletter Winter 2013 (n=14)

Data Collection: CAM self -administered (n=125)
Family Carers n=21
Paid Carers n=104
(June – December 2013)

Figure 5.1. Flowchart of study accrual

5.3. Demographic characteristics

The demographic characteristics of the carers who completed the printed (97.6%) or online (2.4%) questionnaire CAM questionnaire are presented in Table 5.1.

Table 5.1. Carers demographic characteristics

Demographic characteristics	n	%
Gender		
Female	125	100
Male	0	0
Age	36	28.8%
50 years of age and older	84	67.2%
Under 50 years of age	5	4%
Missing		
Carer status		
Nurse	83	66.4%
Family/ HCA/ SCW	42	33.6%
Personal knowledge of cancer		
Yes	78	62.4%
No	47	37.6%

5.4. Reliability of the CAM

The Cancer Awareness Measure and tumour specific Cancer Awareness Measures for breast and cervical cancer were developed to provide a validated measure of awareness of early warning signs, risk factors and seeking medical advice (Stubbings et al., 2009, Linsell et al., 2010, Simon et al., 2012). The ideal Cronbach α coefficient should be above 0.7 (Pallant, 2010). The internal reliability of the Cancer Awareness Measure carers was measured on a number of subscales. Each of the subscales reached the recommended cut off of 0.7, see Table 5.2.

Table 5.2. Cronbach's α results

Scale	**Cronbachs' Alpha (study)**	**Cronbachs' Alpha (validation paper)**	**No. of items**
Breast cancer warning signs	0.841	N/A	11
Cervical cancer warning signs	0.849	0.77	11
Total knowledge score Cervical CAM Warning signs, peak age incidence, awareness of screening and vaccination programme, age that they're offered	0.808	0.84	16
Total knowledge score Breast CAM Warning signs, peak age incidence, awareness of screening programme and age that its offered (first and last age)	0.823	N/A	15
Barriers to seeking help	0.719	0.73	10

5.5. Awareness of cancer signs and symptoms

The first question on the Breast CAM assessed recognition of warning signs and symptoms for breast cancer. The respondents were asked whether they thought any of the signs listed were warning signs for breast cancer. A similar format was used in the first question on the Cervical CAM to assess recognition of warning signs for cervical cancer. The warning signs were potential signs or symptoms for either breast cancer (Breast CAM) or cervical cancer (Cervical CAM).

5.5.1. Recognition of breast cancer warning signs

A lump or swelling in the breast or under the armpit was the most commonly recognised symptom chosen by over 97% of nurses, healthcare assistants, social care workers and family carers. The recognition of a lump or thickening under the armpit as a warning sign for breast cancer was broadly similar among nursing (92.9%) and non- nursing carers (89.2%). It is evident that recognition of warning signs such as redness or puckering/ dimpling of the breast skin is lower among non- nursing professionals particularly recognition of redness of the breast skin as a warning sign for breast cancer (48.2 %).

Nurses had higher awareness levels of warning signs for breast cancer with the exception of a lump or thickening in the breast, nevertheless, gaps in awareness levels were identified among the nurses. The recognition of a rash on the nipple or redness of the breast skin was much lower than that of the lump symptoms with a drop of almost 30% in the number of nurses recognising these symptoms as warning signs for breast cancer.

A chi- square test indicted that there were significant differences in the proportion of nurses that recognised warning signs for breast cancer compared to healthcare assistants, social care workers and family carers see Table 5.3. Nurses had significantly higher awareness levels of five non-lump warning signs for breast cancer when compared to non- nursing carers for the following symptoms related to changes in the nipples (discharge, pulling in, rash and change in size or shape) and change in the breast (change in size or shape of the breast and puckering of the breast skin). A comparison of the recognition of breast cancer warning signs for women aged 50 years of age and over who were age eligible women for the breast screening programme and younger women identified gaps in awareness levels particularly among the younger age group. A lump or thickening in the breast or under the armpit was the most commonly recognised warning sign for breast cancer among both age groups. Bleeding or discharge from the nipple was also well recognised as over 80% of the respondents in both age groups mentioned this as a warning sign for breast cancer.

A chi- square test showed that the recognition of three non- lump symptoms for breast cancer was significantly higher among women aged 50 years of age and older. These women displayed better awareness of the less well known warning signs for breast cancer, a rash on the nipple, were not involved in the breast screening programme, see Table 5.3. Indeed less than 50% the younger women were aware that a nipple rash or breast redness were warning signs for breast cancer.

An examination of the responses of those who had personal knowledge of a close family member with a cancer diagnosis and those who didn’t identified a broadly similar awareness that the pulling in of the nipple could be a warning sign for breast cancer. However, those

Table 5.3. 2x2 Contingency Table of responses (n,%) to statements about breast cancer warning signs.

Warning signs % Yes (n)	***Carer status (n=125)***			***Age (n=120)***			***Personal knowledge (n=125)***		
	Family/ SCW (n=83)	**HCA/ Nurse (n=42)**	**Significance**	**≥ 50 years (n=36)**	**< 50 years (n=84)**	**Significance**	**No (n= 47)**	**Yes (n= 78)**	**Significance**
Lump	97.6 (81)	97.6 (41)	0.992	97.2 (35)	97.6 (82)	0.898	**93.6 (44)**	**100 (78)**	**0.024***
Lump in armpit	89.2 (74)	92.9 (39)	0.507	97.2 (35)	88.1 (74)	0.112	87.2 (41)	92.3 (72)	0.351
Nipple discharge	**81.9 (68)**	**97.6 (41)**	**0.013***	88.9 (32)	86.9 (73)	0.763	83.0 (39)	89.7 (70)	0.273
Nipple pulling in	**65.1 (54)**	**92.9 (39)**	**0.001****	86.1 (31)	69.0 (58)	0.50	74.5 (35)	74.4 (58)	0.989
Nipple position	65.1 (54)	78.6 (33)	0.121	75 (27)	66.7 (56)	0.365	66.0 (31)	71.8 (56)	0.492
Rash	45.8 (38)	64.3 (27)	0.050	**69.4 (25)**	**44.0 (37)**	**0.011***	**36.2 (17)**	**61.5 (48)**	**0.006****
Redness	48.2 (40)	64.3 (27)	0.088	**69.4 (25)**	**46.4 (39)**	**0.021***	46.8 (22)	57.7 (45)	0.237
Change size	**73.5 (61)**	**90.5 (38)**	**0.027***	**91.7 (33)**	**73.8 (62)**	**0.027***	74.5 (35)	82.1 (64)	0.312
Change shape	**69.9 (58)**	**88.1 (37)**	**0.024***	86.1 (31)	71.4 (60)	0.085	70.2 (33)	79.5 (62)	0.240
Pain in one breast	79.5 (66)	83.3 (35)	0.609	83.3 (30)	81.0 (68)	0.757	**70.2 (33)**	**87.2 (68)**	**0.020***
Puckering	**56.6 (47)**	**83.3 (35)**	**0.003****	**83.3 (36)**	**58.3 (49)**	**0.008***	63.8 (30)	66.7 (52)	0.746

Note: * denotes statistically significant associations at the $p<0.05$ level.
** denotes a strong statistically significant association at the $p<0.05$ level

Table 5.4. 2x2 Contingency Table of responses (n,%) to statements about cervical cancer warning signs.

	Carer status (n=125)			*Age (n=120)*			*Personal knowledge (n=125)*		
Warning signs % Yes (n)	**Family/ HCA/ SCW (n=83)**	**Nurse (n=42)**	**Significance**	**≥ 50 years (n=36)**	**< 50 years (n=84)**	**Significance**	**No (n= 47)**	**Yes (n= 78)**	**Significance**
Vaginal bleeding	**68.7 (57)**	**90.5 (38)**	**0.007****	80.6 (29)	75.0 (63)	0.510	72.3 (34)	78.2 (61)	0.457
Lower back pain	**33.7 (28)**	**61.9 (26)**	**0.003****	50.0 (18)	40.5 (34)	0.335	38.3 (18)	46.2 (36)	0.390
Vaginal discharge	61.4 (51)	64.3 (27)	0.757	72.2 (26)	57.1 (48)	0.119	**48.9 (23)**	**70.5 (55)**	**0.016***
Pain during sex	**47.0 (39)**	**73.8 (31)**	**0.004****	66.7 (24)	52.4 (44)	0.148	48.9 (23)	60.3 (47)	0.217
Heavy periods	**32.5 (27)**	**59.5 (25)**	**0.004****	50.0 (18)	38.1 (32)	0.225	**27.7 (13)**	**50.0 (39)**	**0.014***
Persistent diarrhoea	10.8 (9)	23.8 (10)	0.056	22.2 (8)	10.7 (9)	0.098	8.5 (4)	19.2 (15)	0.106
Bleeding after menopause	56.6 (47)	66.7 (28)	0.279	**80.6 (29)**	**51.2 (43)**	**0.003****	57.4 (27)	61.5 (48)	0.651
Pelvic pain	**57.8 (48)**	**83.3 (35)**	**0.004****	77.8 (28)	61.9 (52)	0.091	**55.3 (26)**	**73.1 (57)**	**0.042***
Bleeding during/after sex	**53.0 (44)**	**73.8 (31)**	**0.025***	72.2 (26)	54.8 (46)	0.074	53.2 (25)	64.1 (50)	0.228
Blood in stool	42.2 (35)	38.1 (16)	0.662	33.3 (12)	42.9 (36)	0.329	29.8 (14)	47.4 (37)	0.052
Weight loss	56.6 (47)	73.8 (31)	0.061	66.7 (24)	39.3 (51)	0.537	59.6 (28)	64.1 (50)	0.613

Note: * denotes statistically significant associations at the p<0.05 level.
** denotes a strong statistically significant association at the p<0.05 level

women with a personal knowledge of cancer in a close family member demonstrated higher awareness levels in the ten other target warning signs for breast cancer.

A chi- square test showed that those women who mentioned that they had personal knowledge about cancer had significantly higher awareness levels of three warning signs for breast cancer, a lump in the breast or armpit, a nipple rash and a pain in one breast or armpit, see Table 5.3. Broadly similar to the findings related to carer status and being older or younger than 50 years of age the awareness levels of a nipple rash and redness of the breast skin were very poor with just 36.2% of respondents without a personal history of cancer in the family being aware of nipple rash as a warning sign for breast cancer. This is concerning as inflammatory breast cancer is a rare type of breast cancer with warning signs include swelling, redness, thickening of the skin of the breast, pitted skin (peau d' orange) and nipple changes (Cancer Research UK, 2014).

5.5.2. Recognition of cervical cancer warning signs.

Awareness about cervical cancer warning signs and symptoms tended to be significantly higher among nurses. Nevertheless, deficits in nurses' awareness levels were identified as just of 23.8% nurses recognised that blood in the stool and less than 25% of nurses recognised that persistent diarrhoea for three weeks or more were signs of advanced cervical cancer. However, by comparison the results showed a poorer awareness among healthcare assistants, social care worker and family carers. The recognition levels varied between 10.8% and 33.7% for the recognition of lower back pain; heavy periods that last longer than usual; and persistent diarrhoea as warning signs of cervical cancer.

A chi- square test identified significant differences in recognition levels between nurses and carers for the following symptoms of cervical cancer vaginal bleeding other than during menstrual periods; lower back pain; pain during sex; heavy periods that last longer than usual; pelvic pain; and bleeding during or after sex, see Table 5.4.

An examination of the data highlighted that women aged 50 years of age and older had better awareness of each of the eleven warning signs for cervical cancer. Abnormal vaginal bleeding is the most common symptom of cervical cancer, however, this also includes bleeding during or after sex, persistent vaginal discharge, menstrual periods that are heavier and longer than usual and bleeding after the menopause. Despite this awareness levels remained particularly low for each of the warning signs with the notable exception of vaginal bleeding between periods which was recognised by over 75% of respondents, see Table 5.4.

A chi- square test identified a significant relationship between the recognition of bleeding after the menopause and being aged 50 years and over, with 80.6% of this age group mentioning this as a warning sign for cervical cancer compared to just 51.2% of the younger age group.

An exploration of the responses for women without a personal history of a close family member with cancer highlighted that apart from recognising that vaginal bleeding between periods as warning sign for early stage cervical cancer there was limited awareness levels of the other target warning signs. Despite the fact that discomfort or pain in the pelvis is a symptom of more advanced cervical cancer just 55.3% of respondents without personal knowledge of a close family member with a cancer diagnosis were aware of this compared to almost 75% of those with personal knowledge about cancer.

Other symptoms of more advanced cervical cancer include persistent lower back pain and unexplained weight loss. Weight loss was equally endorsed by respondents with and without personal knowledge about cancer. It is plausible to expect that this was due to the well-known association of weight loss with cancer patients. However, the situation for lower back pain is much different, with a low level of recognition about the association of persistent lower back pain with a more advanced stage of cervical cancer among both groups.

A chi- square test revealed that there was a significant difference in the awareness levels of respondents with a personal knowledge about cancer compared to those without personal awareness for the following warning signs for cervical cancer: persistent vaginal discharge, menstrual periods which are heavier and longer than usual and persistent pelvic pain, see Table 5.3. The awareness levels about the link between heavier and longer periods were particularly low among both groups ranging from 27.7 % to 50%. This is concerning given that importance of noticing changes in vaginal bleeding and discharges in a woman’s body.

Gaps in awareness levels about cervical cancer warning signs were apparent among the respondents. It is crucial that education about the early detection of cervical cancer is provided to nurses, healthcare assistants, social care workers and family carers who provide care to women with intellectual disabilities. The gaps identified in this analysis informed the development of the EMBRACES- ID intervention.

5.6. Confidence to detect changes

This section explores the frequency of breast self- examination (BSE) among the respondents, although, there is no clear evidence that any particular frequency is appropriate. It also examines the respondents' confidence levels to notice a change in their breast or a warning sign for cervical cancer. The three demographic characteristics explored were age, carer status and personal knowledge of a close family member with cancer.

A large proportion of the carers (68.7%) and nurses (78.6 %) reported that they regularly checked their breasts for changes. Furthermore, 68.7% of the nurses and 69% of the carers felt confident that they would be able to detect a change in their own breast. A chi- square test indicated that there were no statistically significant differences in opinion found between being a carer or a nurse in relation to breast self-examination and detecting breast changes see Table 5.5.

A large majority of women who were eligible to participate in the Breast Check programme (83.3%) mentioned that they undertook regular BSE compared to women aged under 50 years of age (67.9%). However, there was almost a 14% decrease in the confidence levels of the older group to notice a change in their breast even though they were familiar with how their breasts should look and feel (69.4%). All the younger women who undertook regular BSE were confident that they would detect a breast change, although it is apparent that this may relate to warning signs associated with a lump as discussed in section 5.5.1. Chi- square tests indicated that there was no significant difference either in the frequency of BSE or the confidence levels of the older and younger women to notice a change in their breast, see Table 5.5.

Respondents who had personal knowledge of a cancer diagnosis in a close family member reported higher levels of regular self- examination (76.9%) and were more confident that they would detect a breast change (71.8%) due to their increased breast awareness compared to respondents who did not have personal knowledge of cancer. A chi- square test indicated that there was no significant difference in the frequency of BSE or confidence to detect a breast change between those respondents with a personal knowledge about cancer compared to those without a personal knowledge about cancer.

Respondents were much less confident that they would notice a cervical cancer warning sign. This is hardly surprising given the poor awareness of early and more advanced symptoms of

Table 5.5. 2x2 Contingency Table of responses (n,%) about confidence to detect a breast or cervical cancer symptom

Confidence and skills to detect changes in the breast or cervix		***Carer status (n=125)***			***Age (n=120)***			***Personal knowledge (n=125)***	
% Yes (n)	**Family/ HCA/ SCW (n=83)**	**Nurse (n=42)**	**Significance**	**≥ 50 years (n=36)**	**< 50 years (n=84)**	**Significance**	**No (n= 47)**	**Yes (n= 78)**	**Significance**
Regular breast self-examination	68.7 (57)	78.6 (33)	0.244	83.3 (30)	67.9 (57)	0.082	63.8 (30)	76.9 (60)	0.114
Detect breast change (very/ fairly confident)	68.7 (57)	69.0 (29)	0.966	69.4 (25)	67.9 (57)	0.864	63.8 (30)	71.8 (56)	0.352
Detect cervical change (very/ fairly confident)	**25.3 (21)**	**50 (21)**	**0.006****	**47.2 (17)**	**27.4 (23)**	**0.035***	27.2 (13)	37.2 (29)	0.375

Note: * denotes statistically significant associations at the p<0.05 level.
** denoted a strong statistically significant association at the p<0.05 level.

cervical cancer as evidenced in section 5.5.2. Just 50% of nurses were confident that they would notice a cervical cancer warning sign compared to 25.3% of healthcare assistants, social care workers and family carers. With respect to older and younger age groups the findings are even poorer with 42.7% of the older group and 27.4% of the younger group confident that they would notice a change. Broadly similar poor confidence levels to detect a cervical cancer symptom were observed among respondents with (37.2%) and without (27.2%) personal knowledge of a close family member with a cancer diagnosis.

A chi- square test indicated significant differences in the confidence level of nurses to detect a cervical symptom when compared to non – nursing carers. Nurses demonstrated significantly higher confidence levels to notice a cervical cancer symptom. However, only 50% of nurses were confident that they would notice a change down below while 25% of carers mentioned that they felt confident that they would notice a cervical cancer symptom. A further chi- square test indicated significant differences in the confidence levels of the older group of respondents to notice a cervical cancer symptom compared to the younger group. Just 47.2% of the older group were confident that they would notice a change while just 27.4% of the younger group demonstrated similar confidence levels to detect a change.

5.7. Knowledge of the risks of developing breast or cervical cancer

Respondents were asked in the Breast CAM and the Cervical CAM about their level of awareness of the risk factors for breast and cervical cancer. The format used measured how many risk factors respondents could recall without prompting.

5.7.1. Awareness of the risk factors for developing breast cancer

The principal risk factor for breast cancer mentioned by 68% of all respondents was genetics or having a close family member with breast cancer. Smoking was mentioned as a risk factor for breast cancer by 45.6% of respondents while just 24% of respondents indicated that stress might affect a woman’s chance of developing breast cancer. Awareness of the breast cancer risk posed by alcohol intake; low physical activity and obesity was reported by less than 20% of respondents.

Few or no respondents knew that nulliparity or late age at first childbirth (0%); early menarche (0%) and late menopause (0.8%); previous radiation to the chest area (0.8%); personal history of breast cancer (1.6%); the use of the oral contraceptive pill (1.6%);

Table 5.6. Breast cancer risk factors recall

Breast cancer risk factor categories	**Responses n (%)**
Non modifiable risk factors	
Genetic/ family history of breast cancer	85 (68)
Age (not specified)	5 (4)
Personal history of breast cancer	2 (1.6)
Previous chest radiation	1 (0.8)
Late menopause	1 (0.8)
Early menarche	0 (0)
Lifestyle related risk factors	
Drinking alcohol	24 (19.2)
Overweight/ Obese	17 (13.6)
Physical inactivity	6 (4.8)
Hormone replacement therapy after menopause	4 (3.2)
Contraceptive pill	2 (1.6)
Nulliparity or having first child later in life	0 (0)
Unclear risk factors	
Tobacco smoke	57 (45.6)
Diet	27 (21.6)
Environmental factors	10 (8)
Controversial risk factors	
Use of spray deodorants	3 (2.4)
Breast implants	1 (0.8)
Other risk factors	
Stress	30 (24)
Sun exposure	7 (5.6)
Lack of breast awareness	7 (5.6)
Chance	4 (3.2)
Protective factors	
Breast feeding	1 (0.8)

hormone replacement therapy (3.2%) and age (4%) were risk factors for breast cancer. The protective effect of breast feeding on the woman's body was mentioned by just 0.8% of respondents. Other potential risk factors for breast cancer suggested by respondents included sun exposure (5.6%); lack of breast awareness (5.6%) and chance (3.2%). These results are presented in Table 5.6.

Respondents were asked to recall risk factors that they thought might affect a woman's chance of developing breast cancer. The maximum number of risk factors recalled was seven. Just over 10% of respondents were unable recall any of the target risk factor for breast cancer. A detailed breakdown of the number of risk factors recalled for all respondents is shown in Table 5.7.

Table 5.7. Total number of breast cancer risk factors recalled for carers

Risk factors recalled	**Carer n=125 n (%)**
No risk factors	13 (10.4%)
1 risk factor	19 (15.2%)
2 risk factor	24 (19.2%)
3 risk factors	33 (26.4%)
4 risk factors	15 (12%)
5 risk factors	13 (10.4%)
6 risk factors	6 (4.8%)
7 risk factors	2 (1.6%)

Direct logistic regression was performed to assess the impact of a number of variables on the likelihood that respondents would recall a risk factor for breast cancer. The model contained three independent variables age; carer status; and personal knowledge of a close family member with cancer. Although the full model containing all the independent variables was statistically significant χ^2 (3, n=125) = 11.49, p<0.005, none of the predictor variables was strongest with regard to recalling a risk factor for breast cancer, see Table 5.8.

Table 5.8. Logistic regression predicting likelihood of recalling a breast cancer risk factor

	B (S.E.)	**p**	**OR (Upper- Lower 95% (CI)**
Age	-0.4 (0.71)	0.51	0.63 (0.16-2.5)
Carer status	19.6 (6.4E3)	0.99	3.1E8 (0)
Personal Knowledge of cancer	0.07 (0.62)	0.91	0.93 (0.27- 3.16)
Constant	2.03 (0.73)	0.01	7.67

Model characteristics: n=125; Cox and Snell R square= 0.091; Nagelkerke R square= 0.183

χ^2= 11.49; Hosmer and Lemeshow Goodness of Fit Test= 1.0

5.7.2. Awareness of cervical cancer risk factors

'Being a smoker' was the risk factor mentioned by 29.6% of respondents. None of the respondents recalled having a sexual partner who is not circumcised or who has had many previous partners as risk factors. The risk associated with HPV infection and irregular smear tests was mentioned by only 10.4% of respondents. However, 38.4% of respondents mentioned that genetics/ family history are potential risk factors for cervical cancer. The results are presented in Table 5.9.

The carers were asked to recall risk factors that they thought might affect a woman's chance of developing cervical cancer. The maximum number of risk factors recalled was five. A detailed breakdown of the number of risk factors recalled for all respondents is shown in Table 5.10.

Direct logistic regression was performed to assess the likelihood that respondents would recall a risk factor for cervical cancer, having adjusted the model for age, carer status and personal knowledge of a close family member with cancer. The full model containing all the predictors was statistically significant $\chi2$ (3, n=125) = 18.36, p< 0.005, indicating that the model was able to distinguish between respondents who did and did not recall a risk factor for cervical cancer. The model as a whole explained between 14.2 % (Cox and Snell R square) and 20.5 % (Nagelkerke R square) of the variance in recalling a cervical cancer risk factor recall, and correctly identified 72.5% of cases.

Table 5.9. Cervical cancer risk factor recall

Cervical cancer risk factors	**Responses n (%)**
Cancer Research UK CAM cervical cancer target risk factors	
Being a smoker	37 (29.6)
Having many sexual partners	15 (12)
Not going for regular smear tests	13 (10.4)
Infection with HPV	9 (7.2)
Starting to have sex at a young age (before the age of 17)	7 (5.6)
Having many children	4 (3.2)
Infection with chlamydia (sexually transmitted infection)	4 (3.2)
Long term use of the contraceptive pill	2 (1.6)
Having a weakened immune system	2 (1.6)
Having a sexual partner who is not circumcised	0 (0)
Having a sexual partner with many previous partners	0 (0)
Other risk factors mentioned	
Family history	
Unprotected sex	
Chance	
Not vaccinated against cervical cancer	

Table 5.10. Total number of cervical risk factors recalled

Risk factors recalled	**Carer (n=125) n (%)**
No risk factors	34 (27.2%)
1 risk factor	17 (13.6%)
2 risk factor	27 (21.6%)
3 risk factors	23 (18.4%)
4 risk factors	19 (15.2%)
5 risk factors	5 (4%)

As shown in Table 5.11 carer status was the only independent variable that made a unique statistically significant contribution to the model. It was the strongest predictor of recalling a risk factor, recording an odds ratio of 11.5. This indicated that nurses were over 11 times more likely to recall a risk factor for cervical cancer than health care assistants, social care workers or family carers, controlling for all other factors in the model.

Table 5.11. Logistic regression predicting likelihood of recalling a cervical cancer risk factor

	B (S.E.)	**p**	**OR (Upper- Lower 95% (CI)**
Age	0.41 (0.47)	0.39	1.5 (0.6- 3.8)
Carer status	**2.44 (0.76)**	**0.00***	**11.5 (2.6- 51.2)**
Personal Knowledge of cancer	0.01 (.045)	0.99	1.0 (0.4- 2.4)
Constant	0.19 (0.48)	0.98	1.2

Model characteristics: n=125; Cox and Snell R square= 0.142 ; Nagelkerke R square= 0.205; χ^2= 18.36; Hosmer and Lemeshow Goodness of Fit Test= 0.985

5.7.3. Breast and cervical cancer and age

Respondents were asked what age group they believed would be most likely to develop breast or cervical cancer in the next year and it is evident that the majority of respondents were unaware of the increased risk of breast cancer with age. In fact, only 7.1% of nurses and 1.2% of carers mentioned that a 70 year old woman is the most likely to develop breast cancer in the next year. The awareness levels were comparable in the group of women aged 50 years of age and older who were eligible for the mammography programme (8.3%) and the younger group (1.2%). It seems that having personal knowledge of cancer did little to improve the very poor awareness levels, as only 3.8% of those with personal knowledge of cancer were aware of the increased risk of cancer with age. Awareness levels were even worse in the group with no personal knowledge of cancer as only one person in this group mentioned that a 70 year old woman was most likely to develop cancer in the next year.

Chi- square tests indicated that there were no significant differences in awareness levels with regard to age, carer status and personal knowledge of cancer, see Table 5.12.

Respondents were asked their opinion on what age group of women were most likely to develop cervical cancer in the next year. In general the majority of respondents were unaware that that a woman aged 30 to 49 years of age is most likely to get cervical cancer. Awareness levels of the risk of developing cervical cancer was higher among nurses (35.7%) when compared to healthcare assistants, social care workers and family carers (21.7%). Awareness levels were broadly similar in the fifty years of age and older group (25%) when compared with the younger age group (27.4%). A higher proportion of those with a personal knowledge of cancer (29.5%) mentioned that a woman age 30-49 years of age was most likely to get cervical cancer in the next year compared to just 21.3% of women without personal knowledge of cancer. Chi- square tests indicated that there was no significant difference in the opinions of respondents related to the age group most likely to get cervical cancer based on age, carer status or personal knowledge of cancer.

5.8. Awareness of breast and cervical screening programmes

This section explores carers awareness about the breast and cervical screening programmes, and the HPV vaccination programme in Ireland. It also explores the screening uptake rates among the carers.

5.8.1. Awareness of breast screening programme

Awareness of the BreastCheck screening programme was considerably higher among nurses (96.7%) when compared with healthcare assistants, social care workers and family carers (82.9%). Broadly similar awareness levels were observed among women who were eligible to participate in the screening programme (94.4%) and those women in the younger group (90.5%); and among women who had personal knowledge of cancer (93.6%) and those without this personal knowledge of cancer (89.4%), see Table 5.13.

Almost 28% of the respondents were age eligible to attend the screening programme. Approximately 80% of women age 50 years and older reported that they had both received an invitation to screening (82.9%) and had availed of the opportunity to have a mammogram (80%).

Women in Ireland get invited to their first mammography screening appointment when they reach 50 years of age, and this would be well advertised in the media. Despite this just over 50% of the non- nursing carers, women under 50 years of age and those without a personal history of cancer were aware of the age of the first invitation for mammography. The awareness levels were higher for nurses, women age eligible for the breast screening programme and those with a personal knowledge of breast cancer.

At the time of the survey in 2013 women were last invited to avail of a free mammogram in the Republic of Ireland at 64 years of age. All respondents demonstrated very poor awareness of the last age invitation to the screening programme. Women who were age eligible to attend the breast screening programme comprised 28% of the total sample. The majority of these women age 50 years and over reported that they had both received an invitation to screening (82.9%) and had availed of the opportunity to have a mammogram (80.6%). Chi- square tests indicated that there were no significant differences in the opinions of respondents related to awareness about the breast screening programme based on age, carer status or personal knowledge of cancer, see Table 5.13.

5.8.2. Awareness of cervical screening programme

There was high awareness about the CervicalCheck screening programme in the Republic of Ireland. Nurses had higher awareness levels about the programme (95.2%) than healthcare assistants, social care workers or family carers. These awareness levels were almost equally distributed among the younger and older age groups and those with and without a personal knowledge of cancer, around four fifths of these respondents mentioned that they were aware of the CervicalCheck screening programme. A chi- square test found there was a statistically difference in the proportion of nurses that were aware of the CervicalCheck programme when compared with non- nursing carers, see Table 5.14. Chi- square tests indicated no significant difference in awareness levels between the older and younger respondents or those with and without personal knowledge of cancer.

Despite high awareness levels about the programme, it was evident that respondents were much less informed about the operational guidelines for the programme which was introduced in the Republic of Ireland in 2008. Women are first invited to have a free smear test at 25 years of age, however, all respondents demonstrated poor awareness of this. Awareness levels varied between 19.1% for those who had not personal knowledge of cancer to 45.2% for nurses, see Table 5.14. Chi- square tests detected significantly higher knowledge levels about the screening programme among nurses when compared to non- nursing carers. No significant differences were noted among the older and younger age group or those respondents with and without a personal knowledge of cancer.

Table 5.12. 2x2 Contingency Table of responses (n,%) about cancer and age

Breast and cervical cancer and age		***Carer status (n=125)***			***Age (n=120)***			***Personal knowledge (n=125)***	
% Yes (n)	**Family/ HCA/ SCW (n=83)**	**Nurse (n=42)**	**Significance**	**≥ 50 years (n=36)**	**< 50 years (n=84)**	**Significance**	**No (n= 47)**	**Yes (n= 78)**	**Significance**
A 70 year old woman breast cancer	1.2 (1)	7.1 (3)	0.110**	8.3 (3)	1.2 (1)	0.080**	2.1 (1)	3.8 (3)	1.00**
A woman aged 30-49 years cervical cancer	21.7 (18)	35.7 (15)	0.093	25 (9)	27.4 (23)	0.787	21.3 (10)	29.5 (23)	0.313

Notes: * denotes statistically significant associations at the p<0.05 level.
** Fisher Exact Probability test results reported where χ2 result violated.

Table 5.13. 2x2 Contingency Table of responses (n,%) about breast screening programmes

		Carer status (n=125)			***Age (n=120)***			***Personal knowledge (n=125)***	
Knowledge about BreastCheck % Yes (n)	**Family/ HCA/ SCW (n=83)**	**Nurse (n=42)**	**Significance**	**≥ 50 years (n=36)**	**< 50 years (n=84)**	**Significance**	**No (n= 47)**	**Yes (n= 78)**	**Significance**
Aware of BreastCheck	82.9 (74)	97.6 (41)	0.100	94.4 (34)	90.5 (76)	0.471	89.4 (42)	93.6 (73)	0.399
First invitation age (50 years)	55.4 (46)	71.4 (30)	0.083	**75.0 (27)**	**53.6 (45)**	**0.028***	59.6 (28)	61.5 (48)	0.828
Last invitation (64 years)	2.4 (2)	7.1 (3)	0.202	2.8 (1)	3.6 (3)	0.824	4.3 (2)	3.8 (3)	0.910
Received invitation	28.9 (24)	28.6 (12)	0.968	**83.3 (30)**	**4.8 (4)**	**0.000****	27.7 (13)	29.5 (23)	0.827
Attended Mammography	26.5 (22)	31.0 (13)_	0.601	**80.6 (29)**	**4.8 (4)**	**0.000****	72.3 (13)	28.2 (22)	0.948

Notes: * denotes statistically significant associations at the p<0.05 level.
** denotes a strong statistically significant associations at the p<0.05 level.

Table 5.14. 2x2 Contingency Table of responses (n,%) about cervical screening programmes

	Carer status (n=125)			***Age (n=120)***			***Personal knowledge (n=125)***		
Knowledge about CervicalCheck % Yes (n)	**Family/ HCA/ SCW (n=83)**	**Nurse (n=42)**	**Significance***	**≥ 50 years (n=36)**	**< 50 years (n=84)**	**Significance***	**No (n= 47)**	**Yes (n= 78)**	**Significance***
Aware of CervicalCheck	**75.9 (63)**	**95.2 (40)**	**0.007***	83.3 (30)	83.3 (70)	1.000	80.9 (38)	83.3 (65)	0.724
Age first invitation	**18.1 (15)**	**45.2 (19)**	**0.001***	25.0 (9)	27.4 (23)	0.787	19.1 (9)	32.1 (25)	0.116
Received invitation	61.4 (51)	73.8 (31)	0.169	58.3 (21)	70.2 (59)	0.205	**53.2 (25)**	**73.1 (57)**	**0.023***
Attended screening	61.4 (51)	73.8 (31)	0.169	58.3 (21)	69.0 (58)	0.257	**51.1 (24)**	**74.4 (58)**	**0.008****
Vaccination Programme	**62.7 (52)**	**90.5 (38)**	**0.001****	83.3 (30)	66.7 (56)	0.102	68.1 (32)	74.4 (8)	0.449
Age Vaccination	**30.1 (25)**	**59.5 (25)**	**0.002****	36.1 (13)	39.3 (33)	0.743	34.0 (16)	43.6 (34)	0.291

Note: * denotes statistically significant associations at the p<0.05 level.

** denotes a strong statistically significant associations at the p<0.05 level.

A large proportion of respondents mentioned that they had received a postal invitation to attend the CervicalCheck screening programme. Chi- square tests identified that while there was a significant difference in the amount of respondents mentioning that they had received an invitation in the group with and without a personal knowledge of cancer, there was no significant difference noted among those in the younger or older age group or based on carer status. The uptake levels of screening were very high with the vast majority of those who mentioned that they had received an invitation to attend the screening programme had taken the opportunity to participate in the programme, see Table 5.14.

The Irish HPV vaccination programme operates through a school based programme. All girls in their first year of secondary are offered the HPV vaccine. Nurses demonstrated higher awareness levels (90.5%) about the HPV Vaccination programme than carers. Women aged 50 years of age and older and women with a personal history of cancer also had higher awareness levels about the vaccination programme. Chi- square tests indicated that nurses had significantly higher awareness levels than non- nursing carers, although being in an older or younger age group or having a personal knowledge of cancer or not did not significantly impact on awareness levels, see Table 5.14.

Awareness of the age group of girls that the vaccination is offered was much poorer. Apart from the fact that 59.5% of nurses mentioned that the vaccination was offered to young girls in their first year of secondary school, including to those girls with intellectual disabilities attending special schools, awareness levels were very poor among respondents. Chi- square tests found that there was a significant difference in the proportion of nurses who were aware were aware of the age criteria for the vaccination programme was offered when compared to non –nursing carers, while being in an older or younger age group or having a personal knowledge of cancer or not did not have a significant impact on knowledge levels, see Table 5.14.

5.9. Barriers to seeking help

Sometimes people put off going to see the doctor even if they have a symptom that they think might be serious. Respondents were given a set of emotional, practical and service barriers which might impact on the respondent making an appointment to seek early medical intervention for a warning sign for breast or cervical cancer. The results are presented in Table 5.15.

The most common barrier to seeking help for nurses, health care assistants and family carers was worry about what the doctor might find (40.5% nurses, 49.4% carers). Other barriers that were almost equally endorsed by nurses and carers were being too scared (40.5% nurses, 37.3% carers); being too embarrassed (33.3% nurses, 34.9% carers) and being too busy to make an appointment (28.6% nurses, 31.3% carers). Barriers which were less likely to impact on the respondents making an appointment include difficulty in making an appointment (16.9% nurses, 14.3% carers), the doctor being difficult to talk to (11.9% nurses, 8.4% carers) and difficulties arranging transport to the doctor's surgery (0% nurses, 2.4% carers).

The most common barrier to seeking help for women aged 50 years of age and over and those aged less than 50 years of age also was worry about what the doctor might find (33.3% older group, 52.5% younger group). Broadly similar results were observed between the two age groups for being too scared to seek medical help (27.8% older group, 41.7% younger group) and being too embarrassed to seek early intervention (22.2% older group; 38.1% younger group).

Practical barriers to seeking prompt medical assistance were almost equally endorsed by both the older and younger respondents. The women in both age groups mentioned being too busy to make an appointment (30.6% older group, 28.6% younger group), having too many other things to worry about in their day to day lives (22.2% older, 25% younger), and the service barrier that both older (22.2%) and younger (26.2%) of women would be worried about wasting the doctors time if the symptom turned out to be less serious than they originally thought. Barriers which were less likely to impact on the respondents making an appointment to discuss a symptom they thought might be serious includes difficulty in making an appointment (5.6% older, 17.9% younger), the doctor being difficult to talk to (8.3% older, 8.3% younger) and difficulties arranging transport to the doctor's surgery (2.8% older, 1.2% younger).

The most common barrier to seeking help for women aged 50 years of age and over and those aged less than 50 years of age also was worry about what the doctor might find (33.3% older group, 52.5% younger group). Broadly similar results were observed between the two age groups for being too scared to seek medical help (27.8% older group, 41.7% younger group) and being too embarrassed to seek early intervention (22.2% older group; 38.1% younger group).

Practical barriers to seeking prompt medical assistance were almost equally endorsed by respondents with and without personal knowledge of a close family member with a diagnosis of cancer. The women in both groups mentioned being too busy to make an appointment (31.9% personal knowledge, 29.5% without personal knowledge), having too many other things to worry about in their day to day lives (25.5 % personal knowledge, 23.1% without personal knowledge), and the service barrier that both women with personal knowledge of cancer (27.7%) and those without personal knowledge (24.4%) of women would be worried about wasting the doctors time. Barriers which were less likely to impact on the respondents making an appointment to discuss a symptom they thought might be serious includes difficulty in making an appointment (8.5% personal knowledge, 20.5% no personal knowledge), the doctor being difficult to talk to (8.5% personal knowledge, 10.3% no personal knowledge) and difficulties arranging transport to the doctor’s surgery (2.1% personal knowledge, 1.3% no personal knowledge).

Respondents were asked if there was anything else that might put them off going to the doctor. A small number of respondents mentioned that the cost of a doctor’s visit, which is approximately €60, would be a factor that would need to be considered. The general consensus was that other living cost would have to take precedence over a doctor’s visit.

Chi- square tests indicated a significant difference between nurses and non- nursing carers in relation to the service barrier of not wanting to waste the doctor’s time. A small proportion of carers (35.5%) reported that they would be worried about wasting the doctor’s time if they presented with a symptom that they thought might be serious in comparison to 11.9% of nurses, see Table 5.13. Chi- square tests did not identify any other significant differences in relation to carer status, age profile or personal knowledge about cancer diagnoses.

5.9.1. Delays in seeking help

Respondents were asked how long they would wait before seeking medical assistance for a suspected breast or cervical cancer symptom. On a positive note that over 85% of respondents reported that they would seek help from a doctor within two weeks of discovering a symptom that they thought might be breast cancer. Similarly it was reassuring that over 75% of respondents mentioned that they would seek medical intervention within two weeks of noticing a symptom they thought might be cervical cancer.

Direct logistic regression was performed to assess the impact of emotional, service and practical barriers on the likelihood the respondents would seek medical assistance within two weeks of the self- discovery of a breast or cervical cancer symptom. Each model contained eleven independent variables which consisted of four emotional barriers, three practical barriers and three service barriers.

The full model for medical help seeking within 2 weeks of discovering a breast cancer symptom contained the eleven independent variables was not significant χ^2 (10, n=125)=2.456, p>0.005. This indicated that none of the emotional, practical or service barriers were strongest in predicting the likelihood that women would seek help within two weeks for a breast cancer symptom. Similarly for seeking early medical intervention on the self- discovery of a cervical cancer symptom the full model with the eleven independent variables was not significant χ^2 (10, n=125) = 11.238, p>0.005. This demonstrated that none of the barriers to seeking help were greatest in predicting the odds that a woman would seek medical assistance within two weeks. The next section explores the findings of the Adapted CAM undertaken in the comprehensive needs assessment in Phase I of the study.

5.10. Introduction to the Phase I Adapted CAM results

This section presents the descriptive results of the Phase I Adapted CAM for women with mild to moderate intellectual disabilities data analysis. Firstly the study accrual is outlined in section 5.11., followed by a demographic profile of the CAM respondents in section 5.12. The reliability statistics of the CAM are then examined and presented in section 5.13. Finally the results of the CAM are presented using the chi- square test to test for differences in cancer and screening awareness, and barriers to seeking help between women who live with family carers and women who live in residential/ community settings, age profiles and personal knowledge of cancer are presented in sections 5.14.-5.18.

5.11. Study Accrual

Initially 47 women were recruited following the information meetings during the time frame June to November 2013. Two women withdrew from the study during this time. Figure 5.2. summarises the recruitment pathway for women with mild to moderate intellectual disabilities participated in a face-to-face CAM interview.

Table 5.15. 2x2 Contingency table of responses (n,%) about barriers to seeking medical help

Barriers to seeking help % Yes (n)	***Carer status (n=125)***			***Age (n=120)***			***Personal knowledge (n=125)***		
	Family/ HCA/ SCW (n=83)	**Nurse (n=42)**	**Significance**	**≥ 50 years (n=36)**	**< 50 years (n=84)**	**Significance**	**No (n= 47)**	**Yes (n= 78)**	**Significance**
Emotional barriers									
Worried about what the doctor might find	49.4 (41)	40.5 (17)	0.345	33.3 (12)	52.4 (44)	0.055	36.2 (17)	52.6 (41)	0.075
Too scared	37.3 (31)	40.5 (17)	0.734	27.8 (10)	41.7 (35)	0.150	31.9 (15)	42.3 (33)	0.247
Too embarrassed	34.9 (29)	33.3 (14)	0.858	22.2 (8)	38.1 (32)	0.091	25.5 (12)	39.7 (31)	0.105
Confident to talk about symptom	84.3 (70)	90.5 (38)	0.344	91.7 (33)	84.5 (71)	0.292	87.2 (41)	85.9 (67)	0.833
Practical barriers									
Too busy	31.3 (26)	28.6 (12)	0.752	30.6 (11)	28.6 (24)	0.827	31.9 (15)	29.5 (23)	0.775
Other things to worry about	28.9 (24)	14.3 (6)	0.070	22.2 (8)	25.0 (21)	0.745	25.5 (12)	23.1 (18)	0.756
Difficult for me to arrange transport	2.4 (2)	0 (0)	0.311	2.8 (1)	1.2 (1)	0.534	2.1 (1)	1.3 (1)	0.715
Service barriers									
Worried about wasting the doctor's time	**32.5 (27)**	**11.9 (5)**	**0.013***	22.2 (8)	26.2 (22)	0.645	27.7 (13)	24.4 (19)	0.682
Difficult to make an appointment	16.9 (14)	14.3 (6)	0.710	5.6 (2)	17.9 (15)	0.077	8.5 (4)	20.5 (16)	0.076
Doctor difficult to talk to	8.4 (7)	11.9 (5)	0.534	8.3 (3)	8.3 (7)	1.000	8.5 (4)	10.3 (8)	0.748

*Note: * denotes statistically significant associations at the p<0.05 level.*

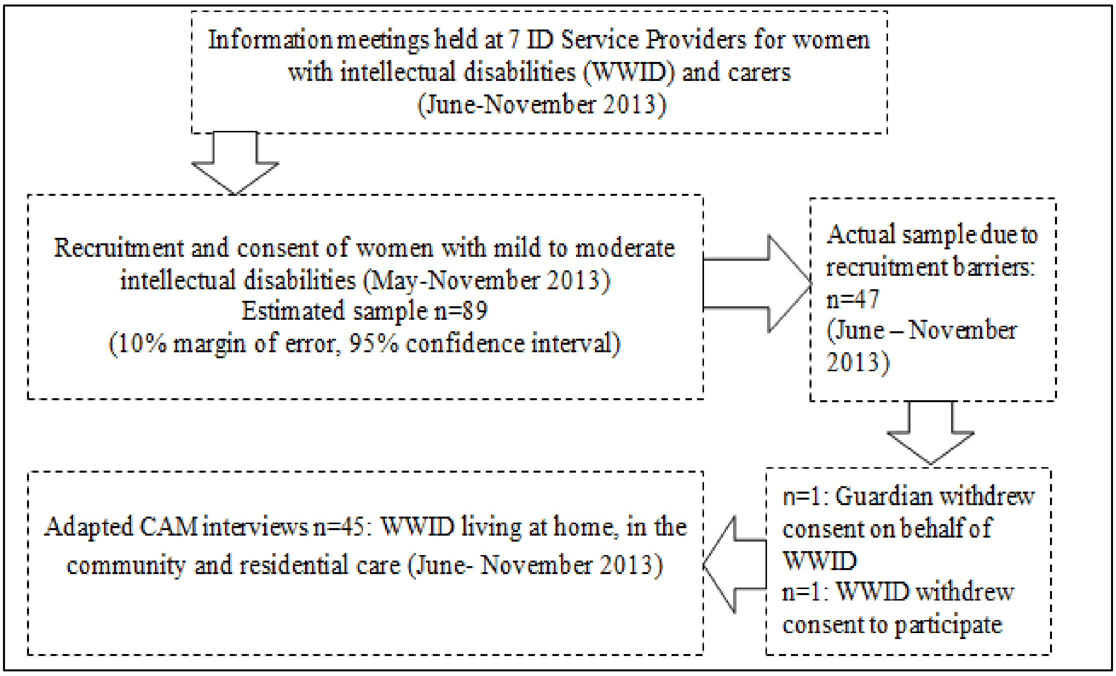


Figure 5.2. Flowchart of study accrual

5.12. Demographic characteristics

The demographic characteristics of the women with mild to moderate intellectual disabilities who completed the Adapted CAM questionnaire are presented in Table 5.16.

Table 5.16. Demographic profile of women with mild to moderate intellectual disabilities

Demographic characteristic	**n**	**%**
Gender		
Female	45	100
Male	0	0
Age		
40 years of age and older	17	37.8
Under 40 years of age	28	62.2
Residential status		
Family	28	62.2
Residential/Community	17	37.8
Personal knowledge of cancer		
Yes	17	37.8
No	28	62.2

Table 5.17. Cronbach’s α results Adapted CAM

Scale	**Cronbachs’ Alpha (Study)**	**Cronbachs’ Alpha (validation paper)**	**No. of items**
Breast cancer warning signs	0.880	N/A	11
Cervical cancer warning signs	0.905	0.77	11
Total knowledge score Cervical CAM Warning signs, peak age incidence, awareness of screening and vaccination programme, age that they’re offered	0.847	0.84	15
Total knowledge score Breast CAM Warning signs, peak age incidence, awareness of screening programme and age that its offered (first and last age)	0.807	N/A	Breast last age removed no variance- no correct answer given 14
Barriers to seeking help	0.679	0.73	10

5.13. Reliability of the Adapted CAM

The ideal Cronbach α coefficient should be above 0.7 (Pallant, 2010). The internal reliability of the Adapted Cancer Awareness Measure for women with mild to moderate intellectual disabilities was measured on a number of subscales. All but one of the subscales ‘Barriers to seeking help’ reached the recommended cut off of 0.7, see Table 5.17. However, given that it was important to identify challenges which may impede women with mild to moderate intellectual disabilities seeking early medical intervention for warning signs for cancer the ‘Barriers to seeking help’ scale was retained.

5.14. Awareness of cancer signs and symptoms

The first question on the Breast CAM assessed recognition of warning signs and symptoms for breast cancer. The respondents were asked whether they thought any of the signs listed were warning signs for breast cancer. A similar format was used in the first question on the Cervical CAM to assess recognition of warning signs for cervical cancer.

5.14.1. Recognition of breast cancer warning signs

A lump or swelling in the breast was the most commonly recognised symptom mentioned by over 75% of women with intellectual disabilities. The women who resided in residential/ community settings demonstrated higher recognition levels of the each of the eleven target warning signs. By comparison the results show a greater awareness deficit among women living with family caregivers as less than half women recognised a breast rash or a change in size of the breast as a symptom of breast cancer. A chi- square test did not identify any significant differences in the recognition levels of any of the target symptoms between women residing with family caregivers or in residential/ community settings, see Table 5.18.

Women over 40 years of age had higher recognition of the warning signs of breast cancer than women aged younger than 40 years of age. A lump in the breast was the most cited breast cancer warning sign among the two groups at 94.1% and 67.9% respectively. However, awareness of non- lump warning signs such as a rash on or around the nipple (39.3%), change in size (39.3%) and pain in one breast (50%) were particularly low among the younger age group. A chi-square test detected statistically significant differences in the recognition levels between the two age profiles of the following warning signs: a lump in the

Table 5.18. 2x2 Contingency Table of responses (n,%) to statements about breast cancer warning signs.

		Residential status (n=45)			***Age (n=45)***			***Personal Knowledge (n=45)***	
Warning signs % Yes (n)	**Family (n=28)**	**Residential/Community (n=17)**	**Significance**	**≥ 40 years (n= 17)**	**< 40 years (n= 28)**	**Significance**	**Yes (n= 17)**	**No (n=28)**	**Significance**
Lump	75.4 (21)	82.4 (14)	0.565	**94.1 (16)**	**67.9 (19)**	**0.040***	76.5 (13)	78.6 (22)	0.869
Lump in armpit	64.3 (18)	74.6 (13)	0.392	82.4 (14)	60.7 (17)	0.128	64.7 (11)	71.4 (20)	0.637
Nipple discharge	60.7 (17)	82.4 (14)	0.128	82.4 (14)	60.7 (17)	0.128	70.6 (12)	67.9 (19)	0.848
Nipple pulling in	64.3 (18)	70.6 (12)	0.664	76.5 (13)	60.7 (17)	0.277	64.7 (11)	67.9 (19)	0.828
Nipple position	60.7 (17)	64.7 (11)	0.789	70.6 (12)	57.1 (16)	0.367	64.7 (11)	60.7 (17)	0.789
Rash	42.9 (12)	64.7 (11)	0.155	**70.6 (12)**	**39.3 (11)**	**0.042***	52.9 (9)	50 (14)	0.848
Redness	64.3 (18)	64.7 (11)	0.977	76.5 (13)	57.1 (16)	0.189	64.7 (11)	64.3 (18)	0.977
Change size	42.9 (12)	58.8 (10)	0.299	64.7 (11)	39.3 (11)	0.098	58.8 (10)	42.9 (12)	0.299
Change shape	64.3 (18)	76.5 (13)	0.392	82.4 (14)	60.7 (17)	0.128	76.5 (13)	64.3 (18)	0.392
Pain in one breast	53.6 (15)	58.8 (10)	0.731	**76.5 (13)**	**42.9 (12)**	**0.028***	64.7 (11)	50.0 (14)	0.336
Puckering	57.1 (16)	58.8 (10)	0.912	70.6 (12)	50.0 (14)	0.175	70.6 (12)	50.0 (14)	0.175

Note: * denotes statistically significant associations at the $p<0.05$ level.

breast or armpit, a rash on the nipple and a pain in one of the breasts or armpit. Women in the older age group demonstrated higher awareness levels of these three warning signs that women in the younger age group, see Table 5.18.

The warning signs recognition levels of women who had personal knowledge of cancer, such as a close family member having a cancer diagnosis were compared with those of the women who had no personal knowledge of a person with a cancer diagnosis. Lumps in the breast or armpit were more commonly recognised than non-lump warning signs for breast cancer. Almost 50% of the women in each group did not recognise that a rash on the nipple could be a warning sign for breast cancer. A chi- square test found no statistically significant difference that indicated that women with intellectual disabilities with a personal knowledge of cancer had a greater awareness of breast cancer warning signs that those women without a personal history of breast cancer.

5.14.2. Recognition of cervical cancer warning signs.

Awareness about cervical cancer warning signs and symptoms tended to be low among women who lived with family as well as among women who lived in residential or community settings. A heavy period that lasts longer than usual was the most commonly recognised symptom of cervical cancer by all respondents (58.8-60.7%). There was very poor awareness the most common symptom of cervical cancer of unusual vaginal bleeding at times other than at menstruation which was recognised by only 35.7- 41.2% of the respondents. A chi- square test identified no significant differences in the recognition levels between women residing with family caregivers or in residential/ community settings for any of the target symptoms, see Table 5.19.

A greater number of older women over the age of 40 years of age recognised that heavy periods (82.4%) and bleeding after the menopause (70.6%) may be warning signs for cervical cancer than did women under the age of forty years of age. However, the recognition of the nine remaining warning signs was poor among both groups. In particular the recognition levels for unusual vaginal bleeding between periods, persistent discharge which lasts for three weeks or longer, and pain during or after sex were found to be as low as 35.7 % in the younger age group. An examination of the data using a chi- square test showed that the only statistically significant difference in recognition of cervical cancer warning sign was in relation to heavy periods that last much longer than regular periods, see Table 5.19.

It is evident that women with personal knowledge of cancer in a close member of their family had higher recognition of each of the 11 target warning signs for cervical cancer. Women with no personal knowledge of cancer had an extremely low awareness of any of the warning signs for cervical cancer ranging from 50% for period which are heavier than normal periods to 25% for unusual vaginal bleeding between periods. Chi- square tests identified statistically significant differences in the recognition levels between the two groups for unusual vaginal bleeding between periods and persistent pain for three weeks or longer in the pelvic region, see Table 5.19. The final warning sign in which a significance difference was observed for weight loss even though a person was not actively trying to lose weight.

The recognition of the warning signs for cervical cancer was extremely low among the women with mild to moderate intellectual disabilities. Recognition levels dropped as low as 25% for vaginal bleeding between periods for women with no personal knowledge of cancer and 29.4% for persistent lower back pain for women with mild to moderate intellectual disabilities who live in residential or community settings. A notable exception was the recognition of heavy periods which last longer than normal periods by 82.4% of women with intellectual disabilities over the age of 40 years of age.

5.15. Confidence to detect changes

Chi- square tests were used to compare the confidence and skills of women with mild to moderate intellectual disabilities to detect changes in their own breast or a cervical cancer symptom. The analysis was based on residential status, age and personal knowledge of cancer in a close family member.

5.15.1. Confidence and skills to detect a breast change

Of the sample of women who lived in residential/ community settings, 52.9% reported that they rarely or never checked their breast for changes. However, a much lower proportion of women who lived with family carers (28.6%) reported they rarely or never checked their breasts for changes. Furthermore, regardless of residential status over 40% of the women felt unconfident that they would be able to detect a change in their own breast. A chi- square test indicated that there was no significant difference in opinion found between women living with family or women living in residential/ community settings in relation to breast self-examination and confidence to notice a change in their breast.

Table 5.19. 2x2 Contingency Table of responses (n,%) to statements about cervical cancer warning signs.

		Residential status (n=45)			***Age (n=45)***			***Personal Knowledge (n=45)***	
Warning signs % Yes (n)	**Family (n=28)**	**Residential/Community (n=17)**	**Significance**	**≥ 40 years (n= 17)**	**< 40 years (n= 28)**	**Significance**	**Yes (n= 17)**	**No (n=28)**	**Significance**
Vaginal bleeding	35.7 (10)	41.2 (7)	0.714	41.2 (7)	35.7 (10)	0.714	**58.8 (10)**	**25 (7)**	**0.023***
Lower back pain	50 (14)	29.4 (5)	0.175	52.9 (9)	35.7 (10)	0.257	52.9 (9)	35.7 (10)	0.257
Vaginal discharge	53.6 (15)	52.9 (9)	0.967	52.9 (9)	53.6 (15)	0.967	58.8 (10)	50 (15)	0.565
Pain during sex	42.9 (12)	41.2 (7)	0.912	47.1 (8)	39.3 (11)	0.609	47.1 (8)	39.3 (11)	0.609
Heavy periods	60.7 (17)	58.8 (10)	0.9	**82.4 (14)**	**48.1 (13)**	**0.017***	76.5 (13)	50 (14)	0.079
Persistent diarrhoea	42.9 (12)	47.1 (8)	0.783	52.9 (9)	39.3 (11)	0.371	52.9 (9)	39.3 (11)	0.371
Bleeding after menopause	57.1 (16)	52.9 (9)	0.783	70.6 (12)	46.4 (13)	0.114	70.6 (12)	46.4 (13)	0.114
Pelvic pain	57.1 (16)	58.8 (10)	0.912	64.7 (11)	53.6 (15)	0.463	**76.5 (13)**	**46.4 (13)**	**0.048***
Bleeding during/after sex	39.9 (11)	52.9 (9)	0.371	47.1 (8)	42.9 (12)	0.783	58.8 (10)	35.7 (10)	0.130
Blood in stool	39.3 (11)	58.8 (10)	0.203	58.8 (10)	39.3 (11)	0.203	64.7 (11)	35.7 (10)	0.059
Weight loss	46.4 (13)	52.9 (9)	0.672	52.9 (9)	46.4 (13)	0.672	**70.6 (12)**	**35.7 (10)**	**0.023***

Note: * denotes statistically significant associations at the p<0.05 level.

A higher proportion of women under forty years of age (57.1%) reported they rarely or never checked their breasts for changes compared to 47.1% of women in the older age group. Regardless of age group over 40% of the women mentioned that they felt unconfident that they would be able to detect a change in their own breast. A chi- square test identified that there were no statistically significant differences in opinion found between these two age profiles in relation to breast self-examination and detecting breast changes.

Women without personal knowledge of a close family member with cancer (57.1%) more frequently mentioned they rarely or never checked their breasts for changes compared with 47.1% of women with a personal knowledge of cancer. Among the women with personal knowledge of cancer, 23.5% didn’t feel confident that they would notice a change in their breast in comparison to 53.6% of women with a personal knowledge of cancer. A chi- square test indicated a significant association between confidence levels to detect changes in their own breast and personal knowledge of cancer in a close family member, $\chi2$ (1, n=45) = 3.91, p=0.048.

5.15.2. Confidence to detect a cervical cancer symptom

A chi- square test indicated that there was no significant difference found in the confidence levels of the women who reside with family carers to detect a cervical cancer symptom when compared to women who live in residential/ community settings. However, women who lived in residential/ community settings demonstrated higher confidence levels to detect a symptom (58.8%) than women living with family carers (50%).

A significant difference was not detected by the chi- square test regarding the confidence levels of women aged 40 years and over to detect a cervical cancer symptom when compared to women aged under 40 years of age. Despite this a higher proportion of women in the older age group (57.1%) reported that they were confident that they would notice a warning sign for cervical cancer when compared to women in the younger age group (33.3%).

The chi- square test showed that there was no significant difference in the confidence levels between women with and without personal knowledge of cancer to notice a cervical cancer warning sign. Over 40% of the women in both groups felt confident that they would notice a change associated with a cervical cancer symptom such as unusual bleeding between periods or unpleasant discharge.

5.16. Knowledge of the risks of developing breast or cervical cancer

Respondents were asked in the Breast CAM and the Cervical CAM about their level of awareness of the risk factors for breast and cervical cancer. The format used measured how many risk factors respondents could recall without prompting.

5.16.1. Awareness of the risk factors for developing breast cancer

The women were asked to recall risk factors that they thought might affect a woman's chance of developing breast cancer. Smoking was mentioned as a risk factor for breast cancer by 11.1% of the women. Other potential risk factors mentioned were chance (4.4%); hormonal imbalance (2.2%); lifestyle (2.2%); drinking alcohol (2.2%) pregnancy (2.2%) and health history (2.2%), see Table 5.20. The maximum number of risk factors recalled was three by only one woman, who had experienced a close family member with a diagnosis of cancer. However, almost 80% of the women could not recall a single risk factor for breast cancer.

5.16.2. Awareness of cervical cancer risk factors

The women were asked to recall risk factors that they thought might affect a woman's chance of developing cervical cancer. The risk associated with not attending for regular smear tests was mentioned by one woman while another woman mentioned smoking as a risk factor for cervical cancer. The other risk factors for cervical cancer mentioned by the women were lifestyle (2.2%) and stress (2.2%), see Table 5.21. Four women identified one risk factor for cervical cancer. However, over 90% of the women could not recall a risk factor for cervical cancer.

Table 5.20. Breast cancer risk factors recall

Breast cancer risk factor categories	**Responses n (%)**
Non modifiable risk factors	
Hormonal imbalance	1 (2.2)
Health history	1 (2.2)
Lifestyle related risk factors	
Drinking alcohol	1 (2.2)
Lifestyle	1 (2.2)
Unclear risk factors	
Tobacco smoke	5 (11.1%)
Other risk factors	
Pregnancy	1 (2.2)
Chance	2 (4.4)

Table 5.21. Cervical cancer risk factor recall

Cervical cancer risk factors	**Responses n (%)**
Cancer Research UK CAM cervical cancer target risk factors	
Being a smoker	1 (2.2)
Not going for regular smear tests	1 (2.2)
Other risk factors mentioned	
Stress	1 (2.2)
Lifestyle	1 (2.2)

5.16.3. Breast and cervical cancer and age

Respondents were asked what age group they believed would be most likely to develop breast or cervical cancer in the next year. Women who lived in residential/ community care (47.1%) more frequently responded that a 70 year old woman was most likely to develop breast cancer in the next year compared to just 28.6% of women residing with family members.

Analysis indicated that just 35.3% of the women of the women aged 40 years of age and older and 35.7% of the women aged under 40 years of age responded that a 70 year old woman was more likely to get breast cancer in the next year. An exploration of the responses of women with personal knowledge of a close family member with cancer showed that 41.2% of women in this group mentioned that the likelihood of a 70 year old woman getting breast cancer in the next year compared with 32.1% of women in the group that did not have a personal history of cancer. Chi- square tests indicated that there was no significant difference in awareness about the increasing risk of cancer with advancing age associated with living arrangements, age or personal knowledge of cancer.

The women demonstrated a much lower awareness of the most common age group of women who develop cervical cancer i.e. women aged 30-49 years. The awareness level among women living in residential/ community settings (23.5%) was higher than women living with family carers (17.9%). A similar pattern was observed among women over 40 years of age with just 23.5% of the group aware of the peak cervical cancer incidence in the 30-49 age group compared to only 17.9% of the women aged under 40 years of age. The awareness levels were similarly poor among women with personal knowledge of a close family member with a cancer diagnosis (11.8%) and those without personal knowledge of cancer (25%). Chi- square tests indicated that there was no significant difference about the awareness of the peak incidence of cervical cancer during the associated with living arrangements, age or personal knowledge of cancer.

5.17. Awareness of breast and cervical screening programmes

A chi- square test was used to examine for statistically significant differences in the awareness levels of breast and cervical screening programmes for the three demographic variables residential status, age and personal knowledge of cancer.

5.17.1. Awareness of breast screening programme

No significant differences were found in the screening programme awareness and attendance at the programmes between women living with family caregivers or women living in residential/ community settings. Awareness of the BreastCheck screening programme was considerably higher among women living with family caregivers as shown in Table 5.22. Few or none of the women demonstrated an awareness of the age eligibility criteria for breast screening. Four women over the age of 50 years were age eligible for the breast screening programme. Three of these women reported that they had both received an invitation to screening and had availed of the opportunity to have a mammogram. The fourth woman was unsure whether she had received an invitation to attend for a mammogram. A younger woman under the age of fifty years of age also reported that she had received a mammogram due to the discovery of a potential breast cancer symptom.

It was evident that women with (52.9%) and without personal knowledge of a close family (39.3%) member having a diagnosis of cancer had poor awareness about the breast screening programme. Chi- square tests indicated that there was no significant difference in the knowledge of the National Breast Screening Programme among the women with mild to moderate intellectual disabilities based on residential status, age and personal knowledge of a close family member with cancer.

5.17.2. Awareness of cervical screening programme

It was found that the awareness of the CervicalCheck programme was much higher among women who lived with family carers (39.3%) and those women who were 40 years of age and older (47.1). However, personal knowledge of a close family member with a cancer diagnosis (29.4%) did not have any impact on the women’s awareness of the cervical screening programme, and the awareness levels were similar to women without a personal knowledge of cancer (28.6%).

None of the women with mild to moderate intellectual disabilities surveyed demonstrated an understanding that women were invited to attend the cervical screening programme when they reach 25 years of age. Although almost 30% of the women were aware of the Cervical Vaccination Programme, none of the women were aware that girls in first year in secondary school were eligible for the Cervical Cancer Vaccination.

Chi- square tests indicated that there was no significant difference in the knowledge of the National Cervical Screening Programme among the women with mild to moderate intellectual disabilities based on residential status, age and personal knowledge of a close family member with cancer.

It was evident that 84.4% of the women with mild to moderate intellectual disabilities were age eligible to participate in the cervical screening programme. However, only 58.8% of the women mentioned that they had ever been invited to participate in the programme. The remainder of the women reported that they had never been invited to participate or were unsure if they had been invited to participate in the cervical screening programme. In the case of the women who mentioned that they had received an invitation to participate in the cervical screening programme (n=17), 64.7% of these women reported that they had availed of cervical screening. Chi- square tests indicated that there was a significant difference in the womens knowledge about receiving an invitation to cervical screening based on having personal knowledge of a close family member with cancer, see Table 5.23.

5.18. Barriers to seeking help

A chi- square test was used to test for statistically significant differences in relation to emotional, practical and service barriers which might impact on the woman making an appointment to discuss a symptom that they thought may be serious. The demographic variables of interest were age, residential status and personal knowledge of a close family member having a cancer diagnosis, see Table 5.24.

A chi- square test indicated that significant differences were identified in relation to two issues that influence the decision of a woman with mild to moderate intellectual disabilities to seek medical assistance on the discovery of a warning sign for cancer. A significant difference in opinion about what might prevent early medical intervention for a cancer warning sign was detected in the opinions of women based on their age profiles. Younger women under the age of forty (60.7%) reported that they experienced difficulty with making a doctor's appointment compared to women aged 40 years of age and older (23.5%), χ^2 (1, n=45) =5.877, p=0.015. Just 5.9 % of the women with a personal knowledge of cancer felt the doctor would be difficult to talk to compared to 35.7% of the women without personal knowledge of cancer, χ^2 (1, n=45) = 5.097, p= 0.024.

Despite this only a low proportion of the women in each of the three categories reported that they would feel confident talking to a doctor about a change they noticed in their breast or cervical health (5.9- 17.9%). Just 13.3% of the women mentioned that they would prefer to make an appointment with a female doctor to discuss the symptom.

Broadly related to this, it seems that worry about what the doctor might find was another challenge women felt would put them off early medical intervention on the detection of a breast or cervical cancer symptom. This was the most frequently endorsed barrier to early medical intervention cited by between 41.2- 70.6% of the women across the three demographic variables, see Table 5.24. Approximately 50% of the women also mentioned that the embarrassment of talking about their breast and cervical health to a doctor would be a key factor that would delay early help seeking for a cancer warning sign (46.4- 53.6%), see Table 5.24.

5.18.1. Delays in seeking help

Respondents were asked how long they would wait before seeking medical assistance for a suspected breast or cervical cancer symptom. The majority of women with mild to moderate intellectual disabilities (80%) reported that they would seek help from a doctor within one week of discovering a symptom that they thought might be breast cancer. However, it is of concern that the majority of the remaining women (15.6%) were undecided how long they would wait before contacting a doctor about a symptom they thought may be breast cancer.

Responses indicated that approximately 70% of the women would approach their GP within one week of discovering a symptom that they thought might be cervical cancer. However, almost 30% of the women suggested that they were unsure about how long they would delay before contacting a doctor about a symptom they thought might be a symptom of cervical cancer.

Table 5.22. 2x2 Contingency Table of responses (n,%) about breast screening

		Residential status (n=45)			*Age (n=45)*			*Personal Knowledge (n=45)*	
Knowledge about BreastCheck % Yes (n)	**Family (n=28)**	**Residential/Community (n=17)**	**Significance**	**≥ 40 years (n= 17)**	**< 40 years (n= 28)**	**Significance**	**Yes (n= 17)**	**No (n=28)**	**Significance**
Aware of BreastCheck	50 (14)	35.3 (6)	0.336	40 (8)	60 (12)	0.783	52.9 (9)	39.3 (11)	0.371
First invitation age (50 years)	14.3 (4)	0.0%	0.281**	5.9 (1)	10.7 (3)	0.581	17.6 (3)	3.6 (1)	0.108
Received invitation	3.6 (1)	17.6 (3)	0.114**	17.6 (3)	3.6 (1)	0.108	17.6 (3)	3.6 (1)	0.108
Attended Mammography	3.6 (1)	17.6 (3)	0.114**	17.6 (3)	3.6 (1)	0.108	17.6 (3)	3.6 (1)	0.108

Notes: * denotes statistically significant associations at the $p<0.05$ level.
** Fisher Exact Probability test results reported where $\chi2$ result violated.

Table 5.23. 2x2 Contingency Table of responses (n,%) about cervical screening

		Residential status (n=45)			*Age (n=45)*			*Personal Knowledge (n=45)*	
Knowledge about CervicalCheck % Yes (n)	**Family (n=28)**	**Residential/Community (n=17)**	**Significance**	**≥ 40 years (n= 17)**	**< 40 years (n= 28)**	**Significance**	**Yes (n= 17)**	**No (n=28)**	**Significance**
Aware of CervicalCheck	39.3 (11)	23.5 (4)	0.277	47.1 (8)	25.0 (7)	0.128	29.4 (5)	28.6 (8)	0.952
Received invitation	39.3 (11)	35.3 (6)	0.789	47.1 (8)	32.1 (9)	0.317	**58.8 (10)**	**25 (7)**	**0.023***
Attended screening	17.9 (5)	35.3 (6)	0.187	35.3 (6)	17.9 (5)	0.87	35.3 (6)	17.9 (5)	0.187
Vaccination Programme	28.6 (8)	29.4 (5)	0.952	29.4 (5)	28.6 (8)	0.952	29.4 (5)	28.6 (8)	0.952

Notes: * denotes statistically significant associations at the $p<0.05$ level.

Table 5.24. 2x2 Contingency Table of Responses (n,%) about barriers to seeking medical help

Barriers to seeking help **% Yes (n)**		***Residential status*** ***(n=45)***			***Age*** ***(n=45)***			***Personal Knowledge*** ***(n=45)***	
	Family **(n=28)**	**Residential/Community** **(n=17)**	**Significance**	**≥ 40 years** **(n= 17)**	**< 40 years** **(n= 28)**	**Significance**	**Yes** **(n= 17)**	**No** **(n=28)**	**Significance**
Emotional barriers									
Worried about what the doctor might find	64.3 (18)	41.2 (7)	0.130	52.9 (9)	57.1 (16)	0.783	70.6 (12)	46.4 (13)	0.114
Too scared	42.9 (12)	35.3 (6)	0.616	35.3(6)	42.9 (12)	0.616	47.1 (8)	35.7 (10)	0.451
Too embarrassed	53.6 (15)	41.2 (7)	0.120	47.1 (8)	50(14)	0.848	52.9 (9)	46.4 (13)	0.672
Confident to talk about symptom	21.4 (6)	5.9 (1)	0.163	11.8 (2)	17.9 (5)	0.585	17.6 (3)	14.3 (4)	0.763
Practical barriers									
Too busy	50 (14)	35.3 (6)	0.336	35.3 (6)	50 (14)	0.336	29.4 (5)	53.6 (15)	0.114
Other things to worry about	35.7 (10)	23.5 (4)	0.392	23.5 (4)	35.7 (10)	0.392	29.4 (5)	32.1 (9)	0.848
Difficult for me to arrange transport	25 (7)	35.3 (6)	0.460	35.3 (6)	25 (7)	0.460	17.6 (3)	35.7 (10)	0.195
Service barriers									
Worried about wasting the doctor's time	42.9 (12)	29.4 (5)	0.367	29.4 (5)	42.9 (12)	0.367	52.9 (9)	28.6 (8)	0.102
Difficult to make an appointment	53.6 (15)	35.3 (6)	0.233	**23.5 (4)**	**60.7 (17)**	**0.015***	64.7 (11)	35.7 (10)	0.059
Doctor difficult to talk to	28.6 (8)	17.6 (3)	0.408	29.4 (5)	21.4 (6)	0.546	**5.9 (1)**	**35.7 (10)**	**0.024***

*Note: * denotes statistically significant associations at the $p<0.05$ level.*

5.19. Introduction

This section reports on the findings of the carers interviews about their perspectives on the issues facing women with severe to profound intellectual disabilities about cancer awareness and participation in screening programmes. Section 5.20. introduces the study accrual and section 5.21. describes the demographic profile of the interviewees. The key themes that emerged during the data analysis using the Miles and Huberman framework (1994) are presented in section 5.22., and discussed in sections 5.23.- 5.29. Finally, the chapter concludes in section 5.30.

5.20. Study accrual

Following the information meetings at the intellectual disability service providers, two of the seven participating services expressed an interest for staff to participate in the carers interviews as well as two mothers of women with severe to profound intellectual disabilities. Male carers were not excluded from participating in the interview, however, only two male carers attended the information meetings and none was interested in taking part in an interview. In total (n=25) female carers consented to participate in the Phase I interviews to discuss their perspectives about the issues facing women with severe to profound intellectual disabilities about cancer awareness and participation in screening programmes. In total 23 paid carers and one of the mothers agreed participated in an individual face to face interviews. Another mother declined to participate in a face to face interview but agreed to participate in a telephone interview.

Each interview lasted approximately 10-25 minutes. During the interviews the research questions were kept firmly in mind through the use of the interview guide. All of the face to face interviews were digitally recorded and field notes were kept for the telephone interview. The time frame for undertaking Phase I of the study was limited to an eight month period from May to December 2013.

5.21. Demographic characteristics

The demographic characteristics of the carers who participated in the interviews are presented in Table 5.25.

Table 5.25. Demographic characteristics of the carers

Demographic Characteristics	**n**		**%**	
Gender				
Female	100		25	
Age (years)				
20-29	4	4	16	16
30-39	6	6	24	24
40-49	7	7	28	28
50-59	8	8	32	32
Carer status				
Parent	2		8	
Social Care Worker	1		4	
Student Nurse	3		12	
Staff Nurse	11		44	
Clinical Nurse Manager 1	3		12	
Clinical Nurse Manager 2	5		20	

5.22. Data analysis

An examination of the data in the individual interviews using Miles and Huberman’s framework (Miles and Huberman, 1994) revealed six themes encompassing cancer and screening awareness for women with severe to profound intellectual disabilities and their carers; challenges and facilitators associated with the screening process for the women; issues related to family engagement with the intellectual disabilities service provider about screening; and finally education as an intervention to increase cancer and screening awareness for the women. These emerging themes together with the subthemes identified within each theme are presented in Table 5.26., and are supported with narrative accounts from carers in the discussions in section 5.23. through to 5.29.

5.23. Carers personal cancer and screening awareness

This theme explores the carers own personal cancer and screening awareness. Three subthemes were identified in this theme namely the carers knowledge of the warning signs for breast and cervical cancer, their awareness of the national cancer screening programmes in Ireland and the experiences of age eligible carers at screening appointments. First, the carers knowledge of cancer warning signs is explored.

Table 5.26. Emerging themes and subthemes from the carers interviews

Theme	Subtheme
Carers personal cancer and screening awareness	*Knowledge of cancer warning signs* *Screening awareness* *Screening experiences*
Cancer awareness and screening in women with severe to profound intellectual disabilities- carers perspectives	*Comprehension difficulties* *Right to screening* *Dismissed and forgotten*
Who decides about cervical screening?	*Opting women off the cervical screening programme* *Ethical considerations for nurses*
Barriers and facilitators for screening	***Barriers*** *Screening service providers understanding of intellectual disabilities* *Consent* *Physical disabilities and environmental barriers* *Anxieties and fear* ***Facilitators*** *Individualised screening protocol* *Advance preparation for screening* *Support during screening procedure* *The use of sedation*
Engaging families	*Family history* *Protectionism* *Family consent for procedures*
Education interventions	*Women with severe to profound intellectual disabilities* *Family carers* *Paid carers*

5.23.1. Knowledge of cancer warning signs

It was evident that there were differences in cancer awareness between nurses and non- nursing professionals. Both these carers, a staff nurse and a social care worker discussed vastly different cancer awareness levels, yet both provided care to women with severe to profound intellectual disabilities in an intellectual disabilities day service:

> '*Well, just any change in your breast , nipples, inverted nipples, any rashes around there, any lumps you know in the breast area or anything, or lumps under your arm' (P7 Staff Nurse)*

> *'I wouldn't be very familiar with all the signs I should be looking for' (P5 Social Care Worker)*

Nurses showed an in depth knowledge of the need to be aware of the relationship of irregular bleeding and vaginal discharges to cervical cancer:

> *'I suppose bleeding and irregular bleeding that's not associated with menstruation. I suppose any odourous discharge that you're not impressed with. I suppose if you're having severe pain that's not natural for you in your menstruation' (P22 Student Nurse)*

The next subtheme looks at the carers perspectives about breast self- examination and their own participation in the breast and cervical screening programmes.

5.23.2. Screening awareness

Carers recognised the importance of breast awareness and regular checking of the breasts. However, these carers agreed that this doesn't happen very often in their own lives:

> *'Em, I suppose it's important to check your breasts fairly regularly which probably a lot of people don't. I don't do it very often' (P23 Staff Nurse)*

> '*Yeah, I would do my own checks, but to be honest they're random. It's kind of, it would be when I think of it, eh, it could be twice a month, it could be once every two months' (P3 Parent)*

Carers who were age eligible to participate in CervicalCheck and BreastCheck frankly discussed their personal opinions about participating in screening programmes and the benefits of screening. The following statements succinctly captured the overarching beliefs expressed about screening:

> *‘Well I suppose, from my own point of view I would always go to, when I am offered screening, I would always have participated in it. And obviously I’m a believer in catching things sooner rather than later, you know’ (P2 Clinical Nurse Manager 2)*

> *‘It’s up to you to get your smear done every three years, they’ll remind you once you’re on CervicalCheck they’ll remind you to do that’ (P3 Parent)*

Although carers were on the whole positive about the benefits of screening, there were major discrepancies among the participants about the age ranges that screening was offered. The following statements clearly demonstrated the apparent confusion around screening among healthcare workers and parents:

> *‘Eh well within the general population I know like eh you’re sent out automatically eh over 50 isn’t it for a breast screen’ (P14 Clinical Nurse Manager 1)*

> *‘As far as I know it’s from the age of 25 you get checked, you have smears’ (P6 Clinical Nurse Manager 1)*

> *‘Well I know there is actually a screening programme, but I don’t know what age you have to be to go to it to be perfectly honest. I know there is one in Ireland’ (P19 Student Nurse)*

> *‘When you come to a certain age you get, em, you get tested I think it’s 55 you get your first mammogram’ (P3 Parent)*

> *‘I think it’s from 18 to early 20’s anyway now’ (P17 Clinical Nurse Manager 1)*

Many carers admitted that they were not confident of the recommended screening intervals recommended in particular the cervical screening programme as demonstrated in the following comments:

> *‘Well, you know, smears every four years, five years is it, I’m not quite sure of that’ (P7 Staff Nurse)*

> *‘Every two years then for cervical smears’ (P23 Staff Nurse)*

There was good awareness of the cervical cancer vaccination programme for female students in First Year in Secondary School that has been implemented in Ireland in recent years:

> *‘For teenagers, 12 year old with the cervical, you know, the cancer vaccination, which is just after being introduced free in the last year’ (P7 Staff Nurse)*

> *'I know that the development of the vaccine for teenagers for girls between the ages of 11 and 13 for the HPV virus' (P22 Student Nurse)*

The next subtheme explores the personal reflections of the age eligible carers about their experiences and feelings about the screening procedures.

5.23.3. Screening experiences

Carers disagreed about their personal experiences of mammography. These two Clinical Nurse Managers offer two contrasting views about the experience of screening:

> *'Funnily enough, I've had three or four mammograms and they've never bothered me at all. It's a squeezing for a second or two' (P23 Clinical Nurse Manager 2)*
>
> *'It's not only an x-ray, when they put that pressure down, it's no joke' (P24 Clinical Nurse Manager 2)*

There was agreement among carers that the smear test was a very invasive procedure. Feelings of fear and embarrassment were palpable among age eligible women who participated in the screening programme:

> *'Pap smears, um, I've had a lot of them, not that I like them!' (P4 Clinical Nurse Manager 2)*
>
> *'I just think the smear test is worse because you are actually… something's actually going in somewhere it shouldn't be' (P8 Staff Nurse)*
>
> *'You're a bit apprehensive, you know, about going in for the first time for a smear (P7 Staff Nurse)*

This theme explored the personal cancer and screening awareness of nursing and non- nursing carers who provide daily care to women with severe to profound intellectual disabilities. It is clear that the nurses were more knowledgeable about cancer awareness and screening programmes. Valuable insights were ascertained about the carers thoughts related to participating in the screening programmes and the feelings they associated with the procedures on a personal level.

5.24. Cancer awareness and screening in women with severe to profound intellectual disabilities: Carers perspectives

The next theme which arose in data analysis was the carers perspectives on the issues related to cancer awareness for women with severe to profound intellectual disabilities. The first subtheme identified was the comprehension difficulties associated with the intellectual disability which impacted the women's understanding of cancer awareness. Another subtheme identified that women with severe to profound intellectual disabilities were entitled to the access the screening programmes as women in the general population do. The final subtheme argued that women with severe to profound intellectual disabilities seem to be forgotten by society because of their disability.

5.24.1. Comprehension difficulties

These nurses reported that the body awareness of women with severe to profound intellectual disabilities was limited due to comprehension difficulties associated with the level of intellectual disability. They explained that this would create major barrier for the women with regard to being breast aware or identifying cancer warning signs themselves:

> *'I suppose the difficulty for the women is their ability to understand' (P9 Clinical Nurse Manager 2)*
>
> *'Awareness would be very, very limited, like you could imagine with a severe to profound, you'd know, she'd understand simple tasks, but as I say 'Look it, feel your breast, she wouldn't understand that' (P7 Staff Nurse)*
>
> *'They're not going to be able to identify the changes themselves' (P22 Student Nurse)*

However, despite this these nurses contended that women with severe to profound intellectual disabilities were as likely to develop cancers as women in the general population:

> *'People with ID, you know, suffer from this as well like, you know' (P18 Staff Nurse)*
>
> *'But, they are still women, like us, going through the very same thing' (P20 Clinical Nurse Manager 2)*

The next subtheme explores the carers perspectives about to right to screening for women with severe to profound intellectual disabilities:

5.24.2. Right to screening

These nurses confirmed that the national screening programmes do contact age eligible women with severe to profound intellectual disabilities to invite them to participate in the breast and cervical screening programmes:

> *'The appointments are sent out, eh, and I know like once you get to a certain age like the general population do get their appointment' (P 14 Clinical Nurse Manager 1)*
>
> *'We receive a letter from the screening programme, you know, they always come' (P11 Staff Nurse)*

These nurses made a strong argument that the women had the same rights and entitlements to screening as women in the general population:

> *'It's just that they are entitled to have the screening just as much as everyone else' (P21 Staff Nurse)*
>
> *'They've a right to it as much as we have… it's something that could still harm them, no one knows' (P8 Staff Nurse)*

However, this Clinical Nurse Manager 2 provided insight into why women with intellectual disabilities would not be considered to be suitable candidates to participate in either of the screening programmes by the service providers. The crux of the matter seemed to pivot on issues related to their understanding of the procedure:

> *'Our women I should say are not put forward for either mammograms or cervical tests. I suppose the main reason being that, em, they would actually have no understanding of why they are actually going for these procedures' (P2 Clinical Nurse Manager 2)*

Notwithstanding this intellectual disability service providers reported that the women at their services do benefit from an annual clinical breast exam as part of the annual health assessment. The woman would be referred to the GP in the event that warning signs for breast cancer were found:

> *'We would do screening, well breast exams, once a year, em, with the service users, em, as part of our health screening tool, and I suppose, if we were to find something that we were worried about we would refer it off to a GP' (P25 Clinical Nurse Manager 2)*

Nevertheless, despite this rally for the same rights and entitlements to screening as women in the general population, a sense that the women with severe to profound intellectual disabilities were dismissed and forgotten was palpable. The next subtheme explores this perspective further with nursing staff.

5.24.3. Dismissed and forgotten

There was a really strong feeling that that women with severe to profound intellectual disabilities were dismissed as a result of their disability and were somewhat opted out and forgotten already even though they can develop cancers:

> *'I suppose people can brush it off and say ' sure she doesn't know' but you have to say if that was you, you'd like to know' (P22 Student Nurse)*
>
> *'I think, you know, working with people with intellectual disabilities, so much is dismissed because they have an intellectual disability' (P20 Clinical Nurse Manager 2)*
>
> *'Seems quite scary that they're kinda opted out or forgotten already' (P12 Staff Nurse)*

This theme looked at carers perspectives about issues related to cancer awareness and participation in the screening programmes for women with severe to profound intellectual disabilities. While intellectual disabilities service providers do incorporate breast awareness into their annual health checks, the area of participation in screening programmes by the women seems to be more problematic and contentious.

The age profile of the women with severe to profound intellectual disabilities was primarily lower than fifty years of age. Thus the majority of the interviews focused on issues related to participation in the cervical screening programme. The next theme explores the principal concerns raised by the carers about who actually decides if the woman with severe to profound intellectual disabilities participates in the screening programme or not.

5.25. Who decides about cervical screening?

In this theme nurses and a parent candidly explain how the decision about the woman participating in the cervical screening programmes are made. The first subtheme looks at how the decision to opt women off the screening programme is made. Subsequently, the second subtheme looks at the ethical considerations that nurses take into account when coming to terms with the decision making processes involved in opting the woman off the cervical screening register is made.

5.25.1. Opting women of the cervical screening programmes

In Ireland you can choose to have a free smear test with any doctor or nurse registered with the national screening programme. It appears that when an intellectual disabilities service provider receives notification that a woman with a severe to profound intellectual disabilities is due to have a smear test the first port of call was the GP as highlighted by this Clinical Nurse Manager:

> *'If we get a cervical reminder for a service user, em, we bring it to the GP, but actually because of the level of ability, signs the opt-off, because they wouldn't comply' (P25 Clinical Nurse Manager 2)*

It seems that the GP's concern about the woman's level of understanding of the procedure informs the decision not to complete the smear test unless the woman was presenting with clinical symptoms:

> *'Unless she presented for clinical reasons, you know to warrant a screening, that they wouldn't proceed, and they felt it was too traumatic for her' (P25 Clinical Nurse Manager 2)*

> *'Their lack of understanding, the discomfort, and not being able to understand the procedure that he felt they didn't need a smear' (P10 Staff Nurse)*

However, this seems to negate the importance of early intervention for cervical cancer through smear tests to identify changing cells which could lead to cervical cancer (American Cancer Society Inc., 2014a). There also appears to be a general consensus that women with severe to profound intellectual disabilities would not be sexually active so did not require a cervical smear due to decreased risk of cervical cancer. This Clinical Nurse Manager argues that:

> *'I mean we would have, the, I suppose, understanding that most of our people are not sexually active and have never been' (P2 Clinical Nurse Manager 2)*

This is one of the primary reasons why a woman with severe to profound intellectual disabilities would be opted off the screening register by the GP as discussed by this Clinical Nurse Manager and staff nurse:

> *'The GP said the risk is small compared to somebody who was sexually active, and to put them through that would be more unfair' (P4 Clinical Nurse Manager 2)*

> *'The GP would have felt, because they, they're not sexually active women, and it would have been very distressing for them to have smears taken, that he felt, em, that there was no need at that time' (P10 Staff Nurse)*

It seems that the intellectual disability service provider would take the guidance given by the GP into account and did not pursue cervical screening for the woman as stressed by this Clinical Nurse Manager:

> '*We go with their guidance, you know' (P2 Clinical Nurse Manager 2)*

Nevertheless these Clinical Nurse Managers and staff nurses were concerned about the lack of a baseline or ongoing assessment of the cervix of women with severe to profound intellectual disabilities based on presumptions of sexual inactivity:

> *'Some GP's take the view that if they're not sexually active they don't need it. And I know, that is a great argument, but, I have the big but, I think everybody should have at least one cervical smear test carried you in their lives, even to have a baseline' (P20 Clinical Nurse Manager 2)*
>
> *'Because even though our service users are not sexually active, it's most important that they still need screening. Once in five years is not going to harm' (P16 Staff Nurse)*
>
> *'She didn't need to have it because she wasn't a sexually active woman, but so you know, she still should have had it as well as everybody else' (P21 Staff Nurse)*

Family carers too often disagreed with the GP perspectives. This parent was shocked that her daughter who had been on the contraceptive pill for a long time, and assumed to be sexually inactive was refused a cervical smear and asked:

> *'What's the story with this- don't nuns get cancer' (P1 Parent)*

The carers tension is really tangible about the obstacles of the presumption of sexual inactivity facing women with severe to profound intellectual disabilities accessing the cervical screening programme. The next subtheme looks at the ethical considerations nurses pinpointed about how contentious and problematic theses opt off decisions were for the women in relation to the early detection of cervical precancerous cells and cervical cancer.

5.25.2. Ethical considerations for nurses

This nurse discussed her understanding that the ethical issues arose due to the women's level of understanding and also because of the nature of the cervical screening procedure:

> *'There are ethical issues raised there because of their level of understanding of the procedure, and the nature of the procedure as well' (P8 Staff Nurse)*

This Clinical Nurse Manager suggested that there was a need for evidence on the benefits and harms of screening. She suggested that this information was necessary to advise the nurses of the reasons why they should promote participation in the screening procedure for women with severe to profound intellectual disabilities:

> *'How many die and don't die because they've had screening, kind of, at least that's some evidence, hard evidence as to why we should be pursuing it a little more' (P2 Clinical Nurse Manager 2)*

Nurses faced an ethical dilemma in these situations. This nurse describes it as coming to terms with the fact that all had been done from a nursing perspective to promote screening for the woman with severe to profound intellectual disabilities, but still a decision to opt the woman off the screening register was made by the GP:

> *'But at least if you've done your best and they've said no, you know, you've gone all the way of what you could have done' (P16 Staff Nurse)*

It appears that carers were often at odds with primary care professionals in relation to opting women with severe to profound intellectual disabilities off the screening programme based on issues such as presumptions of sexual inactivity and inability to consent. It was also evident at an organisational level that women in intellectual disability services may be denied screening based on assessment of understanding and ability to give consent. Proactive carers constantly strived to promote strategies to ensure women with severe to profound intellectual disabilities have equal access to preventative healthcare.

5.26. Barriers and facilitators for screening

A number of barriers were identified which carers perceived to have a negative influence on the screening participation of women with severe to profound intellectual disabilities including negative attitudes to disabilities among healthcare professionals, consent, sexual inactivity, and challenges related to physical and environmental barriers.

5.26.1. Screening service providers understanding of intellectual disabilities

Carers spoke candidly about the limited understanding of the needs of women with severe to profound intellectual disabilities sometimes experienced in mainstream services. Parents, social care workers and nursing professionals reported that this compounded the fear and anxiety experienced by the women at screening:

> *‘People don’t take the time to explain’ (P3 Social Care Worker)*
>
> *‘Some people can deal with people with disabilities very well and other people panic internally… and they don’t know how to communicate properly and how to react to the situation’ (P3 Parent)*
>
> *‘Just because they have an intellectual disability, particularly when you mention behavioural difficulties, it sorts of shuts a door on you’ (P9 Clinical Nurse Manager 2)*

In seems then that staff in mainstream services may not have the necessary communicative skills and understanding of what an intellectual disability is to facilitate the active participation of women with severe to profound intellectual disabilities in their own healthcare decisions. The next subtheme explores issues of consent and their impact on the participation of these women in the screening programmes.

5.26.2. Consent

Although invitation letters were sent to the women from the screening programmes, nurses discussed how the ethical implications of the informed consent procedure impacted on the women’s opportunity to be part of the screening programme. A key barrier to participating in screening identified by nurses was the inability of many women with severe to profound intellectual disabilities to give the consent required to participate in the screening. This was despite the fact that the nurses were aware of the benefits of screening for the women:

> *‘They wouldn’t be able to sign consent so while we would have an awareness of the need for it, they actually aren’t able to consent’ (P25 Clinical Nurse Manager 2)*
>
> *‘Ok, we can understand and comprehend what’s going on, why it’s done, but with the learning disabilities it’s hard you know ‘(P7 Staff Nurse)*
>
> *‘Consent, first of all, because if they can’t speak how can they agree or disagree to what you’re asking to be done to them?’ (P8 Staff Nurse)*

It seems then that the informed consent process was crucially important for the woman with severe profound intellectual disabilities. The need to provide information in an accessible form tailored to the women’s communicative needs and level of comprehension is considered crucial to facilitate the women to consent. Other factors which could impact negatively on the women’s participation in the screening programme related to physical disabilities and environmental barriers.

5.26.3 Physical disabilities and environmental barriers

These carers raised concerns about challenges such as physical disabilities and environmental barriers at screening services which they perceived to have had a negative impact on the women successfully participating in the screening programmes. These nurses agreed that even the physical act of standing for the mammography procedure or indeed having another person touch her breast might be too much for the women to handle:

> *'It would be just, maybe even the physical thing of getting somebody to just stand there for long enough' (P2 Clinical Nurse Manager 2)*
>
> *'She really has severe scoliosis, so I don't know how they'd do a mammogram on her' (P7 Staff Nurse)*

This parent illustrated the difficulties experienced when she took her daughter for cervical screening due to the physical environment and lack of lifting equipment at the screening location. It was evident that parents and nursing staff were willing to go the extra mile to facilitate cervical screening for this young lady, albeit at the expense of appropriate manual handling guidance:

> *'To manoeuvre her wheel chair in and out of there has been a nightmare, to try and get her onto the examination bed, eh, you're physically lifting with nurses' (P3 Parent)*

It is evident that while physical disabilities and environmental barriers acted as formidable challenges, the women's anxieties and fears also presented huge difficulties for the women's successful participation in screening programmes. The next subtheme 'Anxiety and fear' explores the experiences of women with severe to profound intellectual disabilities who did attend a breast or cervical screening appointment through the eyes of their carers.

5.26.4. Anxiety and fear

There was a consensus among nurses who had supported the women with severe intellectual disabilities to a screening appointment experienced severe anxieties at screening appointments. The nurses agreed that this was likely related to their comprehension and communication difficulties:

> '*It's a lot harder for them to understand what is happening to them, they're afraid as well' (P21 Staff Nurse)*
>
> *'You know, they're just so frightened, that's reality' (P2 Clinical Nurse Manager 2)*

> *'It could be frightening as well, not knowing what's going to be done to them' (P8 Staff Nurse)*

This Clinical Nurse Manager gave a harrowing account of how this fear had manifested itself during the mammogram for the woman she had supported to the screening appointment:

> *'She actually pulled her breast out when they went to apply more pressure; by the second squeeze she'd had enough' (P4 Clinical Nurse Manager 2)*

It is overwhelming to imagine how a woman with severe to profound intellectual disabilities would be so scared that she would pull her breast out of the clamping mechanism on the mammography equipment. While this theme explored barriers reported to the successful participation in screening programmes for women with severe to profound intellectual disabilities, the next theme explores facilitators to screening participation suggested by the carers.

5.27. Facilitators

5.27.1. Individualised screening protocols

A key facilitating factor suggested by family and nurses alike was that the screening programmes should be individualised to the needs of women with severe to profound intellectual disabilities. They did acknowledge that the screening programmes had reasonable accommodations in place, however they proposed that these accommodations could be extended even further to meet the women's needs at screening.

First it was suggested that a designated area could be provided in the screening service for women with intellectual disabilities to help them to relax prior to the procedure. Second, a parent described how a particular day could be allocated to the needs of women with severe to profound intellectual disabilities where the relevant support, and staff cognisant to the women's needs would be available:

> *'Well, if there was a designated area in the checking service, both in breast and cervical screening, designated to people with a learning disability' (P10 Staff Nurse)*
>
> *'So if there was a day or a week where they allocated a week to have the people relevant to come in you know at that particular time where they would be seen' (P3 Parent)*

These nursing professionals explained that they felt this could go a step further to ensure the women with severe to profound intellectual disabilities were supported to make choices to have screening. They suggested that the women could have the cervical screening in the comfort of their own home or day service with the procedure carried out by a familiar nurse. As suggested by this Clinical Nurse Manager could stave off a lot of the problems associated with the women's participation in the screening programme:

> *'If they could have it at home, if somebody, the nurse, could come in their own surroundings and take the smear' (P12 Staff Nurse)*

> *'I suppose if maybe someone who knew somebody very well was shown how to do it. It would solve a lot of problems' (P2 Clinical Nurse Manager 2)*

This subtheme explored suggestions for individualising the programme for the women at a service level. The next theme examines the impact of advance preparation for the screening appointment including advance visits to the screening programme where practicable.

5.27.2. Advance preparation for screening

Carers demonstrated a tenacity to ensure that the women would be given every opportunity to participate in the screening programme. Carers suggested solutions to prepare the women for breast and cervical screening but remained cognisant of the difficulties faced in trying to achieve this:

> *'I think the preparation is really key' (P14 Clinical Nurse Manager 1)*

> *'Even a step by step before we even get to the process , you would have to introduce really slowly to a person , to even lie her down , that would be another part , do you know , it would have to be very slow the build up towards it really to try prepare her' (P8 Staff Nurse)*

> *'Maybe even a trial run to see how it goes without actually going in for the smear at all, just to see and relax in the room, and get the used to familiar surroundings' (P14 Clinical Nurse Manager 1)*

> *'And even if it takes breaking down, you know, we'll go here today and have a look today, and go back another day and get it done, you know' (P22 Student Nurse)*

The nursing staff who support women with severe to profound intellectual disabilities to screening programmes were strong advocates for advance preparation for the procedure. Trial runs and breaking down the procedure into understandable chunks for the women was considered beneficial for the women to promote successful completion of the screening procedure. The next subtheme explores the difference that support from a familiar carer makes to the woman with severe to profound intellectual disabilities successfully completing the screening procedure.

5.27.3. Support during screening

Carers revealed that despite these anxieties many women with severe to profound intellectual disabilities had successfully participated in screening. This Clinical Nurse Manager explained the importance of the support of a familiar carer to help the women with severe to profound intellectual to successfully complete the screening procedure:

> *'It's not just anybody bringing them. They need a bit of familiarity. I think that's the big crux' (P4 Clinical Nurse Manager 2)*

These nurses and Clinical Nurse Manager describe the principal strategy of carer support used to facilitate women with severe to profound intellectual disabilities to participate in cervical screening:

> *'She was really nervous you know. Two of her carers went in with her, held her hands really, really tightly' (P7 Staff Nurse)*
>
> *'We held her hand throughout the thing as well, so as to alleviate any distress for her' (P15 Staff Nurse)*
>
> *'She just wanted me to support her, she would have held my hand (P4 Clinical Nurse Manager 2)*

While this subtheme looked at personal support to help the women engage with the screening process the carers also discussed the use of sedation to help the women to comply with the procedure. The next subtheme explores the use of sedation for the procedure further.

5.27.4. The use of sedation

This nurse and Clinical Nurse Manager discussed the use of sedation as one possible intervention to help improve the cancer screening for women with severe to profound intellectual disabilities:

> *'Well, definitely, I think, it's not that they should be treated any differently than anyone else, but yet, I think there should be some little thing in place or to discuss with the family and the GP that there would be any little premed' (P7 Staff Nurse)*

> *‘They can’t consent, em, they couldn’t comply with the procedure, em, you know, they would either need sedation or, em, they’d need sedation really, I suppose’ (P25 Clinical Nurse Manager 1)*

Although this Clinical Nurse Manager cautioned that it’s not just a matter of giving a premed, a decision must have been made that cervical screening is a vital necessity for the woman with severe to profound intellectual disabilities:

> *‘The process is quite invasive eh you don’t like to premed really unless it’s a vital necessity’ (P14 Clinical Nurse Manager 1)*

A second possibility suggested was that if the woman had an occasion to need a general anaesthetic, that screening, in particular cervical screening could be undertaken at that time:

> *‘I suppose if somebody went for a general anaesthetic for something else, just to capture it’ (P2 Clinical Nurse Manager 2)*

> *‘And considering the general anaesthetic at some point if required if it was deemed that we really need to have a look you know’ (P 12 Staff Nurse)*

This theme presented the profession and family carers perspectives of the key barriers facing women with severe to profound intellectual disabilities participating in cancer screening programmes. It also described proposed interventions which could act as facilitators to improve cancer screening rates among this demographic. The next theme explores the views of the professional carers regarding the difficulties involved in engaging families about cancer awareness and screening for their female relative.

5.28. Engaging families

The carers in the intellectual disability services acknowledged that many families were reluctant to send their daughter/ sibling forward for screening as they wanted to protect her from the invasiveness of the screening procedures. There was a general consensus that this attitude was something that needed to be addressed particularly with older families as staff considered this as a hindrance to the provision of appropriate health care for the women. The day service staff felt particularly strongly that this could have negative ramifications for the woman’s health especially where the women lived at home. Three key subthemes were identified, family history, protectionism and family consent for procedures. A key issue arose in relation to the often fragmented family health histories that women with severe to profound intellectual disabilities presented with.

5.28.1. Family history

This subtheme explores the issues of family health histories, particularly breast cancer incidence in family members of women with severe to profound intellectual disabilities. These Clinical Nurse Managers discussed the importance of having a complete family history of cancer to ensure women who were considered at risk due to cancer in first degree relatives could be prioritised for screening:

> *'There was a history of cancer in the family, she had a sister who died of breast cancer, and four people in her immediate family had had breast cancer' (P4 Clinical Nurse Manager 2)*
>
> *'I suppose maybe we should say more specifically, is there a history of breast cancer in your family? You know, or really ask the question, you know. Because I think somebody like that person will be kind of focused on a little bit more, and she's probably at slightly higher risk I'd imagine. And even if these people were definitely sent for mammograms, it probably would help, I imagine' (P2 Clinical Nurse Manager 2)*

Another issue of concern discussed was the risk of breast cancer increasing with age and the need for families to provide intellectual disabilities services with relevant family health histories for the women:

> *'I would feel strongly that family give all relevant information, especially now as the age profile is getting older, and people in their family are affected by cancers' (P20 Clinical Nurse Manager 2)*

The Clinical Nurse Managers and Social Care Workers who coordinate services offered more insight into their perspectives as to why this reluctance to provide family histories. The next subtheme explores their perspectives in more detail.

5.28.2. Protectionism

The general consensus was that the parents, particularly older parents, did not access health services for their daughters unless they presented for clinical reasons which could be too late for effective early intervention:

> *'People with an intellectual disability who are living at home, the parents don't really access the services, unless their daughters actually present with clinical reasons why they need it, and generally it might be too late by then' (P9 Clinical Nurse Manager 2)*

Another issue identified by the day services Clinical Nurse Managers was that the families were not engaging with the services about facilitating screening appointments for their female relative with severe to profound intellectual disabilities:

> *'There would be a few of the girls over 25. I assume at this stage they would have got information, they would have got a leaflet about it, there's none of the families have ever said anything about it to us' (P6 Clinical Nurse Manager 1)*

The crux of the matter was reported to be that parents tended to be reluctant to accept that their daughters with severe to profound intellectual disabilities were young women and not children. In addition the parents did not see the value in putting their daughter through the trauma of a screening procedure when she was not presenting with any clinical symptoms. These parental attitudes of protectionism were felt to be a huge challenge for the services to overcome.

> *'They worry- they want to protect them' (P5 Social Care Worker)*

> *'Her parents would be elderly and, em, there's this attitude 'Sure while she's well leave her alone…Why would you be putting the cratur through that kind of an ordeal' (P17 Clinical Nurse Manager 1)*

The situation was compounded in the professional carers view when the woman with severe to profound intellectual disabilities carer was an aging father. The overall feeling was that the fathers would be very uncomfortable to be exposed to his daughter's body to observe clinical warning signs for breast or cervical cancer.

> *'And they're very. some of them are really uncomfortable with, ahm, having to get exposed to their daughter's in that way really' (P12 Staff Nurse)*

Conversely, this Clinical Nurse Manager explained that even where families acknowledged the importance of screening for their daughter or sibling and their risk of developing cancer, barriers in the community posed a formidable challenge for the women with severe to profound intellectual disabilities participating in the screening programmes:

> *'But it is not that the parents are not aware of the importance of it, it's not that they don't know it's actually happening for their daughter, because they would have consented to it. It's the barriers in the community, I would say that, but, that doesn't mean that they're not prone to developing a cancer' (P20 Clinical Nurse Manager 2)*

It appears that more engagement with families to obtain a detailed family history of cancer is necessitated to assess the risk of their daughter/ sibling developing cancer. Although it seems that even though families may be willing to accept the importance of cancer screening for their daughter/ sibling, formidable community challenges impact negatively on successful screening participation for women with severe to profound intellectual disabilities. Another concern addressed by professional carers is the practice of having familial consent for the woman with severe to profound intellectual disabilities to participate in the screening programme. The next subtheme explores the issue of next of kin consent further.

5.28.3. Family consent for procedures

Nurses reported that services often felt confined as the families had to consent to the screening procedure on behalf of the woman. However, staff recognised the quandary between fact that next of kin consent is not legally required and engaging positively with families of women with severe to profound intellectual disabilities:

> *'The girl lives at home with her parents so, em, she is over 18 but she hasn't the ability to give consent so her parents would always give consent and they didn't give consent for that procedure' (P6 Clinical Nurse Manager 2)*
>
> *'Especially if it's the smear, it can be quite invasive and they mightn't sanction it like, you know, if they didn't feel it was a necessity' (P24 Staff Nurse)*
>
> '*And it's the parents, we have to ask the parents' consent, em, signed consent from the parents or the next of kin… They're always involved anyway, every decision that we make, you know' (P11 Staff Nurse)*
>
> '*Although the National Consent Policy will tell us we don't actually need consent for any person over the age of 18 years of age from their parents. But, we, kind of, would like their support and agreement in how we carry out or provide care or assistance' (P17 Clinical Nurse Manager 1)*

It is apparent that families do decide not to allow their female relative to participate in the screening programme despite the guidance in the National Consent Policy. However, the dilemma for the nurses includes balancing the need to involve families in care decisions for the women with severe to profound intellectual disabilities with the women's right to participate in the screening programmes.

The final theme which emerged during the data analysis is the need for education for women with severe to profound intellectual disabilities, family carers, nursing and non- nursing care staff.

5.29. Education interventions

The key issues that came to light in this theme was that education was essential to improving cancer awareness and improving screening participation rates for women with intellectual disabilities. The educational needs of the following core groups will be addressed in this theme. First, carers suggested that accessible information should be provided to women with severe to profound intellectual disabilities to improve their decision making capacity about participating in the screening programmes as well as develop their understanding about cancer warning signs and risk factors.

5.29.1. Women with severe to profound intellectual disabilities

In this subtheme the carers made suggestions about useful strategies to improve the women's cancer awareness. The carers acknowledged that it may be easier to explain breast awareness to the women as the breast was a more visible part of the body than the cervix. Despite this it was accepted that is may be a very complicated process to achieve this:

> *'It's probably a little easier to explain the breast one to our ladies than the cervical one, because it's a little more obvious' (P9 Clinical Nurse Manager 2)*
>
> *'You're trying to explain like what's going to happen or whatever, but it is quite a complicated thing to explain even through picture cards or,eh, Lámh, anything like that then' (P14 Clinical Nurse Manager 1)*
>
> *'I think first of all the language use is very important. Just use ordinary simple language' (P5 Social Care Worker)*

The principal consideration in the design of an educational initiative for women with intellectual disabilities was that the programme be designed to the communicative and cognitive needs of the women with severe to profound intellectual disabilities. Among the strategies mentioned were the use of visual media and Lámh, the standardised Irish manual sign system for people with communication difficulties. The next subtheme examines the perspectives of the professional carers about engaging the families in educational initiatives about cancer and screening awareness.

5.29.2 Family carers

There was a general agreement that engaging families in educational initiatives about cancer and screening awareness was crucial to maintaining strong links between the families and the intellectual disabilities service provider. Strategies suggested by Clinical Nurse Managers included the provision of face to face group training sessions for families. This was considered essential in facilitating the families to make more informed decisions about screening for their female relative.

> *'I really think families really do need to get more information and I think it needs to be in a kind of a forum session, because, I think you can send people leaflets or can have, do you know, kind of information being sent home. But I don't think it gets the message across' (P6 Clinical Nurse Manager 1)*
>
> *'I suppose the more information they have in relation to making the decision the better' (P25 Clinical Nurse Manager 2)*

However, the professional carers also acknowledge that it was essential for themselves as a group to improve their personal knowledge of breast and cervical cancer and screening awareness. The next subtheme explores the issue of professional carers training needs further.

5.29.3. Paid carers

There was broad agreement that staff awareness levels needed to be enhanced to educate and assist women with severe to profound intellectual disabilities with regard to cancer and screening awareness. This training was considered important to ensure that the staff could explain the core issues about cancer and screening awareness to women with severe to profound intellectual disabilities and their families to enhance informed decision making about the screening programmes:

> *'Maybe even us as professionals need a little bit of training as well' (P10 Staff Nurse)*
>
> *'You know, you need to be really educated on how you would identify the triggers' (P22 Student Nurse)*
>
> *'But, maybe as staff, maybe, we all need to group too, to be brought up to date. That like, we have training on everything else, that maybe it is important to have just a few good sessions here' (P16 Staff Nurse)*

> *'I do think it would be better to train the people that work closer with them' (P5 Social Care Worker)*

> *'And try and, you know, giving education ourselves with regard to cervical smears and mammograms. But, also we could relate that back to the family members as well, and the patient, service user given their level of understanding' (P15 Staff Nurse)*

The additional need for cancer and screening awareness education for non- nursing staff such as healthcare assistant was acknowledged by nursing staff. This nurse suggested that this was important to ensure that those who were providing care for women with severe to profound intellectual disabilities were aware of cancer warning signs and risk factors. It was essential that non- nursing staff had a working knowledge about screening programme and the issues that this presented for women with severe to profound intellectual disabilities:

> *'You know, especially the care staff , they are not in the nursing field, you know, so, at least they still, if not much, at least they know about breast cancer and the cervical cancer, you know, so' (P11 Staff Nurse)*

The final comment in this conversation is left to a young student nurse who captured the essence of the need for cancer and screening awareness training for carers supporting women with severe to profound intellectual disabilities:

> *'Because if we don't understand, how the hell are we supposed to make somebody else understand?' (P13 Student Nurse)*

5.30. Chapter summary

First this chapter outlined the results of the baseline evaluation of the carers breast and cervical cancer awareness, knowledge of the risk factors for both these types of cancer, awareness and participation in cancer screening programmes and barriers to seeking medical assistance in the event of self- discovery of a symptom. Gaps in awareness levels and opinions were evident among nurses, healthcare assistants, social care workers and family carers. Nurses demonstrated higher awareness levels across the knowledge indicators than carers.

Next there was an exploration the findings of the Adapted CAM for women with mild to moderate intellectual disabilities undertaken as part of the Phase I comprehensive needs assessment. Gaps in awareness levels were detected among the women about the non- lump symptoms for breast cancer the warning signs for cervical cancer. Knowledge about the risk factors for breast and cervical cancer included the peak age of incidence for both cancers was also extremely poor. Women’s understanding about the breast and cervical screening programme was limited, although it was evident that women do participate in the screening programmes. Service barriers were most likely to impact on the woman making an appointment with a doctor to discuss a symptom they thought might be serious, although emotional barriers also had a major impact on this decision.

Finally this chapter outlined the perspectives of carers with severe to profound intellectual disabilities about the challenges facing the women with regards to cancer awareness and cancer screening programmes. Carers argued that the women faced a diverse range of barriers including physical, attitudinal and environmental barriers. It was evident that many carers believe that women with severe to profound intellectual disabilities have an entitlement to the same range of preventative health screenings as women in the general population. The next chapter explores the results of the second phase of the study.

Chapter 6: Phase II Results

6.0. Introduction

This chapter reports on the findings of the feasibility testing of the EMBRACES-ID intervention. Sections 6.1.- 6.11. present the findings from the baseline, post intervention and 12 week follow up interviews and CAM surveys with the carers who supported the women with intellectual disabilities to the intervention and participated in the intervention. Next, sections 6.12.- 6.24. examine the findings from the three interviews and CAM surveys undertaken with the women with mild to moderate intellectual disabilities who had participated in the intervention. Finally the chapter concludes with a summary in section 6.25.

6.1. Introduction to the findings of the carers EMBRACES-ID interviews and CAM survey

This section reports on the findings of the interviews and CAM surveys with the carers who participated in the EMBRACES-ID intervention. First section 6.2. describes the study accrual including the factors which impacted on retention of the carers in the study for the duration of the intervention.

6.2. Study accrual

The recruitment phase for carers of women with mild to moderate intellectual disabilities to the EMBRACES-ID intervention began in June 2014. Following the advertisement of the intervention five intellectual disabilities services in the South East region expressed an interest in participating in the EMBRACES-ID intervention. The liaison person at each of the intellectual disabilities service providers facilitated the recruitment of the carers to the intervention. Although male carers were not excluded from participating in the intervention no male carers participated. In total 9 carers participated in the EMBRACES-ID intervention.

Every effort was made to be flexible with intervention delivery, for example to facilitate holidays and data collection in intellectual disability service providers. All appointments were confirmed by email with the liaison person in the services. Despite this there was a 43.75% attrition rate among carers from the EMBRACES-ID intervention, see Table 6.1.

Table 6.1. Retention rates of carers

Study stage completed	Recruitment	Attrition
Pre-test	n=16	N/A
Post-test	n=9	7
12 week follow-up	n=9	0

The key challenge to the retention for the carers involved in the study was that the participants were third level social care students and their work placements had ceased in the intellectual disabilities service prior to completing the intervention. Service related issues such as no longer providing care support to the woman with mild to moderate intellectual disabilities attending the intervention or the woman deciding to leave the study and being on sick leave from work were also cited as reasons for attrition from the study, see Table 6.2. The time frame for undertaking the feasibility and acceptability of the intervention was from September 2014 to March 2015.

Table 6.2. Reasons for attrition for carers

Reasons given	% (n)
Alternative employment duties	12.5 (2)
Woman they support leaving the study	6.25 (1)
Illness	6.25 (1)
Returned to college	18.75 (3)

6.3. Demographic characteristics of the carers

The demographic characteristics of the carers of women with mild to moderate intellectual disabilities who successfully participated in the EMBRACES-ID intervention are presented in Table 6.3.

Table 6.3. Demographic characteristics of the carers

Demographic characteristic	**n**
Age	
50 years of age and older	2
Under 50 years of age	7
Relationship status	
Single	3
Married/ living with partner	5
Separated/ divorced	1
Employment status	
Employed full- time	7
Employed part-time	1
Student	1
Education	
Leaving Certificate or equivalent	1
FETAC Level 5 or equivalent	2
Diploma/ Certificate	1
Ordinary Degree (Level 7)	2
Honours Degree (Level 8)	1
Postgraduate Degree	2
Carer Status	
Healthcare Assistant	2
RGN	1
Social Care Worker	3
Educator	1
Student Social Care Worker	1
Service Manager	1
Personal knowledge of cancer	
Yes	9
No	0
Attended smear test	
Yes	5
No	4
Attended mammogram	
Yes	2
No	7
Number of classes attended/ total	
3 classes/ 4 classes	2
4 classes/ 4 classes	7

6.4. Qualitative data collection

Carers were invited to participate in a face to face individual interview at the baseline assessment, however, due to working arrangements just six of the carers participated in these interviews, and the three remaining carers were invited to self-complete the interview protocol at baseline assessment. Carers self-completed the post intervention and the 12 week follow up interview protocol. At the post intervention stage each carer was also requested to complete an evaluation form to test the acceptability of the intervention. Each of the digitally recorded baseline interviews was transcribed for analysis, and the self-reported interview protocol were also transcribed and imported into NVivo for analysis.

6.5. Qualitative data analysis

An exploration of the interview data was undertaken using Miles and Huberman's Framework (Miles and Huberman, 1994), and two major themes emerged from the data. The overarching themes encompassed the carers personal cancer and screening awareness and carers perspectives on the challenges which impacted on the participation of women with mild to moderate intellectual disabilities in the cancer screening programme. These themes together with their related subthemes are presented in Table 6.4., and are supported by narrative accounts of the carers perspectives in sections 6.6.-6.7.

Table 6.4. Emerging themes and subthemes from the EMBRACES-ID carers interviews.

Theme	Subtheme
Carers personal cancer and screening awareness	*Breast and cervical cancer prevention* *Understanding the purpose of cancer screening* *Post intervention awareness of warning signs*
Access to screening programmes	*Same right to screening* *Screening participation decisions* *Lack of carer screening awareness*

6.6. Carers personal cancer and screening awareness

This theme explores carers personal breast and cervical cancer and screening awareness. First it explores the carers understanding about the factors involved in breast and cervical cancer prevention programmes. Next, it examines carers understanding about the purpose of the screening programmes. Finally, it explores changes in carers awareness of the warning signs for breast and cervical cancer following participation in the EMBRACES-ID intervention.

6.6.1. Breast and cervical cancer prevention

This subtheme explores the carers knowledge about breast and cervical cancer prevention. Carers mentioned during the baseline interviews that felt that they had higher awareness levels about breast cancer prevention when compared to cervical cancer. There was a general consensus that cancer prevention only involved breast and cervical screening for early detection and treatment of cancer albeit that knowledge about the age eligibility for the screening programme was ambiguous:

> *'Not as much about the prevention maybe, it's more the signs and symptoms. I wouldn't now I'll be honest' (P2 Healthcare Assistant)*
>
> *'I know more about breast cancer than I would about cervical, like … I don't know much about cervical at all to be honest' (P3 Student Social Care Worker)*
>
> *'I know that the earlier that you can, the earlier its diagnosed the better. I don't know a lot I guess' (P6 Social Care Worker)*
>
> *'Like, I think its 25 years plus for the cervical smear tests… em,em breast cancer, if you found a change go yourself until you turn 55 or thereabouts' (P7 Social Care Worker)*
>
> *'I'm aware of sort of checking, screening and I can have a mammogram done... after the age of fifty... so I'll be having it'* (P9 Educator)

Although other carers did demonstrate an understanding of the lifestyle related risk factors for cancer in addition to the screening programmes as having an important role to play in the prevention of breast and cervical cancer during the baseline interviews:

> *'Good diet, little alcohol and screening' (P4 Service Manager)*
>
> *'Don't smoke/ drink too much alcohol; exercise regularly, go for a mammogram when called, go for cervical screening when called' (P9 Social Care Worker)*

During the post intervention interviews it was evident that the carers were more aware of the the process of cancer prevention incorporating the control of risk factors, mainly lifestyle related risk factors, in addition to being breast aware and participating in the screening programme. The lifestyle related factors mentioned were regular exercise, healthy diet, limiting alcohol intake and ceasing smoking:

> *'Exercise regularly, healthy diet, no more than one unit of alcohol per day, self-examination…help to prevent breast cancer' (P2 Healthcare Assistant)*
>
> *'Staying healthy, doing exercise, stop smoking, cutting alcohol, losing weight and being active, eating healthy can reduce your risk of getting cancer' (P3 Student Social Care Worker)*
>
> *'The earlier you find it, the better the chance of survival. It's important to do monthly self-checks and if you find something you should tell a doctor as soon as possible' (P6 Social Care Worker)*

Carers mentioned in the post intervention interview that HPV awareness needed to be promoted more among the general population as a risk factor for cervical cancer, including the importance of protected sex using condoms to reduce the risk of contracting HPV during sexual activity:

> *'HPV, this infection should be promoted more, stop smoking and have smear tests' (P2 Healthcare Assistant)*
>
> *'Having protected sex' (P3 Student Social Care Worker)*
>
> *'Use protection when having sex' (P9 Social Care Worker)*

This subtheme examined the carers knowledge about cancer risk and prevention during the baseline and post intervention interviews. It was apparent that there was improved awareness about the key elements of cancer prevention such as risk factor control and early detection of breast and cervical cancers among the carers following the intervention. The next subtheme examines the carers understanding of the purpose of the breast and cervical cancer screening programmes.

6.6.2. Understanding the purpose of cancer screening

During the baseline interviews it was obvious that the carers were very aware that the purpose of the breast screening programmes was to detect cancers at very early stages which could ultimately reduce the chance of a woman dying from breast cancer:

> *'It could help, like, if you caught it early, could help, em, prevent it, yes… because you could reduce it, like, get rid of it faster maybe' (P3 Student Social Care Worker)*
>
> *'Ahm well the earlier you catch it then you have a better chance of, of treating it sooner and before it gets bigger, and that's my opinion I guess' (P6 Social Care Worker)*

> *'Yes, because it makes people more aware of breast cancer and the screening can help identify something which may be of concern and need further testing' (P9 Social Care Worker)*

Similarly carers demonstrated a clear understanding during the baseline interviews that early detection of precancerous or abnormal cervical cells during cervical screening was essential to prevent cervical cancer developing:

> *'Yes definitely, because, em, I know say myself and friends as well we've gone before for screening for cervical cancer and it has come back sometimes with abnormal cells, which leads you again onto another test. I was fine, other people weren't. But once they had treatment, they were fine after that' (P8 Educator)*

> *'Yes, again it makes people aware of cervical cancer and the screening can identify something unusual which may need further testing' (P9 Social Care Worker)*

The awareness levels about the purpose of the breast and cervical screening programmes remained consistently high following participation in the EMBRACES-ID intervention. It was apparent that the carers opinions about the purpose of breast cancer screening were stronger in the post intervention interviews:

> *'Yes, if it is caught early there are treatments to kill the cancer' (P3 Student Social Care Worker)*

> *'Absolutely, after the course I learned what size lump the mammogram can pick up. I couldn't believe it was such a small size. If found at that size then people can get really early treatment' (P9 Social Care Worker)*

A comparable pattern was found in the post intervention interviews in relation to the carers improved knowledge about the purpose of the cervical screening programme and its role in cancer prevention and reducing mortality from cervical cancer:

> *'Yes, it can flag something unusual which may need to be investigated further… as it can take a long time (20 years- possibly) to develop into something very serious, the screening every 3-5 years can highlight something before it becomes a problem' (P9 Social Care Worker)*

Carers mentioned that their confidence about performing personal breast self-examination had improved following participation in the intervention:

> *'Had no idea how to check or do a BSE, now I know how to perform this examination' (P1 Healthcare Assistant)*

This subtheme described the carers understanding of the purpose of cancer screening at baseline interviews, and highlighted the changes in awareness levels about the screening programme and procedures following participation in the intervention. The next subtheme explores the improvements in the recognition breast and cervical warning signs that carers reported following participation in the EMBRACES-ID programme

6.6.3. Post intervention awareness of warning signs

Carers seemed confident that they were more knowledgeable about the warning signs for breast cancer and the importance of early medical intervention for self-discovered symptoms following their participation in the EMBRACES-ID intervention:

> *'I would definitely be more diligent and have a much better awareness of signs/ symptoms as well now as realising the importance of getting my breasts checked as soon as possible should I notice a change' (P2 Healthcare Assistant)*
>
> *'I feel more breast aware and have a deeper understanding of the importance of breast self-examination. I have a more holistic understanding of breast cancer (risk factors, health, signs, symptoms, treatment)' (P6 Social Care Worker)*
>
> *'I definitely have a better understanding, the changes to look out for, things which can impact on the chances of getting breast cancer' (P9 Social Care Worker)*

Similarly carers reported increased awareness about cervical cancer warning signs following the intervention, and reiterated that their baseline awareness levels were very poor:

> *'I knew nothing about cervical cancer so everything I learned was new' (P3 Student Social Care Worker)*
>
> *'I learned a lot about this, the importance of looking out for changes etc as I would not have been too sure of the symptoms' (P7 Social Care Worker)*
>
> *'Cervical cancer was the one I was probably most worried about but after the programme I am much more relaxed about it after hearing how it can be treated and so successfully treated. I'm also more aware of the things to look out for and what can affect the chances of getting cervical cancer. I had no idea smoking could have such an impact' (P9 Social Care Worker)*

This theme discussed the carers knowledge about cancer prevention including risk factor reduction and the importance screening in this process. It examined the carers understanding of the purpose of the cancer screening programmes, the important role of early detection and treatments for cancer and their impact on reduced mortality from breast and cervical cancer. It described the self-reported improvements in the awareness of breast and cervical cancer warning signs following participation in the EMBRACES-ID intervention. The next theme explores carers opinions about women with intellectual disabilities accessing the breast and cervical screening programmes in the same way as women in the general population.

6.7. Access to screening programmes

This theme first reports on the carers perspectives about access to breast and cervical screening programmes for women with mild to moderate intellectual disabilities. Next, it explores the factors the carers reported as having an impact on the participation of women with mild to moderate intellectual disabilities in the screening programme.

6.7.1. Same right to screening

Carers argued that women with mild to moderate intellectual disabilities had the same right to access cancer screening opportunities as women in the general population. They felt that women with intellectual disabilities had the right to obtain screening at the recommended screening intervals set out by the screening programmes namely every two years for a mammogram and every 3-5 years for a smear test dependant on the woman's age and previous smear test results:

> *'Because I don't know why they wouldn't get the same opportunity as every other woman, like' (P3* Student Social Care Worker*)*
>
> *'Women with ID should not be excluded from breast cancer screening because all women can develop breast cancer regardless of disability' (P6 Social Care Worker)*
>
> *'I think every person is the same, and there is no reason why the* ladies in the centre *attending our services shouldn't have screening. I think it is important for everybody to have it, and they're as important as everybody else. And again all of them are very much aware of screening as well, and they've had family members who've had cancer and that so I think it's important for them as well, definitely' (P8 Educator)*

> *'Its so important because like many women who don't have an intellectual disability – many women I don't think check their breasts. So for some the first sign that something is wrong is through the screening intervention. Also, women with intellectual disabilities may not be able to communicate a change or something wrong/ different so this can keep things in check' (P9 Social Care Worker)*

A subtle difference in carers opinions was detected when discussing equal access for women with mild to moderate intellectual disabilities to the cervical screening programme. Many carers had little reservation about the women making a choice to accessing the breast screening programme, however, this did not seem to be the case with cervical screening. These carers posed the arguments that issues of consent and presumption of sexual inactivity are valid reasons for non- participation in the screening programme:

> *'But it does depend on the person and the wishes of the person. If it is too upsetting on the woman or the lack of understanding I would say no'. (P1 Healthcare Assistant)*
>
> *'It is their right, should be supported to access. There are some people who have never been, unlikely to be sexually active and could be removed from database' (P4 Service Manager)*

While this subtheme explored the carers perspectives about women with mild to moderate intellectual disabilities having equal access to the screening programme, the next subtheme explores issues around decision making for women with intellectual disabilities accessing the screening programmes

6.7.2. Screening participation decisions

The focus of this subtheme was decision making for women with mild to moderate intellectual disabilities about participating in the breast or cervical screening programme. It was evident that carers generally agreed that women should be offered the choice to access the screening programmes:

> *'All women should be entitled to screening if it is their wishes'. (P2 Healthcare Assistant)*
>
> *'Its always their choice' (P8 Educator)*

Despite this carers raised concerns about the decision making processes for women with mild to moderate intellectual disabilities. The key issue centered on whether the women were being given the relevant information about the screening procedure and the purpose of the screening programme:

> *'It's easy to say no and I personally feel people are allowed to make this decision without being properly informed and encouraged' (P2 Healthcare Assistant)*
>
> *'Women with ID should be offered the same choices and information regarding cancer screening so that they can make an informed choice about accessing breast cancer screening like everybody else' (P6 Social Care Worker)*

Some carers considered that carers or doctors sometimes didn't provide the relevant information to the women to facilitate them to make informed decisions about participation in screening, particularly the cervical screening programme. These carers offered further insight into why they felt this was the case citing issues such as protectionism and attitudes about the sexuality of adult women with intellectual disabilities:

> *'I believe families and GP's and staff take the soft option and don't really discuss it with the client in a way that they can understand' (P2 Healthcare Assistant)*
>
> *'It's nearly a taboo still with older parents as well you know, all that comes into play' (P2 Healthcare Assistant)*
>
> *'I do wonder if all women with an ID are being given the opportunities to make an informed decision themselves, particularly around cervical smear, which is invasive and unpleasant for some women. Some parents/ carers may not want to upset the person by putting them through the ordeal but then are they putting them at further risk?' (P9 Social Care Worker)*

Although it seems some doctors do provide women with intellectual disabilities with the relevant information to enable them to make choices about participation in the screening procedure. This carer described the role of the GP in assessing whether the woman with intellectual disabilities fully understood the implications of 'opting off' the screening register. In this case the doctor was not certain that the woman understood these implications and proceeded with the cervical screening procedure:

> *'Also I have witnessed where a woman with an ID attempted to answer questions by the doctor re 'Opting out' of the cervical smear and it was very evident that the person did not fully understand. Therefore, the doctor was unwilling to have that person 'opt out' as she clearly could not make an informed decision' (P9 Social Care Worker)*

This subtheme reported the carers concerns as to who was actually making the decision about screening participation and the importance of the provision of relevant information to clarify the womens decision making process. The next subtheme examines issues which carers felt impacted on the participation of women with intellectual disabilities in the screening programme and proposed strategies to address this.

6.7.3. Lack of carer screening awareness

Although carers were supportive of the rights of women with intellectual disabilities to participate in the cancer screening programmes, a number of issues were mentioned which carers felt impacted on the womens participation in the screening programmes. This carer argued that while women with intellectual disabilities had the same need and right to access the screening programmes their participation in the programmes was dependant on the carers personal cancer and screening awareness:

> *'But I think we don't know enough about it, and maybe us as carers mightn't and families' (P2 Healthcare Assistant)*
>
> *'They have the same need and right as every other woman. However, accessibility and uptake are dependent on supporters awareness' (P4 Service Manager)*

In a similar vein carers maintained that it was important that more planning and training was involved in improving cancer and screening awareness for women with intellectual disabilities and their carers, particularly family carers:

> '*Staff should receive training in explaining to the person what is involved in the process' (P2 Healthcare Assistant)*
>
> *'Raising awareness of this with women with ID and families is so important' (P7 Social Care Worker)*

It was acknowledged that a considerable effort was required to educate women with intellectual disabilities about cancer and screening awareness. Carers contended that the provision of information in an accessible form, appropriate support structures and advance preparation for the procedure could enhance the womens knowledge and understanding about the topic:

> *'It's a must but a lot of groundwork need to be done educating people with ID' (P2 Healthcare Assistant)*

> *'Everyone understands at different levels so it is important that this information be given appropriately and with extra support in place where needed so that it is easier to obtain the recommended screening' (P6 Social Care Worker)*
>
> *'More education and preparation around the visit can help' (P9 Social Care Worker)*

One carer suggested that carers perspectives about women with intellectual disabilities not requiring breast or cervical screening needed to be challenged:

> *'Staff working with women with intellectual disabilities need to change their own mindset and views towards screening for people with ID' (P2 Healthcare Assistant)*

She went on the suggest that based on her experiences of supporting women with intellectual disabilities to medical appointments that it was necessary for doctors in mainstream services to receive training about how to communicate effectively with women with intellectual disabilities. Despite the fact that the doctor would have the medical skills to perform the screening procedure, she was adamant that successful participation by the women in the screening procedure hinged on the doctors manner of communicating with the women:

> *'In the communication methods, rather than the actual, you know, how they communicate with the person' (P2 Healthcare Assistant)*

While this section explored the findings of the carers EMBRACES-ID intervention interviews, the next section explores the descriptive results of the carers CAM administered at pre and post EMBRACES-ID intervention.

6.8. Quantitative data collection and analysis

Carers were invited to self-administer the baseline, post intervention and 12 week follow up CAM surveys. The surveys were coded and imported into SPSS for descriptive statistical analysis.

6.9. Reliability of the EMBRACES-ID carers CAM

The internal reliability of the carers CAM for the feasibility and acceptability testing of the EMBRACES-ID intervention was tested on a number of subscales during the baseline assessment. All but one of the subscales 'Barriers to seeking help' meet the recommended cut off point of 0.7 at the baseline CAM survey, see Table 6.5. As it was considered crucial to identify factors which impact on carers seeking medical assistance for symptoms they thought might be serious, the subscale ‘Barriers to seeking help’ was retained in the CAM survey.

Table 6.5. Cronbach’s α results for the EMBRACES-ID carers CAM

Scale	Cronbachs Alpha (T0)	Cronbachs Alpha (Validation study)	No. of items
Breast cancer warning signs	0.905	Not available	11
Total knowledge score Breast CAM: Warning signs, peak age incidence, awareness of screening intervention and age that its offered (first and last age)	0.867	Not available	15
Cervical cancer warning signs	0.853	0.77	11
Total knowledge score Cervical CAM: Warning signs, peak age incidence, awareness of screening and vaccination intervention, age that they’re offered	0.764	0.84	16
Barriers to seeking help	*0.468**	0.73	10

6.10. Carers personal cancer and screening awareness

The first CAM was self-administered at the baseline assessment (T0), the second CAM at post intervention (T1) and the final CAM survey was undertaken at the 12 week follow up survey (T2). As the sample size was very small (n=9) only the proportion of the carers recognising cancer warning signs and risk factors, reporting confidence to detect breast or cervical changes, and awareness of and participation in the breast and cervical screening programme, and the HPV vaccination programme are presented in sections 6.10.1.- 6.10 .8.

6.10.1. Recognition of breast cancer warning signs

This section reports on the recognition of breast cancer warning signs among the carers at each of the three measurement points T0-T2. The baseline, post intervention and 12 week follow up awareness levels are presented in Table 6.6.

A lump or thickening or thickening in the breast or armpit, and puckering or dimpling of the breast skin were the most commonly recognised warning sign for breast cancer among the carers at baseline, post intervention and at 12 week follow up. Recognition of the non- lump warning signs redness of the breast skin and nipple rash was much lower at the baseline CAM survey, with less than half the participants recognising these as warning signs for breast cancer.

However, following the EMBRACES-ID intervention knowledge about these warning signs doubled among the carers. For the remainder of the target warning signs it was evident that participation in the intervention improved awareness of the breast cancer warning signs.

Table 6.6. Recognition of breast cancer warning signs

Warning sign	**T0 (n=9)**	**T1 (n=9)**	**T2 (n=9)**
Lump or thickening in the breast	8	9	9
Lump or thickening under the armpit	8	9	9
Puckering or dimpling of the breast skin	8	9	9
Discharge or bleeding from the nipple	7	8	8
Changes in the size of breast or nipple	7	8	6
Change in position of the nipple	7	7	8
Pulling in of the nipple	6	9	9
Pain in one of the breasts or armpit	6	9	9
Changes in the shape of the breast or nipple	6	8	8
A nipple rash*	**4**	**9**	**8**
Redness of the breast skin *	**4**	**8**	**9**

6.10.2. Breast self- examination and the confidence to detect breast changes

This section examines changes in the carers confidence and skills to detect a breast change following their participation in the EMBRACES-ID intervention. The results are presented in Table 6.7.

Table 6.7. Confidence and skills to detect a breast change

Confidence and skills to detect a breast change	**T0 (n=9)**	**T1 (n=9)**	**T2 (n=9)**
Breast confidence (Very/ fairly)	7	8	9
Breast self- examination (weekly/ monthly)	5	5	6

There was a small change in the number of carers reporting that they felt they had the confidence and skills to detect a change in their own breast at the post intervention and 12 week follow up CAM surveys. In particular at the 12 week follow up survey all carers were confident that they had the relevant skills to notice a change in their own breast.

There was a change in attitude detected towards regular breast self- examination to become more familiar with how your breast should look and feel detected at the 12 week follow- up CAM assessment. Nonetheless almost one third of the carers demonstrated no change in attitude towards breast self-examination following participation in the EMBRACES-ID programme despite reporting that they felt more confident that they would notice a change in the own breast.

6.10.3. Breast cancer risk factors awareness

This section reports on the carers awareness about impact of a range of non- modifiable and lifestyle related risk factors which may increase the chance of developing breast cancer, see Table 6.8.

The carers were very knowledgeable that a genetic or family history of breast cancer and a personal history of breast cancer could increase a woman’s risk of developing breast cancer. However, it was evident at the baseline CAM survey that carers awareness of the other non-modifiable risk factors related to early menarche and late menopause was much lower. Although good knowledge gains about these two risk factors were noted in the post intervention survey, the awareness levels had dropped slightly in the 12 week follow- up period. There was extremely poor awareness among the carers of the increasing risk of breast cancer with age which remained persistently low across the three CAM surveys. The majority of carers reported that they believed a 50 year old woman most likely to get breast cancer.

Table 6.8. Level of agreement about breast cancer risk factors

Risk factors	**T0 (Strongly agree/ agree) (n=9)**	**T1 (strongly agree/ agree) (n=9)**	**T2 (Strongly agree/ agree) (n=9)**
Non modifiable risk factors			
Having a past history of breast cancer	9	9	9
Having a close relative with breast cancer	8	8	9
Starting your periods at an early age	2	6	4
Having a late menopause	1	5	3
Age and breast cancer risk (70 years and older)	1	0	0
Lifestyle related risk factors			
Drinking more than one unit of alcohol a day	6	8	9
Being overweight (BMI over 25)	6	7	9
Using HRT	3	8	8
Having children late in life or not at all	3	4	5
Doing less than 30 minutes of moderate physical activity 5 times a week	2	8	6

There were relatively high awareness levels about the breast cancer risk associated with alcohol intake about recommended daily limits and being overweight identified in the baseline carers CAM survey. Baseline knowledge about the association between lifestyles with poor levels of physical activity and the increased risk of breast cancer was very poor, Similarly, awareness about nulliparity or having a first child later in life was also poorly recognised as a risk factor for breast cancer in the baseline CAM interview.

Awareness about the breast cancer risk factors was found to be higher for each of the risk factors in the post-intervention carers CAM. Many carers remained unsure about the risk associated with nulliparity or having children later in life and breast cancer. Fluctuations in carers knowledge about breast cancer risk factors were evident in the 12 week follow up CAM for a number of risk factors, see Table 6.8, which may have been affected by the administration of the CAM on multiple occasions.

6.10.4. Breast screening programme awareness and participation rates

This section examines changes in the carers awareness levels about the National Breast Screening Programme from the baseline CAM assessment. The results are reported in Table 6.9.

Table 6.9. Screening programme awareness

Screening programme awareness	**T0 (n=9)**	**T1 (n=9)**	**T2 (n=9)**
Aware of BreastCheck programme	8	9	9
First mammogram at 50 years of age	5	8	7
Attended mammogram	2	2	2

Knowledge about the screening programme was high prior to the commencement of the intervention and improved marginally following the intervention. At the baseline CAM assessment it was obvious that awareness about the age eligibility for the first invitation to have a free mammogram i.e. 50 years of age was lower (n=5), but did improve slightly following the intervention. Both the carers who were aged 50 years of age or older and were eligible to participate in the screening programme reported that they had taken the opportunity to have a mammogram when invited by BreastCheck.

6.10.5. Recognition of cervical cancer warning signs

This section reports the results of the baseline CAM survey to assess the pre- intervention awareness about cervical cancer warning signs among the carers. It also presents the results of the post intervention and 12 week follow up CAM surveys to monitor for any changes in carers awareness of cervical cancer warning signs following participation in the EMBRACES-ID intervention, see Table 6.10.

Carers overall awareness of the warning signs for cervical cancer did improve following participation in the EMBRACE-ID intervention, see Table 6.10. The largest improvements in awareness were found in relation to the following cervical cancer warning signs: persistent pelvic pain that lasts for three weeks or longer, vaginal bleeding after the menopause and menstrual periods that that are heavier or longer than usual.

The carers awareness about the warning signs for more advanced cervical cancer i.e. blood in the stool or urine and persistent diarrhoea that lasts for three weeks or longer were observed to be very poor at the baseline assessment (T0). The awareness levels remained relatively low at the post intervention survey (T1) among the carers. Moderate gains in awareness levels about these warning signs were noted in the 12 week follow up CAM assessment (T2).

Table 6.10. Awareness of cervical cancer warning signs

Warning sign	**T0 (n=9)**	**T1 (n=9)**	**T2 (n=9)**
Discomfort or pain during sex	7	9	9
Vaginal bleeding between periods	6	9	9
Persistent vaginal discharge	6	9	9
Vaginal bleeding during or after sex	6	9	9
Persistent lower back pain	6	9	9
Unexplained weight loss	6	5	8
Persistent pelvic pain	5	9	9
Vaginal bleeding after the menopause	4	8	9
Menstrual periods that are heavier or longer than usual	2	7	8
Blood in the stool or urine *	**2**	**4**	**6**
Persistent diarrhoea*	**1**	**2**	**6**

Despite this one third of the carers remained unaware of these warning signs for more advanced cervical cancer.

6.10 6. Confidence to notice a cervical change

This section examines whether there were any changes in the carers opinions about their ability to notice a cervical cancer change from the baseline CAM assessment to the post- intervention and 12 week follow-up CAM surveys. The results are presented in Table 6.11.

Less than half the carers mentioned that they would be confident that they would notice a cervical cancer change in the baseline CAM assessment. The carers confidence to notice a cervical change greatly improved following participation in the EMBRACES-ID intervention. Each of the carers reported that they were confident that they would notice as cervical change following the intervention.

Table 6.11: Confidence to notice a cervical change

Confidence notice a cervical change	**T0 (n=9)**	**T1 (n=9)**	**T2 (n=9)**
Cervical confidence (Very/ fairly)	4	8	9

6.10.7. Cervical cancer risk factor awareness

This section monitors changes in the carers knowledge about risk factors in the pre and post intervention CAM surveys, the results are shown in Table 6.12.

‘Not going for regular smear tests’ to pick up early changes in cervical cells was the most common risk factor mentioned by the majority of the carers during the three CAM surveys, see Table 6.12. Carers equally endorsed the risk associated with HPV infection and being a smoker at the baseline and post intervention CAM surveys, although slight gains in awareness levels were observed in the 12 week follow up CAM survey.

Just over half of the carers were aware that the long term use of the contraceptive pill could increase the risk of a woman developing cervical cancer at the baseline CAM survey. A good improvement in the awareness of this risk factor was detected in the post intervention and 12 week follow up CAM surveys. Almost half the carers mentioned that women in the age group 30- 49 years of age were most like to develop cervical cancer in the next year at the baseline CAM survey. Following participation in the EMABRACES-ID intervention it was evident during the post intervention and 12 week follow up CAM surveys that the majority of carers were of the opinion that a woman of any age could develop cancer.

Just one third of the carers were aware that infection with chlamydia, having many sexual partners and having a partner who had many previous sexual partners were risk factors that could increase a woman’s chance of getting cervical during the baseline CAM assessment.

There were good knowledge gains detected in the post intervention and 12 week follow up CAM surveys with a larger proportion of the carers agreeing that these were risk factors for cervical cancer.

Table 6.12. Level of agreement about cervical cancer risk factors

Risk factors	**T0 (Strongly agree/ agree) (n=9)**	**T1 (Strongly agree/agree) (n=9)**	**T2 (Strongly agree/ agree) (n=9)**
Not going for regular smear tests	8	9	9
Infection with HPV	7	7	9
Smoking any cigarettes at all	7	7	8
Long term use of the contraceptive pill	5	9	8
Age and cervical cancer incidence (30-49 years)*	**4**	**1**	**1**
Infection with chlamydia	3	8	7
Having many sexual partners	3	7	7
Having a sexual partner with many previous partners	3	6	5
Having a weakened immune system	2	5	6
Starting to have sex at a young age (before the age of 17)	2	5	5
Having a sexual partner who is not circumcised	0	4	3
Having many children	0	2	3

Baseline awareness levels were extremely low, with few carers recognising having a weakened immune system, early sexual activity, male circumcision status and parity were risk factors for cervical cancer. The knowledge gains for these risk factors were observed to the low to moderate in the post intervention and 12 week follow up CAM surveys.

6.10.8. Cervical screening and HPV vaccination programme awareness and screening participation rates

This section explores the carers knowledge about the National Cervical Screening Progamme, CervicalCheck and self-reported participation rates in the screening programme at the three measurement times. It also describes the carers knowledge about the schools based HPV

Vaccination programme in Ireland during the three CAM assessments. The results are displayed in Table 6.13.

Table 6.13. Screening awareness and participation rates and HPV vaccination programme awareness

Screening programme awareness	**T0 (n=9)**	**T1 (n=9)**	**T2 (n=9)**
Aware of CervicalCheck programme	7	9	9
First smear test offered at 25 years of age	3	8	8
Attended cervical screening	5	5	5
Aware of HPV vaccination programme	5	8	8
Age HPV vaccination first offered	2	5	5

The National Cervical Screening programme offers free smear tests at recommended screening intervals since 2008. The majority of carers demonstrated awareness of the screening programme in each of the CAM surveys. Despite this baseline awareness that a woman was first offered an invitation to attend the programme at 25 years of age was low, although improved awareness was detected at the post intervention and 12 week follow up CAM surveys. Eight of the carers had been age eligible to attend the cervical screening programme, aged between 25 and 60 years. Almost two thirds of these carers (62.5%) reported that they had taken to opportunity to attend for the smear test at each of the CAM assessments.

There were changes detected in the carers awareness of the HPV vaccination programme which has been implemented in Ireland since 2010 and is offered to young girls in the first year of secondary school in the post intervention and 12 week follow up CAM surveys. The majority of carers demonstrated awareness of the HPV vaccination programme and almost two thirds of the carers were aware of the age profile of the recipients of the vaccine.

6.11. Barriers to seeking help

It was evident at each of the CAM assessments that the majority of carers would seek medical intervention for a self-discovered symptom of breast cancer within two weeks. However, the baseline assessment found that carers were more reluctant to seek help for a cervical cancer symptom they thought might be serious. Changes in these opinions were detected in the post intervention and 12 week follow up interview with the majority of carers reporting that they would be more likely to seek medical advice within two weeks, see Table 6.14.

Table 6.14. Seek medical intervention within two weeks

Seek help <2 weeks	**T0 (n=9)**	**T1 (N=9)**	**T2 (n=9)**
Breast symptom	7	7	8
Cervical symptom	5	9	8

Carers were asked about their anticipated time to delay seeking medical intervention for a symptom they thought might be serious in each of the three CAM surveys. Their opinion about which emotional, practical and service related barriers might influence their medical help seeking for a this perceived serious symptoms was also assessed in each of the three CAM surveys The results of the baseline assessment and the post intervention and 12 week follow up assessments are presented in Table 6.15.

The most common barriers to seeking help mentioned by carers during the baseline survey were being worried about what the doctor might find (n=6) or too scared (n=6) to discuss breast or cervical health with the doctor. There was a decrease in the carers mentioning both these emotional barriers as influencing their decision to seek early medical intervention at the post intervention survey. Despite this in the 12 week follow up survey proportion of carers citing being worried about what the doctor might find and being too scared as the principal challenges they perceived as delaying early medical help seeking for a symptom they thought might be serious were identical to baseline results.

Carers (n=7) reported they felt confident that they could talk to the doctor about a symptom they thought might be serious during the three CAM surveys. However, two carers remained unconfident that they could discuss a breast or cervical change they thought might be serious following participation in the EMBRACES-ID intervention.

Carers reported in each of the three CAM surveys that service related and practical barriers remained were less likely to act as barriers to them seeking medical help for a symptom they thought might be serious. Despite this around one third of the carers mentioned that worry about wasting the doctors time would have an impact on their help seeking activities during the baseline CAM assessment and this remained relatively constant at the post intervention and 12 week follow up CAM survey.

Table 6.15. Barriers to seeking help

Barriers to seeking help **Yes (n)**	**T0 (n=9)**	**T1 (n=9)**	**T2 (n=9)**
Emotional barriers			
Worried about what the doctor might find	6	4	6
Too scared	6	5	6
Too embarrassed	5	4	2
Confident to talk about symptom	2	2	2
Practical barriers			
Too busy	3	2	3
Other things to worry about	0	1	2
Service barriers			
Worried about wasting the doctor's time	3	4	3
Difficult to make an appointment	2	1	2
Doctor difficult to talk to	0	2	2

While this section reported the findings of the EMBRACES- ID carers interviews and CAM results, the next section explores the findings of the interviews with the women with mild to moderate intellectual disabilities who participated in the EMBRACES-ID intervention.

6.12. Findings for women with mild to moderate intellectual disabilities interviews and CAM survey

This section reports on the findings of the interviews and CAM surveys with the women with intellectual disabilities who participated in the EMBRACES-ID intervention. First section 6.13. describes the study accrual including the factors which impacted on retention of the women in the study for the duration of the intervention.

6.13. Study accrual

The recruitment phase for women with mild to moderate intellectual disabilities for the EMBRACES-ID intervention also commenced in June 2014. The liaison person at each of the intellectual disabilities service providers facilitated the recruitment of the women to the intervention. In total 25 women with mild to moderate intellectual disabilities participated in the interview and were invited to have a keyworker or family member present at the interview. Most women declined the invitation to have a keyworker or family member present due to the sensitive nature of the topics discussed.

Every effort was made to be flexible with intervention delivery e.g. to facilitate holidays and data collection in intellectual disability service providers. All appointments were confirmed by email with the liaison person in the services. The intervention facilitator had experience working and communicating with people with intellectual disabilities. These were important strategies used to ensure good participation and retention in the EMBRACES-ID intervention. Despite this there was an attrition rate of 28.5% among women with mild to moderate intellectual disabilities from the EMBRACES-ID intervention, see Table 6.16.

Table 6.16. Retention rates of women with mild to moderate intellectual disabilities

Study stage completed	**Recruitment**	**Attrition**
Pre-test	n=35	N/A
Post-test	n=25	10
12 week evaluation	n=25	0

The key challenge to retention for three of the women was related their communication difficulties. These women had difficulties with their expressive language and made the decision to withdraw from the intervention. Two women cited embarrassment and fear of the course content as instrumental in their decision to leave the intervention. Lack of interest in the course material, issues related to the co-signing of the consent form by a family carers and developing an illness were other factors cited which impacted on the retention of the women in the programme. Two women had to withdraw from the programme due to staff unavailability and a respite from home placement, both of which impacted on the women being able to secure transport to and from the programme for the four week time frame, as shown in Table 6.17.

Table 6.17. Reasons for attrition of women with mild to moderate intellectual disabilities

Reasons given	**% (n)**
Communication difficulties	30 (3)
Embarrassment/ fear of course content	20 (2)
Issues of consent	10 (1)
Lack of interest	10 (1)
Illness	10 (1)
Respite	10 (1)
Lack of staff support	10 (1)

6.14. Demographic characteristics of women with mild to moderate intellectual disabilities

The demographic characteristics of the women with mild to moderate intellectual disabilities who successfully participated in the EMBRACES-ID intervention are presented in Table 6.18.

6.15. Qualitative data collection

Each interview lasted 15-20 minutes. The interview questions were framed by the interview guide at the pre-test, post intervention and 12 week interviews. In the post intervention interview the women were also invited to evaluate the acceptability of the interventions and materials used. Each of the digitally recorded interviews was transcribed for analysis. Once again the time frame for undertaking the feasibility and acceptability of the intervention was from September 2014- March 2015.

Table 6.18. Demographic characteristics of women with mild to moderate intellectual disabilities

Demographic characteristic	n	%
Age		
40 years of age and older	13	52
Under 40 years of age	12	48
Relationship status		
In a relationship	2	8
Single	23	92
Employment status		
Part-time	9	36
Sheltered workshop	15	60
Retired	1	4
School type		
Special	21	84
Mainstream	4	16
Living arrangement		
Family	17	68
Community group home	8	32
Personal knowledge of cancer		
Yes	21	84
No	4	16
Attended smear test		
Yes	7	28
No	18	72
Attended mammogram		
Yes	5	20
No	20	80
Number of classes attended/ total		
3 classes/ 4 classes	8	32
4 classes/ 4 classes	17	68

6.16. Qualitative data analysis

An exploration of the data in the individual interviews using Miles and Huberman's framework (Miles and Huberman, 1994) resulted in five themes including the womens personal knowledge about cancer and screening; challenges associated with their participation in the screening programmes; the role of the carers as facilitators of access to healthcare and finally the womens perspective on communicating with the healthcare professional at medical appointments These emerging themes together with the subthemes identified within each theme are presented in Table 6.19., and are endorsed by narrative accounts of the womens perspectives in sections 6.17.-6.20.

Table 6.19. Emerging themes and subthemes from the women with intellectual disabilities

Theme	Subtheme
Personal knowledge about cancer and screening	*Knowing somebody with cancer* *Cancer prevention* *Warning signs and risk factor awareness* *Understanding of the purpose of screening* *Early help seeking for a cancer symptom*
Factors affecting participation in the screening programme	*Invitations and recall to the screening programme* *Reasons for non- participation in the cervical screening programme* *Personal experience of the screening tests*
The role of carers	*Reliance on carers to make medical appointments* *Carers support for primary care and screening*
Communication with the doctor	*Talking to the doctor* *Preference for a female health care provider*

6.17. Personal knowledge about cancer and screening

This theme explores the personal understanding of women with mild to moderate intellectual disabilities about cancer and screening. The first subtheme explores the womens personal knowledge of knowing someone with a cancer diagnosis. The second subtheme peruses the women's understanding of cancer prevention. The next subthemes explores the confidence of women with intellectual disabilities to notice a cancer warning sign, their cancer risk factor awareness and their understanding about the purpose of cancer screening programmes. The final subtheme explores the womens perspectives about seeking early medical intervention on for a self-discovered cancer symptom.

6.17.1. Knowing somebody with cancer

During the pre-test interviews it was apparent that women with mild to moderate intellectual disabilities were generally aware that people do get ill from cancer, and that cancer can be diagnosed in different parts of the body. The women demonstrated awareness that people with a cancer diagnosis might die, and some of the women disclosed that they had experienced the illness or death of a parent from cancer. There was also awareness that people can recover from a cancer diagnosis with treatment:

> *'My Mum had bowel cancer, years and years ago, thank God she got the all clear' (P4 Pre-test)*
>
> *'And my sister, she had breast cancer… she had breast cancer removed'* (P14 Pre-test)
>
> *'And my, my Daddy he had cancer… he's dead' (P23 Post intervention)*
>
> *'My Mammy had it, she got sick… She has,em, the breast' (P25 Pre-test)*

Women with intellectual disabilities were exposed to media representations of cancer in programmes such as current affairs programmes and cancer diagnoses in soap opera characters. Women described how their baseline cancer awareness levels were influenced by the media:

> *'Ah Brenda in, in, in Emmerdale' (P6 Pre-test)*
>
> *'I follows them all on the telly... I likes watching, you know, the programmes that do be often on, you know, Morning Ireland, if I could watch it '(P11 Pre- test)*
>
> *'I'd usually watch the programmes that explain and talk about cancer and other things' (P19 Pre-test)*

During the interviews women provided insight into how women with intellectual disabilities are frightened by the thoughts of a cancer diagnosis. During the baseline interviews it was noted that the genetic link to cancer seemed to be generally misunderstood by women with intellectual disabilities. It is apparent that women may have assumed that only one person in a family could receive a diagnosis of cancer:

> *'It frightens you cancer doesn't it...it does though, it frightens me anyway'* (P11 Pre-*test)*
>
> *'No my family don't get that, just my mother that's all, not the rest of them' (P20 Pre-test)*

In the post intervention interviews the majority of women with intellectual disabilities reported that they didn't drink alcohol or smoke. Women seemed to misunderstand their risk of developing cancer in the future due to their present health status. Knowledge about non-lifestyle related risk factors for breast and cervical cancer remained persistently poor:

> *'I don't drink alcohol, I don't smoke at all either, that's bad for you' (P4 12 week)*
>
> *'Well I don't have that cervical cancer' (P9 12 week)*
>
> *'But touch wood now, I'm alright'* (laughs) *(P13 12 week)*

While this subtheme explored the womens perspectives on the fear that the word cancer evokes, it also looked at the misunderstanding among the women about their own risk of developing cancer in the future. The next subtheme explores the womens understanding about cancer prevention.

6.17.2. Cancer prevention

This subtheme explores the changes in opinion about how much women understood about cancer prevention as a result of completing the EMBRACES-ID intervention. It is apparent that women did not associate reducing exposure to modifiable risk factors for cancer and participation in screening programme to promote earlier detection of cancer as factors involved in cancer prevention:

> *'Em, I don't really know anything about that' (P7 Pre-test)*
> *'I learned everything about mammograms, everything really' (P7 Post intervention)*
>
> *'I heard of it, but I wouldn't like understand some of it, I understand a bit of it' (P11 Pre-test)*
> *'If you notice a change go to the doctor as soon as possible, don't be embarrassed, talk about it' (P11 Post intervention)*
>
> *'Not much, nothing really' (P13 Pre-test)*
> *'Em, do you know, em, your, the breast and your, em, where the cancer would be.. go to the doctor'(P13 Post intervention)*

Other women reported no changes in opinion about what they understood about cancer prevention after participating in the programme, which may be attributed to their cognitive difficulties:

> *'No, I don't' (P6 Pre-test)*
> *'I don't know what' (P6 Post intervention)*

The majority of the women associated cancer prevention with developing symptoms of cancer which required urgent medical attention. While this is essential to earlier diagnosis and more successful treatment, it is only part of the area of cancer prevention. This subtheme explored changes in the womens understanding about the purpose of cancer prevention before and after participating in the programme. The next subtheme examines the womens knowledge about cancer warning signs and risk factors for cancer.

6.17.3. Warning signs and risk factor awareness

Women demonstrated a greater understanding about their confidence levels to notice a breast or cervical cancer symptom following their participation in the EMBRACES-ID intervention:

> *'Yes I'd, it'd be bright red sure beside your nipple, of course you'd notice it.. even if you wore glasses you'd notice a change' (P4 12 week)*
>
> *'I would know if, I would know if there was a problem' (P5 12 week)*

However, women who are on contraception mentioned that they did not routinely get periods. These women felt that they were not very confident that they would notice a cervical cancer symptom.

> *'I don't know because I'm on the bar' (P12 Post intervention)*
>
> *'I used to have the Mirena for five year' (P22 12 week)*

Women were asked if they thought pain or discomfort during sex might be a sign of cervical cancer. Their answers suggested that the women may not understand that women may have sex with men who are not their husbands:

> *'Em, Husband and wife'* (P9 Post intervention)

Even after participating in the intervention the women remained embarrassed about discussing sexual activity. It was not uncommon for the women of all ages to laugh or smile in response to the questions about pain or bleeding during or after sex or the illustrations in the CAM to cover their embarrassment:

> *'No, Jesus, not really' (smiling widely) (P6 Post intervention)*
>
> *'No that, that wouldn't be true anyway, how can you have pain if you're having sex' (laughs) (P7 12 week)*

Despite this risk factor awareness levels were much higher among the group especially in relation to the lifestyle related and genetic risk factors for cancer following participation in the intervention:

> *'Well I, well if you smoke too much you might get cancer' (P5 12 week)*
>
> *'Em, it's easy to get breast cancer when they're smoking or you're, I heard when you're eating the wrong things' (P14 Post intervention)*
>
> *'If it ran in the family, eating the right stuff' (P15 Post intervention)*
>
> *'And drinking Guinness and smoking' (P17 12 week)*

Despite this women continued to confuse treatment options for breast and cervical cancer with risk factors for cancer following the intervention:

> *'Em, she had breast cancer but she her two breasts off' (P1 12 week)*
>
> *'They would lose the breast' (P7 12 week)*
>
> *'The hair would be coming out' (P9 12 week)*
>
> *'My Mom mentioned it, em, chemotherapy everything' (P16 12 week)*

This subtheme examined the womens understanding of cancer warning signs and risk factors at baseline and following their participation in the intervention. The next subtheme examines the womens perspectives on purpose of cancer screening.

6.17.4. Understanding of the purpose of screening

The womens views were ascertained on whether they understood the purpose of cancer screening and whether it could reduce the chance of somebody dying from breast or cervical cancer. This subtheme looks at changes in awareness levels between baseline and post intervention knowledge about the purpose of cancer screening.

At baseline women demonstrated very limited understanding about cancer screening and knowledge about the purpose of screening was equally limited as a result. Changes in awareness levels were found at the post intervention stage, with women demonstrating a higher awareness that screening could identify cancer at very early stages:

> *'You get up on a thing, it's like an xray' (P11 Pre- test)*
>
> *'If found early, could get treatment to stop it from spreading' (P11 Post intervention)*

> *'To see the, if see do they have, see, the, the, the, what do you call it, the…' (P12 Pre-test)*
> *'Because it's good for you to know if you have lumps on your boobs, or lumps anywhere else' (P12 Post intervention)*
> *'Well you mightn't survive it… and you get the thing taken off…your breast (P15 Pre-test)*
> *'Yes, because I would catch it in time if it was there' (P15 Post intervention)*
> *'No' (P18 Pre-test)*
>
> *'To get a check up and get looked at, you might want to know if you've got cancer' (P18 Post intervention)*
>
> *'No, I never heard of that before, no' (P20 Pre-test)*
> *'It saves a person's life' (P20 Post intervention)*

Very few women had an understanding of the purpose of screening prior to the intervention. It seemed that their knowledge about the purpose of screening was also improved by attending the intervention:

> *'It could tell if you have it, or it could tell that you might get it, that's what, ain't it' (P21 Pre-test)*
> *'Well it, it, the smears test would tell if you have it or not… the changes I think' (P21 Post intervention)*

Despite improvements in awareness levels some women remained confused and continued to misunderstand the reasons behind cancer screening even though they had completed the EMBRACES-ID programme:

> *'Em no, if they just went for the checkup it might save their life, they might be able to take out the tumour straight away' (P1 Pre-test)*
> *'Because, because some of them gets it bad and it comes back' (P1 Post intervention)*
>
> *'No, I don't think so' (P7 Pre-test)*
> *'Em, as long as they get their treatment they would be, yes' (P7 Post intervention)*

Women seemed aware that they had the opportunity to make choices about participating in their own healthcare decisions with regard to participating in the breast and cervical cancer screening programme:

> *'It's their own lives and, they, they should have a choice' (P4 12 week)*
>
> *'I think they would be advisable to them' (P7 12 week)*
>
> *'I think all women should get it done in case they have a lump in the breast or there is something wrong down below' (P15 Post intervention)*

Women with intellectual disabilities were adamant that they had the same right as other women to participate in the screening programme:

> *'They have every right, the same as everybody else and equal' (P11, Post intervention)*
>
> *'It is very important as bad cells and lumps can be seen' (P24 12 week)*

A distinction between women with intellectual disabilities and members of staff at the intellectual disabilities services providers was detected. Women were unsure whether staff also had to go to screening appointments:

> *'Yes they should go their self and staff' (P9, 12 week)*
>
> *'Not just women, but do every, I know we're all women and I know we're all human, but, do every staff get called' (P20 Post intervention)*

This subtheme explored the opinions of women with mild to moderate intellectual disabilities about the purpose of screening including changes in awareness levels following participation in the EMBRACES-ID intervention. The next subtheme explores the womens attitudes about early help seeking for a cancer symptom.

6.17.5. Early help seeking for a cancer symptom

A few women mentioned at the baseline intervention that they would make an appointment straight away if they had a symptom they thought might be serious:

> *'I'd tell my first cousin, and my first cousin would bring me to the doctor' (P11, Pre-test)*
>
> *'As, as soon as, as soon as possible as I find it because I wouldn't like it to get bigger and bigger' (P18 Pre-test)*

Some of the women who were unsure how soon they would seek medical intervention for a self-discovered cancer symptom at baseline interview demonstrated changes in opinions after the intervention. Women were more confident that they would contact their doctor to discuss a symptom they thought might be serious during the post intervention interviews:

> *'Eh em, I'd contact him at the last minute' (P1, Pre-test)*
> *'Go straight away' (P1, 12 week)*
>
> *'Don't know' (P5, Pre- test)*
> *'I think you might have complications so I think you should go to the doctor (P5, 12 week)*
>
> *'I don't know' (P7, Pre-test)*
> *'I'd go straight away' (P7, 12 week)*

However other women demonstrated no change in opinion. They remained really embarrassed about discussing issues about their breasts or cervical health with a doctor despite participating in the EMBRACES-ID intervention:

> *'Private stuff' (P22 Pre-test)*

A small group of women appeared to have confusion about the concept of time which may impact on their ability to seek early intervention for a self-discovered symptom of breast or cervical cancer:

> *'Eh once a day' (P6 Post intervention)*
>
> *'One a month' (P3 12 week evaluation)*

The majority of women with mild to moderate intellectual disabilities indicated that they would seek medical intervention as soon as possible for a symptom of breast or cervical cancer. The next theme explores factors which impact on participation in the breast and cervical screening programmes from the perspectives of women with mild to moderate intellectual disabilities.

6.18. Factors affecting participation in the screening programme

A number of factors were identified which women with mild to moderate intellectual disabilities which impacted on their participation in the screening programme including invitations and recall to the programme, reasons for non- participation in the programmes, personal experience of the screening test and understanding the screening test results.

6.18.1. Invitations and recall to the screening programme

This subtheme explores the womens experience of being invited to and attending the smear test. Some women were not aware if they had received a letter to invite them to screening. Literacy and language barriers were also mentioned as factors which had an impact on their knowledge as to whether they had received a letter or not:

> *'I'm not sure if I got a letter' (P13 Post intervention)*
>
> *'I might…I don't know how to spell sm-smear test' (P18, 12 week)*

Other women discussed their reactions to receiving the invitation letters from CervicalCheck. They perceived that if they hid the letter the invitation would go away, and offered insight into the womens fear at the thought of the smear test. The use of the word 'we' highlighted the dependence of women with intellectual disabilities on carers to facilitate them to access healthcare:

> *'Ah yes, but I tried to put it in by the fire because every time I got one, not strike the match but, umm'(P2 12 week)*
>
> *'I did , and I fecked it in the bin, I fecked another one, and then they kept sending them in , and then we had to go in the end' (P4 Pre-test)*

The screening interval in Ireland for the BreastCheck programme is approximately two years (21-27 months). These women who had attended mammography in the past suggested that they seem to be slipping through the net as their recall for mammography was longer than the specified time:

> *'I changed house, you see, and I got do you know the Breastcheck, I haven't got one this four year and C told, rang up, rang 'em up and she said 'We sent out letters'. I never got one' (P11 Pre-test)*
>
> *'I notice now, I notice now they don't, em, now, you know, call you back' (P17 Post intervention)*

The next subtheme explores challenges women with intellectual disabilities perceived to have a negative impact on their participation in the cervical screening programme.

6.18.2. Reasons for non- participation in the cervical screening programme

It seems that doctors do not just opt the woman off the screening register without first checking with the woman as to whether she is sexually active. Despite this no consideration appeared to have been given as to whether the women ever had sex with a woman or any other established risk factors for cervical cancer:

> *'I got a letter a few times, but I didn't go, because the doctor said I don't need to go... because I didn't have a baby, you see' (P1 Post intervention)*
>
> *'Went in and told them I never had sex, but they said 'You can't get it done then' (P12 Pre-test)*
>
> *'She said 'Did you ever have sex?' and I said 'No'… never, in my life'… because she wrote down and said 'No, you don't have to get it done' (P15 Pre-test)*

It is clear that this woman's decision not to have the smear test was based on the advice given to her by a healthcare professional. However, the conversation centered on whether the woman had experiences heterosexual sex and not on any other risk factors for cervical cancer:

> *'I, they wanted to know if I had sex with my boyfriend, and I said I didn't, and so I didn't take it' (P7 12 week)*
> *'And was that your choice not to take it?' (Interviewer)*
> *'No, they advised not to' (P7 12 week)*

This lady attended for a smear test with a family caregiver, and in this case the doctor took the time to explain to the woman her reasons as she felt the woman didn't require a smear test:

> '*She said it wouldn't be a very nice experience for me, so she said I wouldn't put you through it… And when you haven't, when you haven't had sex, like, there's something up there that's not broken'* (P11, Pre-test)

These women spoke about reasons which impact on womens participation in the cervical screening programme. Key reasons given include not being comfortable with screening or the infantalisation of women with intellectual disabilities which allows their reproductive health to be ignored:

> *'Because, you see, Mammy said that, see Mammy said that 'I wouldn't not be not ready, but I wouldn't be that comfortable'' (P2 Post intervention)*
>
> *'Because I'm too young… too young to know' (P20 Post Intervention)*

Women with intellectual disabilities are at risk of being socialised into other people's perceptions of the cervical screening experience

> *'My sister has to get it done, she hates it. She wishes she was asleep for it' (P15 Pre-test)*

This subtheme explored challenges related to participation in the screening programme for women with mild to moderate intellectual disabilities. The next subthemes presents the experiences of women with mild to moderate intellectual disabilities who had participated in the breast and cervical screening programme.

6.18.3. Personal experience of the screening tests

This subtheme first explores the experiences of women who had participated in the cervical screening programme. The first woman had successfully completed in the cervical screening programme following a pharmaceutical intervention to relieve the distress:

> *'It wouldn't be a pleasant thing to go for. Jesus, they had to give me in tablets to relax me and all' (P4 12 week)*

However, she was adamant that she would have to consider her decision carefully to participate in the screening programme in the future, as she found the procedure very distressing:

> *'I'd have to think about it very carefully about would I or not, and that's being serious' (P4 12 week)*

Another woman explained her reaction when the doctor tried to insert the speculum into her vagina. As a result the test was abandoned:

> *'I screamed the place down…it was very sore (P15 Pre-*test)

Fear was a key factor related to non-participation in the cervical screening programme from the perspectives of women with mild to moderate intellectual disabilities.

Women with mild to moderate intellectual disabilities who had successfully participated in the mammography programme were very vocal about the pain associated with the mammogram. Despite the pain experienced during the procedure this woman did attend the recall mammography appointment on two occasions.

> *'But it was a sore yoke I thought' (P17, Post intervention)*

Another woman who attended the symptomatic breast clinic with a lump which her doctor wanted checked out also described her experience of the mammogram:

> *'Oh, I swear it was sore… oh stop, they press it down on you really, really tight. Oh Lord, stop' (P12 Post intervention)*

A key challenge discussed by one of the women who had successfully completed two mammograms was the impact her arthritis has on her ability to move her arms to enable the breast to be placed correctly in the mammography plates. Despite this she acknowledged that with appropriate support she was facilitated to maintain the correct posture to allow the mammogram to be taken:

> *'I find it hard to put my arms up like that…See with the arthritis, I was kind of stiff going over on it there…I couldn't go over like all the rest of them could…I had to get help for something' (P11 Pre-test)*

The women were aware that they would get test results from the screening programme.and demonstrated the ability to understand the implications of the test results:

> *'But it worked out grand, the results came back perfect'* (P4, Post intervention)

> *'It was clear now the two times I went so…They said everything was grand, I got it in my own house' (P11 Pre-test)*

This theme focused on cancer and screening knowledge changes following participation in the EMBRACES-ID programme. The next theme looks at the role of carers in facilitating women with mild to moderate intellectual disabilities to access healthcare appointments.

6.19. The role of carers

This theme first explores the perspectives of women with mild to moderate intellectual disabilities about the support they require to assist them to make medical appointments. Second it describes the support women perceived they needed from carers at the medical appointment.

6.19.1. Reliance on carers to make medical appointments

Women with mild to moderate intellectual disabilities often rely on the support of their professional and family carers to organise medical appointments, even though women may be independent in other areas of their life, such as having part-time jobs:

> *'See, but at the moment Mammy normally rings' (P2 Post intervention)*

> *'My family make an appointment or staff, whatever.'(P20 Post intervention)*

> *'No, see anyone from here could make an appointment' (P22 12 week)*

The womens responses provided insight into the extent of the dependence on and reassurance of her carer (X) needed to support the women to attend a medical appointment:

> *'X, not hard to get an appointment with my doctor, so it's not?' (P4 12 week)*

> *'But if I had to go like, I'd, I'd,…my brother he'd ring up' (P13 12 week)*

6.19.2. Carers support for primary care and screening

Women were asked about the practical barriers that might have an impact on seeking early medical help for a cancer symptom. The majority of the women were also reliant on professional and family carers to provide transport to the medical appointment:

> *'Yes, my Mum do' (P8 12 week)*
>
> *'My sister might walk me' (P9 12 week)*
>
> *'Eh, like my brother or sister' (P10 12 week)*
>
> *'No, my brother would, probably, he'd normally bring me' (P13 12 week)*
>
> *'No, my sister brings me up, she might have an appointment as well, she might have to go the same day' (P15, Pre- test)*

Women rely on carers support when they attend the doctor and feel content knowing that this support is available when they need it at a medical appointment:

> *'Ahh, I would have to have Mammy with me at the doctor' (P2 Post intervention)*
>
> *'My Mom would bring me and then she might go in with me' (P16 Pre-test)*

The next theme explores the challenges women reported related to their attendance at medical appointments.

6.20. Communication with the doctor

This section explores the factors women with mild to moderate intellectual disabilities felt impacted on their confidence to talk to their doctor about a medical problem. The first subtheme explores challenges the women encounter during the medical consultation, while the second examines the womens perspectives about dealing with male health care providers.

6.20.1. Talking to the doctor

In this subtheme the women talk about the challenges they encounter when conversing with doctors in mainstream services. Among the challenges identified include the volume of speech, and difficulty understanding speech patterns influenced by different sociocultural backgrounds:

> *'Like a foreigner, I think' (P12 Post intervention)*

> *‘He talks to me very, very low’ (P15 Pre-*test)

While some doctors discussed health concerns with adult women with mild to moderate intellectual disabilities, others requested that a woman left the consultation room while the test results were discussed a family member.

> *‘Sometimes, he asks me questions alright, yes’ (P9 12 week)*
>
> *‘And then I wait out in the waiting room’ (P21 12 week)*

While this subtheme explored womens perspectives about talking to health care providers, the next subtheme looks at womens preferences a female healthcare provider.

6.20.2. Preference for a female health care provider

It seems that the women were very adamant that they didnot wish to show their bodies to male health care provider out of embarrassment:

> *‘I don’t like to take the clothes off in front of a man because, you know… I’m easy with women, but not easy with men, you see’ (P20 Post intervention)*
>
> *‘Men doctors are embarrassing’ (P23 Post intervention)*

Regardless of age women who prefer a lady doctor were very sure that they found it too difficult to talk about their breast and cervix to a male doctor. The women alluded to the fact that they believed that female doctors were more understanding based on the fact that they are female themselves.

> *‘Yes, because as I said is a man, I need a female, its too difficult to say it, but if its lady doctor its okay’ (P16 12 week)*
>
> *‘Now it would have to be a lady doctor… a lady doctor I think would understand’ (P17 12 week)*

This section described the study accrual for women with mild to moderate intellectual disabilities and their carers into the EMBRACES-ID intervention. It reported the demographic profile of the participants and issues related to their retention in the study and intervention. It explored the findings of the EMBRACES-ID interview suite at baseline, post intervention and 12 week follow up for women with intellectual disabilities and their carers about their knowledge of cancer risk and prevention and factors which impacted on screening participation for women with intellectual disabilities. The next section explores the Adapted CAM findings for women with mild to moderate intellectual disabilities.

6.21. Quantitative data collection and analysis

Women with mild to moderate intellectual disabilities were invited to complete the baseline, post intervention and 12 week follow up Adapted CAM surveys as part of the interview process. The researcher completed the CAM with the women, who were invited to have a family member or keyworker present at the interview. The surveys were coded and imported into SPSS for analysis

6.22. Reliability of the EMBRACES- ID Adapted CAM

The CAM toolkits were developed to provide a validated measure of awareness of early warning signs, risk factors and seeking medical advice (Stubbings et al., 2009; Linsell et al., 2010; and Simon et al., 2012) as mentioned in Section 5.4. The ideal Cronbach α coefficient should be above 0.7 (Pallant, 2010). The internal reliability of the Cancer Awareness Measure of the Adapted CAM was measured on a number of subscales at baseline, post intervention and at the 12 week follow up survey.

All but one of the subscales ‘Barriers to seeking help’ reached the recommended cut off of 0.7 at the baseline assessment, see Table 6.20. However, given that it was important to identify challenges which may impede women with mild to moderate intellectual disabilities seeking early medical intervention for warning signs for cancer the ‘Barriers to seeking help’ scale was retained for each of the Adapted CAM measurements.

6.23. The personal cancer and screening awareness of women with intellectual disabilities

This section explores whether there was there a change in the cancer and screening awareness levels among women with mild to moderate intellectual disabilities across the three time points measured. The first Adapted CAM was administered at the first interview (T0) to assess baseline cancer and screening awareness among the women prior to the commencement of the EMBRACES-ID intervention. The second Adapted CAM was administered one week after the completion of the EMBRACES-ID intervention (T1) to monitor changes in cancer and screening awareness levels.

Table 6.20. Cronbach's α results

Scale	**Cronbachs Alpha T0**	**Cronbachs Alpha Validation study**	**No. of items**
Breast cancer warning signs	0.883	Not available	11
Total knowledge score Breast CAM Warning signs, peak age incidence, awareness of screening programme and age that its offered (first and last age)	0.868	Not available	15
Cervical cancer warning signs	0.948	0.77	11
Total knowledge score Cervical CAM Warning signs, peak age incidence, awareness of screening and vaccination programme, age that they're offered	0.921	0.84	16
Barriers to seeking help	*0.436*	0.73	10

Finally the last Adapted CAM was administered at T2 which was on average 12- 13 weeks following the completion of the EMBRACES-ID intervention. The aim of the three month follow up survey was to examine whether any changes in awareness levels were retained by the women. Cochran's Q tests were used to determine if there were statistically significant changes in the awareness levels prior to and following participation in the EMBRACES-ID intervention.

Sections 6.23.1.- 6.23.8. explore changes in breast and cervical cancer and screening awareness from baseline surveys to post intervention and 12 week follow-up Adapted CAM surveys. Section 6.24. examines changes in opinions about emotional, practical and service barriers which might impact on early help seeking for symptoms of breast or cervical cancer.

6.23.1. Warning signs for breast cancer

It was evident that the majority of women recognised a lump in the breast or armpit as a warning sign for breast cancer at each of the three measurement times. This section describes the knowledge changes detected for the warning signs for breast cancer in the Adapted CAM.

Cochran's Q tests showed that the changes in recognition levels from the baseline survey to the 12 week follow up survey for seven warning signs were not statistically significant as detailed in Table 6.21. Despite this there were knowledge gains detected from baseline levels among the women who had completed the EMBRACES-ID intervention for six of these seven warning signs.

Womens awareness levels that the pulling in of the nipple may be a warning sign for breast cancer remained the same as the baseline levels, χ^2 (2) 0.00, p=1. Similarly the same proportion of women (n=23) were aware that a lump or thickening in the breast may be a warning sign for breast cancer at the post- intervention and 12 week surveys. It was noted in the 12 week follow up survey that awareness of a lump or thickening under the armpit, discharge or bleeding from the nipple and puckering or dimpling of the breast skin as warning signs for breast cancer were lower than post intervention measurements. Conversely, at the 12 week survey there were knowledge gains identified for six of the warning signs for breast cancer, see Table 6.21.

Cochran's Q tests indicated statistically differences between baseline and three month follow up survey recognition levels of four warning signs for breast cancer among the women with mild to moderate intellectual disabilities for the observed p value (p<0.005). The key knowledge changes detected related to a lump or thickening under the armpit and three non-lump symptoms a rash on around the nipple, redness of the skin on the breast and puckering or dimpling of the breast skin.

Post hoc comparison involves a further examination of the data after a significant effect has been identified (Norman and Streiner, 2008, Pallant, 2013). A post hoc test was undertaken for the four warning signs to determine if the differences found in the Cochran's Q tests were significant. As the probability of making a Type I error on any one comparison is 0.05, a Bonferroni correction sets a more stringent alpha level for k repeated measures tests i.e. 0.05/ k comparisons (Norman and Streiner, 2008, Pallant, 2013). In this analysis the Bonferroni corrected p- value for comparison is 0.05/ 3= 0.017. Following this test, it was concluded that the difference was significant only in the case of two warning signs, awareness of a lump in or thickening under the armpit and puckering or dimpling of the breast skin see Table 6.21.

6.23.2. Breast self- examination and confidence to detect a change

This section first examines the case in relation to changes in the frequency of breast self-

Table 6.21. Cochran's Q test for breast cancer warning signs

Warning sign	**T0 (n=25)**	**T1 (n=25)**	**T2 (n=25)**	**Observed p value (0.05)**	**Bonferroni corrected p value (p=0.017) ****
Lump or thickening in the breast	20	23	23	0.105	-
Lump or thickening under the armpit	**14**	**23**	**20**	**0.011***	**0.011****
Discharge or bleeding from the nipple	16	20	19	0.385	-
Pulling in of the nipple	15	15	15	1.000	-
Change in position of the nipple	12	16	17	0.350	-
A nipple rash	**11**	**18**	**17**	**0.028***	**0.028**
Redness of the breast skin	**15**	**17**	**23**	**0.024***	**0.024**
Changes in the size of breast or nipple	13	13	17	0.390	-
Changes in the shape of the breast or nipple	14	14	17	0.570	-
Pain in one of the breasts or armpit	13	17	19	0.135	-
Puckering or dimpling of the breast skin	**10**	**18**	**17**	**0.017***	**0.017****

Notes: * denotes statistically significant changes in the three proportions

** denotes statistically significant changes for Bonferroni correction examination among women with mild to moderate intellectual disabilities who participated in the intervention. It then explores changes in the womens opinions about their ability to detect a change in their breast following the intervention.

A Cochran's Q test did not identify a significant difference in the proportion of women who reported more frequent BSE from the baseline survey to the 12 week post- intervention survey. There was nevertheless a small increase in the number of women who reported that they would carry out more frequent BSE following participation in the EMBRACES-ID intervention (n=20) compared to BSE levels reported by the women in the baseline survey (n=15), see Table 6.22.

A Cochran's Q test indicated a strong statistically significant difference in the proportion of women with mild to moderate intellectual disabilities who reported that they were more confident that they would notice a change in their breasts following participation in the EMBRACES-ID intervention χ^2 (2) 16.16, p=0.00. Following a post hoc Bonferroni- adjusted significance test, it was concluded that the difference was significant, see Table 6.22.

6.23.3. Breast cancer risk factor awareness

This section examines the changes in risk factor awareness among women with mild to moderate intellectual disabilities following participation in the EMBRACES-ID intervention. First, it describes the case for the recall of risk factors for breast cancer by the women. Next, it examines changes in the womens awareness of the increasing risk of with advancing age.

A Cochran's Q test did not indicate any significant differences in the proportion of women who recalled a breast cancer risk factor at any of the three time frames, χ^2 (2), 2.28, p=0.319. Despite this the womens recall of breast cancer risk factors did marginally improve following the intervention (n=10) compared to baseline measurements (n=6), see Table 6.23.

Few women demonstrated an understanding about the link between increasing age and its association with developing breast cancer despite participating in the intervention. A Cochran's Q test did not identify any significant difference from baseline to follow up surveys in the proportion of women who understood the link between breast cancer and age, χ^2 (2) 0.750, p=0.687. The next section examines changes in awareness about the breast screening programme.

Table 6.22. Cochran's Q test for confidence and skills to detect a breast change

Confidence and skills to detect a breast change	T0 (n=25)	T1 (n=25)	T2 (n=25)	Observed p value (0.05)	Bonferroni corrected p value (p=0.017)
Breast confidence (Very/ fairly)	11	22	19	**0.000***	**0.000****
Breast Check (weekly/ monthly)	15	17	20	0.232	-

Notes: * denotes statistically significant changes in the three proportions
** denotes statistically significant changes for Bonferroni correction

Table 6.23. Cochran's Q test for breast cancer risk factor recall

Risk factor awareness	T0 (n=25)	T1 (n=25)	T2 (n=25)	Observed p value (0.05)
Breast cancer risk factor recall	6	10	10	0.319
Age and breast cancer risk	5	3	4	0.687

6.23.4. Screening programme awareness

This section describes changes in the womens awareness levels about the National Breast Screening Programme following participation in the intervention. First it examines the case of screening programme awareness then it describes knowledge changes in relation to age eligibility for the primary invitation for a mammogram.

Awareness about the National Breast Screening Programme improved following participation in the EMBRACES- ID intervention. Twenty women with mild to moderate intellectual disabilities mentioned that they were aware of the BreastCheck programme post intervention compared to eleven women in the baseline survey, see Table 6.24. A Cochran's Q test indicated a statistically significant difference in the womens awareness of BreastCheck from baseline to follow up Adapted CAM measurements, χ^2 (2), 12.11 p= 0.002. Following a post hoc Bonferroni- adjusted significance test it was determined that the difference was significant, see Table 6.24.

In relation to age eligibility for the BreastCheck programme, a Cochran's Q test found a strong statistically significant difference in the knowledge levels from baseline to follow up surveys about the eligibility for participation in the BreastCheck programme from 50 years of age, χ^2 (2) 14, p=0.001. It was concluded that the difference was significant following a post hoc Bonferroni- adjusted significance test, see Table 6.24.

Four of the women were over the age of 50 years of age and mentioned that they had received an invitation to attend the breast screening programme. Each of these women had taken the opportunity to attend to have a mammogram. A Cochran's Q test found no variance between the number of age eligible women attending the breast screening programme from the baseline survey to the 12 week follow up survey , χ^2 (2), 0.00 p= 1.000.

This section discussed the findings of the Adapted breast CAM in relation to knowledge changes detected in relation to breast cancer and screening awareness among women with mild to moderate intellectual disabilities who participated in the EMBRACES-ID intervention. The next section presents the results of the Adapted cervical CAM for these women.

6.23.5. Cervical cancer warning signs

It was evident that the overall knowledge levels for cervical cancer warning sign

Table 6.24. Cochran’s Q test for screening programme awareness

Screening programme awareness	**T0 (n=25)**	**T1 (n=25)**	**T2 (n=25)**	**Observed p value (0.05)**	**Bonferroni corrected p value (p=0.017)**
Aware of BreastCheck programme	**11**	**22**	**20**	**0.002***	**0.002****
First mammogram at 50 years of age	**4**	**15**	**10**	**0.001***	**0.001****
Breast attend	4	4	4	1.00	-

Notes: * denotes statistically significant changes in the three proportions
** denotes statistically significant changes for Bonferroni correction

awareness levels did improve among the women with mild to moderate intellectual disabilities following completion of the EMBRACES-ID intervention. The greatest improvements in awareness were observed in relation to the recognition of vaginal bleeding between periods, persistent diarrhoea, and persistent pelvic pain as warning signs for cervical cancer, see Table 6.25. There was greater awareness levels noted at the 12 week survey when compared to the post- intervention survey for 10 of the 11 target warning signs for cervical cancer. The womens awareness levels that unexplained weight loss may be a warning sign for cervical cancer remained constant during the post intervention and 12 week follow up survey, see Table 6.25. Nevertheless, a Cochran's Q test did not detect a statistically difference in the proportion of women who recognised a warning sign for cervical cancer post intervention when compared to the baseline levels, see Table 6.25. The next section examines the changes in womens confidence to notice a cervical cancer symptom.

6.23.6. Confidence to notice a cervical cancer symptom

In the 12 week survey the majority of women with mild to moderate intellectual disabilities who participated in the EMBRACES-ID intervention (n=20) mentioned that they would feel confident that they would notice a cervical cancer symptom compared to the baseline confidence levels reported by the women (n=12).

A Cochran's Q test indicated a statistically significant difference in the womens confidence levels that they would notice a cervical cancer symptom following participation in the EMBRACES-ID intervention χ^2 (2) 7.125, p=0.028. Following a post hoc Bonferroni- adjusted significance test, it was concluded that the difference was not significant, see Table 6.26. The next section examines changes in the womens cervical risk factor awareness following participation in the EMBRACES- ID intervention.

6.23.7. Cervical cancer risk factor awareness

This section examines the changes in cervical cancer risk factor awareness among women with mild to moderate intellectual disabilities following participation in the EMBRACES-ID intervention. First, it describes the case for the recall of risk factors for cervical cancer by the women. Next, it examines changes in the womens awareness that women aged 30-49 years of age is the most likely to get cervical cancer in the next year.

The womens awareness of risk factors for cervical cancer was extremely low at the baseline

Table 6.25. Cochran's Q test for cervical cancer warning signs

Warning sign	**T0 (n=25)**	**T1 (n=25)**	**T2 (n=52)**	**Observed p value (0.05)**
Vaginal bleeding between periods	12	15	18	0.125
Persistent lower back pain	12	14	17	0.257
Persistent vaginal discharge	11	13	15	0.336
Discomfort or pain during sex	12	12	15	0.500
Menstrual periods that are heavier or longer than usual	12	12	13	0.939
Persistent diarrhoea	10	12	16	0.097
Vaginal bleeding after the menopause	11	13	14	0.678
Persistent pelvic pain	11	13	18	0.062
Vaginal bleeding during or after sex	10	13	15	0.257
Blood in the stool or urine	10	17	15	0.101
Unexplained weight loss	10	12	12	0.717

Table 6.26. Cochran' Q test for confidence to notice a cervical change

Confidence notice a cervical change	**T0 (n=25)**	**T1 (n=25)**	**T2 (n=25)**	**Observed p value (0.05)**	**Bonferroni corrected p value (p=0.017)**
Cervical confidence (Very/ fairly)	**12**	**13**	**20**	**0.028***	**0.028**

Notes: * denotes statistically significant changes in the three proportions

Table 6.27. Cochran's Q test for cervical cancer risk factor recall

Risk factor awareness	**T0 (n=25)**	**T1 (n=25)**	**T2 (n=25)**	**Observed p value (0.05)**
Cervical cancer risk factor recall	3	8	8	0.103
Age and cervical cancer incidence	2	0	1	0.363

Table 6.28. Cochran's Q test for screening programme awareness and participation rates

Screening programme awareness	**T0 (n=25)**	**T1 (n=25)**	**T2 (n=25)**	**Observed p value (0.05)**
Aware of CervicalCheck programme	10	16	14	0.061
First smear test at 25 years of age	1	4	3	0.247
Smear test invitation	13	10	10	0.165
Attended smear test	7	4	5	0.097

survey, only three women with mild to moderate intellectual disabilities. There was an improvement observed in the womens recall of cervical cancer risk factors following the intervention, see Table 6.27. A Cochran's Q test did not indicate any significant differences in the proportion of women who recalled a cervical cancer risk factor at any of the three time frames, χ^2 (2) 4.54, p=0.319.

The majority of women did not mention that a woman aged 30-49 years was most likely to get cervical cancer in the next year in each of the Adapted Cervical CAM surveys, see Table 6.27. A Cochran's Q test did not identify any significant difference from baseline to follow up surveys in the proportion of women who mentioned the age group with peak incidence of cervical cancer, χ^2 (2). 2.00, p=0.368. The next section examines changes in screening programme awareness.

6.23.8. Screening programme awareness and participation rates

This section describes changes in the womens awareness levels about the National Cervical Screening Programme following participation in the intervention. First it examines the case of screening programme awareness then it describes knowledge changes in relation to age eligibility for the first invitation for have a smear test.

The womens knowledge about the National Cervical Screening Programme improved marginally following participation in the EMBRACES-ID Intervention (n=8) compared to baseline awareness levels (n=3), see Table 6.28. A Cochran's Q test indicated that there was no statistically significant difference in the womens awareness about the CervicalCheck programme from baseline to follow up Adapted CAM measurements, χ^2 (2) 5.6, p=0.061.

In relation to age eligibility for the Cervical Check programme from the age of 25 years, poor awareness levels were detected at baseline as only one woman mentioned that she was aware of the CervicalCheck programme. Poor awareness levels persisted following participation in the programme as few women (n=4) reported awareness of the cervical screening programme, see Table 6.28. A Cochran's Q test did not find a statistically significant difference in the knowledge levels from baseline to follow up surveys about the eligibility for participation in the CervicalCheck programme from 25 years of age, χ^2 (2) 2.8, p=0.247.

In the sample 23 women with mild to moderate intellectual disabilities (92%) were over the age of 25 years of age and eligible to participate in the cervical screening programme. At the baseline assessment 13 of the women (56.5%) reported that they had received an invitation to attend the screening programme, and seven women (30.4%) reported that they had attended the cervical screening programme. The remainder of the women were unsure if they had received an invitation to attend the screening programme.

The number of women who reported that they received a screening invitation and participated in the screening programme fluctuated between the post intervention and 12 week follow up CAM surveys, see Table 6.28. A Cochran's Q test indicated that there was no statistically significant difference in relation the receipt of screening invitations and participation in the cervical screening programme detected from the baseline to follow up Adapted CAM measurements.

The next section explores whether there was changes in womens perspectives about emotional, practical and service barriers that might impact on early help seeking for symptoms which might be considered serious following participation in the intervention.

6.24. Barriers to seeking help

The perspectives of women with mild to moderate intellectual disabilities about making an appointment to seek early medical intervention for a warning sign for breast or cervical cancer were gathered using the baseline, post intervention and 12 week follow-up Adapted CAM surveys.

The majority of women with mild to moderate intellectual disabilities mentioned in each of the surveys that that they would make an appointment with their doctor within two weeks to discuss a breast or cervical cancer warning sign they thought might be serious. A greater proportion of these women reported that they would seek medical intervention for a cervical change they thought might be serious following participation in the intervention than was the case with medical help seeking for a breast symptom.

Cochrans Q tests indicated that there were no significant differences in the proportion of women reporting over the three measurement points that they would seek medical help within two weeks in the event that they noticed a breast or cervical change they thought might be serious, see Table 6.29.

Despite this the most common barriers to seeking help mentioned by women with mild to moderate intellectual disabilities during the baseline survey were being too embarrassed (n=15) or too scared (n=12) to discuss breast or cervical health with the doctor. There was a

Table 6.29. Cochran's Q tests for seeking medical intervention within two weeks

Seek help <2 weeks	T0 (n=25)	T1 (n=25)	T2 (n=25)	Observed p value (0.05)
Breast symptom	19	20	20	0.895
Cervical symptom	16	18	19	0.459

decrease observed in the proportion of women mentioning both these emotional barriers of being too embarrassed to too scared to seek early medical intervention at the post intervention survey (n=9), see Table 6.30. However, in the 12 week follow up survey the number of women citing embarrassment (n=14) and being too scared (n=14) as the principal challenges they perceived as delaying early medical help seeking for a symptom they thought might be serious was broadly similar to baseline results, see Table 6.30.

The Cochran's Q tests indicated that there was no statistically significant differences in the womens opinions about embarrassment χ^2 (2) 3.875, p=0.144 or being scared χ^2 (2) 2.235, p=0.327 as factors which caused delays in medical help seeking from baseline to follow up Adapted CAM measurements. The impact of these emotional barriers to medical help seeking remained relatively stable among women with mild to moderate intellectual disabilities despite participating in the EMBRACES-ID intervention.

During the baseline survey few women (n=5) felt confident that they could talk to their doctor about their breast or cervical health which indicated that a large majority of the women (n=20) didn't feel confident that they could approach this issue with their doctor see Table 6.30. Broadly similar results were observed during the post intervention survey and the 12 week follow up survey with few women mentioning that they felt confident to discuss the issue with their doctor despite having participating in the intervention, see Table 6.30.

A Cochran's Q test indicated that there was no statistically significant differences in the womens opinion about confidence to discuss breast or cervical cancer symptoms they thought might be serious with the doctor, χ^2 (2) 0.40, p=0.819 from baseline to follow up Adapted CAM measurements. The women with mild to moderate intellectual disabilities mentioned during each of the three surveys that service related barriers were less likely to have an impact on their early medical seeking for symptoms they felt might be serious, see Table

Table 6.30. Cochran’s Q test for barriers to seeking help

Barriers to seeking help	T0 (n=25)	T1 (n=25)	T2 (n=25)	Observed p value (0.05)
Emotional barriers				
Worried about what the doctor might find	6	4	8	0.368
Too scared	12	9	14	0.327
Too embarrassed	15	9	14	0.144
Confident to talk about symptom	5	6	7	0.819
Practical barriers				
Too busy	9	3	3	0.063
Too many other things to worry about	7	2	2	0.082
Difficult for me to arrange transport	2	3	5	0.417
Service barriers				
Worried about wasting the doctor's time	6	4	8	0.368
Difficult to make an appointment	10	10	11	0.867
Doctor difficult to talk to	5	6	4	0.794

6.30. Generally women reported that they were not worried about wasting the doctors time, didn’t find it difficult to arrange an appointment for the doctor and didn’t perceive that the doctor was difficult to talk to about the woman’s concerns about her breast or cervical health, see Table 6.30.

Cochrans Q tests indicated that there were no significant differences in the proportion of women reporting that service barriers impacted on their early help seeking behaviours. Their opinions remained relatively stable over the three measurement points. The Cochrans Q results were as follows: worry about wasting the doctors time, χ^2 (2) 2.000, p=0.3682; finding the doctor difficult to talk, to χ^2 (2) 0.462, p=0.794 and experiencing difficulties in making an appointment with the doctor, χ^2 (2) 0.286, p=0.867.

Few women reported in each of the three CAM surveys that practical barriers including being too busy to make an appointment, having too many other things to worry about and experiencing difficulties in arranging transport to the doctors surgery were likely to impact on their medical help seeking behaviours, see Table 6.30. Despite this a larger proportion of women reported that being too busy to make an appointment and having too many things to worry about were less likely to impact on their medical help seeking for a symptom they thought might be serious following participation in the EMBRACES-ID intervention, see Table 6.30.

Cochrans Q tests indicated that there were no significant differences in the proportion of women reporting that practical barriers impacted on their early help seeking behaviours over the three measurement points. The Cochrans Q results were as follows: too busy to make an appointment- χ^2 (2) 5.538, p=0.06; too many other things to worry about χ2 (2) 5.00, p=0.082 and experiencing difficulties in arranging transport to a doctors appointment χ2 (2) 1.750, p=0.417.

6.25. Chapter summary

This chapter explored the findings of the interviews and CAM surveys undertaken at the baseline, post intervention and the 12 week follow up assessments. It was evident that there were challenges to the retention of carers and women with mild to moderate intellectual disabilities. Women with intellectual disabilities were more likely to mention emotional barriers such as fear and embarrassment as reasons to leave the study, while carers mentioned service related barriers such as staff shortages.

There was improved awareness of the key elements of cancer prevention programmes among the carers. In general there was an improvement noted in the recognition of early warning signs and risk factors for breast and cervical cancer, and improved awareness about screening programmes. Carers raised concerns about informed decision making among women with mild to moderate intellectual disabilities about access to the screening programmes. Carers were very supportive about women with intellectual disabilities accessing the breast screening programme. Despite this they seemed more hesitant about the women accessing the cervical screening programme due to the invasive nature of the test. Carers suggested that more training was needed to raise cancer and screening awareness for women with intellectual disabilities, their carers and mainstream healthcare professionals.

Women with intellectual disabilities demonstrated some knowledge changes in the area of cancer prevention. However, confusion about cancer risk factors and warning signs, and associating cancer prevention with developing symptoms of cancer which required urgent medical attention was evident in the post intervention assessment. Women with intellectual disabilities argued that they had the same right to access screening as women in the general population, although a concerning distinction between staff and the women was detected in related to screening participation. Women with intellectual disabilities also gave valuable insight into their experiences of being invited to the screening programmes and participating in the screening programmes. The women also discussed the perspectives on accessing mainstream health services including the valuable role played by their carers in this regard.

The majority of carers and women with intellectual disabilities reported that they would attend a doctor within two weeks of noticing a symptom they thought might be serious. Despite this the emotional barriers to early help seeking remained relatively consistent over the course of the three assessments. The next chapter explores the integration and overview of the findings.

Chapter 7: Integration and overview of findings

7.0. Introduction

The mixed methods approach used in the study for was integration through interpretation and reporting procedures (Fetters et al., 2013). This chapter explores the mixed methods integration at two key junctures in the study. First, section 7.1. explains how the findings from the carers interviews in the Phase I were used to frame important questions about attitudes about screening behaviours in Phase II. Second, section 7.2. details the use of a convergence coding matrix to integrate the survey and interview data about self- efficacy, outcome expectations, confidence and skills to perform breast self-examination (BSE). The chapter also examines the acceptability and feasibility testing of the EMBRACES-ID intervention for women with mild to moderate intellectual disabilities and their carers in sections 7.4. – 7.5. Finally the chapter concludes with a summary in section 7.6.

7.1. Attitudes about screening behaviours in women with intellectual disabilities

The benefit of a mixed methods two phase design is that the Phase I findings were used to develop the questions in the Phase II EMBRACES- ID interview protocol for the women and their carers. In the Phase I Comprehensive Needs Assessment a key issue which carers raised was that the women had an equal right to screening as women in the general population. These carer arguments from section 5.24.2 are reiterated here for clarity:

> *'It's just that they are entitled to have the screening just as much as everyone else' (P21 Staff Nurse)*
>
> *'They've a right to it as much as we have… it's something that could still harm them, no one knows' (P8 Staff Nurse)*

Three interview questions were developed to test attitudes about screening behaviours among the population of women with intellectual disabilities. These questions were asked at the pre-test, post intervention and 12 week follow up interviews with carers and women with mild to moderate intellectual disabilities who completed the EMBRACES-ID intervention.

The focus of the first two questions was to explore attitudes about women with intellectual disabilities having equal access to the breast and cervical cancer screening programmes:

> *'How do you feel about women with intellectual disabilities having access to breast cancer screening opportunities that are available to women?'*
>
> *'How do you feel about women with intellectual disabilities having access to cervical screening opportunities that are available to women?'*

The third question was designed to explore attitudes about women with intellectual disabilities receiving smear tests and mammograms at the intervals recommended for women in the general population:

> *'How do you feel about women with intellectual disabilities obtaining the recommended screening to prevent cancer?'*

This section explored the use of qualitative data from Phase I to inform the development of the feasibility and acceptability study in Phase II. The next section looks at the use of the triangulation of data sets to generate a wider perspective of the participants thoughts about performing breast self-examination.

7.2. Breast self-examination (BSE) integration

Although there are no firm recommendations on the frequency of BSE (Cancer Research UK, 2011) it is important for all women to be aware about how their breasts should look and feel. Perceived self- efficacy is a good predictor about how well people adhere to behaviours that facilitate them to be more proactive in managing their own health (Bandura, 1997). It was proposed that participants who reported a strong sense of self- efficacy about performing BSE would have positive outcome expectations and confidence about the value of performing BSE at acceptable frequencies to ensure breast awareness.

During the interviews participants in the EMBRACES-ID intervention were asked two questions which measured the secondary outcome, self- efficacy to perform BSE, see Appendix V, Volume II. The purpose of the first question was to assess the sense of self-efficacy participants demonstrated about performing BSE:

> *'I would be interested in knowing how confident you are at performing breast self-examination?'*

The second question was designed to elicit the participant's outcome expectations about BSE, which is usually indicated by the frequency of BSE carried out by the participant:

> *'I would be interested in knowing how often you have performed BSE in the last year?'*

During the Breast-CAM survey, see Appendix V, Volume II, participants were asked to respond to two questions which measured the confidence and skills of women to check their breast and notice a change in their breast:

> *'How often do you check your breasts?'*
> *'Are you confident you would notice a change in your breasts?'*

The mixed methods approach used in the study for assessing the participants self-efficacy to perform BSE was integration through interpretation and reporting procedures (Fetters et al., 2013). Based on guidance from Farmer et al. (2006) and O' Cathain et al. (2010) the mixed methods integration of the baseline and post- intervention interview and CAM data was presented in a 'convergence coding matrix'. The convergence coding matrix displayed the findings emerging from each component (triangulation) in order to detect convergence, partial agreement or dissonance between the findings. These key terms are operationalised in Table 7.1.

Table 7.1. Convergence coding matrix terms

Key term	**Operationalisation of term**
Convergence	Interview findings were in agreement with the CAM responses
Partial agreement	Agreement between one element of either the interview findings or the CAM responses
Dissonance	No agreement identified between the interview findings or the CAM responses

Adapted from O'Cathain et al. (2010)

7.2.1. Carers

Two categories of participants emerged from the convergence coding matrix for carers, see Table 7.2. The carers in Category 1 included carers who demonstrated a high sense of self efficacy to perform BSE at the baseline assessment. Conversely the carers in Category 2 presented with a low sense of self efficacy to perform BSE during the baseline interview. The results of the baseline and post intervention assessments are presented in sections 7.2.3. to 7.2.6.

7.2.2. Women with mild to moderate intellectual disabilities

Five categories of participants emerged from the convergence coding matrix for women with mild to moderate intellectual disabilities, see Table 7.3. The women in Category 1 included women who had previously had a mammogram, whether at the national breast screening programme or symptomatic breast clinic. The women in Categories 2-5 were women with mild to moderate intellectual disabilities under 50 years of age who were not eligible to participate in the BreastCheck programme. These categories were classified according to the perceived sense of self- efficacy to perform BSE detected in the baseline interview. The results of the baseline and post intervention assessments are presented in sections 7.2.7 to 7.2.15.

7.2.3. Baseline assessment for carers Category 1

Two participants (P1C and P6C) demonstrated a low sense of perceived self- efficacy about performing BSE and mixed outcome expectations related to the frequency of BSE during the baseline interviews. While P1C reported in the baseline CAM survey that she felt unsure that she would notice a change in her breast, P6C mentioned that she was confident she would notice a breast change. Both participants mentioned that they rarely checked their own breasts for changes. The mixed methods integration detected convergence between the interview and CAM findings for P1C, and partial agreement for P6C as seen in Table 7.4.

P1C reported that she felt unsure that she would notice a change in her breast despite having had a previous mammogram on the national screening programme:

> *'No, I'm not at all' (P1C Pre-test)*

Table 7.2. Categories of carers

Carers Category	Description	Number of participants (n=9)	Participant identification Carers
1	Strong sense of self–efficacy about performing BSE Constant post intervention	7	P2C, P3C, P4C, P5C, P7C P8C, P9C
2	Low sense of perceived self-efficacy about performing BSE Improvement detected post intervention	2	P1C, P6C

Table 7.3. Categories of women with mild to moderate intellectual disabilities

WWID Category	Description	Number of participants (n=25)	Participant identification WWID
1	Women who had completed a mammogram	5	P2, P3, P5, P15, P17
2	Strong sense of self–efficacy about performing BSE Constant post intervention	6	P1, P7, P10, P14, P20, P21
3	Low sense of perceived self-efficacy about performing BSE Improvement detected post intervention	9	P4, P9, P11, P12, P16, P18 P19, P22, P23
4	Low sense of perceived self-efficacy about performing BSE No improvement detected post intervention	3	P6, P13, P25
5	Low sense of perceived self-efficacy about performing BSE Special interest cases	2	P8, P24

P6C was in her mid- twenties and seemed embarrassed to disclose that she would not be confident that she would notice a change in her breast. During the interview she was observed to laugh when responding to this question:

> *'Not very confident (laughs)' (P6C Pre-test)*

7.2.4. Post intervention assessment for carers Category 1

The post intervention convergence coding matrix is presented in Table 7.4. During the post intervention interviews and CAM assessment P1C demonstrated an improvement in perceived self- efficacy to perform BSE and increased confidence and skills to detect a breast change. P1C discussed how the skills demonstration by the intervention facilitator and opportunities to practice BSE on the breast models was important to her increased confidence about performing BSE:

> *'Yes, confident now that we have been shown during the course on the proper way to do BSE by our tutor' (P1C Post intervention)*

Nevertheless P1C mentioned she still had not checked her own breasts for changes, and correspondingly responded in the CAM that she rarely checked her breasts for changes signifying convergence in the mixed methods integration. Further analysis of the CAM data found that although P1C had attended the breast screening programme, she had never had a smear test. P1C demonstrated improved awareness about breast and cervical cancer warning signs following the intervention and mentioned that she would seek medical intervention for a symptom she thought might be serious within two weeks.

Although it was evident that embarrassment about discussing breast or cervical health with the doctor and worry about what the doctor would find were likely to impede on P1C's actual behaviour in relation to early help seeking, screening or BSE. In this case the mixed methods approach is advantageous to give a more complete picture of the woman's perspectives about breast and cervical cancer and screening awareness.

P6C also demonstrated a higher sense of self- efficacy to carry out BSE, improved outcome expectations about BSE following the EMBRACES-ID intervention and increased confidence and skills to detect a breast change. Convergence was detected in the mixed method integration. P6C discussed her improved confidence about performing BSE:

> *'I would know the signs and symptoms to look out for and I also know the proper technique to perform a BSE' (P6C Post intervention)*

Further analysis of the CAM data identified that P6C had improved awareness of seven warning signs for breast cancer following participation in the EMBRACES-ID intervention. P6C agreed with P1C about how the BSE skills demonstration by the intervention facilitator and opportunities to practice BSE on the breast models was beneficial for developing self-efficacy about BSE.

7.2.5. Baseline assessment for carers Category *2*

Seven participants (P2C, P3C, P4C, P5C, P7C, P8C and P9C) demonstrated a strong sense of perceived self- efficacy about BSE and outcome expectations related to the frequency of BSE during the baseline interviews. These carers generally reported in the baseline CAM survey that they felt confident that they would notice a change in their breast and checked their breasts for changes at regular intervals. The mixed methods integration detected convergence between the interview and CAM findings for six of the carers (P2C, P3C, P4C, P5C and P8C), and partial agreement for P9C, see Table 7.5.

Broadly speaking the carers demonstrated good breast awareness, and were confident that they would detect a change in their breasts:

> *'Yes, I did breast examination and I am confident to do it' (P5C Pre*-*test)*

> *'Yes, I'd be pretty okay, yes' (P7C Pre*-*test)*

Just one of the carers, P8C, mentioned during the baseline interview that she had previously had a clinical breast examination. She went on to discuss how her GP had shown her the technique to carry out BSE and that was the reason she felt so self- efficious about performing BSE:

> *'Yes, I'm pretty confident, em, I've been to the doctor, and he's done it and he's shown me how to do it' (P8 Pre*-*test)*

These carers expressed positive outcome expectations about performing BSE in the baseline interviews as they discussed their BSE routines over the past year. Although the frequencies were varied, it was evident that the carers had a good awareness about how their breasts normally look and feel:

> *'I check them every month' (P2C Pre*-*test)*

> *'About every six months' (P7C Pre*-*test)*

> *'5-6 times' (P9C Pre*-*test)*

Although it seemed that some of the younger carers were embarrassed talking openly about their breasts during the baseline interview. Both P6C (age 26), as noted in section 7.2.3 and P3C (age 19) laughed to cover their embarrassment:

> *'I check them like every week, do you know, just whenever I can like' (laughs) (P3C Pre-test)*

7.2.6. Post intervention assessment for carers Category 2

During the post intervention interviews and CAM assessment a high sense of perceived self-efficacy to perform BSE, the confidence and skills to detect a breast change or the frequency with which BSE was noted among these carers. Mixed methods integration detected convergence in qualitative and quantitative responses of P2C, P3C, P4C, P7C and P8C and partial agreement for P5C and P9C, see Table 7.5.

P5C and P9C both mentioned that they checked their breasts regularly for changes in the post intervention interview:

> *'I am confident enough in performing breast self- examination for I have ideas and knowledge of how to perform this' (P5C Post intervention)*
>
> *'I would fairly confident at performing breast self- examination' (P9C Post intervention)*

Despite this P5C responded in the CAM assessment that she was not confident that she would notice a breast change. While P9C responded that she rarely checked her breasts. P9C was unaware that there was not a recommended frequency for BSE, although this seemed to have had little influence on her high level of personal breast awareness:

> *'7/8 times I'm not sure what/ how often is recommended' (P9C Post intervention)*

7.2.7. Baseline assessment for women with intellectual disabilities Category 1

Four women with mild to moderate intellectual disabilities (P3, P5, P15, P17) were aged over 50 years of age and had successfully participated in the BreastCheck programme. Another woman (P2), who was younger than 50 years of age, was referred by her GP to the symptomatic breast clinic to have a lump investigated. This section explores the integration of the mixed method findings about perceived self- efficacy about BSE, outcome expectations related to BSE frequency and the BSE confidence, skills and behaviour assessment for these five women. The convergence coding matrix is presented in Table 7.6.

Table 7.4. Convergence Coding Matrix for carers Category 1

P No.	**Breast confidence (Baseline interview)**	**Breast check (Baseline interview)**	**Breast confidence and check (Baseline CAM)**	**MMR Integration Baseline assessment**	**Breast confidence (Post intervention interview)**	**Breast check (Post intervention interview)**	**Breast confidence and check (Post intervention CAM)**	**MMR Integration Post intervention assessment**
P1C	No, I'm not at all	No	Breast_confid- 0 Breast_check- 0	Convergence	Yes, confident now that we have been shown during the course on the proper way to do BSE by our tutor	No	Breast_confid- 1 Breast_check- 0	Convergence
P6C	Not very confident (laughs)	No	Breast_confid- 1 Breast_check- 0	Partial agreement	I would feel much more confident at performing breast self- examination after taking this course as I would know the signs and symptoms to look out for and I also know the proper technique to perform a BSE	Once, since this course started	Breast_confid- 1 Breast_check- 1	Convergence

Table 7.5. Convergence Coding Matrix for carers Category 2

P No.	Breast confidence (Baseline interview)	Breast check (Baseline interview)	Breast confidence and check (Baseline CAM)	MMR Integration Baseline assessment	Breast confidence (Post intervention interview)	Breast check (Post intervention interview)	Breast confidence and check (Post intervention CAM)	MMR Integration Post intervention assessment
P2C	Yes	I check them every month	Breast_confid- 1 Breast_check- 1	Convergence	Fairly confident as I regularly get cysts and have to get them checked out. Personally I am inclined to delay getting them checked out as I have them on and off and automatically think they are only cysts. Having done the course I realise I should not be so casual.	Once a month	Breast_confid- 1 Breast_check- 1	Convergence
P3C	Yes	I check them like every week do you know just whenever I can like (laughs)	Breast_confid- 1 Breast_check- 1	Convergence	I am very confident since I did the course, I learned how to check myself properly and how often	I check myself at least once a month around the same time each month	Breast_confid-1 Breast_check-1	Convergence
P4C	Reasonably confident	Six	Breast_confid-1 Breast_check- 1	Convergence	Totally	6 times and once since course began	Breast_confid- 1 Breast_check- 1	
P5C	Yes, I did breast examination and I am confident to do it	I haven’t been done it last year. But this year I am doing BSE	Breast_confid- 1 Breast_check-1	Convergence	I am confident enough in performing breast self-examination for I have ideas and knowledge of how to perform this. As a woman I am now aware of the risk of breast cancer	This is my first time to do BSE only this year… I read and knew about BSE but I didn’t perform it or I hesitated to perform it	Breast_confid- 0 Breast_check- 1	Partial agreement

Table 7.5. Convergence Coding Matrix for carers Category 2

P No.	Breast confidence (Baseline interview)	Breast check (Baseline interview)	Breast confidence and check (Baseline CAM)	MMR Integration Baseline assessment	Breast confidence (Post intervention interview)	Breast check (Post intervention interview)	Breast confidence and check (Post intervention CAM)	MMR Integration Post intervention assessment
P7C	Yes, I'd be pretty okay, yes	About every six months	Breast_confid- 1 Breast_check- 0	Convergence	Pretty confident	6 times approximately	Breast_confid- 1 Breast_check- 1	Convergence
P8C	Yes, I'm pretty confident, em I've been to the doctor, and he's done it and he's shown me how to do it.	I would do it once a month	Breast_confid- 1 Breast_check- 1	Convergence	I am quite confident in performing breast self-exam. I have been shown by my GP	Once a month (sometimes twice a month).	Breast_confid- 1 Breast_check- 1	Convergence
P9C	Fairly confident	5-6 times	Breast_confid- 0 Breast_check- 1	Partial agreement	I would fairly confident at performing breast self-examination	7/8 times I'm not sure what/ how often is recommended	Breast_confid- 1 Breast_check- 0	Partial agreement

During the baseline assessment P2 mentioned that she had attended the symptomatic breast clinic to have a lump investigated. In the interview P2 responded that she did not feel self-efficious about performing BSE and never checked her breasts for changes. These findings were reiterated in the CAM survey as P2 reported that she did not feel confident to carry out BSE and never checked her breasts at all. The mixed methods integration detected convergence in her responses.

P3 reported that she was not confident about carrying out BSE in both the interview and CAM survey. The mixed methods integration identified partial agreement in P3's responses. Conflicting responses were detected between the interview and CAM findings about the frequency of BSE. P3 mentioned in the interview that she used to check her breasts when she menstruated, but ceased checking after the menopause:

> *'Only if I, when I used to get my periods, I don't get them now. I used to feel sore on my breasts' (P3 Pre-test)*

Despite this P3 reported in the CAM survey that she checked her breasts at least once a month. The mixed methods approach is useful as it can detect anomalies in the self-reporting among women with mild to moderate intellectual disabilities about the confidence to perform and the frequency of BSE that could be addressed during the EMBRACES-ID intervention.

P5 reported that she had attended the breast screening programme on two occasions and was very interested in health related television shows. P5 discussed the technique used for BSE in response to the BSE self- efficacy interview question:

> *'What, is it that way, is it that way?'(P5 Pre-test)*

P5 explained how she occasionally needed assistance to help her carry out BSE due to her arthritis. The mixed methods integration identified convergence in the P5's responses that she felt confident to undertake BSE and she checked her own breasts at least once a month.

P15 reported that she didn't feel self-efficious about performing BSE so didn't check her breasts at all. Convergence was identified with the CAM responses as she reported that she was not confident about performing BSE and rarely checked her breasts. The mixed methods approach was valuable to identify women who lacked self-efficacy about performing BSE and its role in facilitating the women to be breast aware. It may be that these women perceive the process of BSE to be more difficult than it actually is, and the intervention could address this by teaching the required skills to effectively perform BSE.

Dissonance was identified between the findings of the BSE self-efficacy and outcome expectations questions and the CAM confidence, skills and behaviour questions at the baseline assessment for P17. In the interviews P17 commented that she was confident to perform BSE, but didn't see the purpose of doing it because of her breast size:

> *'Yes, but now you see I've got small ones' (P17 Pre-test)*

In the baseline CAM responses P17 mentioned that she did not feel confident about checking her own breasts but did check them at least once a month. The mixed methods approach was useful as it gave an indication of the woman's poor understanding about breast cancer and the importance of being breast aware despite having participated in the BreastCheck programme on two occasions.

7.2.8. Post intervention assessment for women with intellectual disabilities Category 1

During the post intervention interviews and CAM assessment, see Table 7.6, P2 demonstrated an improvement in perceived self- efficacy to perform BSE and increased confidence and skills to detect a breast change. Nevertheless P2 was adamant that she would not check her own breasts for changes. In the interview she shook her head from side to side to signify that she would not perform BSE, while in the CAM she responded that she rarely checked her breasts for changes. In this case the mixed methods approach is advantageous to monitor for convergence in the integration of the findings from both strands of enquiry to give a more complete picture of the womens perspectives about BSE.

Following participation in the EMBRACES-ID intervention P3 mentioned in the post intervention CAM assessment that she was more confident about BSE and was currently checking her breasts for changes at least once a month. Partial agreement was detected at this juncture as P3 did not respond to the frequency of BSE question in the post intervention interview.

Convergence was detected between the findings from both the post intervention interview and CAM survey for P5's responses. P5 reiterated her confidence about carrying out breast self-examination at regular intervals and commented that:

> *'I do it every week especially since I started the course' (P5 Post intervention)*

It was observed in the post intervention interview and CAM findings that P15 still had low perceived self-efficacy to perform BSE and lacked the confidence to carry out the procedure. However, P15 provided further insight into her low perceived efficacy towards performing

BSE and mentioned that she had attended a healthcare professional to have clinical breast examination:

> *'Sometimes I go to the doctor' (P15 Post intervention)*

It was apparent that P17 had an increased awareness about breast awareness including carrying out regular BSE following the provision of intervention materials in various formats including breast models, videos and accessible information. Although there was dissonance observed between the interview and CAM responses in relation to self- efficacy to carry out BSE, outcome expectations and confidence, skills and behaviours to carry out BSE, the woman reported that:

> *'Now if I'm having a bath I check my breasts every day' (P17 Post intervention)*

Despite the fact that the women had participated in mammography, some women seemed unsure about their confidence to perform BSE and rarely checked their breasts themselves.

7.2.9. Baseline assessment for women with intellectual disabilities Category 2

Six participants (P1, P7, P10, P14, P20 and P21) demonstrated a strong sense of perceived self-efficacy about BSE and outcome expectations related to the frequency of BSE during the baseline interviews. These women also reported in the baseline CAM survey that they felt confident that they would notice a change in their breast and checked their breasts for changes at regular intervals. The mixed methods integration detected convergence between the interview and CAM findings for five of the women (P1, P7, P10, P14 and P10), and partial agreement for P21, see Table 7.7.

These six women demonstrated good breast awareness, and were confident that they would detect a change in their breasts:

> *'Sometimes they might be hard, sometimes they might be soft' (P1 Pre-test)*
>
> *'I didn't find anything wrong with them yet' (P10 Pre-test)*
>
> *'Ah yes, ah yes, very confident' (P20 Pre-test)*

In relation to the outcome expectations about performing BSE the women discussed that they performed BSE on a very regular basis:

> *'Non- stop…everyday' (P7 Pre -test)*
>
> *'I think I've checked them once or twice' (P10 Pre-test)*

'I check them, em, every night' (P20 Pre- test)

'About two months' (P21 Pre-test)

P14 explained about her routine in relation to the frequency of BSE and her attitude towards early help seeking for a self-discovered symptom she thought might be serious:

'*After my shower, if anything on it I tell my doctor' (P14 Pre- test)*

Although there are no clear recommendations about the frequency that women check their breasts, daily checking of the breasts appears excessive and might lapse over time. The EMBRACES-ID intervention addressed the importance of being aware how your breasts normally look and feel over the lifecourse to facilitate early recognition of changes.

7.2.10. Post intervention assessment for women with intellectual disabilities Category 2

During the post intervention interviews and CAM assessment P7, P10 and P20 demonstrated little change in perceived self- efficacy to perform BSE, the confidence and skills to detect a breast change or the frequency with which BSE was undertaken. Mixed methods integration continued to detect convergence in these womens qualitative and quantitative responses, see Table 7.7.

Nevertheless there was an improvement in awareness levels about the warning signs for breast cancer detected following participation in the EMBRACES- ID intervention. The women discussed the changes they were likely to check for at the post intervention interview:

'Eh, lumps and under the arm' (P7 Post intervention)

'I even checked once already to see did one of the nipples go in, but it didn't' (P10, Post intervention)

Conversely for P1 and P14 only partial agreement was detected in the mixed methods integration of the post intervention interview and CAM data. Both women mentioned that they were self-efficious about performing BSE in the post intervention interview. For example, while P14 described her perceived self- efficacy to carry out BSE she did not respond to the frequency of BSE question in the post intervention interview:

'I'm able to do it myself' (P14 Post intervention)

The post intervention integration of the interview and CAM findings identified convergence in P1's responses. Although P1 mentioned that she rarely checked her own breasts for changes in the post intervention interview she had previously discussed in the baseline assessment that she carried out BSE on a weekly basis. The mixed methods integration is useful to identify women with mild to moderate intellectual disabilities who may misunderstand the questions asked or demonstrate social desirability in their answers.

7.2.11. Baseline assessment for women with intellectual disabilities Category 3

Nine participants (P4, P9, P11, P12, P16, P18, P19, P22 and P23) demonstrated a low sense of perceived self- efficacy about performing BSE and mixed outcome expectations related to the frequency of BSE during the baseline interviews. These women primarily reported in the baseline CAM survey that they felt unsure that they would notice a change in their breast and rarely checked their own breasts for changes. The mixed methods integration detected convergence between the interview and CAM findings for five of the women (P4, P9, P16, P19 and P23), and partial agreement for four of the women (P11, P12, P18 and P22), see Table 7.8.

Some of these women in demonstrated poor breast awareness, and were not sure that they would detect a change in their breasts. They were more likely to have a female family carer assist them with the breast examination or attend a GP for a clinical breast examination:

> *'No, my sister would for me' (P4 Pre-test)*
>
> *'Eh no, I haven't done that' (P9 Pre-test)*
>
> *'No, em, I have to ask my Mom' (P16 Pre-test)*
>
> *'No I don't … its been fine every time I had an exam' (P18 Pre- test)*

Other women mentioned that they did carry out BSE on a regular basis, despite being unsure that they would notice a breast change:

> *'Yes, I do it once per week' (P11 Pre-test)*
>
> *'Usually I check my breast if I'm having a shower' (P19 Pre-test)*

7.2.12. Post intervention assessment for women with intellectual disabilities Category 3

During the post intervention interviews and CAM assessment these nine women demonstrated positive changes in perceived self- efficacy to perform BSE, increased confidence and skills to detect a breast change and the frequency with which BSE was undertaken. Mixed methods integration detected convergence in the qualitative and quantitative responses for P4, P9, P11, P12, P18, P19, P22 and partial agreement for P16 and P23, see Table 7.8.

There was an improvement in the womens confidence to detect changes in their own breast. For example P4, who had lost her mother to breast cancer, mentioned in the baseline CAM assessment that she aware of a lump in the breast or redness of the skin of the breast as warning signs for breast cancer. Following participation in the EMBRACES-ID intervention P4 reported awareness of a wider range of warning signs for breast cancer including nipple changes and puckering of the breast skin, and an increased sense of self-efficacy to notice these changes:

> *'I would be confident because I would watch for lumps or if it was all red. I'd check the nipple for a leak or if it was burst in some way' (P4 Post intervention*)

P4 continued by discussing her improved outcome expectations about BSE and how she now checked her breasts regularly following participation in the EMBRACES-ID intervention:

> *'Since doing the course I check my breasts once a month' (P4 Post intervention)*

Other women also mentioned improved frequency of BSE following the intervention. Although there are no strict guidelines for the frequency of BSE, it is recommended to feel the breasts in the bath or shower to help build familiarity about how the breasts feel. These women discussed this in the following comments:

> '*Shower' (P11 Post intervention)*
>
> *'Eh, after a shower' (P12 Post intervention)*
>
> *'When I'm having a shower or something' (P18 Post intervention)*
>
> *'Well I'd probably look in my own bathroom' (P23 Post intervention)*

P19 described the technique she would use when carrying out BSE in the shower:

> *'Just go in the shower and just check around like that' (P19 Post intervention)*

These improved self- efficacy beliefs, outcome expectations, confidence and skills about carrying out and the frequency of BSE demonstrate the value of using of breast models, textual information, illustrations and BSE videos in giving the women the necessary skills to successfully perform BSE. Despite this P9 still remained apprehensive about performing BSE, but didn't rule out performing BSE in the future:

> *'But, em, when I do feel ready' (P9 Post intervention).*

7.2.13. Baseline assessment for women with intellectual disabilities Category 4

Three participants (P6, P13, and P25) generally demonstrated a low sense of perceived self-efficacy about performing BSE and poor outcome expectations related to the frequency of BSE during the baseline interviews. P13 and P25 reported in the baseline CAM survey that they felt unsure that they would notice a change in their breast and rarely checked their own breasts for changes. P6 mentioned that she was confident that she would notice a change in her breasts and that she regularly performed BSE. The mixed methods integration detected convergence between the interview and CAM findings for two of the women (P13 and P25), and dissonance for P6, see Table 7.9.

The baseline responses from P6 demonstrated dissonance, it may have been that she misunderstood the questions. Nevertheless P6 had attended the GP for a clinical breast exam and was satisfied that her breasts were healthy:

> *'I went to the doctor and she said that not bad' (P6 Pre-test)*

P13 reiterated that she did not perform BSE or didn't feel confident that she would notice a change in her breast. Similar to P6 she felt confident that her breasts were healthy following a clinical breast exam at the GP.

> *'Yes, I do…eh, at the doctors' (P13 Pre-test)*

Conversely, P25 had never performed BSE and felt unsure that she would notice a change in her breasts at all:

> *'Em, no I don't' (P25 Pre-test)*

7.2.14. Post intervention assessment for women with intellectual disabilities Category 4

During the post intervention interviews and CAM assessment the three women demonstrated little change in perceived self- efficacy to perform BSE, confidence and skills to detect a breast change or the frequency with which BSE was undertaken. Mixed methods integration detected convergence in the post- intervention interview and CAM responses for P25, partial agreement for P13 and dissonance for P6, see Table 7.9.

Although she had participated in the EMBRACES-ID intervention P6 remained adamant that she did not need to carry out BSE to develop her personal breast awareness:

> *'Myself no' (P6 Post intervention)*

P13 and P25 reported a low sense of perceived self- efficacy to perform BSE following the intervention. P25 mentioned that even though she had learned a lot about breast and cervical cancer and screening in the EMBRACES-ID intervention, she remained apprehensive about performing BSE:

> *'I haven't done it yet. Really I'm not confident yet… I know myself I'm not and that's being honest' (P25 Post intervention)*

7.2.15. Baseline assessment for women with intellectual disabilities Category 5

Two participants P8 and P24 demonstrated a low sense of perceived self- efficacy about performing BSE and mixed outcome expectations related to the frequency of BSE during the baseline interviews. These women reported in the baseline CAM survey that they felt unsure that they would notice a change in their breast and rarely checked their own breasts for changes. The mixed methods integration detected convergence between the interview and CAM findings for P24 and partial agreement for P8, see Table 7.10.

P8 discussed a very personal insight into touching her breasts and the carers reactions:

> *'I have an awful problem with feeling them a lot… I told you I have a habit of doing that. I was told, told to keep my hands away from them' (P8 Pre-*test)

It seems women with intellectual disabilities may receive a very negative form of sex education from carers which including guidance not to touch sexual parts of their bodies such as the breasts. This may have implications for the woman becoming breast aware and negatively impact on the potential detection and treatment of any future breast cancers.

7.2.16. Post intervention assessment for women with intellectual disabilities Category 5

During the post intervention interviews and CAM assessment, see Table 7.10, P8 demonstrated little change in perceived self- efficacy to perform BSE, confidence and skills to detect a breast change or the frequency with which BSE was undertaken. Mixed methods integration detected dissonance in P8's post- intervention interview and CAM findings. It seems that although P8 had received the relevant information and practice about how to perform BSE during the intervention, it was difficult to change the deep seated attitude she had developed towards touching her breasts.

On the other hand P24 demonstrated improvements in the sense of perceived self- efficacy to perform BSE, confidence and skills to detect a breast change or the frequency with which BSE was undertaken. Mixed methods integration detected convergence in P24's post intervention interview and CAM responses.

During the interview P24 was observed to point to the breast when discussing BSE. However, the issue of mislabelling body parts could have implication if the woman was attempting to explain pain or another symptom to a carer or a healthcare professional:

> *'The hips, there' (P24 Post intervention)*

7.3. Introduction the acceptability and feasibility testing of EMBRACES-ID

Qualitative research is a valuable way to allow a wider range of stakeholder perspectives to be incorporated in the findings (Craig et al., 2008), and was used in the acceptability and feasibility testing of the EMBRACES-ID intervention. EMBRACES-ID would be considered for full trial pending the results of the feasibility and acceptability assessment, including a retention target of 80% for women with mild to moderate intellectual disabilities and their carers (Treweek, 2015).

First, in section 7.4. the acceptability assessment considers the appropriateness and relevance of the EMBRACES-ID intervention for women with mild to moderate intellectual disabilities and their carers and explores how the participants reacted to the EMBRACES-ID intervention (Craig et al., 2008, Bowen et al., 2009, Feeley et al., 2009, Richards et al., 2015). Second, section 7.5. explores the delivery of the intervention by the facilitator and examines the retention rates for the women with mild to moderate intellectual disabilities (Feeley et al., 2009, Richards, 2015).

A network model detailing the key elements involved in the delivery of the EMBRACES-ID intervention is shown in Figure 7.1. Oval nodes represent the tentative theory that when women with mild to moderate intellectual disabilities and their carers complete the

Table 7.6. Convergence Coding Matrix for women with intellectual disabilities Category 1

P No.	Breast confidence (Baseline interview)	Breast check (Baseline interview)	Breast confidence and check (Baseline CAM)	MMR Integration Baseline assessment	Breast confidence (Post intervention interview)	Breast check (Post intervention interview)	Breast confidence and check (Post intervention CAM)	MMR Integration Post intervention assessment
P2	-	No	Breast_confid-0 Breast_check-0	Convergence	Yes	Oh (shakes head)	Breast_confid-1 Breast_check-0	Convergence
P3	-	Only if I, when I used to get my periods, I don't get them now. I used to feel sore on my breasts	Breast_confid-0 Breast_check-1	Partial agreement	Yes	-	Breast_confid-1 Breast_check-1	Partial agreement
P5	What is it that way, is it that way ?	Em, well my home helps would probably give me a hand with it as well, like	Breast_confid- 1 Breast_check- 1	Convergence	I am very confident but I would get my home help to help me sometimes	I do it every week, especially since I started the course	Breast_confid-1 Breast_check-1	Convergence
P15	-	-	Breast_confid-0 Breast_check-0	Convergence	Not very	Sometimes I go to the doctor	Breast_confid-0 Breast_check-0	Convergence

Table 7.7. Convergence Coding Matrix for women with intellectual disabilities Category 2

P No.	Breast confidence (Baseline interview)	Breast check (Baseline interview)	Breast confidence and check (Baseline CAM)	MMR Integration Baseline assessment	Breast confidence (Post intervention interview)	Breast check (Post intervention interview)	Breast confidence and check (Post intervention CAM)	MMR Integration Post intervention assessment
P1	Sometimes they might be hard, sometimes they might be soft…	Once a week	Breast_confid- 1 Breast_check 1	Convergence	Yes	Rarely	Breast_confid-1 Breast_check -0	Convergence
P7	Yes	Non- stop…every day	Breast_confid-1 Breast_check-1	Convergence	Yes	Eh, lumps and under the arm	Breast_confid- 1 Breast_check-1	Convergence
P10	I didn't find anything wrong with them yet.	I think I've checked them once or twice	Breast_confid-1 Breast_check-1	Convergence	I even checked once already to see did one of the nipples go in, but it didn't	I checks them after a shower	Breast_confid-1 Breast_check-1	Convergence
P14	Yes, I do it myself	After my shower, if anything on it I tell my doctor	Breast_confid-1 Breast_check-1	Convergence	I'm able to do it myself	-	Breast_confid-1 Breast_check-1	Partial agreement
P20	Ah yes, ah yes, very confident	I check them, em every night	Breast_confid-1 Breast_check-1	Convergence	Yes	Em, every, after my, between the bedroom and bathroom	Breast_confid-1 Breast_check-1	Convergence
P21	Oh, often	About two months	Breast_confid-1 Breast_check-0	Partial agreement	Yes, I am yes	All the time	Breast_confid-1 Breast_check-1	Convergence

Table 7.8. Convergence Coding Matrix for women with intellectual disabilities Category 3

P No.	Breast confidence (Baseline interview)	Breast check (Baseline interview)	Breast confidence and check (Baseline CAM)	MMR Integration Baseline assessment	Breast confidence (Post intervention interview)	Breast check (Post intervention interview)	Breast confidence and check (Post intervention CAM)	MMR Integration Post intervention assessment
P4	-	No, my sister would for me	Breast_confid-0 Breast_check- 0	Convergence	I would be confident because I would watch for lumps or of it was all red. I'd check the nipple for a leak or if it was burst in some way.	Since doing the course I check my breasts once a month	Breast_confid-1 Breast_check-1	Convergence
P9	Eh no, I haven't done that	Only once (doctor)	Breast_confid-0 Breast_check-1	Convergence	Ehm, yes	But, em, when I do feel ready	Breast_confid-1 Breast_check-0	Convergence
P11	-	Yes, I do it once a week	Breast_confid-1 Breast_check-1	Partial agreement	Yes	Shower	Breast_confid-1 Breast_check-1	Convergence
P12	_	No	Breast_confid-0 Breast_check-1	Partial agreement	Em yes	Eh, after a shower	Breast_confid-1 Breast_check-1	Convergence
P16	No, em, I have to ask my Mom	_	Breast_confid-0 Breast_check-0	Convergence	Yes	-	Breast_confid-1 Breast_check-1	Partial agreement
P18	-	No, I don't… it's been fine every time I had an exam	Breast_confid-1 Breast_check-0	Partial agreement	Yes	When I'm having a shower or something	Breast_confid-1 Breast_check-1	Convergence
P19	-	Usually I check my breasts if I'm having a shower	Breast_confid-0 Breast_check-1	Convergence	Yes	Just go in and have shower and just check around like that	Breast_confid-1 Breast_check-1	Convergence
P22	-	No	Breast_confid-0 Breast_check-1	Partial agreement	Yes	Ah, twice	Breast_confid-1 Breast_check-1	Convergence
P23	-	-	Breast_confid-0 Breast_check-0	Convergence	Oh yes, sometimes	Well, I'd probably look in my own bathroom	Breast_confid-1 Breast_check-0	Partial agreement

Table 7.9. Convergence Coding Matrix for women with intellectual disabilities Category 4

P No.	Breast confidence (Baseline interview)	Breast check (Baseline interview)	Breast confidence and check (Baseline CAM)	MMR Integration Baseline assessment	Breast confidence (Post intervention interview)	Breast check (Post intervention interview)	Breast confidence and check (Post intervention CAM)	MMR Integration Post intervention assessment
P6	-	I went to the doctor and she said that not bad…there	Breast_confid-1 Breast_check-1	Dissonance	-	Myself, no	Breast_confid-1 Breast_check-1	Dissonance
P13	-	Yes, I do … eh, at the doctors	Breast_confid-0 Breast_check-0	Convergence	No response	No Response	Breast_confid-1 Breast_check-0	Partial agreement
P25	Em, no I don't	No	Breast_confid-0 Breast_check-0	Convergence	I haven't done it yet. Really I'm not confident yet… I know myself I'm not and that's being honest	-	Breast_confid-0 Breast_check-0	Convergence

Table 7.10. Convergence Coding Matrix for Category 5

P No.	Breast confidence (Baseline interview)	Breast check (Baseline interview)	Breast confidence and check (Baseline CAM)	MMR Integration Baseline assessment	Breast confidence (Post intervention interview)	Breast check (Post intervention interview)	Breast confidence and check (Post intervention CAM)	MMR Integration Post intervention assessment
P8	-	I have an awful problem with feeling them a lot… I told you I have a habit of doing that. I was told, told to keep my hands away from them	Breast_confid-0 Breast_check-1	Partial agreement	Yes	-	Breast_confid-0 Breast_check-1	Dissonance
P24	-	No	Breast_confid-0 Breast_check-0	Convergence	Yes, I do, yes	The hips, there.	Breast_confid-1 Breast_check-1	Convergence

EMBRACES-ID intervention they would demonstrate improved awareness about cancer warning signs risk factors and screening programmes and early medical help seeking in the discovery of a symptom they thought might be serious. Rectangular nodes represent the key elements of EMBRACES-ID intervention acceptability and feasibility from the perspectives of the women with mild to moderate intellectual disabilities and their carers. Each of the elements identified in the network model will be presented in more detail, beginning with the acceptability assessment.

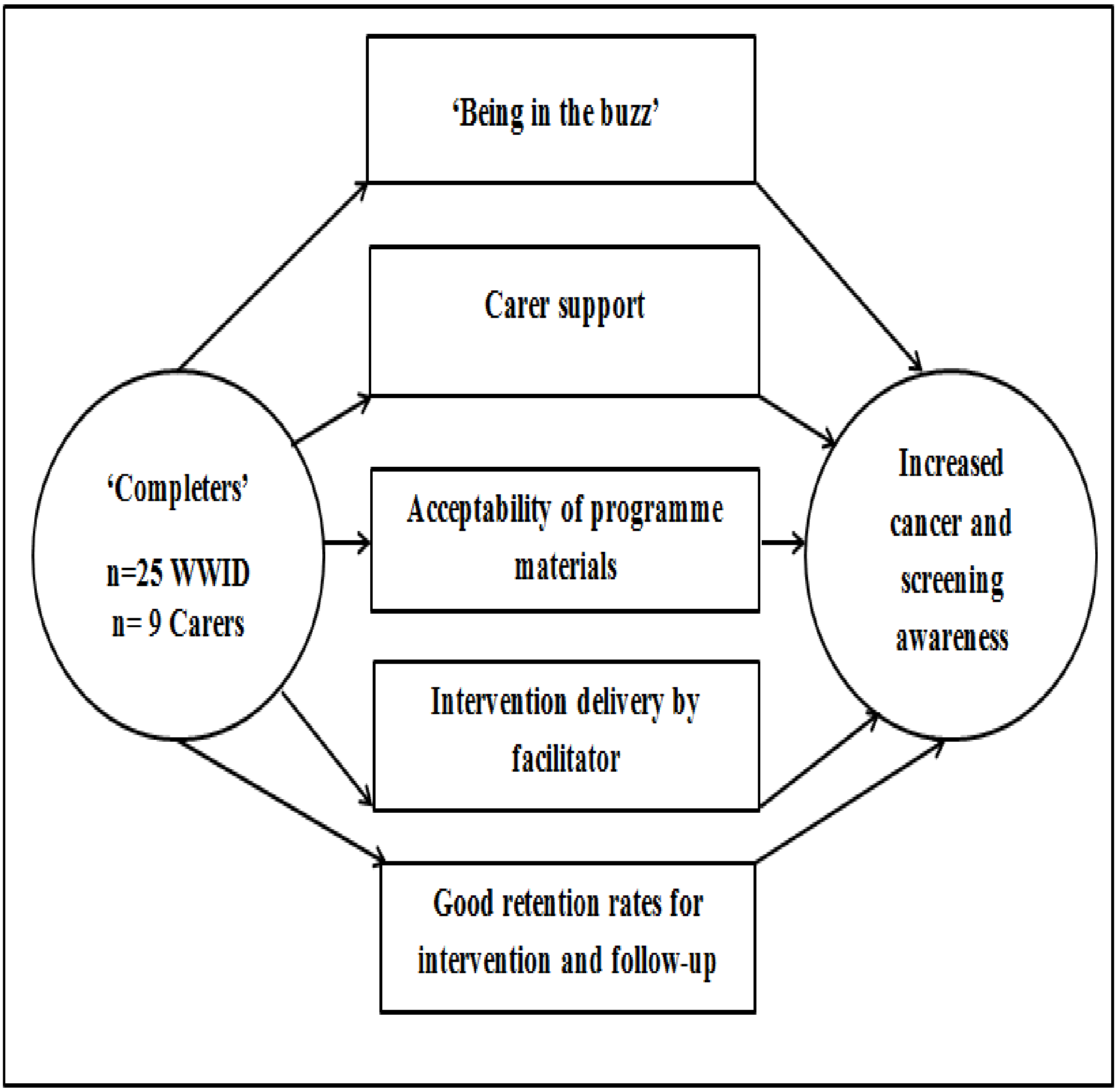


Figure 7.1. A network model of cancer and screening awareness

7.4. EMBRACES-ID intervention acceptability assessment

7.4.1. ‘Completers’

‘Completers’ were characterised as those participants who attended at least 3 of the 4 EMBRACES-ID classes or had full attendance at each of the sessions. In total 25 women with mild to moderate intellectual disabilities and nine carers completed the EMBRACES-ID intervention. Each of these 34 participants was awarded a Certificate of Participation, see Appendix VI, Volume II.

7.4.2. ‘Being in the buzz’

In the main women with mild to moderate intellectual disabilities mentioned that they found the course very interesting. The women spoke about their enjoyment of the classes such as ‘being in the buzz’ with their peers and carers, and the positive effects of participating in the intervention such as learning about cancer and screening through various media. This was reliant on the provision of high quality classroom content led by a good group facilitator, peer and carer support:

> *‘That’s what I mean, I just liked the whole buzz’ (P7 Evaluation)*
>
> *‘I found it, I found it inter.., very interesting (P21 Evaluation)*

7.4.3. Carer support

Carers suggested that carer support which facilitated the women with mild to moderate intellectual disabilities to engage with the EMBRACES-ID intervention was helpful to improve the acceptability of the intervention for the women:

> *‘Staff assistance was beneficial to some of the services users… explanations, encouragement’ (P2 Healthcare Assistant)*

Carers describe a number of challenges which they considered could have impacted negatively on the delivery of the intervention. The key challenge seemed to have been related to the ability of the intellectual disabilities service provider to meet the intervention requirement with respect to carer participation in the intervention and the recommended group size of 5-6 women with mild to moderate intellectual disabilities.

This carer discussed how the staff accompanying the women to the EMBRACES-ID intervention should be familiar with each other. This would be useful to ensure that conversations about breast and screening awareness could be initiated in the care setting among the women with intellectual disabilities and staff:

> *'Staff accompanying clients should know each other' (P2 Healthcare Assistant)*

The carer argued that the unavailability of the same staff for the duration of the intervention was very frustrating as this impacted on the womens involvement in the intervention:

> '*Staff being delayed for various reasons, no transport, staff shortages' (P2 Healthcare Assistant)*

Closely related to this was the inability of some of the intellectual disability service providers involved in the study to facilitate small group sizes with a maximum of 5-6 women due to staff commitments and restrictions on the availability of the training room for the duration of the project. This resulted in one larger group with eight participants and this carer argued that this may have impacted on the womens engagement with the intervention:

> *'Our group was great in that they shared but I think one or two people kept very quiet and maybe would have been a little more vocal if there were smaller numbers' (P9 Social Care Worker)*

7.4.4. Acceptability of the programme materials

Some of the women mentioned that they found the curriculum difficult when the course first started, but as the weeks went on they found the programme material easier to understand:

> *'Just one day there was too much information, blew my head up but apart from that the rest of it went well... I really enjoyed getting on with everybody, it was good' (P4 Evaluation)*

> *'At first, em, it was hard to understand' (P17 Evaluation)*

Various types of media were used in the EMBRACES-ID programme. The women preferred when the information presented in the video clips rather than the booklet. The breast cancer awareness videos showed breast self-examination and the mammography procedure. The cervical screening awareness videos showed an animation of the cervical screening procedure and conversations with women about their perceptions of cervical cancer screening:

> *'I liked mm, I, I liked the look, I liked looking at it on the laptop' (P2, Evaluation)*

> *'Well the way that you showed it on the video madam, the way that you checked on that' (P18 Evaluation)*

'The, the film, the videos' (P19 Evaluation)

Another popular part of the programme was the anatomically correct doll which was used to generate discussion about how a woman's body was different to a man's body by showing the group the doll and undressing the doll. The purpose of the doll was to alleviate embarrassment during the discussion. In the main women liked the doll because they found it helpful. Although some women couldn't overcome their embarrassment and used to put the doll's underwear back on, or found the idea of the doll to be hilarious:

'Eh, I just liked the doll' (P1, Evaluation)

'The doll was the fucking funniest thing' (P14 Evaluation)

'Because the doll was helpful, it is so helpful' (P16 Evaluation)

'Yes, putting the shorts on her' (laughter) (P23 Evaluation)

Teaching the women deep breathing as a relaxation technique was a part of each class. The women practiced this deep breathing technique daily over the duration of the course. One woman found the technique very useful to help her overcome anxieties related to medical appointments:

'And the, when you learned to breathe' (P2 Evaluation)

Another issue addressed by the EMBRACES-ID intervention was to give the women direct experience to become familiar with the equipment used for cervical screening. The women gave their thoughts about being shown the speculum, cytobrush and specimen bottle. Some women mentioned that they found this scary and embarrassing:

'It was kind of frightening...and embarrassing' (P1 12 week)

'Learning how to do it was quite scary' (P11 Post intervention)

Some women also mentioned that they were relieved that they did not have to attend the doctor as a result of the attending the course:

'Just saying that, not saying that I have to go to the doctor to do this now…not saying that now so I'm not' (P4 12 week)

'Thank God, thank God I don't have to see him' (P13 12 week)

This section presents carers perspectives the use of interactive and visual media in addition to the intervention booklet which they felt enhanced the quality of the intervention. It examines the perspectives of the carers about the acceptability of the intervention materials for women with mild to moderate intellectual disabilities which they felt improved the womens engagement and indeed their own engagement with the intervention. Carers reported that the type of interactive materials used in the intervention improved their own cancer awareness particularly in the area of breast self-awareness:

> *'The interactive doll and especially the silicone breast samples were excellent' (P2 Healthcare Assistant)*
>
> *'I think the pictures, diagrams, video, the doll, the pillows were all very good and made it easier to understand' (P3 Student Social Care Worker)*
>
> *'Even by the pictorial information used and shared has a big impact for the awareness of breast cancer and for us women to do prevention early as possible' (P5 Nurse)*
>
> *'Hands on practice for self-exam' (P6 Social Care Worker)*
>
> *'Good use of objects e.g .doll, breasts, beads, diagrams made understanding much clearer' (P8 Educator)*
>
> *'The breasts with the lumps gave a good indication of what lumps can feel like' (P9 Social Care Worker)*

While there was a general agreement among the carers that the use of interactive materials such as the Health Edco© breast self- examination model and the Breastology Bag© were advantageous for the development of breast awareness skills for the women with mild to moderate intellectual disabilities, it seems that this was not the case in relation to cervical screening.

The 'Guidelines for good practice in taking smear tests in women with intellectual disabilities' (National Cancer Screening Service, 2011) suggested showing the speculum and brush to the woman and allowing her to handle them. This carer discussed her concerns in relation to the use of the speculum and cytobrush by the intervention facilitator to explain the cervical screening procedure to the women during the EMBRACES-ID intervention:

> *'Not 100% sure if showing the class the instrument used for the smear test is a good idea- would it put people off??' (P2 Healthcare Assistant)*

Conversely this carer felt that the used of the speculum and cytobrush was a very beneficial aspect of the EMBRACES-ID intervention for alleviating distress about the cervical screening procedure:

> *'The instrument they use for the screening of cervical cancer, when you see it and I know what they are going to do, it does not seem so frightening' (P1 Healthcare Assistant)*

Some carers also mentioned that the use of simple language in the intervention booklet was very important to engage women with mild to moderate intellectual disabilities while taking their cognitive and communication difficulties into account to improve their cancer and screening awareness:

> *'It was kept simple and the language used made it easy to understand…the pictures helped everybody to understand and engage about the content' (P2 Healthcare Assistant)*
>
> *'Use of simple language for better understanding' (P6 Social Care Worker)*
>
> *'Having a book along with pictures and the videos, it gave everybody a better idea of what happens at different times' (P9 Social Care Worker)*

Although other carers mentioned that they felt there was too much textual information provided in the intervention booklet and suggested that more emphasis on visual media sources may be more suitable to improve the womens interaction with the intervention materials:

> *'More pictures and videos, less writing on the booklet' (P1 Healthcare Assistant)*

Although the EMBRACES-ID intervention had provided accessible information supplemented with various types of media suited to the cognitive characteristics of adults with intellectual disabilities these carers argued that they felt that the educational sessions needed to be longer to meet the learning needs of women with mild to moderate intellectual disabilities:

> '*More time allocated to the class' (P1 Healthcare Assistant)*
>
> *'Possibly some extra time allocated to the class' (P2 Healthcare Assistant)*

7.5. EMBRACES-ID intervention feasibility assessment

7.5.1. Intervention delivery by facilitator

Carers mentioned that the creation of a relaxed atmosphere in the classroom and good quality intervention delivery by the facilitator using key elements of Social Cognitive Theory such as modelling and reinforcements was essential to improve participant engagement with the intervention given the sensitive topics under discussion, see Figure 7.1:

> *'The complete information and ideas given by the speaker, how she explained and delivered the important information needed for the awareness' (P5 Nurse)*
>
> *'I think it was delivered in a very confident manner and any questions/ queries were answered in a simplistic way which was important to all at the intervention' (P7 Social Care Worker)*
>
> *'M has been a brilliant facilitator. Everything was kept very relaxed, questions asked at anytime, people could leave anytime. Reassurance was given a lot throughout. M always smiled, encouraged and had a laugh throughout' (P9 Social Care Worker)*

7.5.2. Retention rates for 'Completers'

Completers demonstrated a high level of engagement with the EMBRACES-ID intervention as evidenced in the good retention rates for the intervention and follow up. The high rate of attrition from the study was concerning for 'non-completers' of the intervention. These were characterised as those participants who were recruited but attended only two classes or less of the four EMBRACES-ID intervention classes.

The acceptable retention target for women with mild to moderate intellectual disabilities and their carers was set at 80%. However, there was an observed attrition rate of 28.5% for women with mild to moderate intellectual disabilities and 43.75% for carers. The reasons for given for attrition have previously been discussed in sections 6.2. and 6.13.

7.6. Chapter summary

This chapter first explored the attitudes towards screening for women with intellectual disabilities as discussed by the carers in the Phase I Comprehensive Needs Assessment. It described how the interview findings were used to develop the interview protocol for the feasibility testing of the EMBRACES-ID intervention. Next it examined the convergence coding matrices for carers and women with mild to moderate intellectual disabilities to identify convergence, partial agreement and dissonance between the quantitative and qualitative findings regarding perceived self-efficacy to undertake BSE and the confidence and skills to undertake the process. Subsequently an exploration of the acceptability of the intervention for the participants was undertaken using a qualitative approach. It raised issues such as the value of support and the quality of the intervention materials. Lastly, it presented the feasibility testing of the intervention including the retention rates of the participants who completed the intervention. The next chapter present the discussion of the findings from both phases of the study and concludes the thesis.

Chapter 8 Discussion and conclusion

8.0. Introduction

This chapter considers the relevance and importance of the study findings. The clinical and theoretical implications are identified and discussed in section 8.1. The strengths of the study are presented in section 8.2. The limitations of the study are discussed in section 8.3. Section 8.4 outlines recommendations for practice and future directions for research. Section 8.5 provides a self- reflection of the role of the transformative researcher in this study. An overall summary of the study is provided in section 8.6, and represented diagrammatically in Figure 8.1. Finally the chapter concludes in section 8.7 with some proposed publications which could arise from the findings of this study.

8.1. Implications of the Research Findings

The conclusions drawn from the research findings and review of the literature have implications for theory and clinical practice. In an effort to advance our understanding of the cancer and screening awareness of women with intellectual disabilities, theoretical and clinical implications will be discussed.

8.1.1. Theoretical Implications

As the literature review informed the design of this study, it was necessary to consider implications in relation to the conceptual framework of the study. The conceptual framework proposed that women with intellectual disabilities and their carers who attended the EMBRACES- ID intervention would have improved levels of cancer and screening awareness as a result of carer and peer support and engagement with the targeted intervention designed to suit their learning needs.

The baseline findings of the current study support the body of evidence related to a lower awareness of non-lump symptoms of breast cancer such as nipple and skin changes in the general population, which includes women with intellectual disabilities and their carers (McMenamin et al., 2005, Linsell et al., 2008, Forbes et al., 2011, Hanna et al., 2011, Taggart et al., 2011, Forbes et al., 2013). Similarly, the current study identified poor knowledge about the warning signs for cervical cancer, in particular unusual vaginal bleeding, at the baseline assessment which is comparable with international findings (Low et al., 2012, Ekechi et al., 2014).

There was poor baseline awareness of age related cancer risk, particularly in relation to breast cancer in the current study which has been supported in previous research for example, Mc Menamin et al (2005). This is of interest in the context of a growing and ageing population in Ireland, both in the general and intellectual disability populations (Burke et al., 2014, Kelly and O' Donoghue, 2014).

The baseline results of the current study highlight that women with intellectual disabilities do self-report that they are receiving invitations to the screening programme. There was a very high self- reported participation rate for women with mild to moderate intellectual disabilities in the Irish breast screening programme similar to that reported by Lalor and Redmond (2009). Furthermore the study results demonstrate that over half the age eligible women with intellectual disabilities self- reported that they had been invited to attend the cervical screening programme while less than one third attended. Inequalities in participation in the cervical screening programme among women with intellectual disabilities are supported by previous international studies such as those carried out by Noonan Walsh et al. (2008), Osborn et al. (2012), Cobigo et al. (2013).

During the carer interviews in Phase I carers argued that in particular women with severe to profound intellectual disabilities are losing out on vital screening opportunities and early detection for possible cancers. This argument is in broad agreement with international findings such as the studies carried out by Lalor and Redmond, (2009), Wilkinson et al. (2011b) and Horner-Johnson et al. (2014). This is concerning as almost 14% of Irish women with intellectual disabilities over the age of 20 years have a diagnosis of severe to profound intellectual disabilities (Kelly and O' Donoghue, 2014).

The baseline findings of the current study demonstrate that women with mild to moderate intellectual disabilities generally have very poor confidence to detect changes in their own breasts or to detect a symptom of cervical cancer. Over half the women with mild to moderate intellectual disabilities aged 40 years of age and under in the current study mentioned that they rarely or never check their own breast. This is concerning given that women are not eligible to participate in BreastCheck, the National Screening Programme until they reach 50 years of age (National Cancer Screening Service, 2013), and this may have implications on the early detection and treatment of potential breast cancers.

Furthermore it is worrying that the baseline cervical cancer and screening awareness levels were so limited among women with mild to moderate intellectual disabilities especially those in the age group where the incidence is highest (30-49 years of age) (Cancer Research UK., 2013). It was interesting to note agreement in the findings of the current study with those of Wilkinson et al. (2011b), Parish et al. (2012b), Willis et al. (2015) that women with intellectual disabilities who lived at home with family caregivers demonstrated very low awareness about cancer prevention, in particular cervical cancer. This presents a major challenge in an Irish context as almost 70% of Irish women with intellectual disabilities live at home with family caregivers (Kelly and O' Donoghue, 2014).

The current study found during the baseline interviews with women with intellectual disabilities that they often have exposure to media coverage of high profile cancer deaths and storylines in popular soap operas such as Emmerdale. This seems to be a source of undue stress and worry for these women who may have limited verbal ability or adequate understanding of cancer to discuss their worries. These findings concur with previous research undertaken by Truesdale-Kennedy et al. (2011).

Similar to previous research studies for example, Taggart et al. (2011), nurses in this study demonstrated higher baseline cancer and screening awareness levels than other categories of carers. Nevertheless gaps awareness levels were identified among the nurses, particularly that blood in the stool or persistent diarrhoea for three weeks or more were not recognised as warning signs for cervical cancer. The results in the current study support previous research in this area which contends that carers may not have the relevant levels of knowledge to adequately support the cancer prevention information needs of women with intellectual disabilities for example, Kirby and Hegarty (2010), Hanna et al. (2011), Taggart et al. (2011), Wyatt and Talbot (2013).

Generally speaking, nurses and carers in the present study reported that there was a vital need for more cancer and screening awareness education for all paid and family carers. This need for accessible information and education for women with intellectual disabilities, carers and families was reiterated in the literature for example, Kirby and Hegarty (2010), Tyler et al. (2010), Hanna et al. (2011), Taggart et al. (2015). The crux of the matter for carers was captured by this student nurse as discussed in the carers interviews in Phase I of the study ‘because if we don’t understand, how the hell are we supposed to make somebody else understand’

The Phase II feasibility and acceptability testing of the EMBRACES-ID intervention was also a key element of the conceptual framework of the study. EMBRACES-ID gave the women the opportunity to acquire knowledge and skills in order to make informed choices about their own health care as active participants and was the crux of social justice attainment in this study. There are a number of interesting issues arising from the feasibility and acceptability testing of the intervention.

First, while modest knowledge gains were noted for breast cancer and screening awareness among the women with intellectual disabilities in the post intervention assessment, the gains in cervical cancer and screening awareness were much lower. This was in broad agreement with the small body of international research findings about cancer and screening awareness interventions such as the studies carried out by Parish et al. (2012a), Swaine et al. (2014).

The study contributes to the body of knowledge on the engagement of women with intellectual disabilities with cervical health promotion by suggesting a potential reason for the womens non- engagement with cervical health promotion. The ICD 10 Version 2016 classifies the mental age of women with mild intellectual disabilities as 9- 12 years of age (World Health Organisation, 2016) which is analogous to Piaget's developmental age for the development of concrete operations (Piaget, 1999). It might be reasonable to consider that the poorer knowledge gains in relation to cervical cancer and screening awareness stem from the lack of a frame of reference or schema to concretely operationalise the cervix which is internal to the body.

It is noteworthy in the findings of the current study that that some women with intellectual disabilities in their early thirties mentioned that they were too young to know about cancer. These findings are supported by previous research about attitudes and knowledge about cancer in adults aged between 35-54 years of age in the general population (Keeney et al., 2010). Currently there are 8000 adults with intellectual disabilities between 35-54 years of age in the Republic of Ireland (Kelly and O' Donoghue, 2014). It seems plausible that this population may also be concerned that they are too young to be worried about cancer and cancer prevention especially given the challenges presented by protectionism and infantilism by carers, in particular family carers.

Knowledge gains had improved for two breast cancer warning signs and nine cervical cancer warning signs at the 12 week follow up survey than that recorded in the post intervention survey as seen Tables 6.21. and 6.25. It is plausible to consider that because the women had the access to the programme booklet in the intervening that they may have looked at the booklet or discussed the content with their carers.

It was noted in the 12 week follow up survey that the barriers to help seeking, embarrassment and fear, were similar to the baseline assessment levels among women with intellectual disabilities. It was interesting to note that among carers in the 12 week follow up survey that worry about what the doctor might find and fear were also comparable to baseline survey levels. These results support previous research about fear and fatalism about cancer in the general population (Scanlon et al., 2006, O'Mahony and Hegarty, 2009, Keeney et al., 2010, Forbes et al., 2011, Forbes et al., 2013, Ryan et al., 2015).

The results of the present study illustrate that embarrassment was the principal challenge cited by women with mild to moderate intellectual to delaying early medical help seeking for a symptom they thought might be serious or accessing the cancer screening services. The sensitive nature of the subject matter would make it very difficult for the women to negotiate the consultations, although the women did express a clear preference to have their consultations with a female doctor. It is worth noting that embarrassment about discussing cancer, breast or cervical health was widely cited as a barrier to engaging with healthcare services in the literature pertaining to the general population and women with intellectual disabilities (Tyler et al., 2010, Truesdale-Kennedy et al., 2011, O' Connor et al., 2012, Forbes et al., 2013, Swaine et al., 2013).

However, as the study was exploratory and descriptive, these findings do not prove that participation in the EMBRACES-ID intervention definitively caused the improvements in cancer and screening awareness observed as proposed in the conceptual framework. Future studies could explore the impact of emotional barriers to help seeking for symptoms both among women with mild to moderate intellectual disabilities and their carers.

8.1.1.1. Issues regarding sexuality and decision making

This study highlighted concerns about attitudes towards the presumed asexuality of women with intellectual disabilities and informed consent in relation to participation in the cervical screening programme for women with mild to moderate or severe to profound intellectual disabilities. Guidance from the National Cervical Screening Programme suggests women who have ever been sexually active with either males or females require cervical screening (National Cancer Screening Service, 2011). The general societal assumption of asexuality among women with intellectual disabilities may have consequences for the womens health. The findings of the present study are reflected in the literature for example Swaine et al. (2013), where it was reported by families that doctors advised that cervical screening was not necessary due tosexual inactivity.

Current Irish decision making legislation contends that efforts must be made to support individuals in making decisions for themselves where this is possible. In the recently enacted Assisted Decision Making (Capacity) legislation (Government of Ireland, 2015) it seems that the test becomes whether the person can give full informed consent at the time the healthcare decision is being made. It is interesting to note that one of the women in the current study who had attended breast screening was not sure if she had ever been invited to have a mammogram thus the issue of informed consent is pertinent, and supported similar concerns in the current body of evidence. Although the legislation does not impose the standard of the retention of information, it was demonstrated in this study that many women with intellectual disabilities did retain the information over the 12 week follow up period.

8.1.2. Clinical Implications

As this was an exploratory, descriptive study, it is difficult to draw definitive implications for practice, particularly about improving cancer and screening awareness for women with intellectual disabilities and their carers. However, a number of issues arose which have implications for clinical practice.

Based on the findings of this study it is acknowledged that it is important for adolescents with intellectual disabilities to receive suitable relationship and sexuality education. Programmes such as the Irish Family Planning Association Speakeasy© Programme for people with intellectual disabilities could be run during personal development classes during the senior cycle in secondary school. It is proposed that this would have an impact in a number of key areas. It would prepare women with intellectual disabilities to be in a position to correctly report their sexual histories at a cervical screening appointment and thus be more active participants in their own healthcare as regards informed decision making. Providing women with intellectual disabilities with the relevant information about their sexuality could potentially reduce the fear and embarrassment they face when discussing their breast and cervical health as adults, and possibly reduce sexual abuse rates among women with intellectual disabilities.

A number of services expressed an interest in running the EMBRACES-ID intervention for staff, families and women with intellectual disabilities. Although the intervention did not meet the required retention rates to progress to a full trial, nevertheless it did indicate improvements in cancer and screening awareness levels among those who had participated in the intervention. As the start-up costs for the programme are in the region of €1000, it is proposed that the equipment be stored in a central repository, such as the HSE Health Promotion library for the services to borrow to run their in service training days, as this was a HSE funded study. In accordance with the MRC guidance the provision of the EMBRACES-ID programme manual will allow the intervention to be replicated by intervention facilitators in the intellectual disability services. There was a wide variation in the age range of the women with mild to moderate intellectual disabilities who took part in the current study (age range 23-61). It might be more beneficial to target the EMBRACES-ID intervention to women as they approach screening age or nearer to screening appointment. This would allow for repetition and reinforcement of the relevant information to assist the women to make informed decision in the spirit of the Assisted Decision Making (Capacity) Act legislation and human rights approach to intellectual disability service provision in the Republic of Ireland (UN General Assembly, 2007, Government of Ireland, 2015). It would also allow information about cancer warning signs, risk factors, promoting self- efficacy to notice a breast or cervical change to be repeated to all women on a more regular basis. This could be as part of a personal development programme to improve the body awareness of women with intellectual disabilities.

8.2. Strengths of the current study

This study had a number of key strengths which warrant further discussion. First, the use of a mixed methods transformative approach allowed a wider perspective to be gained on the cancer and screening awareness of women with intellectual disabilities and their carers, and the acceptability of the EMBRACES- ID intervention than the use of either quantitative or qualitative methods in isolation. It is also noteworthy that in the spirit of the transformative feminist tradition neither the voices of the carers or the women with intellectual disabilities were privileged in the analysis of the findings.

It was acknowledged that women with severe to profound intellectual disabilities did not have the communication skills to participate in the CAM assessments, nevertheless, this was not a reason to exclude these women from the study. A decision was made by the research team to include their voices through proxy interviews with carers who knew the women well and were clear advocates for promoting the healthcare needs of the women in their care. Their perspectives provided insight into the challenges facing women with severe to profound intellectual disabilities in relation to cancer and screening awareness and participating in the national screening programmes. In particular a key strength of the current study was that the findings from the carers interviews were instrumental in framing the EMBRACES-ID intervention and interview protocols.

Elsewhere in the literature for example Robb et al. (2009) and Forbes et al. (2013) it is suggested that the use of validated and reliable instruments, such as CAM to assess cancer and screening awareness could lead to the development of a wider body of knowledge for whole populations and population subgroups such as marginalised groups. The CAM was adapted in the current study to an accessible format for women with intellectual disabilities. The Adapted CAM had an internal consistency range of Cronbach's Alpha values ranging between 0.679 and 0.905 as shown in Table 5.17. The current study adds to body of knowledge by directing assessing the breast and cervical cancer and screening awareness of a marginalised population subgroup namely women with intellectual disabilities.

The literature supports the movement towards theoretically driven tailored health promotion interventions which take into account the perspectives of people with intellectual disabilities (Kerr et al., 2013, Naaldenberg et al., 2013, Heller et al., 2014). The next significant strength of this study is that the findings of the Phase I assessment of the cancer and screening awareness of women with mild to moderate intellectual disabilities in conjunction with the findings of the proxy interviews with the carers was used to guide the development of the EMBRACES-ID intervention. The use of Social Cognitive Theory to underpin the intervention was another key strength of the study as it took into account the learning needs and capabilities of women with intellectual disabilities in an effort to develop their self- efficacy to become more active participants in their own healthcare.

Another principal strength of the study is that the CAM and Adapted CAM were valuable tools to assess changes in cancer and screening awareness levels following the EMBRACES-ID intervention and monitor for the retention of knowledge gains in the 12 week follow up interviews. The usefulness of the EMBRACES-ID intervention in improving cancer and screening awareness among women with intellectual disabilities and indeed the retention of the knowledge gains over the 12 week follow up period was evidences in the findings of the CAM and Adapted CAM surveys. Each of the CAM data sets from Phase I and Phase II will be uploaded to the UK Data Archive and become a valuable resource for comparative purposes in future research studies in the area of health inequalities for people with intellectual disabilities.

8.3. Limitations of the current study

This study had a number of limitations which warrant further investigation as they may affect the generalisability of the results. These limitations can be broadly grouped under researcher design, the sample and confounding variables and are discussed in sections 8.3.1. to 8.3.3.

8.3.1. Research design

It is acknowledged in the literature that recognition type questions overestimate actual cancer and screening awareness levels as respondents may guess the answer (Robb et al., 2009). This is particularly important among the intellectual disabilities population who may be overtly acquiescent in their answers (Cameron and Murphy, 2007). Robb et al. (2009) suggest that recall may underestimate cancer and screening awareness levels as it is based on recalling facts from memory. This has implications for women with intellectual disabilities who have cognitive and memory limitations (Snowman et al. 2012). Therefore the results of the quantitative study were descriptive in nature and cannot provide direct evidence for the actual cancer and screening awareness of women with intellectual disabilities and their carers.

It was acknowledged by the research theme that women with severe to profound intellectual disabilities did not have the communication skills to participate in the CAM assessment. Thus a qualitative approach was used to ascertain the key challenges their carers believed impacted on the cancer and screening awareness of women with severe to profound intellectual disabilities and which impacted on their participation in the screening programmes. However, given that the high proportion of nurses involved in the carers sample as a result of purposive sampling, the findings while illustrative of the key challenges facing women with severe to profound intellectual disabilities cannot be generalised to beyond this sample.

It was difficult to establish whether the changes in cancer awareness levels detected among both groups were directly due to the EMBRACES-ID intervention. In particular a comparison of the post intervention assessment and 12 week follow up interview data detected some fluctuations in knowledge levels among women and their carers. Thus the results of the study remain descriptive and no definitive inferences about changes in cancer and screening knowledge changes can be drawn from participation in the EMBRACES-ID intervention.

8.3.2. Sample

The wider body of research indicates that individuals or services who had an expressed an interest in health education programmes were more likely to participate in research studies for example, Tazhibi and Feizi (2014). Over the course of both phases of the study seven intellectual disabilities service providers in large urban areas expressed an interest in participating in the study.

In broad agreement Parish et al. (2012) and Wilkinson et al. (2011b) recruitment to this study using a non-probability purposive sampling frame was from the population of women with intellectual disabilities and their carers who were known to the intellectual disabilities service providers. This affects the generalisability of the results and therefore the external validity of the study because the result may not be representative of the target populations of women with intellectual disabilities and their carers. It remains unclear whether the results of the current study would have been replicated among women with intellectual disabilities and their carers who were unknown to the intellectual disabilities service providers.

The risk of selection bias was minimised by inviting all eligible women in the service to the information meetings and giving them the information about the study. It was more than likely that the women with intellectual disabilities who were recruited to the present study were on the milder continuum of intellectual disability and thus more cognitively and verbally adept. This may have resulted in the sampling of a biased group.

The CAM survey response rate among carers was very poor in Phase I. The response rate for the paid and family carers CAM was 41.6% (125/300). This was despite efforts to improve the response rate by reminder emails to the liaison persons at the services, the inclusion of stamped address envelopes for postal returns, the option to complete the CAM online or over the telephone and a media campaign to recruit family carers. Just one online version of the CAM was completed by a paid carer.

The findings of the current study were similar to previous research carried out in the area where poor response rates were recorded among caregivers of people with intellectual disabilities in ranging from 16.9% recorded by Lin et al. (2010) to 54.4% recorded by Lalor and Redmond (2009). Data was not collected on the non- responders in the present study. As a result of the poor response rate an assessment cannot be made on the cancer and screening awareness of the remaining 58.4% of the carers. This limits the generalisability of these results beyond this sample of carers of women with intellectual disabilities.

There was poor involvement of family carers in throughout both phase of the study. In order to meet the first study objective in Phase I which included an assessment of assess the cancer and screening awareness of family carers of women with intellectual disabilities a comprehensive media campaign was launched in October 2013. This campaign included advertisements about the study in local newspapers, via the Down Syndrome Ireland Facebook page, and the Federation of Voluntary Bodies Winter 2013 Newsletter. However, these strategies demonstrated limited success as just twenty- one family carers were recruited to the CAM sample in Phase I of the study.

There was considerably poorer involvement of families in the carer interviews which were designed to meet the second objective in Phase I. Just two parents took up the invitation to discuss issues related to cancer and screening for their daughters with intellectual disabilities. While in Phase II no family members where recruited to participate in the acceptability and feasibility testing of the EMBRACES-ID intervention, despite repeated invitations via the liaison persons at the participating intellectual disabilities service providers.

The findings of the current study support contemporary research in this area such as the studies of Swaine et al. (2014) and Willis et al. (2015) which acknowledge that poor family carer involvement in research studies limits the generalisability of the results to all family carers of women with intellectual disabilities. It is it is possible that carers who do participate in research studies have different perspectives about cancer and screening awareness among women with intellectual disabilities than those carers who do not participate in research studies. While no definitive reasons can be given as to why family carer involvement was so poor in the current study a number of potential reasons are now discussed.

First, during the information meetings parents expressed their anger at the HSE due to the impact of ongoing budgetary cuts on the level of services which the intellectual disabilities services were in a position to provide to their daughters with intellectual disabilities. Parents suggested at a number of information meetings that HSE research funding should be put to better use and reallocated to the provision of direct care services for their daughters with intellectual disabilities. Second, in the current study the findings highlight the challenges that protectionism and infantilism among parents of women with intellectual disabilities had on the provision of preventative healthcare among the women. It is plausible that the parents did not engage with the study in case it led to their daughters having to participate in the screening programme. Finally, family carers might just have been too embarrassed or scared to discuss breast and cervical health on behalf of their female family member or indeed on their own behalf. Fear and embarrassment to discuss cancer and cancer symptoms is well established in the international body of evidence (Scanlon et al., 2006, O'Mahony and Hegarty, 2009, Keeney et al., 2010, Forbes et al., 2011, Forbes et al., 2013, Ryan et al., 2015). However, whether or not any of these factors had a significant impact on the decision of the family carers not to participate in the study remains unclear, and is an area that could be addressed by future research.

A further limitation in the current study is the lack of male carers in the sample in both phases of the study. It is noteworthy that male carers were not excluded from participating in the study. During interviews with the carers and women with mild to moderate intellectual disabilities it became apparent that dependent on the structure of the family it was plausible that after the death of the primary carer, usually the mother, a father or male sibling could have to take over the role of the primary carer for the woman with intellectual disabilities. Although one father did attend an information meeting, no male carers, either paid or family, were recruited to the study. Nevertheless these findings support international findings that more women than men are likely to participate in health based studies for example for example Forbes et al. (2013). The general reluctance of male carers to become involved in studies such as the current study is an area that warrants further investigation.

In Phase II a key objective was to test the acceptability and feasibility of the EMBRACES-ID intervention, so this phase of the study was underpowered and statistical inferences cannot be drawn from the results. The purpose of the feasibility and acceptability study was to study methodological concerns in the design to make an assessment of whether progression to a full trial would be sensible. A principal element of the feasibility testing of the EMBRACES-ID intervention was to monitor the recruitment and retention rates of women with intellectual disabilities and their carers.

Recruitment to the EMBRACES-ID intervention was steady Initially, 16 carers and 35 women with mild to moderate intellectual disabilities recruited via the seven participating services. A key limitation in the study was that both samples were oversubscribed as a sample size of 12 women with intellectual disabilities and 12 carers would have been sufficient to meet the study objectives (Julious, 2005). It is acknowledged that this had a knock on effect on the effective use of study resources such as researcher time and effort in terms of data collection and analysis. However, the spirit of a transformative worldview is to give voice to those who traditionally have been marginalised to the fringes of society, so in the current study no woman with intellectual disability who expressed an interest in participating in the study was turned away by the research team.

Support from management in the participating intellectual disabilities service providers was noted in relation to the facilitation of the release of staff as far as reasonably practicable to support women with intellectual disabilities to attend the intervention and material support such as the allocation of a room for the intervention. Despite this the participant retention rates during Phase II of the study were considered to be less than optimal. The retention rate for the women with intellectual disabilities was 71.5% while for carers it was 56.25%.

Reasons for the moderate- poor retention rates included lack of interest and communication difficulties among women with intellectual disabilities and work commitments and returning to college among carers. As a result the current study fell short of the preset retention target of 80% for women with intellectual disabilities and carers which indicates that going to a full scale trial is not sensible. Thus it is not planned that that EMBRACES-ID intervention in the would progress to trial status at this time (Treweek 2015). Future research could investigate barriers and facilitators to retention rates for women with mild to moderate intellectual disabilities and their carers in cancer and screening awareness interventions with a view to progression to full trial status.

8.3.3. Confounding variables

As this was a single arm study, each participant received the intervention thus there is a lack of a control group against which to compare the results. The effect of confounding variables on cancer and screening awareness such as media influences and the impact of high profile celebrity deaths from cancer were not measured and analysed at any point in this study. Another area which could have had an influence on the overestimation of cancer and screening awareness for women with intellectual disabilities was the provision of socially desirable answers by women with intellectual disabilities (Cameron and Murphy, 2007). The potential effect of social desirability was not measured in either phase of the current study. Future studies could evaluate the impact of confounding variables on cancer and screening awareness among women with intellectual disabilities.

8.4. Recommendations arising from the study

Arising from the study’s findings a number of recommendations are made. These focus on clinical practice and future research.

8.4.1. Recommendations for clinical practice

- The Registered Nurse Intellectual Disability Nurse is best placed as studies have already shown to provide for the challenges presented by the healthcare needs of a growing and ageing population of women with intellectual disabilities.
- Nursing assessment and care provision must focus on improved cancer and screening awareness for women with intellectual disabilities to ensure early detection and treatment of breast and cervical cancer.
- Training may be required for carers to improve their personal cancer and screening awareness levels so that they can provide relevant support to women with intellectual disabilities. For example, the National Cancer Screening Service provides training to carers to assist them to support women with intellectual disabilities to access the National Screening programmes using a train the trainer type model.
- There must be consideration given by mainstream health professionals to continued professional development in the area of effective communications with people with intellectual disabilities, in this instance those involved in screening programmes.
- The National Cancer Screening Service should consider the inclusion of a diagnosis of intellectual disability on an attendee’s chart to monitor for uptake in cancer screening among this population This would facilitate comparison with the general population and also add to international screening uptake data for women with intellectual disabilities to monitor for inequalities in access to and participation in the screening programmes.

8.4.2. Recommendations for future research

Future studies could address the following issues:

- Widen the sampling frame to recruit women with intellectual disabilities and carers who are unknown to intellectual disabilities services for example through women’s groups or community networks.
- Investigate barriers and facilitators that impact on family carers (male and female) of women with intellectual disabilities engaging with research studies into breast and cervical health for women with intellectual disabilities.
- Investigate barriers and facilitators that impact on male paid carers of women with intellectual disabilities engaging with research studies into breast and cervical health for women with intellectual disabilities.

- Investigate whether legislative restrictions in relation to sexual relationships for adults with intellectual disabilities or the presumption of asexuality for women with intellectual disabilities has the greatest influence on staff attitudes towards cervical screening for women with intellectual disabilities.
- Implement a cancer and screening awareness intervention for BowelScreen, the National Bowel Screening Programme for men and women with intellectual disabilities.
- Implement a gender specific intervention for Testicular and Prostate cancer awareness for men with intellectual disabilities.

8.5. Self-reflection as a transformative researcher

My reasons for pursuing a PhD in cancer research stem from the loss of my parents to cancer. Unfortunately, the only treatment options were palliative care as the cancers were very advanced on diagnosis. In 2002, I lost my 68 year old father following a brave seven month battle with an advanced brain tumour. In 2005, I lost my 68 year old mother, my best friend, after a harrowing nineteen week battle with advanced pancreatic cancer. I continually question what their outcome might have been had there been earlier cancer diagnosis?

I made a decision in 2008 undertake a BSc (Hons) in Intellectual Disability Nursing. During my academic studies I developed a specific interest in the MENCAP: Death by Indifference Campaign in the UK. This highlighted that people with intellectual disabilities were dying when their lives could be saved, and this resulted in part from unequal access to healthcare. I became passionate about the need for transformative research, a need to hear the voices of a broad range of people who are generally excluded from mainstream society.

The transformative paradigm is firmly rooted in a human rights agenda, and as a feminist transformative researcher it was incumbent on me to ensure the voice of the women was heard throughout the whole research process. This was attended to in how this research study was designed, conducted and reported with a view to create a constructed knowledge base that furthers social justice and human rights for women with intellectual disabilities.

I acknowledge that I found myself in a privileged position as a nurse and academic researcher. But more than this I also found myself in a privileged position when the women agreed to participate in the study. This group of women agreed to give up their time, attend my classes and discuss issues with which they found very embarrassing with the group. So with this in mind it was incumbent on me to ensure I gave a social reality to their voice in this research report.

As a non-disabled transformative researcher this makes me consider my stance in terms of privilege that I can feel confident that I have indeed captured the reality of the current state of cancer and screening awareness among women with intellectual disabilities in the Republic of Ireland. I am honoured to have been given the opportunity to gain insight in to the womens perspectives about their personal cancer and screening awareness, and the barriers and facilitators which impact both on their participation in screening programmes and early help seeking in the discovery of a symptom they thought might be serious.

It would be remiss of me not to leave the last words of this thesis to the carers who act as advocates for the women with intellectual disabilities in their care. This poem is taken from the carers interview responses in Phase I.

> *Please don't dismiss me because I have an intellectual disability, and think I am never going to get anything else.*
> *I am going to get the same things that you are going to get;*
> *I suppose people can brush it off and say 'Sure she doesn't know, she doesn't understand'.*
> *But, I am going to come under the same stresses;*
> *I am going to have the same anxieties only I can't communicate them which makes it more difficult.*
>
> *There's a difficulty with her parents; she's forever child in their eyes;*
> *They worry- they want to protect them; they really don't want her to know too much about anything.*
> *But they don't realise that she's a young woman;*
> *They have to remember that she's getting on in her life and her body is changing as well.*
> *She is still a woman, like you, going through the very same thing and everything affects her;*
> *And she has got a right to screening as much as you have.*
>
> *Please don't dismiss me because I have an intellectual disability.*

8.6. Study conclusion

The principal aim of this study was to test the feasibility and acceptability of **EMBRACES-ID** (**E**arly **M**onitoring of **Br**east **a**nd **Ce**rvical **C**ancer **S**igns & **S**creening in **I**ntellectual **D**isabilities).

The study used a two phase transformative mixed methods design with a feminist perspective. The current study advanced on previous studies in the area of health promotion and cancer and screening awareness for women with intellectual disabilities and their carers. Many studies had called for more research into the development and evaluation of targeted health promotion intervention which were based on empirical evidence and a sound theoretical background.

An exploratory, cross sectional design was considered the most appropriate method for Phase I of this study given the small body of literature available in this area. Phase I involved Comprehensive Needs Assessment which addressed two key objectives in the study. These objectives involved a baseline assessment of the cancer and screening awareness of women with mild to moderate intellectual disabilities and their carers using CAM. A quantitative approach was used to assess breast and cervical cancer and screening awareness among women with mild to moderate intellectual disabilities and their carers using the CAM and Adapted CAM. A qualitative approach was used in the carers interviews about their views of the needs of women with severe to profound intellectual disabilities in relation to cancer awareness and screening.

Phase I identified gaps in awareness levels of warning signs, risk factors and knowledge of screening programmes were identified among the women with intellectual disabilities and their carers. Based on the evidence Social Cognitive Theory was determined to be a relevant theory to support the specific learning needs of people with intellectual disabilities. The intervention design then built on current cancer and screening awareness programmes which was amalgamated with accessible information available from healthcare organisations to develop a multimodal cancer education programme for women with intellectual disabilities and their carers.

Phase II of the study was a feasibility and acceptability test of the EMBRACES- ID intervention design to meet five key objectives in the study such as the acceptability of the intervention for the participants and retention of the participants for the duration of the study and follow up period. Quantitative and qualitative data on the primary and secondary outcome measures was collected at three time points from women with mild to moderate intellectual disabilities and their carers.

The CAM and Adapted CAM were used to assess baseline cancer and screening awareness among women with intellectual disabilities and their carers. The CAM was also used to detect knowledge changes following participation in the EMBRACES-ID intervention and also for the retention of these knowledge changes at the 12 week follow up. The qualitative face to face interviews were used to measure the secondary outcome self-efficacy to detect a breast change, understanding of the purpose of cancer screening and exploring perspectives about the screening process at the same three time point. This allowed comparison of the baseline interview findings with the post intervention and 12 week follow up interview findings to monitor for changes in perspectives among the women and their carers. Further qualitative exploration was undertaken at the post intervention stage to test the acceptability of the EMBRACES-ID intervention for the participants.

In Phase II the EMBRACES-ID intervention demonstrated a moderate increase in the awareness levels of cancer warning signs, risk factors, screening programmes and to promote early medical help-seeking on discovery of a symptom of breast or cervical cancer among women with intellectual disabilities and their carers. The value of the mixed method approach was also apparent given that it was feasible to monitor for convergence or dissonance in the participants responses in their baseline assessment self-efficacy to detect a breast change. Furthermore, it was also possible to monitor for changes in self-efficacy to notice a breast change following participation in the EMBRACES-ID intervention. Although the intervention was acceptable to the participant, it failed to meet the preset retention rate of 80% in order to progress to trial status at this particular time.

This study also adds to the body of knowledge on the barriers facing women with intellectual disabilities accessing the cervical screening programme, and gives valuable insight into their experiences at the cervical screening programme. It adds to the body of knowledge on the use of CAM in international settings to allow records to be maintained in the UK Data archive to promote a wider understanding of cancer and screening awareness in the general population in addition to vulnerable subgroups within the general population.

The conceptual framework of the study had suggested that participants who completed the EMBRACES-ID intervention would have improved levels of cancer and screening awareness. However, it was not conclusively found that the improved awareness levels could be attributed to the EMBRACES-ID intervention. Further research is required to explore the key challenges to carers, in particular male carers engaging with research related to breast and cervical health for women with intellectual disabilities. Future studies will also need to consider the cancer and screening awareness needs of women with intellectual disabilities who are not in receipt of services from an intellectual disability provider.

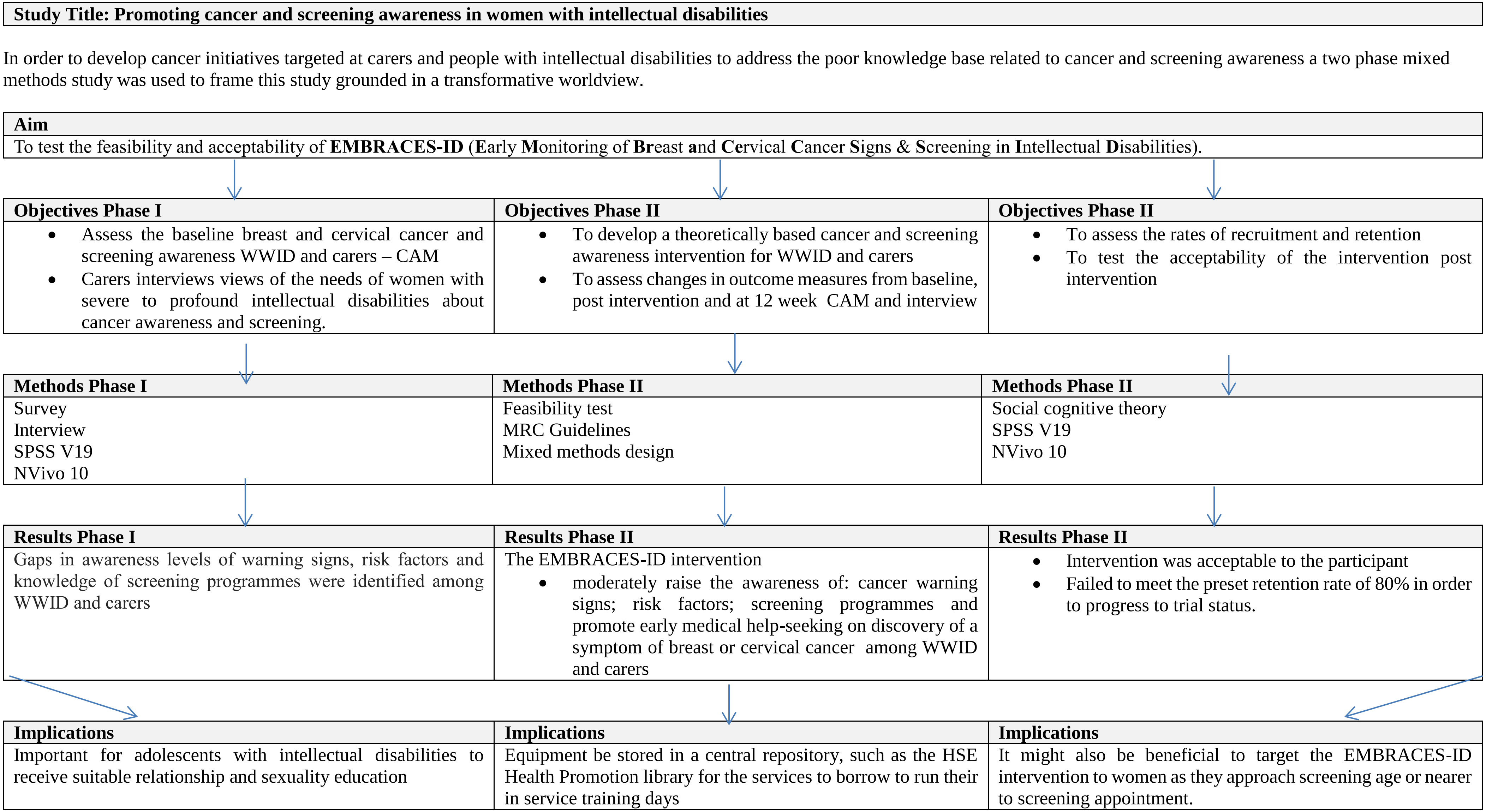
8.7. Future publications

Following the completion of this study consideration has been given to a number of future publications arising from the findings. First, it is anticipated that two papers on the cancer and screening awareness of women with intellectual disabilities and their carers will be prepared for publication to add to the wider body of knowledge in the area and in the area of the use of the CAM in different population subgroups.

Second, the issue of poor family engagement with research studies and their attitudes towards screening, particularly cervical screening, for their daughters or siblings with intellectual disabilities raised some interesting points in this study which could add to the wider body of available literature in this area.

Third, the development of the EMBRACES-ID programme in the context of the MRC Guidelines of feasibility studies with an emphasis in using the SPIRIT and TIDiER checklists has implications for the development of trial protocols. A proposed paper would detail the development of the EMBRACES-ID intervention trial protocol, including the feasibility and acceptability testing and the reasons not to progress to full trial status to add to the developing body of research in this field.

Finally the implications of using a mixed methods approach using interviews and CAM to assess the self- efficacy of women with mild to moderate intellectual disabilities to perform breast self-examination raises some interesting issues in relation to social desirability in answers among this population. The mixed methods approach was useful to monitor if the questionnaire data converged or disagreed with what the women actually said at interview about their confidence to detect a breast change and the frequency with which they carried out breast self-examination. The proposed paper could have implications for nursing practice in the context of reducing healthcare inequalities for women with intellectual disabilities in relation to cancer and screening awareness.



Study Title: Promoting cancer and screening awareness in women with intellectual disabilities

In order to develop cancer initiatives targeted at carers and people with intellectual disabilities to address the poor knowledge base related to cancer and screening awareness a two phase mixed methods study was used to frame this study grounded in a transformative worldview.

Aim

To test the feasibility and acceptability of **EMBRACES-ID** (**E**arly **M**onitoring of **Br**east **a**nd **C**ervical **C**ancer **S**igns & **S**creening in **I**ntellectual **D**isabilities).

Objectives Phase I

- Assess the baseline breast and cervical cancer and screening awareness WWID and carers – CAM
- Carers interviews views of the needs of women with severe to profound intellectual disabilities about cancer awareness and screening.

Objectives Phase II

- To develop a theoretically based cancer and screening awareness intervention for WWID and carers
- To assess changes in outcome measures from baseline, post intervention and at 12 week CAM and interview

Objectives Phase II

- To assess the rates of recruitment and retention
- To test the acceptability of the intervention post intervention

Methods Phase I

Survey
Interview
SPSS V19
NVivo 10

Methods Phase II

Feasibility test
MRC Guidelines
Mixed methods design

Methods Phase II

Social cognitive theory
SPSS V19
NVivo 10

Results Phase I

Gaps in awareness levels of warning signs, risk factors and knowledge of screening programmes were identified among WWID and carers

Results Phase II

The EMBRACES-ID intervention

- moderately raise the awareness of: cancer warning signs; risk factors; screening programmes and promote early medical help-seeking on discovery of a symptom of breast or cervical cancer among WWID and carers

Results Phase II

- Intervention was acceptable to the participant
- Failed to meet the preset retention rate of 80% in order to progress to trial status.

Implications

Important for adolescents with intellectual disabilities to receive suitable relationship and sexuality education

Implications

Equipment be stored in a central repository, such as the HSE Health Promotion library for the services to borrow to run their in service training days

Implications

It might also be beneficial to target the EMBRACES-ID intervention to women as they approach screening age or nearer to screening appointment.

Figure 8.1. Study Overview

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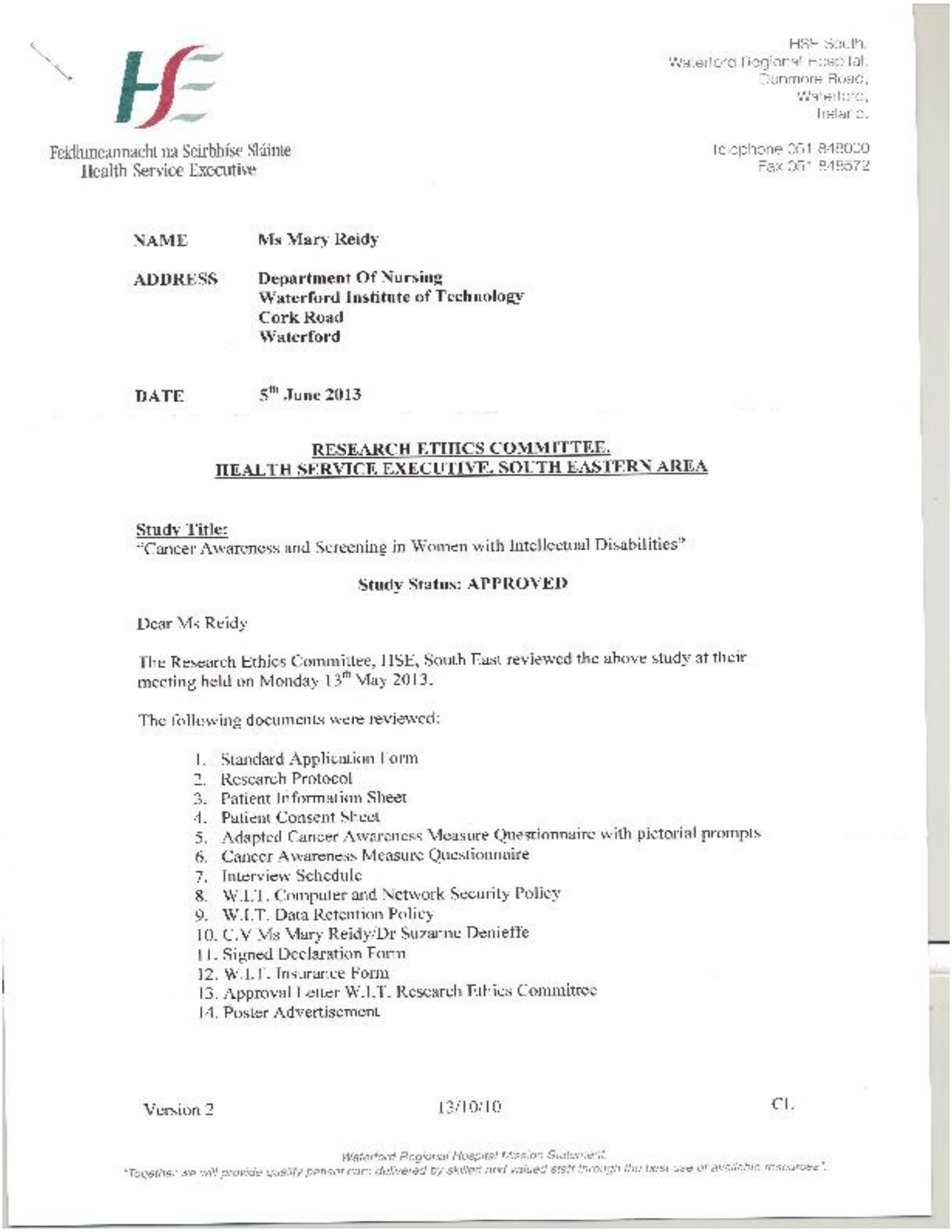
Appendix I: Ethical approval



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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Waterford Regional Hospital,
Dunmore Road,
Waterford,
Ireland.

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NAME **Ms Mary Reidy**

ADDRESS **Department Of Nursing**
Waterford Institute of Technology
Cork Road
Waterford

DATE **5th June 2013**

RESEARCH ETHICS COMMITTEE,
HEALTH SERVICE EXECUTIVE, SOUTH EASTERN AREA

Study Title:
"Cancer Awareness and Screening in Women with Intellectual Disabilities"

Study Status: APPROVED

Dear Ms Reidy

The Research Ethics Committee, HSE, South East reviewed the above study at their meeting held on Monday 13th May 2013.

The following documents were reviewed:

1. Standard Application Form
2. Research Protocol
3. Patient Information Sheet
4. Patient Consent Sheet
5. Adapted Cancer Awareness Measure Questionnaire with pictorial prompts
6. Cancer Awareness Measure Questionnaire
7. Interview Schedule
8. W.I.T. Computer and Network Security Policy
9. W.I.T. Data Retention Policy
10. C.V Ms Mary Reidy/Dr Suzanne Denieffe
11. Signed Declaration Form
12. W.I.T. Insurance Form
13. Approval Letter W.I.T. Research Ethics Committee
14. Poster Advertisement

Version 2 13/10/10 CL

Waterford Regional Hospital Mission Statement
"Together we will provide quality patient care delivered by skilled and valued staff through the best use of available resources".

Julia Kelly <juliakelly@waterford.brothersofcharity.ie>

4/16/13

to me, Margaret

Dear Mary,

I am pleased to let you know that we have approved your research proposal. I attach an undertaking agreement which I would ask that you sign and return to me. I have asked Aileen Moynihan, Nurse Educator in Tory Services to act as the link person for the services and she has agreed to assist you in accessing individuals in our Services to be part of this research or other information that you might require. I trust that this meets with your agreement. Once I have received back the signed undertaking I will formally write approving the research.

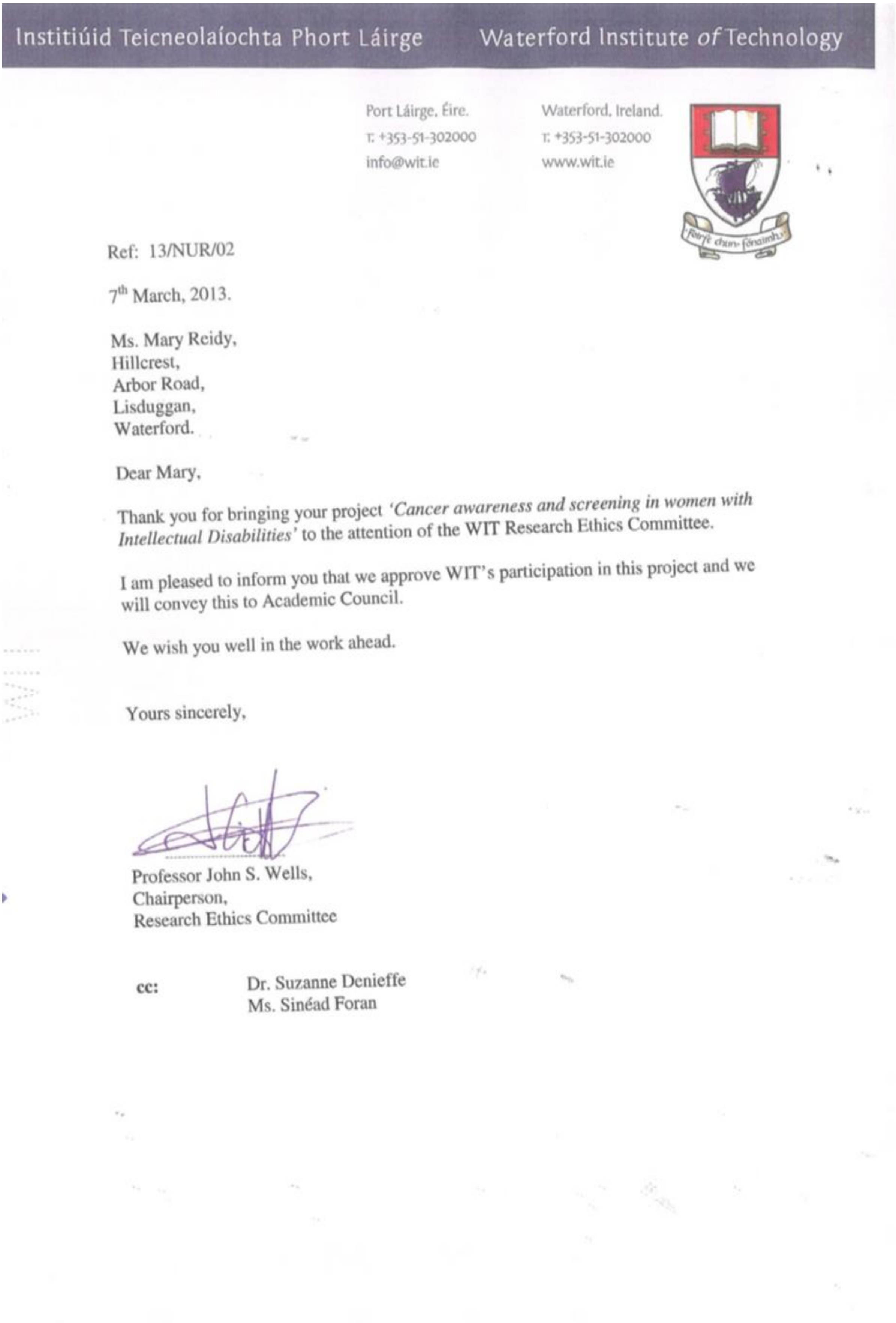
Julia Kelly,

Regional Services Manager

email:juliakelly@waterford.brothersofcharity.ie

Brothers of Charity Services South East, Belmont Park, Waterford.

Phone: 833400 ext 3406 / Direct Dial 833406



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Ref: 13/NUR/02

7th March, 2013.

Ms. Mary Reidy,
Hillcrest,
Arbor Road,
Lisduggan,
Waterford.

Dear Mary,

Thank you for bringing your project *'Cancer awareness and screening in women with Intellectual Disabilities'* to the attention of the WIT Research Ethics Committee.

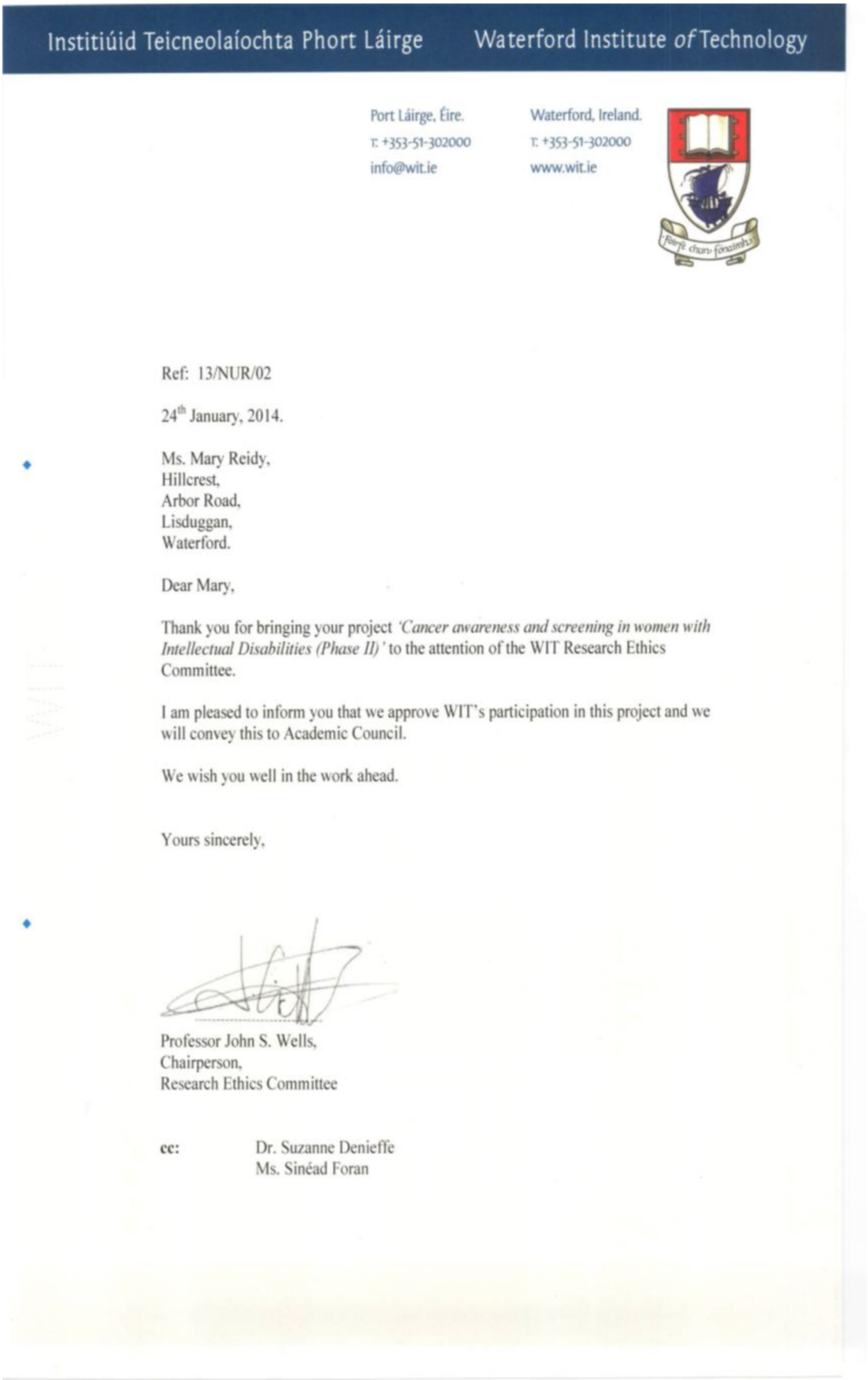
I am pleased to inform you that we approve WIT's participation in this project and we will convey this to Academic Council.

We wish you well in the work ahead.

Yours sincerely,

Professor John S. Wells,
Chairperson,
Research Ethics Committee

cc: Dr. Suzanne Denieffe
Ms. Sinéad Foran



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Ref: 13/NUR/02

24th January, 2014.

Ms. Mary Reidy,
Hillcrest,
Arbor Road,
Lisduggan,
Waterford.

Dear Mary,

Thank you for bringing your project *'Cancer awareness and screening in women with Intellectual Disabilities (Phase II)'* to the attention of the WIT Research Ethics Committee.

I am pleased to inform you that we approve WIT's participation in this project and we will convey this to Academic Council.

We wish you well in the work ahead.

Yours sincerely,

Professor John S. Wells,
Chairperson,
Research Ethics Committee

cc: Dr. Suzanne Denieffe
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Appendix II Publications and Presentations

Article

Cancer screening in women with intellectual disabilities: An Irish perspective

Journal of Intellectual Disabilities
2014, Vol. 18(1) 51–60
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1744629514521067
jid.sagepub.com
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Date accepted: 20 December 2013

Abstract

In the Republic of Ireland, more than 8000 women with intellectual disabilities (IDs), aged 20 years and over, are registered for service provision. Their health needs challenge preventative health services including breast and cervical cancer screening programmes. This review explores the literature about cancer screening participation rates and issues related to screening for Irish women with IDs. Low cancer screening participation rates are evident in Irish women with IDs; and the women shed light on the barriers they perceive related to the screening experience. These experiences are reflected in the international literature for women with IDs. Further research involving the assessment of the breast and cervical cancer awareness in Irish women with IDs and their participation in cancer screening programmes is recommended. Strategies are required to increase their participation in screening programmes that may lead to the earlier diagnosis with better outcomes.

Keywords

breast, cervical, cancer screening, women, intellectual disabilities

Introduction

It is estimated that there are almost 60 million people worldwide with an intellectual disability (ID) (International Association for the Scientific Study of Intellectual Disabilities, 2002). ID is

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characterised by significant limitations in both intellectual functioning and adaptive behaviour as expressed in practical, social and conceptual skills, which originate before the age of 18 years (Schalock et al., 2010). The National Intellectual Disability Database reports that 27,324 people with IDs were registered for service provision in Ireland in 2011; 8050 of those registered are women over the age of 20 years (Kelly, 2012).

In recent years, there have been significant improvements in the life expectancy of people with IDs, which are largely due to improved medical care, rehabilitation services and living conditions (International Association for the Scientific Study of Intellectual Disabilities, 2002; Patja et al., 2000; Sullivan et al., 2004a). The ageing of people with mild IDs is equivalent to that of the general population and the age standardised incidence of cancers in people with IDs is not significantly different to that of the general population (Patja et al., 2000, 2001; Sullivan et al., 2004a). This evolving demographic profile is expected to correlate with increases in cancer prevalence amongst people with IDs (Wilkinson and Cerreto, 2008).

Cancer is a global term for a variety of diseases characterised by uncontrolled cellular growth, increased angiogenesis and/or decreased programmed cell death (Alberts and Hess, 2008). A key objective of cancer screening programmes is to reduce cancer mortality through early diagnosis and treatment (International Agency for Research on Cancer, 2013).

BreastCheck, the Irish national cancer screening service, introduced in 2000, invites eligible women aged 50–64 years with no symptoms of breast cancer to have a free mammogram biennially. The programme has a database register of age-eligible women compiled from information sourced from the Department of Social Protection and General Medical Services in accordance with national legislation. It is the first national screening service provider worldwide to offer a fully digitised mammography service that exhibits a significant improvement in image quality, especially in dense breast tissue. The target uptake at screening is 70%; in 2011, the screening rate was 72.2%. Over 125,000 women participated in the screening programme and 832 women had cancers detected (National Cancer Screening Service, 2013).

CervicalCheck was introduced in September 2008 and offers women between the age of 25 and 60 years the opportunity to have a free cervical smear test. The screening intervals are every 3 years for women aged 25–44 years and every 5 years for women aged 45–60 years. It is estimated that cervical cancer screening can prevent at least 75% of cervical cancers in women aged 60 years and over and at least 45% of cervical cancers in women in their 30s (Cancer Research UK, 2013). In the first 3 years of the programme, 60.9% of the eligible population were screened. Precancerous abnormalities were detected in just over 8000 women, and 104 women were diagnosed with cervical cancer (National Cancer Screening Service, 2012).

Aims

The aims of this article are to explore the cancer screening participation rates in women with IDs in the Republic of Ireland; to examine the participation rates in women with IDs in other countries; and to consider the barriers faced by Irish women with IDs who attend screening and compare these experiences with those of women with IDs internationally.

Review strategy

Electronic databases used in this article included PUBMED, Wiley Online Library, Science Direct, PsychInfo and Academic Search Complete. The keywords used were cervical cancer, breast cancer, screening, learning disabilities, IDs, developmental disabilities and women. The inclusion criteria included studies written in English related to breast and cervical screening in women with IDs. The literature review was restricted to the last 10 years (2003–2013). Initially, 40 articles were retrieved through the five databases; however, a large volume of these articles were duplicated across the databases. A total of six articles met the inclusion criteria and were explored in the review. These studies explored breast and cervical cancer screening in women with and without IDs nationally and internationally (see Table 1). In addition, Irish reports on breast and cervical cancer screening programmes' statistics in the general population were reviewed.

Results

During the course of the literature review, three key themes evolved regarding the context of the study aims. The first theme related to breast cancer and screening in Irish women with IDs, the second theme concerned breast and cervical screening participation rates in women with IDs in the international arena and finally the barriers faced by Irish women with IDs when attending screening compared to the international experience. Each theme will be discussed in the following sections.

Theme 1: Breast cancer and screening in Irish women with IDs

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is a large-scale nationally representative study of Irish people with an ID aged 40 years and over. This study was conducted on 753 Irish people, representing almost 9% of the target population with IDs. Over half the participants were female with an average age of 54.7 years. The study has close harmonisation with TILDA and facilitates the comparison of similarities and differences experienced by the general population and people with IDs. In the IDS-TILDA study, Mc Carron et al. (2011) found that breast cancer incidence (29%) in Irish women with IDs is comparable to the incidence (30%) in Irish women without IDs.

Lalor and Redmond (2009) undertook a survey to explore the extent of breast surveillance for breast cancer among post-menopausal women with IDs living in three residential care settings in Ireland. The findings indicate that 67% of the 90 respondents had successfully completed mammography. This remains lower than the 72.2% uptake for women reported by BreastCheck (National Cancer Screening Service, 2013). The comparison of this convenience sample of post-menopausal women with IDs with national norms relating to mammography uptake seems to indicate evidence of disparities in access to screening programmes. The highest successful completion of the mammogram was recorded in women with mild to moderate IDs; whilst in the severe to profound group, none of the women had successfully obtained a mammogram.

As the BreastCheck database register is compiled from information supplied by the Department of Social Protection and General Medical Services, it would be expected that all age-eligible women would be registered. Evidence of disparities in access to screening services for women with IDs was apparent in this study as 14% of the age-eligible women surveyed were not included in the BreastCheck register.

The authors of this article are unable to discuss the cervical cancer screening uptake of women with IDs in the Republic of Ireland, due to the paucity of literature available on this topic.

Table 1. Breast and cervical cancer screening inequalities for women with IDs.

Author/year/ geographical location	Aim of study	Methods/sample	Key findings (breast and cervical cancer screening)
D'Eath et al. (2005), Ireland	To explore the experience of Irish people with disabilities in accessing mainstream health services; to consider this in the context of international findings and; to present the findings to relevant parties to inform practice, policy or further research.	Thematic analysis of interviews using Miles and Huberman's framework. $n = 32$; 27 people with disabilities including ID and 5 advocates and parents.	Evidence of health service inequalities in the following areas: inequality of access to health services; preventative and screening services, specific groups are particularly disadvantaged such as women with ID; financial barriers to accessing services; communication, attitudinal and physical barriers.
Noonan Walsh et al. (2008), Europe	To promote the quality of life and health of people with ID in Europe; to test the validity and utility of the POMONA health indicators for people with ID; to establish ways to sustain the flow of information about the health of people with ID nationally, at European level and internationally.	Descriptive statistical analysis of the health interview survey; $n = 1253$ people with ID in 14 European countries.	Evidence of less common gender-specific screening checks for breast cancer and cervical cancer in women with IDs.
Lalor and Redmond (2009), Ireland	To identify practices in relation to breast surveillance for post-menopausal women with ID; to identify challenges that affect mammography screening services attendance; to explore the practices related to clinical breast examinations.	Statistical and content analysis of a newly developed questionnaire; $n = 90$: primary carers of post-menopausal women with ID; women with ID participated in questionnaire completion based on ability.	67% of women had successfully completed mammogram; 14% of eligible women had not received an invitation to attend; 16% were unable to complete the procedure due to difficulties such as fear, distress and inability to cooperate; 24% of women had no breast surveillance at all.

(continued)

Table 1 (continued)

Author/year/ geographical location	Aim of study	Methods/sample	Key findings (breast and cervical cancer screening)
Mc Carron et al. (2011), Ireland	To explore issues for people with an ID in areas such as their ageing profile, health and health services needs; to potentially compare the ageing of people with ID directly with the general ageing population.	Descriptive statistical analysis of interviews; $n = 753$ people with ID representing 8.9% of the Irish ID population >40 years.	Access to health checks was high overall; concerns regarding access to screening; lower screening access for people with severe to profound ID; prevalence of cancer diagnosis was slightly lower amongst people with ID than for the general Irish adult population; breast cancer being the most commonly reported cancer in women with ID.
Osborn et al. (2012), United Kingdom	To explore whether rates of cancer screening differ in people with learning disability compared with people without a learning disability in primary care.	A cohort study using data from THIN, research database compiled from 450 general practices across the UK. LD and women with no LD. *Cervical screening cohort* (age-eligible women): $n = 6254$ (LD); $n = 33{,}425$ (no LD). *Breast screening cohort* (age-eligible women): $n = 2956$ (LD); $n = 17{,}354$ (no LD).	Relative rates of screening were significantly lower for people with LD; disparities in cervical screening rates were 45% lower in 2008/9: IRR = 0.76 (0.72–0.81) (95% CI); Disparities in breast screening rates were 35% lower in 2008/9: IRR = 0.54 (0.52–0.56) (95% CI).
Cobigo et al. (2013), Ontario, Canada	To estimate the rates of cervical and breast cancer screening among eligible women with ID; to compare the rates of cervical and breast cancer screening between eligible women with and without ID; to examine if any observed differences between women with and without ID persist after factors such as age, socio-economic status, rurality and health care utilisation are accounted for.	A cohort study using data from the ICES that has anonymised, linked health-related databases for health services in Ontario. WID – women with ID WoID – women without ID $n = 17{,}777$ (WID); $n = 1{,}352{,}366$ (WoID) – 20% random sample of WoID.	The proportion of women with ID who are not screened for cervical cancer is nearly twice what it is in the women without ID. The proportion of women with ID who are not screened for breast cancer with mammography is 1.5 times what it is in the women without ID.

ID: intellectual disability; THIN: The Health Improvement Network; ICES: Institute for Clinical Evaluative Sciences; IRR: Incident rates and rates ratios; LD: learning disability.

Theme 2: Contemporary research from Europe, United Kingdom and Canada on breast and cervical screening participation rates for women with IDs

Europe. POMONA II Health Indicators for People with Intellectual Disabilities: Using an Indicator Set (2005–2008) was a European Commission public health project. It aimed to develop and test a set of health indicators specific to people with IDs with the potential to increase the visibility of people with IDs in health information surveys in member states in the European Union. The data in this exploratory study represented a convenience sample to test an indicator set and may not be deemed representative of people with IDs nationally in the member states. However, the findings suggested evidence of disparities in gender-specific screening tests for European women with IDs; less than half the women with IDs in the sample reported having a mammogram and less than one-third of the women reported participating in cervical cancer screening in the 14 member states in the relevant time periods (Noonan Walsh et al., 2008).

United Kingdom. In the United Kingdom (UK), Osborn et al. (2012) undertook a retrospective cohort study to assess whether people with IDs have poorer access to cancer screening using The Health Improvement Network (THIN) primary care research database. The active participants in THIN represented almost 6% of the UK population, at the time of the study. The two cohort groups of interest were people with ID and a demographically similar group without IDs.

With regard to breast screening in the UK, women with IDs ($n = 2956$) were compared with women without IDs ($n = 17{,}354$) in the mammogram cohort, in 2009. The key finding in this cohort is that age-eligible women with IDs were still 35% less likely to have a mammogram than those without IDs.

Women with IDs ($n = 6254$) were compared with women without IDs ($n = 33{,}425$) in the cervical cohort in the time period 2008–2009. The key finding in this cohort is that age-eligible women with IDs were 45% less likely to have cervical cancer screening than those without IDs.

Canada. A recently published study undertaken by Cobigo et al. (2013) in Ontario, Canada, investigated whether cervical and breast cancer screening programmes were equitable for women with IDs. Two cohorts of adult women with and without IDs living in Ontario who were eligible for health coverage in a 12-month period in 2009–2010 were created. All women with IDs ($n = 16{,}663$) and a random sample of 20% of the women without IDs ($n = 1{,}352{,}366$) were included in the cohorts.

The key findings in this study were that in Ontario the proportion of age-eligible women with IDs who did not receive a mammogram was one and a half times that of age-eligible women without IDs. The proportion of age-eligible women with IDs who were not screened for cervical cancer was almost twice that of age-eligible women without IDs.

Theme 3: Barriers faced by Irish women with IDs when attending screening compared with the international experience

D'Eath et al. (2005) undertook interviews with people with a range of disabilities including IDs, with parents and with advocates in one health service area in Ireland ($n = 32$, age range 21–77 years). Irish women with IDs who had accessed screening perceived a number of barriers, including a lack of awareness amongst the personnel carrying out the procedure about people with IDs and abandonment of the test when the person found it difficult to cooperate during the procedure. People with physical disabilities had further concerns about environmental barriers particularly those surrounding the positioning for a mammogram.

Lalor and Redmond (2009) established that Irish women with more severe IDs have poorer access to breast cancer screening programmes, and these findings are reiterated in Mc Carron et al. (2011). Regrettably, women with IDs often present with later, less treatable stages of cancer and have poorer outcomes (Sullivan et al., 2004a).

In the international literature, there is agreement concerning these perceived barriers to screening for Irish women with IDs. Concerns have been expressed about physical disabilities and stature (Biswas et al., 2005; Sullivan et al., 2004b; Wilkinson et al., 2011), medical personal interactions with women with IDs (Rees, 2011; Sullivan et al., 2004b; Wilkinson et al., 2011), painful experiences of procedure (Biswas et al., 2005; Sullivan et al., 2004b; Truesdale-Kennedy et al., 2011; Wilkinson et al., 2011), lack of understanding about the procedure resulting in stress and anxiety (Parish et al., 2012; Sullivan et al., 2004b; Truesdale-Kennedy et al., 2011; Wilkinson et al., 2011;), and poor provision of accessible information (Kennedy et al., 2011; Sullivan et al., 2004b; Truesdale-Wilkinson et al., 2011).

Discussion

In the IDS-TILDA study, Mc Carron et al. (2011) found that breast cancer incidence in Irish women with IDs is comparable to the incidence in Irish women without IDs. These data clearly challenge the societal misconception uncovered by D'Eath et al. (2005) that Irish women with IDs do not get cancer or need cancer screening.

Current Irish census data suggest a strong link between disability and poor health; of those reporting that they had bad or very bad health, 91.7% also reported having a disability including IDs. There is a marked increase in health disparities between disabled and non-disabled individuals in Ireland after the age of 25 years (Central Statistics Office, 2012). An Irish report on the impact of disability highlighted that a person with a disability present before the age of 25 years has an increased likelihood of having no qualification, a reduced chance of third-level education and a reliance on a social welfare payment as their source of income (Gannon and Nolan, 2005).

Walsh et al. (2010) contend that socio-economic classification and education may offer insight into the individual's ability to acquire and process health-related information. Literacy challenges present a formidable barrier to people with IDs to engage in and take ownership of their own health needs (Mc Carron et al., 2011). Walsh et al. conclude that differences in participation rates in the national cervical screening programme may persist in the short term, and uptake may depend on the women's ability to organise a screening appointment (2010). Unfortunately, this may result in Irish women missing the vital opportunity for the early detection and treatment of cancer. This presents a challenge to health professionals and services providing preventative breast and cervical cancer screening (Bouchardy Magnin, 2004).

Lalor and Redmond (2009) provided evidence that age-eligible women with IDs in the Republic of Ireland have lower participation rates than women in the general population in the breast cancer screening programme. This is similar to the international experience for women with IDs who participate in breast and cervical screening programmes (Cobigo et al., 2013; Noonan Walsh et al., 2008; Osborn et al., 2012). D'Eath et al. (2005) reported that Irish women with IDs who had accessed screening perceived a number of barriers including physical, environmental and attitudinal barriers that reflected the experience of women with IDs internationally.

There is a distinct lack of clarity in the Republic of Ireland on the participation rates of women with IDs in breast and cervical cancer screening programmes. Walsh et al. (2010) did not provide any breakdown of the presence of an ID in their sample. BreastCheck and CervicalCheck do not separate screening uptake for women with IDs from women in the general population (National Cancer Screening Service Communication Department, 2013).

Further research into the assessment of the cancer awareness of Irish women with IDs and their participation in breast and cervical cancer screening programmes is recommended. Strategies need to be developed and evaluated, which aim to increase participation in screening programmes by Irish women with IDs. This is intended to lead to earlier diagnosis of breast and cervical cancer with better outcomes.

Limitations

The principal limitation of this review is the comparison of convenience samples of Irish women with IDs with national norms for cancer screening uptake rates. The authors acknowledge that drawing inferences from this type of comparison may not be empirically sound as the convenience samples may not be deemed representative of Irish women with IDs. However, given the limited evidence base available in an Irish context, these comparisons give valuable insight into the apparent inequalities in cancer screening uptake for Irish women with IDs.

Conclusion

The health needs of Irish women with IDs present a challenge to preventative health services including cancer screening services (Bouchardy Magnin, 2004). International recommendations encompass the provision of tailored health promotion for the women with IDs and their carers to increase cancer awareness and improve participation rates in screening programmes (Cobigo et al., 2013; Mc Carron et al., 2011; Parish et al., 2012; Wilkinson et al., 2011). In this context, it is opportune to assess the breast and cervical cancer awareness and screening awareness amongst Irish women with IDs.

Recommendations

It is timely to investigate the reasons for the differences in screening services uptake for these women when compared with the general population in Ireland. The implementation and evaluation of a tailored health education programme for Irish women with IDs may offer a potential solution to achieve earlier detection and reduce the unnecessary deaths of women with IDs from breast and cervical cancer.

Funding

This work was supported by the Health Service Executive, Ireland [Student Support Grant to M.R.].

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REIDY, M., DENIEFFE, S. & FORAN, S. 2015. Cancer Awareness among Women with Intellectual Disabilities. *Research Matters.* Waterford: Waterford Institute of Technology.

The Department of Nursing & Health Care are working with the HSE to carry out research on cancer awareness and screening in women with intellectual disabilities in the South East. The WIT research team comprises Dr. Suzanne Denieffe, Ms Sinéad Foran, and Ms Mary Reidy.

Cancer prevention is the best long-term strategy for cancer control. Over one third of cancers are preventable by changing lifestyle choices about tobacco use, being physically inactive, having an unhealthy diet and the harmful use of alcohol.

The World Health Organisation recommends education to increase awareness of the warning signs of cancer and seeking medical assistance, as well as cancer screening tests for early forms of the disease. This can lead to earlier cancer diagnosis, more successful treatments and improved outcomes.

In Ireland, over 27,000 people with intellectual disabilities are registered for service provision. Since cancer risk increases with age, a growing and ageing population of people with intellectual disabilities over recent decades has led to increasing cancer rates among this demographic. However, women with intellectual disabilities are more likely to have poorer cancer awareness, and participate less in cancer screening programmes. They also present themselves at later, less treatable stages of cancer than women in the general population, despite cancer rates being similar in both populations.

The principal aim of the WIT-HSE study is to test the feasibility and acceptability of a targeted intervention to raise cancer awareness for women with intellectual disabilities. **EMBRACES-ID** (**E**arly **M**onitoring of **Br**east **a**nd **Ce**rvical **C**ancer **S**igns & **S**creening in **I**ntellectual **D**isabilities) is an intervention designed for women with mild to moderate intellectual disabilities and their carers.

EMBRACES-ID aims to raise the awareness of:

a) Cancer warning signs

b) Risk factors

c) Screening programmes

d) Promote early help-seeking on discovery of a symptom of breast or cervical cancer

In line with the Medical Research Council's Guidance for developing and evaluating complex interventions this work is based on empirical evidence and is theoretically underpinned by Bandura's Social Cognitive Theory.

The study is grounded in a transformative worldview which closely parallels the socio-cultural perspectives of people with disabilities who experience oppression and discrimination in their lives and thus aims to foster real world community partnerships between the researcher and the stakeholders. It is crucial for the research team to engage with the women with intellectual disabilities to build the evidence base which will improve their capacity for health and wellbeing. The relevant Research Ethics Committees granted full ethical approval for the study.

In Phase I of developing the intervention, the project assessed the baseline cancer and screening awareness of women with intellectual disabilities and their carers in the South East region. The information, obtained via a survey, formed the basis for the development of the EMBRACES-ID intervention. The survey comprised 125 carers and 45 women with mild to moderate intellectual disabilities, as well as semi- structured interviews with 25 carers.

Gaps in awareness levels of warning signs, risk factors and knowledge of screening programmes were identified among the women with intellectual disabilities and their carers. For example, carers recalled an average of three risk factors for breast cancer while the majority of women with intellectual disabilities could not name a single risk factor for breast cancer.

These findings reflect international evidence that highlights poor cancer awareness among women with intellectual disabilities.

In the interviews, many causes for this lack of awareness were identified. For example, comprehension and communication difficulties may have a major impact on cancer awareness, in addition to giving consent for screening. Other significant barriers to screening participation include the presumption of sexual inactivity for women with intellectual disabilities, and environmental and structural barriers related to physical disabilities.

Phase II of EMBRACES- ID is ongoing and is expected to finish in late 2015. The awareness-raising programme will be rolled out over eight sessions with the women themselves and their carers. This phase will test the feasibility of the intervention. It will include testing the programme for acceptability as well as the rates of recruitment and retention of participants. The primary outcome measure will be changes in cancer awareness levels. A pre-test/post-test design will test this. Secondary outcomes include measuring the ability to perform breast self-examination, exploring perspectives on screening and medical help-seeking, and checking the understanding of the reasons behind cancer screening.

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accessing primary healthcare. Exchange of health information plays an important role in accessing and benefiting from healthcare, often supported or facilitated by carers and relatives. Nevertheless, the factors that influence health information exchange (HIE) between persons with ID, General Practitioners (GPs), carers and relatives have not been widely studied. Our aim is to provide insight into determinants of HIE between primary care providers, individuals with ID and their support system, and to construct a conceptual model of HIE for this particular setting. **Methods** We conducted an interpretive review of literature on primary healthcare access concerning persons with ID. Studies were included if they described processes related to the verbal (oral or written) exchange of personalized health information concerning patients with ID in primary healthcare settings. Findings have been thematically synthesized into a conceptual model of HIE.
Results Determinants of HIE as described in the literature were found to relate to various topics, such as communication skills, presence of a third party, ability of healthcare providers to adapt to patient needs, and organizational factors. We constructed a multi-layered model comprising individual (both patient and provider), relational and organizational aspects. It distinguishes five dimensions in HIE concerning persons with ID: actors, content, temporal space, place and medium. **Conclusions** HIE depends on specific contextual factors of care. The process of HIE is related to other areas, such as healthcare access, medical communication, continuity of patient care, and health literacy. Our conceptual model can help to improve our understanding of HIE concerning persons with ID in primary healthcare, and to carry out further exploratory and empirical research on this topic.

Intellectual disability medicine in Nijmegen medical school curriculum

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About 1% of the Dutch population has intellectual disabilities (ID). Their health status is vulnerable, inequities and disparities are widely documented in international publications, resulting in a high prevalence of co morbidities and in lower life expectancy. In the curriculum of the Dutch medical schools there is not much attention to the specific health conditions of people with ID. All health professional encounter people with ID in their daily practice. The need for advanced knowledge and skills to serve people with ID adequately has been widely recognized. Attitudes towards persons with ID improve thanks to training. Improvement of the health status of people with ID could be realized by increasing the knowledge and competencies of all doctors during their medical school training (Burge P. et al., Can Fam Physician 2008;54:568–9.e1–6).

In 2009 at Nijmegen University Medical Centre a chair in ID medicine was established. The aim of the chair is to enhance the health of people with ID by integrating research, education, policy and practice. The positioning of the chair in the Department of Primary care and Community health offers an unique change to integrate ID medicine in the curriculum. The Nijmegen medical school curriculum takes 6 years, with 180 ECTS in both the Bachelor as Master period.

As the curriculum is overall very comprehensive and overloaded, the curriculum was analyzed in order to identify possibilities to integrate, several opportunities were identified, like in the course of neurology, child health and psychiatry. In this way, without introducing new comprehensive elements of the curriculum, attention to health problems of persons with ID could be realized.

At the moment, in all 6 years of the curriculum the students encounter the health problems of persons with ID, presented in different ways, like case studies, practice assignments, elective courses and tutorials. Opportunities for traineeships and clerkships are created, as the option to perform a research project in ID medicine.

Follow-up measurements of bone quality in residential clients with intellectual disability: 'A 5-year follow-up on fracture incidence in residential clients of intellectual disability care'

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Aim Multiple risk factors for low bone quality have been identified in the general population. In the population with an intellectual disability (ID) we found additional potential risk factors, for instance: more severe ID, antiepileptic drug use, Down syndrome, hypogonadism and cerebral palsy. These associations were identified in cross-sectional studies. In our present study it will be assessed whether these factors are related to deterioration of bone quality (negative change in Z-score for more than 5%) in people with ID in a follow-up study of 5 years using Quantitative Ultrasound (QUS) of the heel bone. Additionally the predictive value of bone quality measured by QUS for fractures will be assessed. **Methods** We will re-assess a cohort of 99 people with ID, assessed by Mergler et al. (2010). Data about potential risk factors were collected in patients' files in 2007-2008, missing data and whether a fracture has occurred in participants during follow up will be additionally obtained. Bone quality (Z-score) was measured with QUS of the heel bone (Lunar Achilles) at baseline and after 5 years follow-up. For the first study question we will compare two groups, Z-score deteriorated versus Z-score similar or improved. Factors that will be assessed are gender, age, level of ID, mobility status, antiepileptic drug use, cerebral palsy, Down syndrome, Caucasian race, BMI <20 kg/m2, females in menopause, hypogonadism and long term corticosteroid use. For the second study question bone quality in participants with at least one fracture during follow up will be compared with bone quality in participants without fractures. **Results** Results of the regression analyses are not available at this moment, but will be presented. **Conclusions** This is the first longitudinal study on bone quality, associated factors and predictive value of QUS for fracture incidence in people with ID.

Health Care Access Research and Developmental Disabilities: providing evidence of health disparities

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Aim HealthCare Access Research and Developmental Disabilities (Hcardd) endeavors to improve health data on adults with developmental disabilities (DD) in Ontario, Canada. The program aims to describe the healthcare provided to this population particularly in reference to primary care guidelines and to compare this to the care provided to adults without DD. We also seek to increase the impact of findings on policy and services through active stakeholder engagement. **Methods** Researchers have partnered with knowledge users in the health and social services sectors to establish a data sharing agreement to link administrative datasets from health and social services. This has allowed the creation of a cohort of 66 484 adults with DD. The linked data are used to compare health service utilization patterns among adults with DD to adults without DD, and evaluate how consistent care in the DD population corresponds to primary care guidelines. Our partnership approach is supported by Integrated Knowledge Transfer and Exchange (KTE) structure which includes committed relationships between scientists, and knowledge-users (government and service providers). In integrated KTE, stakeholders or potential research knowledge users are engaged in the entire research process. **Results** Our cohort includes 66 484 adults with DD and is the largest known dataset of persons with DD in the world. For comparison, a control group randomly sampled from the population of Ontarians without DD was also drawn. Compared to the control group, Ontarians with DD: (1) are more likely to live in lower income neighborhoods, (2) are younger yet have the same or higher rates of chronic diseases such as hypertension and diabetes, (3) make greater use of acute care (physician visits, ER and hospitalization) yet receive less preventative care e.g. women with DD are significantly less likely to undergo breast and cervical cancer screening. The KTE approach enables a relatively quick dissemination of the research findings to a wide range of audiences, including those in government and service provision.
Conclusions Preliminary results have shown disparities in health and health service use for individuals with DD in Ontario. The improved accessibility and understanding of our work to knowledge users is facilitating an accelerated application in policy and practice.

Cancer awareness and screening in women with intellectual disabilities- an Irish perspective

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Background There have been improvements in the life expectancy of people with intellectual disabilities (ID) in recent years; the age-standardised cancer incidence in people with ID is not significantly different to the general population. However, inequalities in cancer awareness and screening uptake for women with ID when compared with the general population are evidenced internationally. The Irish Cancer Society's Strategy Statement 2013-2017 acknowledged the need to close the gap on inequalities in cancer care for marginalised groups in Irish society. Women with ID are widely recognized as a marginalised societal group. This challenges health professionals and services in provision of cancer control services for Irish women with ID. **Aim** The aims of the study are to explore cancer awareness amongst Irish women with ID; to investigate the reasons for differences in screening services uptake; and to develop and evaluate a potential solution. **Method** This study is grounded in the transformative paradigm and addresses these issues using a two-phase mixed method design. Phase I, assesses the knowledge of women with ID and their carers' regarding cancer awareness and screening programmes. Phase II, comprises the development and evaluation of cancer awareness and screening education programmes: a tailored programme for women with ID and a carers' programme. **Discussion** The study has received full ethical approval from the relevant Irish Research Ethics Committees. Sample recruitment, data collection and data analysis for Phase I is ongoing in the South East region of the Republic of Ireland. Preliminary results from Phase I will be presented.

Presenters	**Date** (mm/yy)	**Title**	**Conference**	**Location**
Reidy M. Denieffe S. Foran S.	11/15	Poster Presentation: **Title: EMBRACES-ID** (**E**arly **M**onitoring of **B**reast **A**nd **C**ervical **C**ancer **S**igns & **S**creening in **I**ntellectual **D**isabilities): Did it work?	UHW Research Meeting.	Waterford, Ireland
Reidy M. Denieffe S. Foran S.	04/15	Three Minute Thesis Competition: **Title:** EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities).	WIT Research Day 2015.	Waterford, Ireland
Reidy M. Denieffe S. Foran S.	11/14	Poster Presentation: **Title: EMBRACES-ID** (**E**arly **M**onitoring of **B**reast **A**nd **C**ervical **C**ancer **S**igns & **S**creening in **I**ntellectual **D**isabilities).	Inaugural UHW Research Meeting.	Waterford, Ireland
Reidy M. Denieffe S. Foran S.	02/14	Oral Presentation: **Title**: Cancer awareness and screening in women with intellectual disabilities in Ireland.	33rd Annual International Nursing Conference RCSI	Dublin, Ireland
Reidy M. Denieffe S. Foran S.	11/13	Oral Presentation: **Title:** Cancer awareness and screening in women with intellectual disabilities.	6th Annual Sibéal Conference	Belfast, Northern Ireland
Reidy M. Deniffe S. Foran S.	11/13	Poster Presentation: **Title:** Cancer awareness and screening in women with intellectual disabilities- An Irish perspective.	IASSID/MAMH International Conference 2013	Nijmegen, The Netherlands
Reidy M. Denieffe S. Foran S.	04/13	Poster Presentation: **Title:** Cancer awareness and screening in women with intellectual disabilities.	WIT Research Day 2013	Waterford, Ireland