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The development of a digital intervention to promote timely presentation of breast cancer symptoms to a healthcare professional

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Thesis submitted to the National University of Ireland, Galway in fulfilment of the requirements for the Degree of Doctor of Philosophy (Psychology)

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Declaration

I declare that this thesis has not been submitted as an exercise at this or any other university.

I declare that this thesis is entirely my own work.

Signed: _____

Emma Carr

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Abstract

Breast cancer is the primary cause of death among women globally and in Ireland, mortality rates from breast cancer are the third highest in Europe. Early diagnosis of breast cancer is linked to more favourable outcomes and enhanced survival rates. Interventions to promote timely presentation to a healthcare professional (HCP) have the potential to increase early detection of breast cancer and therefore improve outcomes and mortality rates.

The *patient interval* refers to i) the time taken to interpret a bodily change and ii) the time taken to act upon that change and seek help from an HCP. Decreasing the patient interval is one way to increase early detection of breast cancer. Interventions designed to decrease the patient interval to date have targeted *breast awareness* which has three key components: breast checking behaviour, knowledge of age-related risk and knowledge of non-lump symptoms. These interventions have been delivered through booklets and in-person consultations which are costly and time intensive to implement. The current research, the *Know Breast Health* intervention, takes a novel approach to decreasing the patient interval for breast cancer in two ways; it targets help-seeking behaviours as well as the components of breast awareness and delivery is through a website to provide greater reach, at lower cost.

This thesis describes the development of a digital intervention to decrease the patient interval for breast cancer. The *Know Breast Health* intervention was developed using the Behaviour Change Wheel and the Person-Based Approach for intervention development. A literature review was conducted to understand the contributing factors to progression through the patient interval for breast cancer and a behavioural diagnosis was conducted to develop potential content for the intervention. A series of qualitative studies were conducted to produce, refine and optimise the content of the *Know Breast Health* intervention. A focus group study generated ideas for the intervention and assessed the acceptability of the proposed content. The results of this study were combined with the findings of the literature review and the behavioural diagnosis to create the *Know Breast Health* Website 1.0. A think-aloud interview study assessed the usability and acceptability of the *Know Breast Health* Website 1.0. This study had an iterative design allowing for multiple rounds of analysis and redesign which led to multiple iterations of the website, ending with version 4.0. The final qualitative study was a retrospective interview study

where participants shared their experiences of using the *Know Breast Health* intervention independently.

This research developed an intervention to promote timely help-seeking to an HCP upon self-discovery of a symptom of breast cancer. Health psychology methodologies were used to create a usable, acceptable and engaging intervention by incorporating target user perspectives throughout the development process, and grounding it in theory and evidence. This research was conducted and reported transparently and systematically to contribute to the growing science of intervention development.

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List of Abbreviations

AMG	AnnMarie Groarke
BCTs	Behaviour Change Techniques
EC	Emma Carr
HCP	Healthcare professional
HSE	Health Service Executive
IMP	Important for behaviour change
NCC	Not changed: Contradicts
NCF	Not changed: Feasibility
NCR	Not changed: Not repeated
NICE	National Institute for Health and Care Excellence
NUIG	National University of Ireland, Galway
REP	Repeated
SES	Socioeconomic status
STF	Straightforward and feasible
TDF	Theoretical Domains Framework
v.1	Version 1
v.2	Version 2
v.3	Version 3
WHO	World Health Organisation

1 Introduction

1.1 Chapter overview

This chapter will provide the background for the current research. The cancer early diagnosis literature will first be examined, focusing on issues regarding definitions and terminology. This will be followed by a discussion of existing interventions in the area of breast cancer early diagnosis. The science of intervention development in the field of health psychology will then be addressed, focusing on digital interventions. Finally, the rationale for the current research will be presented, followed by the thesis outline.

1.2 Breast cancer

In 2018 there were approximately 2.1 million newly diagnosed female breast cancers, accounting for almost 1 in 4 cancer cases among women globally (Bray et al., 2018). In Ireland more than 3,000 women are diagnosed with breast cancer every year and mortality rates from breast cancer are the third highest in Europe (Benson & Jatoi, 2012; National Cancer Registry, 2013). The global incidence of breast cancer is increasing and the development of interventions to improve early diagnosis has been recommended as necessary to decrease the breast cancer burden by the International Agency for Research on Cancer, the American Cancer Society, and the World Health Organisation (WHO; Bray, Jemal, Grey, Ferlay, & Forman, 2012; WHO, 2017). Early diagnosis of breast cancer is linked to more favourable outcomes and enhanced survival rates (Neal et al., 2015). Interventions to promote timely presentation to a healthcare professional (HCP) have the potential to increase early detection of breast cancer and therefore improve outcomes and mortality rates (Bray et al., 2012; O'Mahony et al., 2017). (Abraham, Kelly, West, & Michie, 2009)

1.3 Cancer Early diagnosis

Cancer early diagnosis is defined as “the early identification of cancer in patients who have symptoms of the disease” (WHO, 2017, p. 8). Cancer diagnosed early enables treatments that are less expensive, less complex and more effective, thereby improving outcomes and survival (Neal et al., 2015; WHO, 2017). Figure 1.1 demonstrates the complexity of the patient journey from initial discovery of a symptom to a cancer diagnosis (Olesen, Hansen, & Vedsted, 2009). To receive a diagnosis, individuals must recognise an abnormal change in their body, conclude that change warrants the attention of

an HCP and attend an appointment. Following this, a clinical investigation will be initiated which will involve referrals and further consultations. A diagnosis will follow, a treatment plan devised and finally, treatment will begin. Delays can occur at every milestone in this process, impeding early diagnosis and treatment.

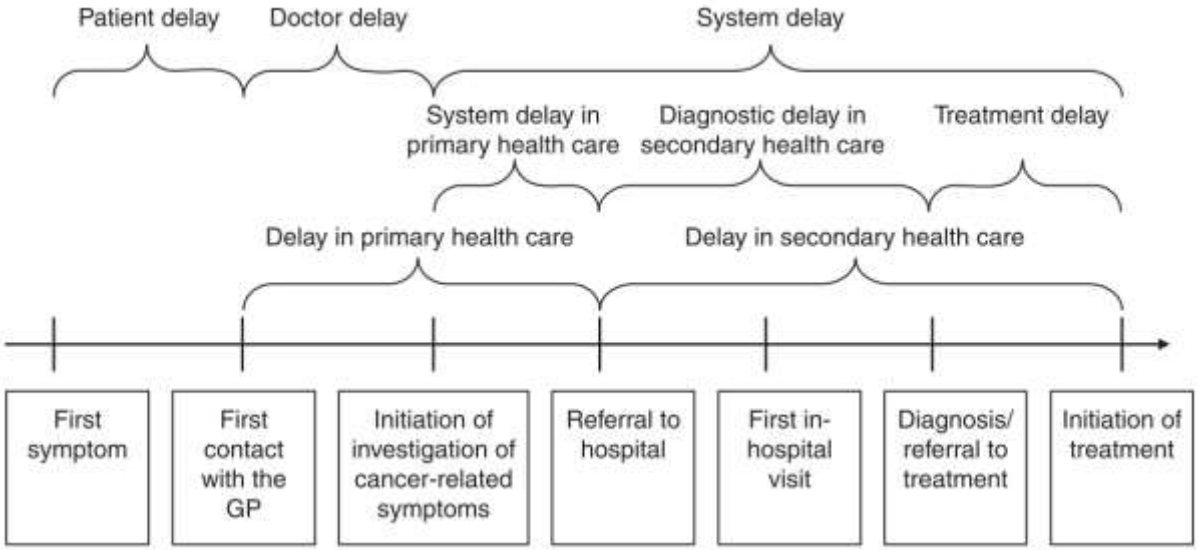

Figure 1.1. An illustration of the overall milestones and time intervals in the patient journey from detecting first symptom to diagnosis and treatment (Olesen et al., 2009).

The WHO in their *Guide to Cancer Early Diagnosis* outline three key stages to early diagnosis in cancer (see Figure 1.2; WHO, 2017). Step one, *awareness and accessing care*, has two key components: (i) symptom appraisal (period from detecting a bodily change to perceiving a reason to discuss the symptoms with an HCP); and (ii) health-seeking behaviour (period from perceiving a need to discuss the symptoms with an HCP to reaching the health facility for an assessment) (WHO, 2017, p. 13). Step two, *clinical evaluation, diagnosis and staging* is known as the diagnostic interval. It consists of accurate clinical diagnosis; diagnostic testing and staging; and referral for treatment. Step three is *access to treatment* and relates to patient access to high-quality, affordable treatment in a timely manner. The focus of this thesis is step one, *awareness and accessing care*.

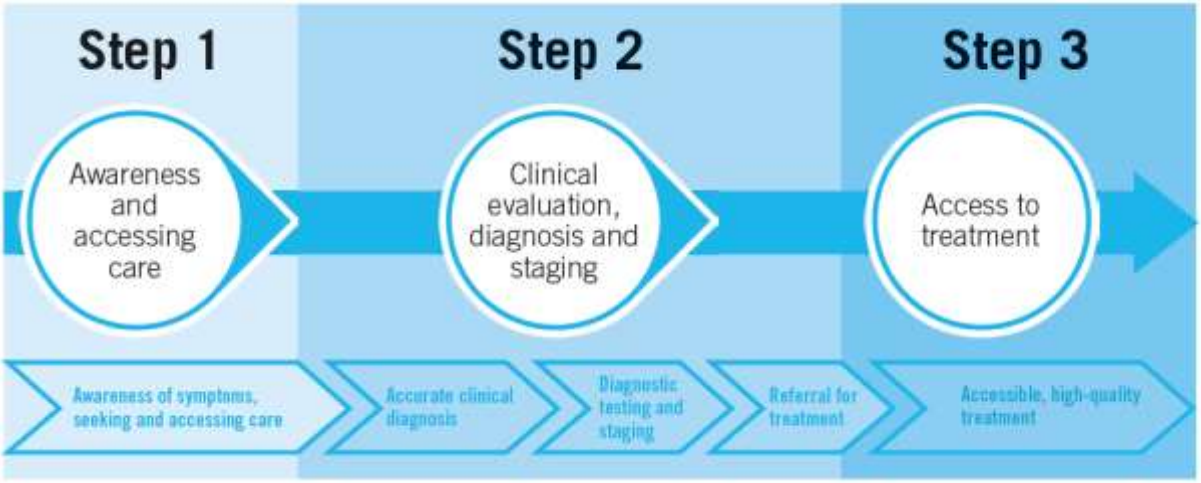

Figure 1.2. Essential elements of cancer early diagnosis taken from the World Health Organisation *Guide to Cancer Early Diagnosis* (WHO, 2017, p. 13).

1.3.1 Terminology

In the cancer research literature generally, and breast cancer literature specifically, the WHO *awareness and accessing care* step has been studied extensively under many different labels. In 2012 a consensus group was formed with the aim of producing guidance for researchers in the field of cancer early diagnosis due to a lack of consistent definitions and methods (Weller et al., 2012). They produced the Aarhus Statement which is a checklist of recommendations relating to definitions of time points, intervals and measurement in cancer early diagnosis research (Weller et al., 2012). This follows numerous calls for a universal language and standardised definitions for this field (Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2009; Lim, 2011; Scott & Walter, 2010). Patient delay was traditionally used to denote the period of time from when a person notices a bodily change to when they report to an HCP. Patient delay is no longer used, however, instead *patient interval* has been adopted as the standard terminology (Weller et al., 2012). This is due to the potentially pejorative nature of the word ‘delay’ as well as its inherent inaccuracies. Research in this area examines help-seeking behaviour and so accounts for both those individuals who delay help-seeking and those who do not. Therefore, early diagnosis researchers do not investigate ‘delay’ but rather the interval of time between first detection a bodily change and receiving treatment (Weller et al., 2012). When referring to women who ‘delay’ seeking help the preferred terminology is postponement of help-seeking (O'Mahony et al., 2017).

The Aarhus Statement breaks down the patient journey to treatment into three time intervals; the patient interval, diagnostic interval and treatment interval (Weller et al.,

2012). They describe four key events on the path to diagnosis: date of first symptom, date of first presentation, date of referral and date of diagnosis (Weller et al., 2012, p. 1264). Date of first symptom and date of first presentation are part of the *patient* interval and date of referral and date of diagnosis are part of the diagnostic and treatment intervals interval (Weller et al., 2012). To increase early diagnosis, delays in all intervals must be reduced. The focus of the current research is the *patient* interval which is made up of two components, defined as (i) the "time taken to interpret bodily changes/symptoms" that is, the *appraisal* interval and (ii) the "time taken to act upon those interpretations and seek help" that is, the *help-seeking* interval (Weller et al., 2012, p. 1264). This aligns with the WHO *awareness and accessing care* step as outlined above (WHO, 2017).

Breast cancer interventions and health promotion campaigns addressing the patient interval have not adopted the Aarhus Statement terminology. Instead, terms such as breast self-examination; breast cancer awareness; breast awareness and early presentation are used when targeting the patient interval. Breast self-examination was the traditional point of intervention for promoting early diagnosis in breast cancer. In 2003 the Cochrane Breast Cancer Group conducted a systematic review to determine whether breast self-examination reduced breast cancer mortality and morbidity by increasing early detection (Kösters & Gøtzsche, 2003). The review included two large population-based studies (n = 388,535) from Russia and China that compared breast self-examination with no intervention. There was no statistically significant difference in breast cancer mortality between the groups (relative risk: 1.05, 95% confidence interval: 0.90 to 1.24; 587 deaths in total). However, there were almost twice as many biopsies (n = 3406) with benign results in the breast examination groups compared to the control groups (n = 1856; relative risk 1.88, 95% confidence interval: 1.77 to 1.99). The review reports no beneficial effect of breast self-examination but does suggest increased harm in terms of increased numbers of benign lesions identified and biopsies performed and the resultant anxieties and costs of these procedures. The review concludes that screening by breast self-examination cannot be recommended. It was updated in 2008 and there was no change to conclusions drawn. The review also states (Kösters & Gøtzsche, 2003, p. 9):

> *It would be wrong, however, to conclude that women need not be aware of any breast changes. It is possible that increased breast awareness may have contributed to the decrease in mortality from breast cancer that has been noted in some countries. Women should, therefore, be encouraged to seek*

medical advice if they detect any change in their breasts that may be breast cancer.

Since then the term *breast awareness* has been adopted as the preferred terminology by many (Cancer Australia, 2019; NHS Breast Cancer Screening Programme, 2018; Irish Cancer Society, 2015). Breast awareness involves individuals having confidence to 'look at and feel' their breasts so that they know what is normal for their own body as well as the knowledge of what changes to look and feel for (O'Mahony et al., 2017). Some definitions also include the concept of presenting to an HCP as soon as possible (Mac Bride, Pruthi, & Bevers, 2012). Breast cancer awareness, similarly, has been defined as "having the knowledge, skills and confidence to detect breast changes and to present promptly to a healthcare professional." (O'Mahony et al., 2017, p. 1).

There is well documented confusion around the distinction between breast awareness and breast self-examination in both the healthcare professions and the general public (Hampton, 2008; Jones et al., 2015; Mark, Temkin, & Terplan, 2014; O'Mahony et al., 2017; Potts, 2014; Thornton & Pillarisetti, 2008). It has been argued that if a woman is looking at and feeling her breasts she is performing a breast examination (Jones et al., 2015; Mark et al., 2014; Thornton & Pillarisetti, 2008). However, breast self-examination is defined as a regular, repetitive monthly palpation to a rigorous set method performed by the woman at the same time each month (Thornton & Pillarisetti, 2008). The specificity of this behaviour is what makes it differ from the self-examination encouraged by breast awareness guidelines. With breast awareness there is no right or wrong way to self-examine and it can be done at any time that is convenient for the individual. It has been referred to as 'breast checking' to distinguish it from breast self-examination (Campbell et al., 2015; Forbes et al., 2011b).

The Cancer Research UK Promoting Early Presentation Group, at Kings College London, developed the Breast Cancer Awareness Measure (Linsell et al., 2010). This is a validated questionnaire which allows for the classification of individuals as 'breast cancer aware' through scoring on three sub-domains: knowledge of symptoms, knowledge of age-related risk and frequency of breast-checking. Users are categorised as 'breast cancer aware' if they select five or more non-lump symptoms from a list of 11 breast cancer symptoms; correctly identify that a 70-year-old woman is most likely to get breast cancer; and engage in at least monthly breast-checking (Linsell et al., 2010). The Breast Cancer Awareness Measure provides the clearest definition of breast awareness and highlights the

second distinction between breast awareness and breast self-examination; breast awareness involves more than self-examination but includes a basic understanding of risk and knowledge of breast cancer symptoms.

1.3.2 Section Summary

Early diagnosis of cancer enables treatments that are less expensive, less complex and more effective, thereby improving outcomes and survival (Neal et al., 2015; WHO, 2017). The patient journey from initial discovery of a symptom to a cancer diagnosis is a long and complex one (Olesen et al., 2009). The WHO in their *Guide to Cancer Early Diagnosis* outline three key stages to early diagnosis in cancer: awareness and accessing care; clinical evaluation, diagnosis and staging; and access to treatment. The focus of this thesis is step one, *awareness and accessing care* which is also referred to as the patient interval.

1.4 Interventions to promote early diagnosis in cancer

The WHO, in their *Guide to Cancer Early Diagnosis* outline interventions to promote early diagnosis (WHO, 2017). For the patient interval it recommends three interventions: (i) empower and engage people and communities, (ii) improve health literacy and reduce cancer stigma, and (iii) facilitate access to primary care (WHO, 2017). These interventions must improve knowledge and awareness and identify barriers to attendance (WHO, 2017). The WHO report outlines that awareness of cancer must go beyond the disease and its symptoms, to an understanding of the healthcare system, its costs, and where and how to present for care. Health literacy must include knowledge of how to self-identify a change that could be cancer and to manage this and any negative affective response. The use of social media and other predominant sources of information is recommended for delivery of these interventions with the caveat that they are used in culturally appropriate ways (WHO, 2017).

Despite the plethora of studies examining barriers to progression through the patient interval for breast cancer (see Chapter 2), interventions targeting this interval are limited in number (O'Mahony et al., 2017). Two systematic reviews conducted in 2009 (Austoker et al.) and 2017 (O'Mahony et al.) identified just six intervention studies targeting the patient interval for breast cancer. The most recent systematic review, published in 2019 (Anastasi & Lusher) searched the literature from 1988 and included nine intervention studies. Six of these, however, were related to the same intervention: The Promoting Early Presentation

intervention, a Cancer Research UK, National Awareness and Early Diagnosis Initiative, which will be discussed in detail next. The interventions included in the systematic reviews focused on the *appraisal* interval of the patient interval and were delivered via educational presentations to groups in community settings (Anastasi & Lusher, 2019; Eskandari-Torbaghan, Kalan-Farmanfarma, Ansari-Moghaddam, & Zarei, 2014; Gabram et al., 2008) and using social networks (Skinner, Arfken, & Waterman, 2000), mass media campaigns (Catalano, Winett, Wallack, & Satariano, 2003; Daniel & Simpson, 2008) and print materials delivered by HCPs in clinical settings (Forbes et al., 2011b; Rimer et al., 2002).

The Austoker et al. (2009) review reports there is some limited evidence for intensive education campaigns to increase cancer awareness and earlier presentation in the short term. However, they also state that it is unclear what the *content* of such campaigns should be. The O'Mahony et al. (2017) Cochrane review concludes that one-to-one interventions in a clinical setting, with print materials to aid discussion have potential to increase older women's breast cancer awareness in the longer term. Once again, however, they also report that conclusions cannot be drawn about the best content of such interventions (O'Mahony et al., 2017). The Anastasi and Lusher (2019) review had the most positive findings for the field. They report that breast cancer awareness interventions are effective at increasing breast cancer awareness, knowledge, and screening uptake and could help reduce late diagnoses, potentially reducing breast cancer mortality rates. Specifically, they recommend interventions delivered by HCPs (Anastasi & Lusher, 2019). This recommendation, however, is likely due to the overrepresentation of the Promoting Early Presentation intervention in their sample (six of the nine studies included). All the reviews contain a heterogeneous mix of studies in terms of the intervention content, population studied and outcomes measured and were classified as moderate and low-quality evidence.

The Promoting Early Presentation intervention, was developed through the National Awareness and Early Diagnosis Initiative led by the National Health Service (NHS) England, Public Health England and Cancer Research UK. The Promoting Early Presentation intervention is a scripted, 10-min, one-to-one interaction delivered by an HCP and supported by a booklet, to increase breast cancer awareness operationalised by the Breast Cancer Awareness Measure (Linsell et al., 2010). The intervention development paper was published in 2008 (Burgess et al.), and since then a range of papers have

detailed the progression of this work. There have been three reports on the Promoting Early Presentation randomised controlled trial (Forbes et al., 2011b; Kaushal et al., 2017; Linsell et al., 2009). It randomised 867 women aged 67–70 attending their final routine appointment for breast screening in the NHS into the Promoting Early Presentation intervention or usual care (Forbes et al., 2011b; Linsell et al., 2009). At the three year follow-up the Promoting Early Presentation intervention group maintained higher breast cancer awareness than the control group (Kaushal et al., 2017). The Promoting Early Presentation intervention has been successfully implemented in clinical practice (Dodd et al., 2017; Forbes et al., 2012) and general practice (Campbell et al., 2015). The latest evolution of the Promoting Early Presentation work is delivery of the intervention during flu vaccination appointments in primary care (Kaushal et al., 2019). The transparent development process and the extensive body of work on the Promoting Early Presentation intervention make it an example of best practice in the early diagnosis literature. The UK parliamentary inquiry into older age and breast cancer recommended to NHS England, Public Health England, and Clinical Commissioning Groups that the Promoting Early Presentation intervention be implemented on a wider scale (APPG, 2013).

1.4.1 Section Summary

There is limited guidance in the empirical literature regarding the content for interventions to target the patient interval for breast cancer. The WHO (2017) recommend empowering and engaging people by improving health literacy, reducing stigma and facilitating access to primary care. The Promoting Early Presentation intervention has proven successful and is delivered by HCPs in a clinic setting and is therefore resource intensive.

1.5 Intervention development in health psychology

In recent years health psychology has placed a renewed focused on using systematic and transparent approaches to intervention development (Conner & Norman, 2017; O'Carroll, 2014; Peters & Marques, 2014). This allows for replication and importantly enables an understanding of what does and does not work in the intervention. The “big question” facing health psychologists, according to West and Michie (2016, p. 29), is:

> *What interventions (defined in terms of features of content and delivery), with what usage (defined in terms of uptake and level and type of engagement in those using it), in what context (defined in terms of features of the target*

population and the setting) has what effect on what behaviours, through what mechanisms of action?

To answer this question a careful development process must take place. The Medical Research Council first published guidance on developing and evaluating complex interventions in 2000 and since then the framework has been highly influential; the 2008 update has been cited more than 6,000 times (Campbell et al., 2000; Craig et al., 2008). The Medical Research Council framework placed a spotlight on the development process and it has been used by health psychologists to guide new methodologies for developing interventions. The Person-Based Approach (Yardley, Morrison, Bradbury, & Muller, 2015b) and the Behaviour Change Wheel (Michie, Atkins, & West, 2014) are two such methodologies. They provide guidance on how to develop interventions that can address the issues posed by the "big question". The Person-Based Approach and the Behaviour Change Wheel are the approaches to intervention development used in the current research.

1.5.1 The Person-Based Approach

The Person-Based Approach to intervention development focuses on understanding the perspectives and psycho-social context of intervention users through iterative qualitative research (Yardley et al., 2015b). It has evolved over the last ten years and is based on over a thousand in-depth interviews aimed at understanding users' needs and their reactions to interventions developed using the Person-Based Approach (Yardley et al., 2015b). Understanding the perspectives of intervention users increases the acceptability and effectiveness of interventions by ensuring they are easy to use and engaging (Yardley et al., 2015b). The Person-Based Approach works in tandem with traditional theory- and evidence-based approaches to develop interventions. It provides a framework for designing, optimising and implementing health psychology interventions (Morrison, Muller, Yardley, & Bradbury, 2018).

There are four stages in the Person-Based Approach, the first of which, is *planning* (Yardley et al., 2015b). During this stage the key behavioural issues, needs, and challenges to be targeted by the intervention must be identified. Psychological theory and empirical evidence must be examined. Previous qualitative studies of user experiences of similar interventions can be used to explore the perspectives and needs of the intervention users. If there is limited available evidence, the Person-Based Approach recommends conducting primary qualitative research as well behavioural analyses or consulting with experts and

other stakeholders (Morrison et al., 2018). The data and evidence collected in the planning stage are combined in stage two; *design*, to produce the *guiding principles* of the intervention. These are the key intervention design objectives that address the behavioural issues, needs, and challenges developed in stage one and identifies the features of the intervention needed to achieve each objective. The design stage also requires the development of the intervention *logic model* which details the hypothesised mechanisms of action of the intervention, and can include the identification of behavioural determinants or behaviour change techniques (Yardley et al., 2015b).

The third stage of the Person-Based Approach is *optimisation*. This involves the evaluation of the acceptability and feasibility of the intervention by examining all intervention components in detail and optimising them from the user perspective. Users' reactions to the intervention are analysed and the results used to iteratively modify the intervention. This can be achieved through think-aloud techniques, where participants use the intervention in the presence of a researcher, and retrospective interviews, where participants use the intervention independently and are then interviewed by the researcher. The refinement and optimisation at this stage maximise the acceptability and feasibility of the intervention (Morrison et al., 2018; Yardley et al., 2015b). The final stage in the Person-Based Approach is *implementation*. Here the intervention must be evaluated and once again modified to improve implementation in future. Effectiveness and cost-effectiveness, where possible, should be evaluated using traditional experimental methods such as randomized controlled trials and audits, as well as process evaluations (Morrison et al., 2018; Yardley et al., 2015b). This thesis describes the planning, design and optimisation stages of the *Know Breast Health* intervention development.

1.5.2 The Behaviour Change Wheel

The Behaviour Change Wheel is a guide for designing interventions (Michie et al., 2014). It was developed based on a synthesis of 19 behaviour change frameworks identified in a systematic review (Michie, van Stralen, & West, 2011). The Behaviour Change Wheel is a systematic and prescriptive guide with clearly defined steps in the development process. The first step in the Behaviour Change Wheel is to understand the behaviour being addressed. The Behaviour Change Wheel outlines how to specify the target of the intervention and, using the COM-B model, determines what needs to change for the target behaviour to occur (Michie et al., 2014). The COM-B is a 'behaviour system' in which an individual's capability, opportunity, and motivation interact resulting in a

given behaviour (Michie et al., 2014). The next step in the Behaviour Change Wheel provides guidance on how to achieve the desired behaviour change through the selection of intervention functions and policy categories. The final stage guides the developer through the process of identifying content and implementation options. This involves selecting the appropriate behaviour change techniques and the mode of delivery of the intervention (Michie et al., 2014).

1.5.3 Digital interventions

Digital interventions (DIs) are health interventions that involve computer technology or digital encoding of information. They included mobile applications (apps), text messages, wearable and ambient sensors, social media, and websites (Michie, Yardley, West, Patrick, & Greaves, 2017). Digital interventions can offer information, education, and emotional, decisional, and/or behavioural support to users as well as providing useful data to HCPs (Alkhaldi et al., 2016; Bradbury, Watts, Arden-Close, Yardley, & Lewith, 2014). Through the promotion of evidence-based health care practice, self-management of chronic conditions and disease prevention, digital interventions can have great impact on population health and healthcare (Michie et al., 2017; Walsh & Groarke, 2019). A website was chosen as the mode of delivery for the *Know Breast Health* intervention.

Digital interventions can be cost effective (Band et al., 2017; Morrison et al., 2015). Unlike in-person and/or paper-based interventions, once developed, the costs of implementation are limited and they can be used by an infinite number of users (Yardley et al., 2015b). They can also be personalised and interactive making them more engaging and rewarding for users (West & Michie, 2016). By removing geographic and time-based constraints, digital interventions can increase access to healthcare for users and have much greater reach than traditional interventions (Bradbury et al., 2014; Kohl, Crutzen, & de Vries, 2013). Digital intervention fidelity is inherently higher than in-person delivered interventions. Fidelity of delivery refers to the extent to which the delivery of interventions adhere to the specifications of the intervention manual (Lorencatto, West, Christopherson, & Michie, 2013). Low delivery fidelity is likely to undermine the effectiveness of interventions (Walton, Spector, Tombor, & Michie, 2017). This is not an issue with digital interventions because the delivery is identical for every user. Finally, the data generated by digital interventions can be vast and, if used correctly, can contribute to the development of theory and our understanding of human behaviour (Michie et al., 2017).

Digital interventions do, however, have some disadvantages over traditional in-person or paper-based interventions. The development process can be expensive and the technology used can become outdated very quickly (Michie et al., 2017). Digital interventions cannot replicate the interactional support delivered through an in-person intervention, which could potentially limit their effectiveness. Perhaps as a consequence of this, digital interventions can have difficulties engaging and retaining users (Alkhaldi et al., 2016; Kohl et al., 2013; Yardley et al., 2016). Overall, however, the literature suggests that digital interventions can improve health behaviours and health outcomes and that they are an acceptable and feasible way to do so (Alkhaldi et al., 2016; Kohl et al., 2013; Payne, Lister, West, & Bernhardt, 2015). Cochrane systematic reviews have found that digital interventions can be effective for promoting physical activity and sexual health (Bailey et al., 2010; Foster, Richards, Thorogood, & Hillsdon, 2013), supporting self-management for diabetes and chronic pain (Eccleston et al., 2014; Pal et al., 2013) and to deliver alcohol reduction, weight loss and smoking cessation interventions (Kaner et al., 2017; Taylor et al., 2017; Wieland et al., 2012). These reviews and others (Kohl et al., 2013) all report small effect sizes with a substantial level of heterogeneity. This is, however, in keeping with interventions delivered through other modalities (e.g. in-person/paper) (Conner & Norman, 2017).

1.5.4 Section conclusion

The Person-Based Approach and Behaviour Change Wheel are methodologies ideally suited to the development of digital interventions. The Person-Based Approach focuses on user perspectives and experience. It aims to empower users to engage with their healthcare by creating acceptable and feasible interventions (Yardley et al., 2015b). By allowing for the identification of the active ingredients of the intervention using behaviour change techniques, the Behaviour Change Wheel will facilitate the development of a clear and precise intervention website. These approaches will produce an intervention that is based in theory, evidence and the perspectives of target users, and so, produce a maximally engaging intervention. Optimising target user engagement will address the issues of attrition reported with some digital interventions (Kohl et al., 2013; Yardley et al., 2015b).

1.6 Thesis focus and aims

The overall aim of this research is to develop an intervention to target step one of the WHO strategy for cancer early diagnosis, *awareness and accessing care*, by reducing the patient interval for breast cancer (WHO, 2017). The objective is to use health psychology

methodologies to create a feasible, acceptable and engaging intervention by incorporating target user perspectives and grounding it in theory and evidence. Finally, this research aims to develop the intervention in a transparent and systematic way in order to contribute to the science of intervention development. This thesis describes the development of the *Know Breast Health* intervention: an internet delivered intervention to promote timely presentation of breast cancer symptoms to an HCP.

1.6.1 A digital intervention

The *Know Breast Health* intervention will be delivered through a website. An internet delivered intervention was chosen as it is a low-cost option, with the potential to reach a wide audience. This is essential given the large target population, namely, women aged 18 – 49. It has been reported that up to 80% of internet-connected adults use some form of digital technology to monitor or modify their health (Perski, Blandford, West, & Michie, 2016). In Ireland, 93% of people own or have access to an internet-enabled device which they check an average of 55 times per day (Deloitte, 2018). Smart tablet use among over 65's increased from 57% to 70% between 2017 and 2018; a clear demonstration of the increasing pervasiveness of digital technology (Deloitte, 2018). Thus, an intervention accessible through the internet is an appropriate and prudent choice.

1.6.2 An intervention for women aged 18 – 49

The *Know Breast Health* intervention aims to promote timely presentation of breast cancer symptoms to an HCP in order to facilitate early diagnosis. It was designed for women aged 18 – 49, although it is suitable for use by women of all ages. Almost one quarter (23%) of breast cancers in Ireland are found in women under 50 years of age (National Cancer Registry, 2013 and 2018). Interventions such as *Know Breast Health* are essential in this age group as early detection through screening is not recommended (Ekwueme & Trogdon, 2016; Marmot et al., 2013). While breast cancer incidence is higher in women over 50, the survival rate is lower in younger women diagnosed with the disease (Ekwueme et al., 2014). This is partly explained by the fact that breast cancer in young women tends to be more aggressive and so less amenable to treatment, but is also a result of more advance stage at diagnosis (Ekwueme & Trogdon, 2016; Paluch-Shimon & Warner, 2015). These factors combined result in poorer survival outcomes (Ekwueme & Trogdon, 2016; Paluch-Shimon & Warner, 2015). Breast cancer in this age group can have a more devastating impact on quality of life as it interrupts employment and career development (Ekwueme et al., 2014; Paluch-Shimon & Warner, 2015). An examination of

the health and economic impact of breast cancer in the United States found that in this age group it produces a greater economic burden to the patient, their families, and society. Diagnosing these cancers earlier results in better outcomes and so there is a need for age-appropriate interventions for this group (Ekwueme et al., 2014; Ekwueme & Trogdon, 2016; O'Mahony et al., 2017).

1.6.3 An intervention to target the patient interval

To date, interventions for the patient interval in breast cancer have focused on the *appraisal* interval (O'Mahony et al., 2017). That is, the time taken for an individual to interpret a bodily change as a symptom that warrants the attention of an HCP (Weller et al., 2012). The second stage of the patient interval, *help-seeking*, is the time taken to act upon those interpretations and seek help (Weller et al., 2012). Factors such as knowledge of causes and treatment of breast cancer, attitudes to HCPs and affective responses can impact help-seeking behaviour and are, therefore, important targets for an intervention aiming to promote timely presentation (Scott, Walter, Webster, Sutton, & Emery, 2013). The Promoting Early Presentation intervention, for example, focuses on increasing breast awareness. This is operationalised by the Breast Cancer Awareness Measure and incorporates symptom knowledge, breast checking and understanding of risk (Linsell et al., 2010). These are essential for the *appraisal* interval but do not address the *help-seek*ing interval. While the Promoting Early Presentation intervention has been extensively studied and is being rolled out across the National Health Service in England, its narrow focus is a limitation, albeit perhaps a necessary one. The Promoting Early Presentation intervention is delivered by HCPs in clinic and general practice settings, where resources are limited. A digital intervention, however, has no such limitations. Delivering the *Know Breast Health* intervention through a website means it can target the entire patient interval, addressing both issues of appraisal and help-seeking.

1.7 Thesis outline

The intervention development map for the *Know Breast Health* intervention is presented in Figure 1.3. The thesis can be divided into three sections, based on the three stages of the Person-Based Approach to intervention development.

1.7.1 Section one: Planning (Chapters 2 – 4)

Chapter 2 is a review of the literature of the factors that influence the patient interval for breast cancer. Chapter 3 develops potential content for the *Know Breast Health*

intervention, by following the Behaviour Change Wheel. A behavioural diagnosis is completed, intervention functions identified and behaviour change techniques selected. Website components (version one) are developed to deliver the behaviour change techniques. The Focus Group Interview Study (Chapter 4) explores content for the *Know Breast Health* intervention.

1.7.2 Section two: Design (Chapter 5 and website 1.0)

In the design stage of the development of the *Know Breast Health* intervention the *logic model* and *guiding principles* are produced in order to provide a blueprint for the *Know Breast Health* intervention Website 1.0. Website components (version two) are developed and integrated with the Behaviour Change Wheel work to create the intervention logic model. Principles of digital health intervention design are combined with the findings of the Focus Group Interview Study to create the intervention guiding principles. Finally Website 1.0 is created.

1.7.3 Section three: Optimisation (Chapters 6 – 7 and website 2.0 – 4.0)

Chapter 6 describes the Think-aloud Interview Study. Here participants' reactions to every intervention element are elicited, observed, and analysed. The intervention was iteratively modified to optimise it from the user perspective. This led to the development of Website 4.0. Chapter 7 describes the Retrospective Interview Study where the acceptability, usability and feasibility of the intervention was explored using thematic analysis. The thesis will conclude with a general discussion.

1.8 Conclusion

Early diagnosis of cancer enables treatments that are less expensive, less complex and more effective, thereby improving outcomes and survival (Neal et al., 2015; WHO, 2017). The focus of this thesis is step one of the WHO, early cancer diagnosis strategy: *awareness and accessing care,* specifically, the patient interval for breast cancer. There is limited guidance in the empirical literature regarding the content for interventions to target the patient interval for breast cancer. By using the Person-Based Approach and the Behaviour Change Wheel the aim of this research is to develop an intervention that is based in theory, evidence and the perspectives of target users. This thesis describes the development of the *Know Breast Health* intervention: an internet delivered intervention to promote timely presentation to an HCP of breast cancer symptoms.

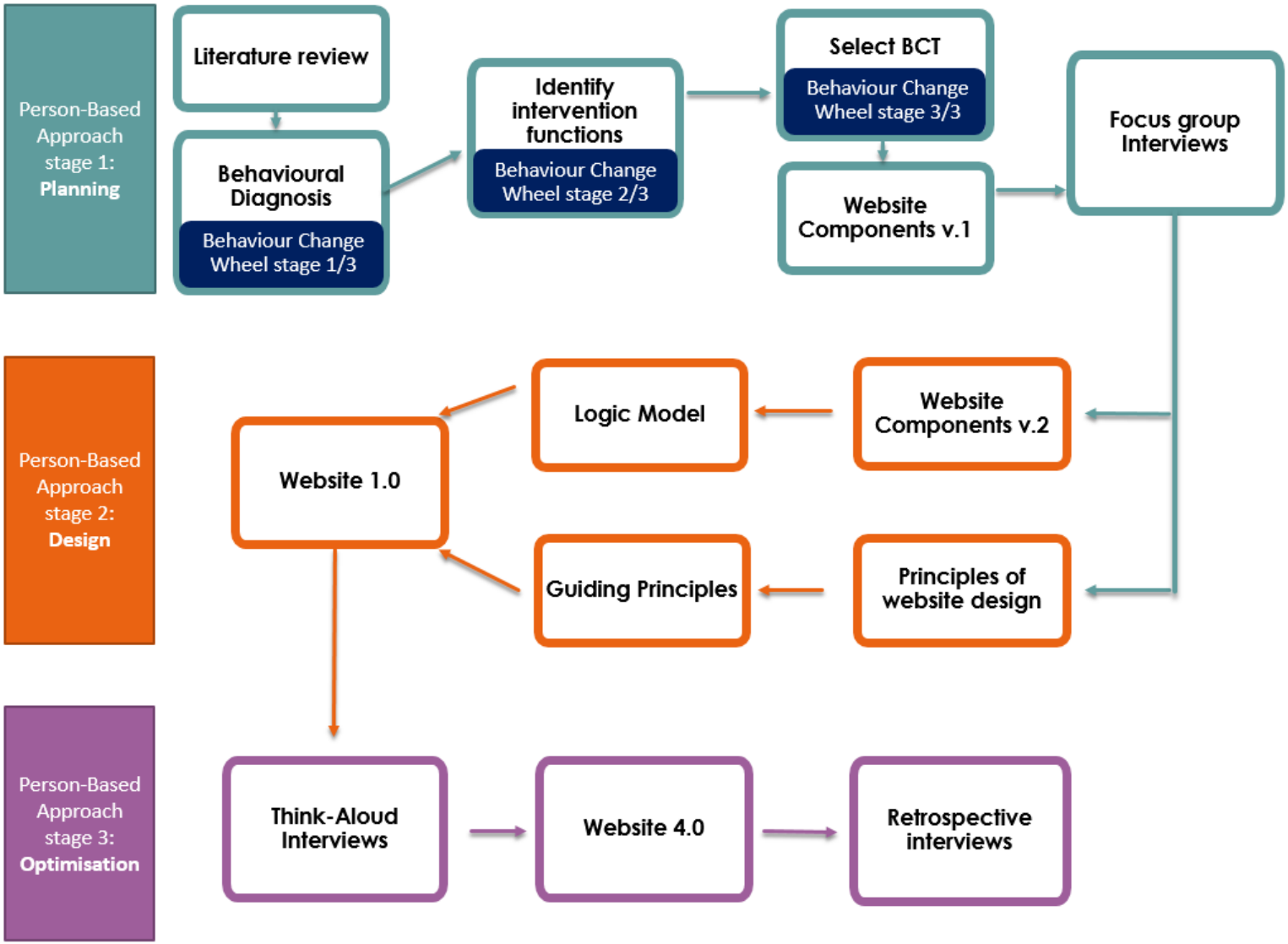

Figure 1.3. The *Know Breast Health* intervention development map.

2 Literature Review: Understanding the Patient Interval for Breast Cancer

2.1 Chapter overview

This chapter presents a review of the literature for the patient interval for breast cancer. Section one will discuss the psychological theory relevant to the patient pathway to treatment for cancer. The main models discussed here will be the Andersen Model of Total Patient Delay and the Model of Pathways to Treatment. Section two will discuss empirical evidence, both quantitative and qualitative, for the factors that influence the patient interval for breast cancer.

2.2 Section 1: Theories of postponement of help-seeking in cancer

The General Model of Total Patient Delay[1] (Andersen, Cacioppo, & Roberts, 1995) has, for more than two decades, underpinned research aiming to understand help-seeking behaviour in cancer. It is the first comprehensive model developed to understand the patient pathway to treatment and is the most widely used psychological model in the area (Scott et al., 2013). The Andersen Model is the foundation of many models developed since: the Judgement to Delay Model (Facione, Miaskowski, Dodd, & Paul, 2002), Understanding Delayed Presentation model (Bish, Ramirez, Burgess, & Hunter, 2005), the Prolonged Delay Model (Rauscher et al., 2010), the Health Seeking Behaviour Framework (O'Mahony, Hegarty, & McCarthy, 2011) and the Model of Pathways to Treatment[2] (Scott et al., 2013). The Pathways Model is the most recent model to build on Andersen and colleagues work (Andersen et al., 1995). It uses the terminology and intervals recommended by the Aarhus statement (Scott et al., 2013; Weller et al., 2012). It therefore represents current best practice guidelines. The Andersen Model and the Pathways Model will now be critically discussed to gain a theoretical understanding of the patient interval for breast cancer.

2.2.1 General Model of Total Patient Delay

The Andersen Model is presented in Figure 2.1. The Anderson Model conceptualises postponement of help-seeking in terms of inferences (appraisal of symptoms), decisions (concluding an HCP consultation is required), behaviours (making an appointment) and events (Andersen et al., 1995receiving medical attention/diagnosis;). *Appraisal delay* is the time taken from detecting something “unexplained”, to inferring an illness, and *illness delay*

[1] Referred to as the Andersen Model throughout the remainder of this thesis
[2] Referred to as the Pathways Model throughout the remainder of this thesis

is the time taken from inferring illness, to deciding to seek medical attention. These definitions match those of an earlier model developed by Safer, Tharps, Jackson, and Leventhal (1979). However, Andersen et al. (1995) differ in their conceptualisation of the remainder of the process to create a more comprehensive model of postponement of help-seeking. The Andersen Model introduces *behavioural delay*, defined as the time taken from deciding to seek medical attention to making the appointment and *scheduling delay*, which occurs from that point to having the consultation with the HCP. Finally, *treatment delay* is the time taken from initial consult to treatment initiation (Andersen et al., 1995). Andersen et al. (1995) found in their empirical work with both newly diagnosed cancer patients and patients waiting for a diagnosis that *appraisal delay* accounted for 60% of the total delay. Therefore, Andersen et al. (1995), posit that the most important factor in postponement of help-seeking is the appraisal process.

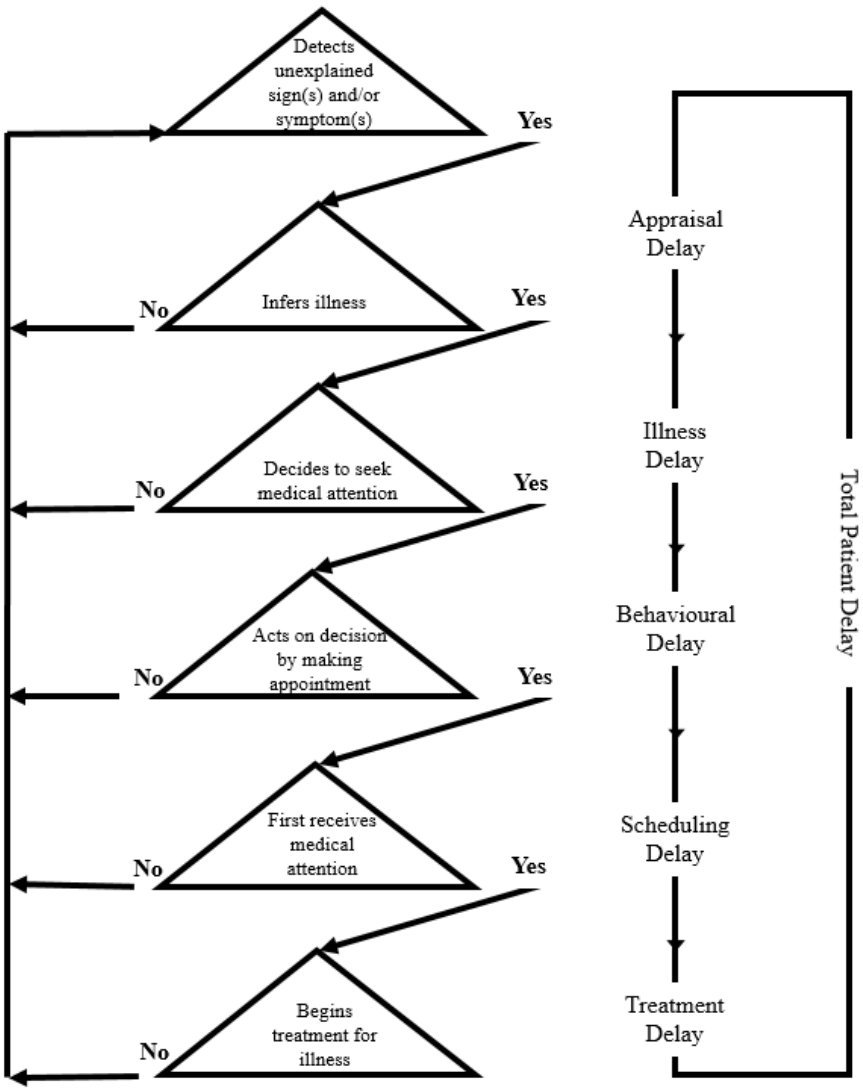

Figure 2.1. General Model of Total Patient Delay (Andersen et al., 1995, p. 35).

The Anderson Model is based on the principles of Psychophysiological Comparison Theory which proffers that individuals go through a psychophysiological comparison process that is based on salient situational events and illness prototypes (Andersen et al., 1995; Andersen & Cacioppo, 1990). That is, the appraisal of symptoms involves the comparison of symptoms (e.g. breast pain) to the known consequences of salient events (e.g. menstruation) and to the schemas the individual has for known illnesses (symptoms associated with monthly menstrual cycle). This psychophysiological comparison process is driven by an inherent need for cognitive clarity about our physiological and psychological state, because, according to the theory, uncertainty of these states is aversive (Andersen et al., 1995; Andersen & Cacioppo, 1990).

Although the psychophysiological comparison process has logical consistency (appraisal is influenced by the familiarity of the symptoms and how well they align to illness prototypes), it is biased towards the most optimistic interpretation (Andersen et al., 1995; Andersen & Cacioppo, 1990). Upon discovery of a bodily change, an individual must interpret the cause of the change. In doing so, the individual may have an optimistic bias or a pessimistic bias (Jones, 1990). The former assumes that the change is transient and not symptomatic of anything threatening to health. The latter assumes that the change is an indication of a serious illness. The pessimistic bias is rare, with the optimistic bias being the norm (Jones, 1990). An optimistic bias can lead to postponement of help-seeking as it can result in denial of the threat posed by the change. When faced with a decision we select one option from many, that is, we make one option dominant over the others. This can be referred to as dominance structuring and it is a necessary strategy for deciding between alternatives (Facione & Facione, 2006). Dominance structuring can lead to biased attentions or a confirmatory bias, as individuals who have decided upon an explanation for a bodily change are likely to seek-out supporting evidence for their explanation (Jones, 1990).

The Andersen Model is the seminal model in understanding postponement of help-seeking. In particular, it explains the process individuals go through when determining the cause of an illness, that is, the appraisal process. This process is driven by a need for cognitive clarity about our physiological and psychological state. The appraisal process identifies the most salient contextual stimuli as the cause, and is prone to optimistic and confirmatory biases. There are however, some limitations to the Andersen Model, which will now be addressed.

2.2.1.1 Limitations of the Andersen Model

Walter, Webster, Scott, and Emery (2012) conducted a systematic review on the application of the Andersen Model to cancer diagnosis. They conducted a narrative synthesis on primary research (n = 10) focused on cancer diagnosis that applied one or more stages of the Andersen Model. They found strong evidence for the existence and importance of *appraisal delay* but did not find support for *illness delay* as a separate interval. There was limited evidence to support *behavioural delay* and *scheduling delay*; but where these intervals did play a role in delay it was due to affective responses (e.g. fear) and competing priorities (e.g. work). This highlights a limitation of the Andersen Model, that is, it does not account for the impact of affect on the patient pathway to treatment. Affective responses can lead to *behavioural delay* and *scheduling delay*. For example, patients have reported feeling too embarrassed to discuss symptoms with the HCP or being fearful of what a consultation might find (Burgess, Hunter, & Ramirez, 2001; Facione, 1993; Jones, 1990).

Walter et al. (2012) note that most of the studies included in the review were atheoretical, lacked consistency in their definitions and were heterogeneous in their methods. The definition of *appraisal delay* is one of the Andersen Model's limitations. It begins with the detection of an "unexplained" symptom however this is not the point at which an individual begins their appraisal process. The appraisal of symptoms includes the process of deciding if the symptom can be explained (Jones, 1990; Scott & Walter, 2010). When we label a bodily state, we rely on the most salient contextual stimuli as an explanation (Jones, 1990). Salient contextual stimuli can lead individuals to believe they have an appropriate explanation for a bodily state or change (for example: 'I am tired because I went to bed late last night'). The belief that the cause of the change has been identified can result in the individual postponing or forgoing help-seeking (Jones, 1990). If there are no salient contextual stimuli for a bodily change the individual will revaluate. It is after this process that a symptom would be deemed 'unexplained', a process the Andersen Model does not include (Jones, 1990; Walter et al., 2012).

In the Andersen Model, the *appraisal delay* period ends when the individual infers they have an illness, from here they move to the *illness delay* process whereby they decide whether or not to seek medical attention. Research has shown, however, that this is not always the case measure (Scott & Walter, 2010). In some cases, an individual who has not inferred illness will decide to see an HCP. These individuals engage in help-seeking as a preventative measure (Scott & Walter, 2010).

The Andersen Model describes a linear progression from initial detection of an "unexplained" symptom to illness inference. It is clear from the research evidence that there is a bidirectional relationship between detecting a bodily change and inferring illness (Scott & Walter, 2010). Often a change in the body initiates a schema for an illness, for example, a cough leads to the perception of a chest infection which leads to scanning for other bodily changes that would support this explanation. Other symptoms are then detected, such as an increased temperature and lethargy. Thus, it is not always a linear progression from identification of a symptom to illness inference. Individuals implement coping strategies and evaluate their effects in a cyclical process of self- regulation, which is described by the Common-Sense Model of Illness Self-regulation[3] (Leventhal, Weinman, Leventhal, & Phillips, 2008; Scott & Walter, 2010). In the previous example, a coping strategy, such as a cough bottle, could be implemented. If symptoms persisted this coping strategy would be revaluated, and a different coping strategy selected, such as consulting an HCP. Thus, the Andersen Model does not allow for this iterative process. Nevertheless, the Andersen Model has provided essential scaffolding for research on the patient pathway to treatment and for understanding the reasons individuals postpone of help-seeking.

2.2.2 The Model of Pathways to Treatment

The Pathways Model (see Figure 2.2) addresses the issues with the Andersen Model outlined above. It is a framework that focuses on self-regulatory processes and uses the Common-Sense Model and Social Cognitive Theory to explain the patient pathway to treatment. The Pathways Model describes the period prior to treatment and the factors that contribute to the duration of this period. It is made up of *events*, *processes*, *intervals* and *contributing factors* (Scott et al., 2013). *Events* are key time points in the pathways to treatment. *Processes* are the cognitive, emotional, behavioural and organisational actions that lead to the different events. *Intervals* refer to the period of time between each event. Finally, *contributing factors* are those that influence the processes and, in turn, the timing of events and duration of intervals (Scott et al., 2013). The contributing factors are key to understanding why individuals postpone help-seeking.

The Pathways Model has corrected a limitation of the Andersen Model by making the detection of a bodily change the first event in the appraisal process. Bodily changes can be both/either visual (e.g. change in size) or sensory (e.g. pain) and can be the result of normal

[3] Referred to as the Common-Sense Model throughout the remainder of this thesis

bodily processes as well as disease, affective responses, and environmental conditions (Scott et al., 2013). The second event in the Pathways Model is when the individual perceives a reason to discuss the symptom with an HCP. At this stage the bodily change can be interpreted as a symptom; a conclusion drawn that this change is abnormal, and so, the individual believes they have a reason to consult an HCP. Again, here the Pathways Model addresses a limitation of the Andersen Model. It states that an individual *perceives a reason* to consult an HCP, rather than, as in the Andersen Model where the individual infers an illness. An individual can decide to consult an HCP without inferring illness, that is, some consultations are preventative (Scott et al., 2013).

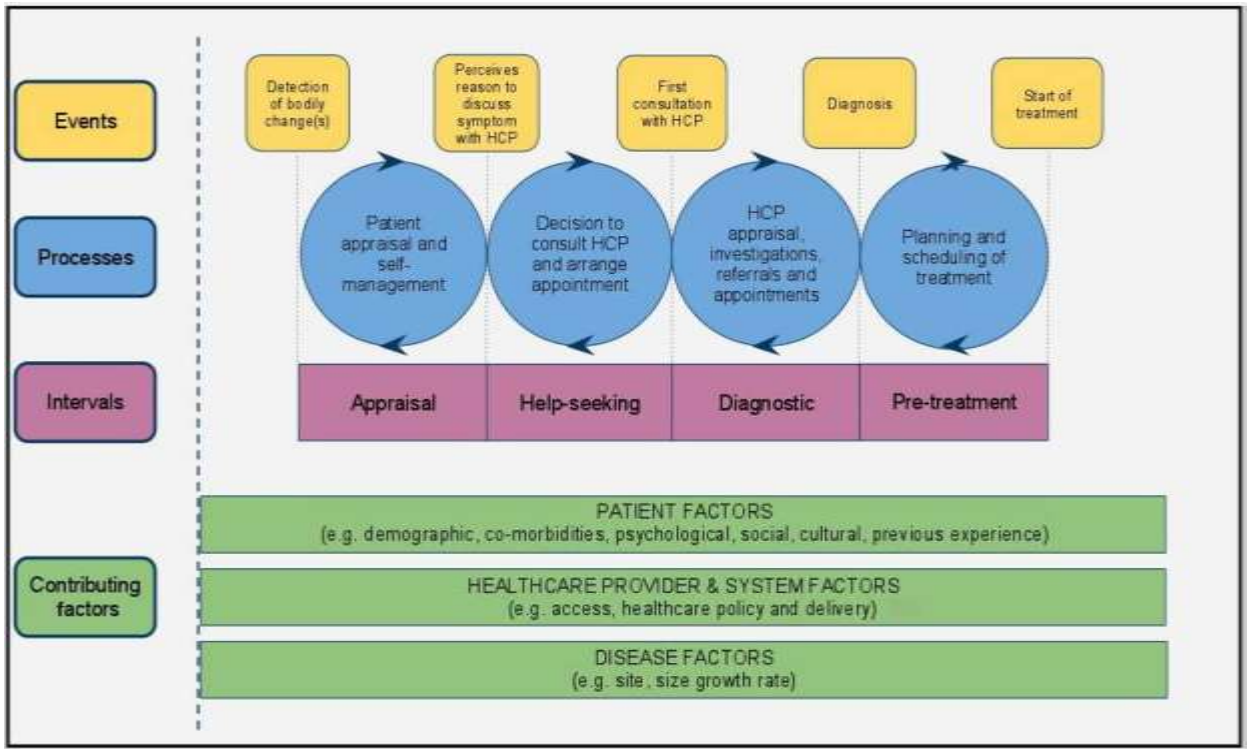

Figure 2.2: The Model of Pathways to Treatment (Weller et al., 2012)

The appraisal interval is the time between the first two events, that is, from detection of a bodily change to perceiving a reason to discuss symptoms with an HCP. The help-seeking interval is the time between perceiving a reason to discuss symptoms with an HCP and the first consultation with an HCP, which is the third key event in the Pathways Model. Together the appraisal and the help-seeking intervals make up the *patient* interval as defined by the Aarhus statement (Weller et al., 2012). The fourth and fifth events in the Pathways Model are receipt of a diagnosis and the start of treatment, respectively (Scott et al., 2013). The

diagnostic interval is the time between the first consultation with an HCP and receipt of a diagnosis while the *pre-treatment* interval describes the time between receipt of a diagnosis and the start of treatment(Scott et al., 2013).

The Pathways Model describes the process that occurs during each interval. During the *appraisal* interval the individual assesses bodily changes; how the changes are appraised determines behaviour (Scott et al., 2013). Often individuals engage in self-management of the bodily change which can lead to postponement of help-seeking. They may decide to continue to monitor the changes to see if they evolve, they may self-medicate, make changes to their lifestyle or seek lay advice. Confiding in others may help the individual to make sense of their bodily change and thus help their appraisal of the changes (Scott et al., 2013). In this way the Pathways Model allows for the iterative nature of the appraisal process, something the Andersen Model failed to do (Walter et al., 2012). During the *help-seeking* interval the individual makes the decision that consulting an HCP is warranted (Scott et al., 2013). The event that marks the end of the help-seeking interval is presenting to an HCP. It is important to note that being in the help-seeking interval does not necessarily mean the individual *intends* to seek help. It is possible for an individual to perceive a reason to discuss a bodily change with an HCP and to simultaneously decide to avoid or postpone help-seeking (Scott et al., 2013). During the *diagnostic* interval, an HCP assesses the patient and makes a diagnosis, this can involve clinical investigations and referrals to specialists (Scott et al., 2013). Finally, during the *pre-treatment* interval, the patient's treatment is planned and scheduled, it ends with the commencement of treatment (Scott et al., 2013).

In the Pathways Model, *contributing factors* determine the speed and direction of the individual passing through the various intervals in the model. These contributing factors, which are essential in understanding postponement of help-seeking, are omitted from the Andersen Model. The Pathways Model postulates three categories of contributing factor. *Patient* factors refer to the individual and their social and cultural context (e.g., demographics, past experience, co-morbidities, cognitions, and emotions). *Healthcare provider and system* factors refer to the healthcare service (e.g., access to generalist and/or specialist healthcare, healthcare policy). *Disease* factors refer to the condition or illness and its clinical and physiological presentation (e.g. the disease type and site). Contributing factors within the Pathways Model are understood through the psychological theories of the Common Sense Model of Illness Self-regulation (Leventhal et al., 2008) and Social Cognitive Theory (Bandura, 2004).

2.2.2.1 Common-Sense Model of Illness Self-Regulation

The Common-Sense Model and Social Cognitive Theory underpin the *appraisal* and *help-seeking intervals* of the Pathways Model (Bandura, 2004; Leventhal et al., 2008; Scott et al., 2013). The Common-Sense Model posits that we appraise our symptoms in terms of our illness representations and our emotional response. This leads to coping responses, which are evaluated, and then the symptoms reappraised in an iterative process of self-regulation (Leventhal et al., 2008). Illness representations, also known as illness beliefs, perceptions or cognitions, are an individual's implicit common-sense beliefs about illness (Leventhal, Diefenbach, & Leventhal, 1992). These cognitions form the schema by which an individual understands and copes with an illness. There are five domains of illness representations: *identity* (the label for the symptom), *consequences* (beliefs about the consequences of the symptom), *timeline* (beliefs about the duration of the symptom), *cure/control* (beliefs about whether the symptom can be treated or managed) and *cause* (beliefs about the cause of the symptom) (Leventhal et al., 2008). *Identity*, *timeline* and *cause* are all integral to the appraisal interval of the Pathways Model. The label an individual gives their symptoms, how long they expect to have it, and their understanding of its causes all feed into their appraisal of it. The *consequences* of the symptom and the understanding of how curable or manageable (*cure/control*) it is, are key considerations in the help-seeking interval of the Pathways Model.

According to the Common-Sense Model, individuals implement a coping strategy and then, taking into consideration emotional responses, evaluate if it has ameliorated the symptoms. The evaluation of the initial coping strategy informs the next coping strategy (Leventhal et al., 2008). For example, if a woman has a pain in her breast that she associates with menstruation (*identity; cause*), she believes that it is within her ability to control (*cure/control*), that it will pass when she moves to the next stage of her cycle (*consequences*; *timeline*), and so, it is not a cause for concern (*emotional response*). Her coping strategy is to wait to see if the symptoms go away. If the breast pain persists, she will evaluate her coping strategy; it has failed to ameliorate the symptoms. She is now unsure of the cause (*cause*), and no longer believes that it is within her ability to control (*cure/control*). She does not know when it will pass (*consequences*; *timeline*) and so is concerned (*emotional response*). Her new coping response is to consult an HCP. This is the process that takes place in the appraisal and help-seeking intervals of the Pathways Model.

2.2.2.2 Social Cognitive Theory

Progression through the appraisal and help-seeking intervals of the Pathways Model is also understood in terms of Social Cognitive Theory (Bandura, 2004). Patient factors are a primary contributing factor outlined by the Pathways Model (Scott et al., 2013). Self-efficacy is a key component of Social Cognitive Theory (Bandura, 2004). In the context of progression through the patient interval, self-efficacy is understood as an individual's perceived ability to seek help from an HCP and overcome any socio-cultural barriers to doing so (Bandura, 2004). Self-efficacy is developed through personal and vicarious experience and through social persuasion (Bandura, 2004). Thus, an individual's prior healthcare habits, past experiences with HCPs, access to the healthcare system and cultural context will impact their help-seeking behaviour. Self-efficacy is therefore also impacted by healthcare provider and system factors as highlighted by the Pathways Model.

Self-efficacy alone, however, will not determine an individual's progression through the Pathways Model (Scott et al., 2013). Outcome expectancies, or the perceived consequences of action, have an impact on progression through the patient interval (Bandura, 2004). For example, for an individual to consult an HCP they must believe that the HCP will be able to help them in some way or there will be little incentive to attend. Outcome expectancies are not necessarily rational and can be physical (e.g. treatment will be painful), social (e.g. I will be perceived as a time-waster) or self-evaluative (e.g. it is a sign of weakness to go to the doctor). An individual's self-efficacy and their outcome expectancies are what determine their goal-setting, in this case, their decision to seek help (Scott et al., 2013). Individuals with higher self-efficacy have greater commitment to goals. However, distal goals associated with symptoms that are not severe or disruptive to normal functioning can lose priority to more proximal goals (e.g. doing the grocery shopping) in the context of busy lives with competing priorities (Bandura, 2004; Locke & Latham, 2002; Scott et al., 2013). In the Pathways Model an individual perceives a reason to discuss their symptom with an HCP, then decides to consult the HCP, makes an appointment and finally, attends the appointment. *Intending* to consult an HCP may not result in help-seeking (Scott et al., 2013). While intentions are important for behaviour it is well documented that they do not always lead to behaviour, thus, the final step of the *help-seeking* interval is the actual consultation with the HCP (Scott et al., 2013; Sheeran, 2002).

2.2.2.3 Habits

Habits are automatic behavioural patterns learned through repeated performance in everyday contexts (Gardner, de Bruijn, & Lally, 2011). It is hypothesised that intentions exert control over behaviour only when habitual processes are not present (Norman & Cooper, 2011). When habits and intentions are conflicting, habits will override intentions, however, intentions will guide behaviour in novel contexts (Gardner, 2012; Gardner et al., 2011). This is important for understanding the progression through the patient pathway to treatment for breast cancer. The discovery of a symptom of breast cancer would be a novel experience for most women and therefore intentions should guide behaviour. However, if avoidance of an HCP is habitual behaviour due to, for example, fear of embarrassment, the intention to attend will not take precedence. Past healthcare habits therefore play a role in the patient interval for breast cancer.

The Pathways Model addresses the shortcomings of the Andersen Model. It incorporates a more detailed understanding of the help-seeking interval, a crucial component of the patient interval for cancer. In particular, the Pathways Model incorporates psychological theories to provide an understanding of the many complex factors that contribute to progression through the patient interval.

2.3 Section 2: The empirical evidence: Contributing factors in the patient interval for breast cancer

The aim of this review is to understand the patient interval for breast cancer to inform the development of an intervention in the Irish healthcare context. Thus, the empirical evidence included in this review included both quantitative and qualitative studies from Europe, Australia and New Zealand. The review found that there are many, complex contributing factors to the patient interval for breast cancer. These many factors can be grouped under four main themes; cognitions and affect, social factors, knowledge and healthcare habits. Each of these will now be discussed in turn.

2.3.1 Cognition and Affect

Cognitions such as illness representations, self-efficacy, outcome expectancies, goals/intentions and emotional responses impact on the appraisal and help-seeking intervals for cancer (Bandura, 2004; Facione et al., 2002; Khakbazan, Taghipour, Latifnejad Roudsari, & Mohammadi, 2014; Leventhal et al., 2008; Scott et al., 2013; Van Osch, Lechner, Reubsaet, de Nooijer, & De Vries, 2007). This was supported by a large survey (n = 49270)

conducted in England addressing cancer symptom awareness and potential barriers to symptomatic presentation for all cancers (Niksic et al., 2015). While the study found that women had better cancer symptom awareness, they reported more barriers to help-seeking than men. Affective barriers such as feeling 'too scared' or 'too embarrassed', and cognitive reactions such as 'worry about what the doctor might find' and 'not feeling confident enough to talk about the symptoms' were identified (Niksic et al., 2015). Cognitions and affect, therefore, appear to play a vital role in the progression through the patient pathway to treatment for breast cancer.

2.3.1.1 Fear

Fear is the most studied affective response in relation to help-seeking behaviour and cancer. Early research hypothesised that fear had a curvilinear relationship with postponement of help-seeking (Facione, 1993). For some women fear leads to prompt presentation to an HCP while for other women fear will result in postponement of help-seeking (Bish et al., 2005; Harirchi, Ghaemmaghami, Karbakhsh, Moghimi, & Mazaherie, 2005; Jones et al., 2014; Nosarti et al., 2000; O'Mahony, McCarthy, Corcoran, & Hegarty, 2013). Fear during the patient pathway to treatment for cancer can relate to many things, for example fear of a diagnosis, fear of treatment and/or fear of the consequences of treatment; see Table 2.1 Facione's "fear cascade" (1993, p.1528). Dubayova et al. (2010) conducted a systematic review on the role of fear in postponement of help-seeking in cancer (n = 11) and in myocardial infarction (n = 4). Of the 15 studies included, one had insufficient level of evidence, three strong level of evidence, and the remainder had moderate level of evidence. Dubayova et al. (2010) found that it was the *intensity* of the fear, driven by its cause and the resulting coping strategies that determined whether fear would lead to help-seeking or postponement. Overall they found that high levels of fear were associated with earlier help-seeking in both diseases but effects on behaviour were ambiguous for low levels of fear (Dubayova et al., 2010). It must be noted that only six of the 15 studies used validated measures of fear.

O'Mahony et al. (2013), in an Irish sample (n = 449) of breast cancer patients, found that women who reported 'being afraid' upon finding a symptom discovery were more likely to engage in prompt help-seeking. Similarly in a UK cross-sectional study (n = 135) of women with breast cancer, those with greater fear engaged in less postponement (Burgess, Ramirez, Richards, & Love, 1998). Perhaps conversely, the much larger Niksic et al. (2015, n = 49270) study found that women were 40% more likely than men to report that they would

be ‘too scared’ to visit their doctor about a symptom (OR= 1.40; 95% CI: 1.31–1.50). That is, they reported that fear would result in postponement of help-seeking. The O'Mahony et al. (2013) and Burgess et al. (1998) studies were conducted with women with breast cancer, who had actually experienced a fear response and acted on it. The Niksic et al. (2015) survey asked people to imagine how they would feel if they discovered a symptom of cancer. This could perhaps explain the difference in findings.

Table 2.1
Fears related to the discovery of breast cancer symptoms, the ‘Fear Cascade’ taken from Facione (1993, p. 1526)

Fear of doctors and hospitals	Fear of abandonment
Fear of ridicule	Fear of loss of control
Fear of embarrassment	Fear of loss of femininity
Fear of chemotherapy	Fear of radiation therapy
Fear of loss of feminine role	Fear of being traumatised
Fear of illness	Fear of losing a sexual partner
Fear of the unknown of cancer	Fear of pain
Fear of the loss of a breast	Fear of isolation
Fear of fear of disfigurement	Fear of surgeries/anaesthesia
Fear of loss of ability to mother	Fear of entering a submissive role
Fear of unmanageable expense	Fear of cancer spreading after surgery
Fear of death	

In a UK cross-sectional study of symptomatic breast cancer patients (n = 692) Nosarti et al. (2000) found that postponement of help-seeking motivated by fear produced the greatest postponement. Nosarti et al. (2000) found that generally, women who postponed help-seeking expressed more fear of the consequences of diagnosis and treatment than those who did not. Burgess et al. (2001) conducted semi-structured interviews with 46 women newly diagnosed with breast cancer to explore the factors that influence help-seeking. Fifteen of the participants had sought help from their GP within two weeks of symptom discovery and 31 had waited 12 weeks or more before presenting. Burgess et al. (2001) found that women who engaged in postponement of help-seeking were more likely to express explicit fears about the *consequences* of diagnosis and treatment. The Common-Sense Model can explain this complicated relationship between fear and help-seeking behaviour. Illness representations determine how we understand and cope with an illness (Leventhal et al., 1992). The research outlined above related to three of the five domains of illness representations; *consequences* (beliefs about the consequences of symptom), *timeline* (beliefs about the duration of symptom), *cure/control* (beliefs about whether the symptom can be treated or managed). These representations shape an individual’s coping strategies and so determine whether they

engage in help-seeking. This explains why fear plays a large role in the patient pathway to treatment for breast cancer. For most women, fear leads to prompt presentation to an HCP. However, those individuals who postpone help-seeking because they are afraid, postpone the longest and do so out of fear of the consequences of diagnosis and treatment.

Breast cancer worry is a specific fear or anxiety of developing breast cancer in the future (Gibbons & Groarke, 2015). A meta-analysis of 12 prospective studies that measured worry about breast cancer found an association between breast cancer worry and breast cancer screening behaviour whereby greater worry predicted a greater screening behaviour (Hay, McCaul, & Magnan, 2006). However the evidence for the impact of breast cancer worry on help-seeking behaviour is ambiguous (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Hay et al., 2006). This is perhaps unsurprising given that breast cancer worry is a type of fear, and fear seems to generate different help seeking responses depending on context. In the same way as the research of fear, some breast cancer worry studies have found that it leads to prompt help-seeking, while others have found it leads to postponement (Hay et al., 2006).

2.3.1.2 Attitudes to Healthcare Professional

An individual's attitude to their HCP impacts on their self-efficacy to consult with their HCP (Burgess et al., 2001; Heisey et al., 2011). Self-efficacy is important for prompt progression through the patient pathway to treatment for cancer (Bandura, 2004; Scott et al., 2013). In a correlational survey with women in Ireland (n = 449), 32.1% of participants reported that their healthcare had been affected by discrimination and 19.5% reported that they had not always been treated respectfully by HCPs (O'Mahony et al., 2013). Qualitative interviews with breast cancer patients who self-discovered their symptoms and postponed help-seeking for more than 12 weeks found that negative experiences can damage the trust relationship with a woman and her HCP which can lead to reduced self-efficacy and postponement of help-seeking (Heisey et al., 2011). Some research has found that having a regular HCP increases help-seeking behaviour (Rauscher et al., 2010). This is likely due to the fact that with a regular HCP a relationship can develop and trust can form between patient and doctor which may lead to individuals feeling more comfortable confiding concerns about bodily changes and less likely to be embarrassed (Burgess et al., 2001).

A systematic review was conducted to examine the impact of a previous 'false alarm' on postponement of help-seeking for subsequent possible cancer symptoms (Renzi, Whitaker, & Wardle, 2015). The review found that attitudes to HCPs was a key cause postponement of

help-seeking. It reported that patients were concerned that their HCP would think they were hypochondriacal and the potential embarrassment of this led to postponement of help-seeking (Renzi et al., 2015). Embarrassment has been found to be associated with postponement of help-seeking. In an English survey (n = 2371) of risk factors for postponement of help-seeking, patients with different types of cancer who reported they were "too embarrassed to go to see the doctor" were three times more likely to postpone help-seeking than others (Forbes, Warburton, Richards, & Ramirez, 2014). de Nooijer, Lechner, and de Vries (2001) investigated factors influencing appraisal of cancer symptoms and consequent help-seeking. Twenty-three patients were interviewed about their experiences of this process. Embarrassment and shame were identified as barriers to prompt help-seeking (de Nooijer et al., 2001). Attitudes to HCPs are critically important for prompt progression through the patient interval. Beliefs that the HCP will find the patient a nuisance, or hypochondrial, or that the HCP will be ineffective or discriminatory result in low self-efficacy for help-seeking and poor outcome expectancies which according to Social Cognitive Theory increase the chance of postponement of help-seeking (Bandura, 2004).

2.3.2 Social factors

Women have reported postponement of help-seeking due to perceived, and/or actual demands of social roles, such as, childcare and work demands (Bish et al., 2005; Burgess et al., 2001; Facione, 1993; Heisey et al., 2011; Neave, Mason, & Kay, 1990). Social Cognitive Theory highlights that competing priorities can diminish an individual's self-efficacy for help-seeking behaviour and impact goal-setting behaviour (Bandura, 2004). It is difficult to prioritise a goal such as consulting an HCP if there are more proximal goals to attend to, such as doing the grocery shopping. Women who postponed help-seeing in the Burgess et al. (2001) qualitative study reported that competing priorities related to the home and family were prioritised over their personal health. In some of these cases individuals were aware that their symptom might be serious but nevertheless felt too busy to arrange an appointment (Burgess et al., 2001). Access to healthcare plays a role in self-efficacy also and this is greatly influenced by socioeconomic factors.

2.3.2.1 Socioeconomic status

A survey of cancer patients in England (n = 2371) examining risk factors for postponement of help-seeking found that those in lower socioeconomic status (SES) areas were 51% more likely to postpone help-seeking than those in the higher SES areas (Forbes et al., 2014). A number of studies have found that income (Facione, 1993; Facione et al., 2002;

Harirchi et al., 2005) and education (Facione et al., 2002; Harirchi et al., 2005; Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009; Van Osch et al., 2007) are associated with postponement of help-seeking. Women with low income and low education are more likely to postpone help-seeking than well-educated, higher-paid women. A meta-analysis (n = 1174) of factors predicting postponement of help-seeking in symptomatic breast cancer found moderate strength evidence that fewer years of education resulted in increased likelihood of postponement (Ramirez et al., 1999).

One factor that may contribute to postponement of help-seeking in low SES groups is access to healthcare services. Women in rural areas or those without local access are more likely to engage in postponement of help-seeking (Harirchi et al., 2005; Unger-Saldana & Infante-Castaneda, 2011). A systematic review and meta-analysis was conducted on disparities in breast cancer stage at diagnosis in urban and rural adult women (Nguyen-Pham, Leung, & McLaughlin, 2014). The review included 879,660 women from USA, NZ, Australia, Denmark, Egypt, South Africa, Poland and Italy. It reported that women living in rural areas were almost 20% more likely to be diagnosed with more advanced breast cancer (Nguyen-Pham et al., 2014). Although some of the countries included in the study have far greater inequalities between their urban and rural populations than others, it is nonetheless a noteworthy disparity. Participants in a large survey conducted in England (n = 49270) examining the association of cancer symptom awareness and barriers to presentation found that people from areas of lowest SES were 50% more likely to cite “transport issues” as a potential barrier to presentation to an HCP (Niksic et al., 2015). Similarly women who face barriers to accessing healthcare or who perceive barriers to accessing healthcare due to their socioeconomic status are more likely to postpone help-seeking (Facione, 1993, 2002; Khakbazan et al., 2014). In a French case–control study (n =619) researchers found that patients with low socioeconomic status are twice as likely to have late stage breast cancer when diagnosed, independent of cancer characteristics and mode of detection (Orsini, Trétarre, Daures, & Bessaoud, 2016).

A factor that may contribute to postponement of help-seeking in low SES groups is knowledge or understanding of cancer. Quaife et al. (2015), in a UK sample (n =6965) found that the low SES group (determined by education level) were more likely to endorse negative statements about cancer. Participants were presented with three positive statements (e.g. cancer can often be cured) and three negative statements (e.g. a cancer diagnosis is a death sentence) and asked to rate their corresponding agreement. Those with a basic education were

more than twice as likely to endorse the negative statement than those with a university degree (Quaife et al., 2015). The Common Sense Model can be used to understand these findings. The information provided in both the positive and negative statements are associated with three of the five domains of illness representations: *consequences* (beliefs about the consequences of symptom), *timeline* (beliefs about the duration of symptom), *cure/control* (beliefs about whether the symptom can be treated or managed) (Leventhal et al., 2008). Illness representations determine how we appraise our symptoms and impact of our affective responses and coping strategies and therefore our behaviour.

2.3.2.2 Age

The literature is mixed on the direction of the association with age and postponement of help-seeking. Some research has found a positive association between age and postponement of help-seeking. Older women (65+) have been found to be at greater risk of postponement of help-seeking (Arndt et al., 2002; Harirchi et al., 2005; Innos et al., 2013; Macleod et al., 2009; Ramirez et al., 1999). When we label a bodily state, we rely on the most salient contextual stimuli as an explanation (Jones, 1990). The positive association between age and postponement of help-seeking may be explained by a focus on salient contextual stimuli of old age; aches and pains and changes are all a common occurrence in old age and so a symptom of an illness could be dismissed as such. Jones (1990, p.85) discusses postponement of help-seeking as “a function of what is normal within one's subcultural group”. Social norms impact on our interpretation of a bodily change. If an individual’s peer group regularly displays negative symptoms, this could lead to a minimisation of bodily changes. However, some studies have found that older age decreases postponement of help-seeking (Friedman et al., 2006; Richardson et al., 1992; Steele, 2010). Steele (2010) hypothesised that for retired individuals there is less of an issue with competing priorities. Retired individuals often have more time and better access to healthcare providers and so this could explain why older age would support a decrease in postponement of help-seeking. Younger women (i.e. those under 55) in the Niksic et al. (2015) study more frequently reported barriers to presentation compared with 55 – 74 year-old participants. In particular, they cited being ‘too busy’ and had the lowest symptom awareness scores across all cancers. Ozmen et al. (2015) in a large survey (n = 1031) of Turkish women found increased postponement of help-seeking for younger women, in particular, between 30 and 39 years. The literature would suggest that women in different age groups have different motivations for postponing help-seeking.

2.3.2.3 Marital status and Symptom disclosure

A seminal systematic review published in the Lancet in 1999 found that marital status was unrelated to postponement of help-seeking (Ramirez et al., 1999). The review did report, however, that not disclosing breast symptoms to another person resulted in increased likelihood of postponement of help-seeking (Ramirez et al., 1999). Burgess et al. (1998; 2006) found that disclosing symptoms was associated with help-seeking. This was replicated in a survey conducted in Ireland (n = 449; O'Mahony et al., 2013). Qualitative work conducted in Ireland with women who discovered a symptom of breast cancer found that they can be reluctant to disclose symptoms to a friend or loved one due to the possible distress it could cause (O'Mahony et al., 2011). Meechan, Collins, and Petrie (2003) assessed the relationship between help-seeking and disclosure of the breast symptom to others through questionnaires and interviews with 85 women with a symptom of breast cancer. They compared women who engaged in prompt help-seeking with those who postponed for more than three months: 80% and 72% respectively had disclosed their symptoms to someone. This indicates that that symptom disclosure is unrelated to help-seeking (Meechan et al., 2003). Overall, the evidence supports that disclosure of a symptom to a person will increase help-seeking behaviour for breast cancer.

2.3.3 Knowledge

An individual's understanding of both the consequences of postponement of help-seeking and the consequences of a diagnosis can impact on help-seeking behaviour (Facione, 1993). As described by the Common-Sense Model, illness representations (i.e. *identity*, *consequences*, *timeline*, *cure/control* and *cause*) are critical to an individual's progression through the patient interval for breast cancer. Knowledge is a key component to the Common-Sense Model domains.

2.3.3.1 Knowledge of breast cancer risk

It is established that individuals do not have accurate perceptions of their breast cancer risk (Austoker et al., 2009; Katapodi, Lee, Facione, & Dodd, 2004). Generally individuals are prone to unrealistic optimism about their chances of developing any illness which can lead to delays in the correct appraisal of a symptom and therefore lead to postponement of help-seeking (Jones, 1990; Kartal, Ozcakar, Hatipoglu, Tan, & Guldal, 2014). O'Mahony et al. (2011) conducted qualitative interviews with ten women who discovered a symptom of breast cancer. The participants ranged in age from 25 to 55 years and engaged in help-seeking within one month (n = 6); one to three months (n = 2) and over three months (n = 2). A

family history of breast cancer was perceived as a risk factor for developing the disease. However O'Mahony et al. (2011) also found that an absence of a family history of breast cancer was associated with postponement of help-seeking. The participant believed she was not at risk of getting breast cancer as there was no history of the disease in her family (O'Mahony et al., 2011). A correct understating of risk is important for prompt progression through the patient interval for breast cancer.

2.3.3.2 Knowledge of symptoms

Symptom knowledge is required for the individual to progress through the *appraisal* interval to the *help-seeking* interval for breast cancer (Scott et al., 2013). By understanding what the symptoms of breast cancer are, women can correctly perceive a reason to consult an HCP. When a symptom does not match our illness representation it can be dismissed (Bishop & Converse, 1986; Leventhal et al., 2008). For example, if a woman does not know that a rash on the breast can be a symptom of breast cancer, she may dismiss it as related to something else. Women who dismiss symptoms as non-threatening are more likely to postpone help-seeking (Ozmen et al., 2015). Unsurprisingly recognition of a symptom as a warning sign of cancer is associated with help-seeking (Quaife et al., 2014). A UK study (n = 6965) examined the association between recognition of warning signs for breast, colorectal and lung cancer and anticipated time to help-seeking for symptoms of each cancer. Individuals that did not recognise a symptom as potentially cancerous were more likely to anticipate postponing help-seeking for more than two weeks (Quaife et al., 2014). The study examined three symptoms of cancer: persistent cough, rectal bleeding, breast changes (unexplained lump or swelling). An unexplained lump or swelling of the breast was correctly identified as a possible sign of breast cancer by 96.9% of women which is in keeping with other research on symptom recognition in breast cancer (Bish et al., 2005; Burgess et al., 1998; Nosarti et al., 2000; O'Mahony et al., 2013; Quaife et al., 2014). Regrettably, the study focused only on this well-known symptom and did not asses any other indicator of breast cancer. Knowledge of non-lump symptoms is considered a critical component of breast awareness (O'Mahony et al., 2017). Ramirez et al. (1999) found moderate evidence that discovery of a non-lump symptom of breast cancer resulted in increased likelihood of postponement of help-seeking. This is supported by evidence that knowledge of non-lump symptoms of breast cancer is low. Studies from the UK report that the mean number of breast cancer symptoms recognised from a list of 11 was 5.3 (Burgess et al., 2008) and that only 18% of respondents (n = 1515) recognised five or more non-lump symptoms from a list

(Forbes et al., 2011a). A survey of women (n = 449) attending breast clinics in two large urban hospitals within the Republic of Ireland found that non-lump symptoms were associated with postponement of help-seeking (O'Mahony et al., 2013). It is, therefore, important that individuals are aware of all the symptoms of breast cancer.

2.3.4 Healthcare habits

An individual's past general help-seeking behaviour impacts on help-seeking for breast cancer symptoms (Facione, 1993). Those who have high rates of help-seeking in the past for other illness are less likely to postpone help-seeking for symptoms of breast cancer. Heisey et al. (2011) conducted qualitative research to identify strategies to promote earlier presentation of symptomatic breast cancer. They conducted interviews with women who had been diagnosed with self-detected breast cancer and who postponed help-seeking for more than 12 weeks. Heisey et al. (2011) identified a previous negative healthcare experience as an indicator of an individual at risk of postponement of help-seeking. Research has found that the negative impact of an unsupportive healthcare experience can persist for months to years (Renzi et al., 2015). These findings are supported by Social Cognitive Theory which states that past behaviour impacts on our self-efficacy and our outcome expectancies which both directly affect our behaviour. Previous engagement with help-seeking, that is, consulting an HCP about bodily changes, will increase self-efficacy for help-seeking and so make it more likely an individual would consult their HCP in the instance of finding a breast cancer symptom. Healthcare habits will manage an individual's outcome expectancy; if previous experiences were positive, they will expect the same for future ones.

2.4 Conclusion

The review of the quantitative and qualitative literature found that there are many, complex contributing factors to the patient interval for breast cancer. Social determinants, such as SES and education level, play a prominent role in help-seeking behaviour for illness. Additionally, individual level factors, such as cognitions and affect, can determine the speed with which a person progresses through the patient interval. A limitation of much of the research discussed is that findings are based on retrospective reports provided by women who have recently been diagnosed with cancer. This crisis event may impact on the accuracy of recall of the process undertaken to engage in help-seeking behaviour (Andersen et al., 1995). Conversely, research conducted with healthy women who are asked to reflect on the imagined process of help-seeking upon self-discovery of a breast cancer symptom may be unable to provide an accurate account because they are not experiencing the emotional and

cognitive response to such an event. This highlights the importance of qualitative research and psychological models and theory in understanding the processes involved in, and the factors that contribute to, the patient interval for cancer.

The Andersen Model is the foundational model for understanding postponement of help-seeking. In particular, it explicates the appraisal interval and describes that individuals are susceptible to optimistic and confirmatory biases in their drive for cognitive clarity about physiological and psychological states. The Pathways Model addresses the shortcomings of the Andersen Model, incorporating a more detailed understanding of the help-seeking interval in particular, and providing an understanding of the many complex factors that contribute to progression through the patient interval.

3 Developing the content of the *Know Breast Health* intervention

3.1 Chapter Overview

This chapter describes the three stages of the Behaviour Change Wheel. It will begin with a description of the Behaviour Change Wheel, the COM-B 'behaviour system' and the Theoretical Domains Framework. The target behaviour for the *Know Breast Health* intervention will be defined and a detailed behavioural diagnosis will first be conducted; outlining the antecedents of the target behaviour. This will be followed by the identification and selection of intervention functions and behaviour change techniques. Finally, the key output from the Behaviour Change Wheel process will be presented: the proposed website components of the *Know Breast Health* intervention.

3.2 The Behaviour Change Wheel

The Behaviour Change Wheel is a guide for designing interventions (Michie et al., 2014). It was developed based on a synthesis of 19 behaviour change frameworks identified in a systematic review (Michie et al., 2011). The Behaviour Change Wheel is a systematic and prescriptive guide with clearly defined steps in the design process. It was developed to facilitate a transparent and systematic design process (Michie et al., 2014). Stage 1 of the Behaviour Change Wheel is *understanding the behaviour,* Stage 2 is *identifying intervention options* and Stage 3 is *identifying content and implementation options* (See Figure 3.1). The key process in the first stage is defining the problem and the behaviour targeted by the intervention. The COM-B and Theoretical Domains Framework (TDF) are then used to identify what needs to change for the target behaviour to occur. This is done through a behavioural diagnosis which is informed by the findings of the literature review conducted in Chapter 2. Stage two requires the selection of intervention functions and the policies that would support them. Policy categories will not be selected for the *Know Breast Health* intervention as that is beyond the scope of the intervention. The final stage is defining the content using behaviour change techniques (BCTs) and selecting implementation options. The latter has already been selected; the mode of delivery of the *Know Breast Health* intervention is a website (see section 1.6.1).

3.2.1 The COM-B Model

COM-B stands for capability, opportunity, motivation and behaviour. The Behaviour Change Wheel posits that for a behaviour to occur a person must have the capability, opportunity and motivation to do it (Michie et al., 2014). Each of these three components is

broken down into two sub-components. *Capability* can be both physical and psychological: physical capability refers to the physical skills, the strength or stamina necessary to perform the target behaviour and psychological capability refers to the knowledge and psychological skills required. *Opportunity* is understood in terms of physical and social opportunity. Physical opportunity is defined as "the opportunity afforded by the environment involving time, resources, locations, cues and physical affordance" (Michie et al., 2014, p. 63). Social opportunity is that which relates to the interpersonal influences, and social and cultural norms that impact how we think about the world. *Motivation* can be reflective or automatic. Reflective motivation refers to our conscious thoughts; our beliefs and intentions. Automatic motivation refers to our emotional reactions, our impulses and reflexes; those behaviours which we are not consciously aware of. Each component of the COM-B can be further elaborated using the TDF allowing for a more detailed understanding of behaviour (Michie et al., 2014, p. 65).

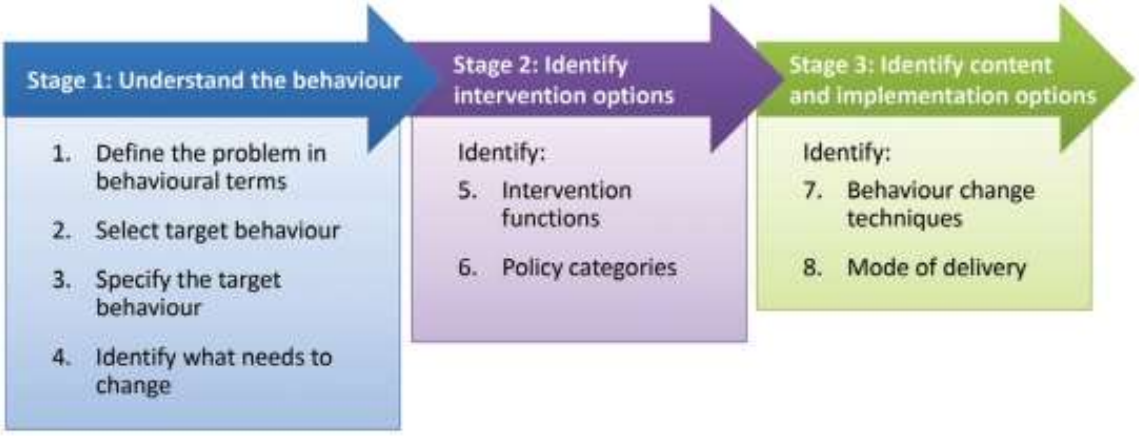

Figure 3.1. Behaviour Change Wheel Intervention Design Process (Michie et al., 2014, p. 25).

3.2.2 The Theoretical Domains Framework

The Theoretical Domains Framework (TDF) was developed by a panel of international experts in behaviour change to provide a theory-informed approach to identifying behavioural determinants. Psychological theorists (n = 18), health service researchers (n = 16) and health psychologists (n = 30) used a six stage consensus approach to identify 33 theories relevant to implementation within the behaviour change literature. They grouped 128 theoretical constructs from these theories into domains (Michie et al., 2005). These were synthesised into a framework, the TDF, which was then validated in a separate analysis by 37 behaviour change experts (Cane, O'Connor, & Michie, 2012). There are 14 domains in the TDF, representing a synthesis of key theoretical constructs from multiple theories. They are

skills; knowledge; memory, attention and decision processes; behavioural regulation; environmental context and resources; social influences; social/ professional role and identity; beliefs about capabilities; optimism; beliefs about consequences; intentions; goals; reinforcement; and emotion. In the Behaviour Change Wheel Guide to Designing Interventions the TDF has been aligned with the COM-B model, that is, each component of the COM-B has corresponding domains in the TDF (see Table 3.1) (Michie et al., 2014).

Table 3.1
The COM-B and associated TDF domains

COM-B		**TDF domains**
Capability	Physical	Skills (Physical)
	Psychological	Skills (cognitive and interpersonal)
		Knowledge
		Memory, Attention and Decision Processes
		Behavioural Regulation
Opportunity	Physical	Environmental Context and Resources
	Social	Social Influences
Motivation	Reflective	Social/ Professional Role and Identity
		Beliefs about Capabilities
		Optimism
		Beliefs about Consequences
		Intentions
		Goals
	Automatic	Reinforcement
		Emotion

3.3 Behavioural diagnosis

The first step in the Michie et al. (2014) behavioural diagnosis is to identify the problem and specify the target behaviour. The problem behaviour in the current research is *postponement* of help-seeking upon self-discovery of a breast cancer symptom. The *Know Breast Health* intervention aims to promote timely progression through the patient interval for breast cancer. Therefore, the target behaviour is *immediate* help-seeking to an HCP upon self-discovery of a breast cancer symptom. The Behaviour Change Wheel provides key questions to help with specifying the target behaviour (see Table 3.2).

Table 3.2
Specifying the target behaviour for the Know Breast Health intervention

Behaviour Change Wheel questions to specify the target behaviour	
Who needs to perform the behaviour?	Individuals with symptom of breast cancer
What do they need to do to achieve the desired behaviour?	1. Detect bodily change* 2. Perceive reason to discuss change with HCP* 3. Arrange and attend appointment with HCP*

When do they need to do it?	Upon self-discovery of a breast cancer symptom
Where do they need to do it?	n/a
How often do they need to do it?	n/a
With whom do they need to do it?	HCP
Target behaviour:	Immediate help-seeking to an HCP upon self-discovery of a breast cancer symptom

* Three key events in the patient interval of the Pathways Model (Scott et al., 2013)

In order for the target behaviour to occur, an individual must firstly detect a bodily change, perceive that there is a reason to discuss this change with an HCP, and finally present to an HCP. These are the three key events in the patient interval for breast cancer as outlined by the Pathways Model (Scott et al., 2013). The Behaviour Change Wheel provides detailed instruction on how to further analyse the target behaviour to identify what needs to change in order for it to occur. This behavioural diagnosis uses the TDF to tease out the antecedents of the target behaviour. This process will now be discussed in detail. In the context of the findings of the literature review, the target behaviour will be considered under each domain of the TDF and the antecedents for the target behaviour identified.

3.3.1 Skills

The TDF domain *skills* is defined as “an ability or proficiency acquired through practice”. Skills can be physical, cognitive or interpersonal (Michie et al., 2014, p. 88). Physical capability is beyond the scope of the *Know Breast Health* intervention. During the appraisal interval individuals need the cognitive skills involved in performing a self-exam, to identify a bodily change and to recognise a symptom of breast cancer. During the help-seeking interval the cognitive and interpersonal skills are needed to schedule and attend an appointment. These skills are the desired antecedent. They will ensure that the decision to consult an HCP is reached and that the individual then attends the appointment thus completing the events required for progression the patient interval (Scott et al., 2013).

3.3.2 Knowledge

The TDF domain *knowledge* is defined as “the awareness of the existence of something” (Michie et al., 2014, p. 88). The target behaviour is more likely to occur if individuals have an understanding of breast cancer as a disease (O'Mahony et al., 2017; Quaife et al., 2014). This includes knowledge of breast cancer symptoms and personal risk. An awareness of one’s own normal bodily state and how to self-examine is also important for

the target behaviour as this facilitates the key events in the appraisal interval: detecting a change and perceiving a reason to discuss the change with an HCP (Scott et al., 2013).

3.3.3 Memory, attention and decision processes

The TDF domain of *memory, attention and decision processes* refer to "the ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives" (Michie et al., 2014, p. 88). The desired antecedents for this domain are remembering all breast cancer symptoms and one's own normal bodily state; detecting and appraising changes; deciding that a symptom requires the attention of an HCP and scheduling time to attend the appointment (O'Mahony et al., 2013; Ramirez et al., 1999; Scott et al., 2013). This includes the ability to form if/then rules and follow them: for example, *if I notice a change, I will go to my HCP.* Research shows that individuals can find it difficult to schedule time to attend an HCP, and so setting a goal to attend upon discovery of a symptom of breast cancer is important for overcoming the impact of competing priorities (Bish et al., 2005; Heisey et al., 2011).

3.3.4 Behavioural regulation

The TDF domain *behavioural regulation* is defined as "anything aimed at managing or changing objectively observed or measured actions" (Michie et al., 2014, p. 88). To facilitate the target behaviour individuals must detect a bodily change (Scott et al., 2013). This requires self-monitoring of the upper body; breasts, armpits and collar bone.

3.3.5 Environmental context and resources

The TDF domain *environmental context and resources* is defined as "any circumstances of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour" (Michie et al., 2014, p. 90). In order to facilitate knowledge of one's own normal bodily state individuals must make time and space in their everyday environment to self-examine. This is important for the ability to detect a change if one occurs (Scott et al., 2013).

3.3.6 Social influences

The TDF domain *social influences* is defined as "those interpersonal processes that can cause individuals to change their thoughts feelings or behaviours" (Michie et al., 2014, p. 90). Symptom disclosure is a desired antecedent of the target behaviour because it can decrease the likelihood of postponement of help-seeking (Burgess et al., 2006; O'Mahony et al., 2013).

3.3.7 Social/ Professional Role and Identity

The TDF domain *professional/social role and identity* is defined as "a coherent set of behaviours and displayed personal qualities of an individual in a social or work setting" (Michie et al., 2014, p. 89). In the context of the target behaviour this domain relates to the responsibilities inherent in individuals social and professional roles that can compete with the decision to consult an HCP (Bish et al., 2005; Heisey et al., 2011). An ability to manage competing priorities of different roles is an antecedent to prompt help-seeking.

3.3.8 Beliefs about capabilities

The TDF domain *beliefs about capabilities* is defined as "acceptance of the truth, reality, or validity about an ability, talent or facility that a person can put to constructive use" (Michie et al., 2014, p. 89). Social Cognitive Theory highlights the importance of high-self efficacy for progression through the patient interval for breast cancer (Bandura, 2004). A number of factors are important antecedents for the target behaviour: high-self efficacy for knowledge of own normal bodily state; for ability to make time to self-examine, for ability to effectively self-examine; for ability to identify symptoms; for making time to attend an appointment (Scott et al., 2013).

3.3.9 Optimism

The TDF domain *optimism* is defined as "the confidence that things will happen for the best or that desired goals will be attained" (Michie et al., 2014, p. 89). Feeling optimistic about the ability of an HCP to help with symptoms of breast cancer is important for engaging in help-seeking. This is due to the important role of outcome expectancies in goal-setting (Bandura, 2004). Patients must be optimistic about their consultation with their HCP. They must believe the HCP will not be dismissive, or feel embarrassed to discuss their concerns. Negative expectations can lead to postponement of help-seeking (Heisey et al., 2011; Rauscher et al., 2010).

3.3.10 Beliefs about consequences

The TDF domain *beliefs about consequences* is defined as "acceptance of the truth, reality or validity about outcomes of a behaviour in a given situation" (Michie et al., 2014, p. 89). Here again having positive outcome expectancies for help-seeking is important for the target behaviour to occur (Bandura, 2004; Scott et al., 2013). Three of the five illness representations from the Common-Sense Model are important antecedents in this domain (Scott et al., 2013)*: consequences* (beliefs about the consequences of the symptom), *timeline* (beliefs about the duration of the symptom) and *cure/control* (beliefs about whether the

symptom can be treated or managed) (Leventhal et al., 2008). Individuals should have accurate information about breast cancer as a disease, the consequences of a diagnosis and treatment to promote immediate help-seeking (Scott et al., 2013).

3.3.11 Intentions

The TDF domain *intentions* is defined as "a conscious decision to perform a behaviour or a resolve to act a certain way" (Michie et al., 2014, p. 89). For the target behaviour to occur key events on the patient interval for breast cancer must be reached: detecting a change and consulting an HCP (Scott et al., 2013). Important antecedents for these events are the intention to detect a bodily change, the intention to know what is normal for them and the intention to consult an HCP immediately upon discovery of a symptom.

3.3.12 Goals

The TDF domain *goals* is defined as "mental representations of outcomes or end states that an individual wants to achieve" (Michie et al., 2014, p. 89). To increase the likelihood of the target behaviour occurring individuals must set goals to: to know what is normal for them, detect a bodily change if one occurs, and to consult an HCP immediately upon discovery of a symptom. These goals, if implemented, will ensure the individual reaches the key events in the patient interval promptly and therefore prevent postponement of help-seeking (Scott et al., 2013).

3.3.13 Reinforcement

The TDF domain *reinforcement* is defined as "increasing the probability of a response by arranging a dependent relationship or contingency between the response and a given stimulus" (Michie et al., 2014, p. 89). Reinforcement is not a relevant domain for the target behaviour. Michie et al. (2014) states that not all domains will be relvant for all interventions.

3.3.14 Emotion

The TDF domain *emotion* is defined as "a complex reaction pattern involving experiential, behavioural and psychological elements by which the individual attempts to deal with a personally significant matter or event" (Michie et al., 2014, p. 90). For the target behaviour to occur individuals must manage their affective response to ensure it does not result in postponement of help-seeking. Fear and embarrassment are too of the most common emotions in relation to the patient interval for breast cancer (Niksic et al., 2015).

3.3.15 Section summary

The *Know Breast Health* intervention aims to promote timely progression through the patient interval for breast cancer. The target behaviour of the intervention is *immediate* help-seeking to an HCP upon self-discovery of a breast cancer symptom. The Behaviour Change Wheel recommends a *behavioural diagnosis* of the target behaviour to understand what needs to happen in order for it to occur (Michie et al., 2014). The 14 domains of the TDF have been used to understand what antecedents will increase the likelihood of the target behaviour occurring. This marks the end of Behaviour Change Wheel Stage 1, *understanding the behaviour,* a summary of this process is presented in Table 3.3. Stage 2, *identifying intervention options,* will now be addressed.

Table 3.3
Summary of the behavioural diagnosis using the COM-B and the TDF to develop the antecedents for the target behaviour

Target behaviour: Immediate help-seeking upon self-discovery of a breast cancer symptom		
COM-B	**TDF**	**Antecedents**
Physical capability	Skills (Physical)	Have the physical skills necessary to visually and manually inspect the upper body; Have the physical skills required to arrange and attend an appointment
Psychological capability	Skills (cognitive and interpersonal)	Perform self-exam; Recognise symptoms; Recognise a bodily change; Schedule and attend appointment
	Knowledge	Knowledge of breast cancer and its symptoms; Knowledge of one's own normal bodily state and how to self-examine
	Memory, Attention and Decision Processes	Remember symptoms of breast cancer and own normal bodily state; Detect and appraise changes; Decide HCP should be consulted, make and attend appointment; form and follow if/then rules
	Behavioural Regulation	Self-monitoring of the upper body
Physical opportunity	Environmental Context and Resources	Time and space to perform self-exam; Access (location) to HCP; Access (financial) to HCP
Social opportunity	Social Influences	Symptom disclosure
Reflective motivation	Social/ Professional Role and Identity	Responsibilities inherent in social and professional roles that can compete with the decision to consult an HCP
	Beliefs about Capabilities	High-self efficacy for knowledge of own normal bodily state; for ability to make time to self-examine, for ability to effectively self-examine; for ability to identify symptoms; for making time to attend an appointment
	Optimism	Optimistic about consultation with HCP

	Beliefs about Consequences	Understanding the consequences of a diagnosis and treatment of breast cancer
	Intentions	Intend to know normal bodily state, to notice a change and to consult HCP if change detected
	Goals	Set goals to: to know normal bodily state, detect a bodily change if one occurs, and to consult an HCP immediately upon discovery of a symptom
Automatic motivation	Emotion	Manage affective responses to prevent postponement of help-seeking

3.4 Identification of intervention functions

Stage two of the Behaviour Change Wheel requires the selection of the intervention functions. Intervention functions are defined as "broad categories of means by which an intervention can change behaviour" (Michie et al., 2014, p. 109). A systematic literature review of 19 frameworks of behaviour change identified 9 intervention functions: education, persuasion, modelling, enablement, training, environmental restructuring, restriction, incentivisation and coercion (Michie et al., 2014). While the TDF allows us to identify the antecedents for the target behaviour, the intervention functions are the means by which we can bring about change in the target behaviour. An expert consensus exercise identified the intervention functions most likely to bring about behaviour change in each domain of the TDF (Michie et al., 2014; Michie et al., 2011). Each intervention function is presented in Table 3.4 with its definition and the TDF domain it can affect change in. For example, if developing an intervention that aimed to target the TDF domain *memory, attention and decision processes* using the Behaviour Change Wheel guidelines the recommended intervention functions would be *training* and *enablement* as the means to change behaviour.

Table 3.4
Intervention functions and corresponding TDF domains taken from Michie et al. (2014)

Intervention function	**Definition**	**Corresponding TDF domain**
Education	Increasing knowledge or understanding	Knowledge Behavioural Regulation Social/ Professional Role and Identity Beliefs about Capabilities Optimism Beliefs about Consequences Intentions Goals
Persuasion	Using communication to induce positive or negative feelings or stimulate action	Social/ Professional Role and Identity Beliefs about Capabilities Optimism Beliefs about Consequences Intentions

Intervention function	Definition	Corresponding TDF domain
		Goals Emotion
Training	Imparting skills	Skills (Physical) Skills (cognitive and interpersonal) Memory, Attention and Decision Processes Behavioural Regulation Reinforcement Environmental Context and Resources
Modelling	Providing an example for people to aspire to or imitate	Behavioural Regulation Social/ Professional Role and Identity Beliefs about Capabilities Optimism Beliefs about Consequences Intentions Goals Emotion Social Influences
Enablement	Increasing means or reducing barriers to increase capability (beyond education and training) or opportunity (beyond environmental restructuring)	Memory, Attention and Decision Processes Behavioural Regulation Beliefs about Capabilities Optimism Goals Emotion Environmental Context and Resources Social Influences
Incentivisation	Creating an expectation of reward	Intentions Goals Reinforcement Emotion
Coercion	Creating an expectation of punishment or cost	Intentions Goals Reinforcement Emotion
Restriction	Using rules to reduce/increase the opportunity to engage in the target behaviour	Environmental Context and Resources Social Influences
Environmental restructuring	Changing the physical of social context	Reinforcement Environmental Context and Resources Social Influences

Following the procedure outlined in the Behaviour Change Wheel, the intervention functions for the *Know Breast Health* intervention were selected (Michie et al., 2014). The antecedent identified for each TDF domain in the behavioural diagnosis was assigned an intervention function or set of intervention functions. That is, the means by which the intervention will work on the antecedent was identified within the context and limitations of an internet delivered intervention using the recommendations from the Behaviour Change Wheel. This is presented in Table 3.5.

Table 3.5
Intervention functions selected for the Know Breast Health intervention

Target behaviour: Immediate help-seeking to an HCP upon self-discovery of a breast cancer symptom			**Recommended Intervention functions**	**Selected Intervention functions**	**Notes**
COM-B	**TDF**	**Antecedents**			
Psychological capability	Skills (cognitive and interpersonal)	Perform self-exam; Recognise symptoms; Recognise a bodily change; Schedule and attend appointment	Training	Training	
	Knowledge	Knowledge of breast cancer and its symptoms; Knowledge of ones own normal bodily state and how to self-examine	Education	Education	
	Memory, Attention and Decision Processes	Remember symptoms of breast cancer and own normal bodily state; Detect and appraise changes; Decide HCP should be consulted, make and attend appointment; form and follow if/then rules	Training Environmental restructuring Enablement	Training Environmental restructuring Enablement	
	Behavioural Regulation	Self-monitoring of the upper body	Training Education Enablement Modelling	Training Education Enablement Modelling	
Physical opportunity	Environmental Context and Resources	Making time and space to perform self-exam	Training Environmental restructuring Enablement Restriction	Environmental restructuring Enablement	Restriction and Training are not relevant to this antecedent
Social opportunity	Social Influences	Symptom disclosure	Environmental restructuring Enablement Restriction Modelling	Enablement Modelling	Environmental restructuring and Restriction are not relevant to this antecedent
Reflective motivation	Social/ Professional	Responsibilities inherent in individuals social and professional roles that can	Education Persuasion Modelling	Education Persuasion Modelling	

Target behaviour: Immediate help-seeking to an HCP upon self-discovery of a breast cancer symptom			**Recommended Intervention functions**	**Selected Intervention functions**	**Notes**
COM-B	**TDF**	**Antecedents**			
	Role and Identity	compete with the decision to consult an HCP			
	Beliefs about Capabilities	High self-efficacy for knowledge of own normal bodily state; for ability to make time to self-examine, for ability to effectively self-examine; for ability to identify symptoms; for making time to attend an appointment	Education Persuasion Modelling Enablement	Education Persuasion Modelling Enablement	
	Optimism	Optimistic about consultation with HCP	Education Persuasion Modelling Enablement	Education Persuasion Modelling Enablement	
	Beliefs about Consequences	Understanding the consequences of a diagnosis and treatment of breast cancer	Education Persuasion Enablement	Education Persuasion Enablement	
	Intentions	Intend to know what's normal, to notice a change and to consult HCP if change detected	Education Persuasion Modelling Incentivisation Coercion	Education Persuasion Modelling Coercion	Incentivisation (creating an expectation of reward) is beyond the scope of an internet delivered intervention
	Goals	Set goals to: to know normal bodily state, detect a bodily change if one occurs, and to consult an HCP immediately upon discovery of a symptom	Education Persuasion Modelling Incentivisation Coercion Enablement	Education Persuasion Modelling Coercion Enablement	
Automatic motivation	Emotion	Manage affective responses to prevent postponement of help-seeking	Incentivisation Coercion Enablement Persuasion Modelling	Coercion Enablement Persuasion Modelling	

3.5 Identification of Behaviour Change Techniques

This section describes stage three of the Behaviour Change Wheel, *identifying content and implementation options* (see figure 3.1, Michie et al., 2014). This involves the identification of the Behaviour Change Techniques (BCTs) that are relevant to the intervention. A BCT is defined as "an observable, replicable and irreducible component of an intervention designed to alter or redirect casual processes that regulate behaviour; that is, a technique is proposed to be an active ingredient" (Michie et al., 2013, p. 82). In 2013 the BCT Taxonomy was published containing 93 BCTs, clustered into 16 groups, developed through an expert consensus process (Michie et al., 2013). EC completed BCT online training in August 2016. The Behaviour Change Wheel, through expert consensus, has linked BCTs to each intervention function and categorised them as 'most frequently used' and 'less frequently used'(Michie et al., 2014, pp. 151 - 155). The Behaviour Change Wheel recommends developers to first consider frequently used BCTs for inclusion in interventions before considering the less frequently used BCTs.

Following the procedure outlined by the Behaviour Change Wheel the BCTs were selected using the APEASE criteria (see Table 3.6). These are criteria used to make context-based decisions on intervention content and delivery (Michie et al., 2014, p. 23). Selecting BCTs for the *Know Breast Health* intervention focused on affordability and practicability within the context of an internet delivered intervention. This process is presented in Table 3.7. The acceptability of the BCTs and their proposed methods of delivery (the components of the website) will be assessed using primary qualitative research in the next stage of the research (Chapter 4).

Table 3.6
Criteria for making context-based decisions on intervention content and delivery taken from Michie et al. (2014, p. 23)

APEASE Criteria	
Affordable	It must be within the accepted budget
Practicable	It must be possible to deliver it as designed, in the context it was intended for
Effective and cost effective	It must be effective in the real-world context and the ratio of effect to cost must be optimised
Acceptable	It must be judged appropriate by relevant stakeholders
Side-effects/safety	Unintended or unwanted consequences must be considered
Equitable	The intervention's impact on health disparities must be considered

Table 3.7
Behaviour Change Techniques recommend by the Behaviour Change Wheel and those selected for the Know Breast Health intervention using the APEASE Criteria (Michie et al., 2014, pp. 151 - 155).

Intervention function	**Recommended Behaviour Change Techniques[1]**	**Selected Behaviour Change Techniques**
Training	2.2. Feedback on behaviour 2.3. Self-monitoring of Behaviour 2.7 Feedback on outcome(s) of behaviour 4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal 8.3 Habit formation	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal 8.3 Habit formation
Persuasion	2.2. Feedback on behaviour 2.7 Feedback on outcome(s) of behaviour 5.1 Information about health consequences 5.3. Information about social and environmental consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing* 15.1 Verbal persuasion about capability*	2.7 Feedback on outcome(s) of behaviour 5.1 Information about health consequences 6.2 Social comparison* 9.1. Credible source 13.2 Framing/reframing* 15.1 Verbal persuasion about capability
Modelling	6.1. Demonstration of the behaviour	6.1. Demonstration of the behaviour
Education	2.2. Feedback on behaviour 2.3. Self-monitoring of Behaviour 2.7 Feedback on outcome(s) of behaviour 5.1 Information about health consequences 5.3. Information about social and environmental consequences 6.3 Information about others' approval* 7.1 Prompts/cues	2.7 Feedback on outcome(s) of behaviour 5.1 Information about health consequences 6.3 Information about others' approval 7.1 Prompts/cues
Enablement	1.1 Goal setting (behaviour) 1.2. Problem solving 1.3. Goal setting (outcome) 1.4. Action planning 1.5. Review behaviour goal(s) 1.7. Review outcome goal(s) 1.9 Commitment* 2.3. Self-monitoring of Behaviour 3.1. Social support (unspecified) 3.2. Social support (practical) 12.1. Restructuring the physical environment 12.5. Adding objects to the environment	1.1 Goal setting (behaviour) 1.2. Problem solving 1.4. Action planning 1.9 Commitment 2.3. Self-monitoring of Behaviour 3.1. Social support (unspecified)
Coercion	2.1. Monitoring of behaviour by others without feedback 2.2. Feedback on behaviour 2.3. Self-monitoring of Behaviour 2.5. Monitoring of outcome(s) of behaviour without feedback 2.7 Feedback on outcome(s) of behaviour 5.5. Anticipated regret*	5.5. Anticipated regret

Intervention function	Recommended Behaviour Change Techniques[1]	Selected Behaviour Change Techniques
Environmental restructuring	7.1 Prompts/cues 12.1. Restructuring the physical environment 12.5. Adding objects to the environment	7.1 Prompts/cues

[1] Most frequently used BCTs
* Less frequently used BCTs

3.6 Website Components

Website components are how the BCTs will be operationalised in the *Know Breast Health* intervention. They are the mode of delivery for the active ingredients of the intervention. They were developed, using the APEASE criteria, to deliver the BCTs. As noted by other intervention developers, the Behaviour Change Wheel does not guide the creation of intervention components or features; imagination and creativity are required to bring intervention functions and BCTs 'to life' (Garnett, Crane, West, Brown, & Michie, 2018; Webster et al., 2015, p. 425). The proposed website components version 1 (v.1) for the *Know Breast Health* intervention are presented in Table 3.8. They will be presented to participants in the next phase of research to assess their acceptability. Each proposed website component and its corresponding BCTs will now be discussed.

3.6.1 Video of HCP demonstrating how to perform self-examination

This proposed website component will address multiple intervention functions: Training, Persuasion, Modelling and Education. This video will show an HCP demonstrate how to self-examine using a synthetic model. This will deliver the BCTs *instruction on how to perform the behaviour* and *demonstration of the behaviour*. The HCP will encourage the individuals to regularly perform self-exams, highlighting that there is no wrong way to perform the exam, but that the goal is to learn what is normal for their body. This will deliver the BCTs *behavioural practice and rehearsal*, *habit formation* and *verbal persuasion about capability*. The HCP will stress the importance of this behaviour, thereby delivering the BCT *information about others' approval*. Finally, as this will be performed by an HCP the BCT *credible source* will be delivered.

3.6.2 Video of a woman performing self-exam

This proposed website component will address multiple intervention functions: Training, Persuasion, Modelling and Education. This video will show a woman performing a self-exam. This will deliver the BCTs *instruction on how to perform the behaviour*, *demonstration of the behaviour* and *social comparison*. The woman will encourage the

individuals to regularly perform self-exams, highlighting that there is no wrong way to perform the exam, but that the goal is to learn what is normal for their body. This will deliver the BCTs *behavioural practice and rehearsal*, *habit formation* and *verbal persuasion about capability*. The woman will state that performing self-exams is how she has learned what is normal for her body thereby delivering the BCT *information about others' approval*.

3.6.3 Video of a consultation

This proposed website component will address multiple intervention functions: Training, Persuasion, Modelling and Education. This video will document a consultation between a woman and an HCP. The patient will tell her doctor that she is concerned about a change in her breast and the HCP will perform a clinical breast exam. This will deliver the BCTs *demonstration of the behaviour*, *social comparison* and *credible source*. The consultation will be portrayed as a helpful and positive experience delivering the BCTs *verbal persuasion about capability* and *information about others' approval*.

3.6.4 Video of HCP explaining the importance of immediate help-seeking

This proposed website component will address multiple intervention functions: Persuasion, Education and Coercion. An HCP will explain the importance of immediate help-seeking upon self-discovery of a symptom of breast cancer. This will deliver the BCTs *information about health consequences*, and *information about others' approval*. The HCP will discuss how some individuals postpone help-seeking and the consequences of such postponement (i.e. the consequences of delayed diagnosis). This will deliver the BCTs *social comparison* and *anticipated regret*.

3.6.5 Text and image-based information provision

This website component will provide information, in multiple formats (text, images, infographics), about breast cancer as a disease, the importance of knowing one's own normal bodily state and the importance of immediate help-seeking upon self-discovery of a symptom of breast cancer. It will address the intervention functions of Persuasion, Education and Coercion. Information about individuals who postpone help-seeking and the consequences of such postponement (i.e. the consequences of delayed diagnosis) will be provided to deliver the BCTs *information about health consequences*, *social comparison* and *anticipated regret*. The importance of immediate help-seeking will be stressed using data from trusted sources such as the Irish Health Service Executive (HSE), Irish Cancer Society and the Irish Cancer Registry to deliver the BCT *credible source*. The importance of self-examination will be explained. To deliver the BCT *verbal persuasion about capability* it will be emphasised that

there is no right or wrong way to do it, it is a flexible process the goal of which is to learn about the normal bodily state. Finally information about the treatability and the positive outcomes associated with an early diagnosis of breast cancer will be highlighted to deliver the BCT *framing/reframing*.

3.6.6 Goal setting, barrier identification, action planning and reminder tools

This proposed website component will address the intervention functions; Training, Enablement and Environmental Restructuring. Goal setting, barrier identification and action planning tools will deliver the BCTs *goal setting (behaviour), problem solving, action planning* and *commitment.* The tools will prompt users to commit to goals to get to know their bodies and for immediate help-seeking upon self-discovery of a breast cancer symptom. The tools ask questions to identify barriers to these goals and prompt users to generate solutions. A reminder function will deliver the BCTs *prompts/cues* and *habit formation.*

3.6.7 Breast health diary and discussion forum

This proposed website component will address the intervention functions Education, Persuasion and Enablement. A diary function will deliver the BCT *self-monitoring of behaviour.* The discussion forum will deliver the BCTs *social support (unspecified), information about others' approval* and *social comparison.*

Table 3.8
Website Components (v.1) with Intervention Functions and BCTs

Website components (v.1)	**Intervention function**	**BCTs**
Video of HCP demonstrating how to perform self-examination	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal 8.3 Habit formation
	Persuasion	9.1. Credible source 15.1 Verbal persuasion about capability
	Modelling	6.1. Demonstration of the behaviour
	Education	6.3 Information about others' approval
Video of a woman performing self-exam	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal 8.3 Habit formation
	Persuasion	6.2 Social comparison 15.1 Verbal persuasion about capability
	Modelling	6.1. Demonstration of the behaviour
	Education	6.3 Information about others' approval
Video of a breast health consultation	Training	6.1. Demonstration of the behaviour
	Persuasion	6.2 Social comparison 9.1. Credible source

Website components (v.1)	Intervention function	BCTs
	Modelling	6.1. Demonstration of the behaviour
	Education	6.3 Information about others' approval
Video of HCP explaining the importance of immediate help-seeking	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source
	Education	5.1 Information about health consequences 6.3 Information about others' approval
	Coercion	5.5 Anticipated regret
Text and image based information provision	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing 15.1 Verbal persuasion about capability
	Education	5.1 Information about health consequences 6.3 Information about others' approval
	Coercion	5.5 Anticipated regret
Goal setting, barrier identification, action planning and reminder tools	Training	8.3 Habit formation
	Enablement	1.1 Goal setting (behaviour) 1.2. Problem solving 1.4. Action planning 1.9 Commitment
	Environmental restructuring	7.1 Prompts/cues
Breast health diary and discussion forum	Education	6.3 Information about others' approval
	Persuasion	6.2 Social comparison
	Enablement	2.3. Self-monitoring of behaviour 3.1. Social support (unspecified)

3.7 Summary

This chapter described the development of the *Know Breast Health* intervention website components (v.1). These website components were developed following the Behaviour Change Wheel stages of intervention development. A detailed behavioural diagnosis was conducted based on the findings of the literature review and the antecedents of the target behaviour established (see Table 3.3). The antecedents identified for each TDF domain in the behavioural diagnosis were assigned a set of intervention functions (Table 3.5) and the BCTs were selected using the APEASE criteria (Table 3.7). Finally, the website components (v.1) were developed. They will be presented to participants in the next phase of research, a Focus Group Interview Study, to assess their acceptability.

4 Exploring the content for the *Know Breast Health* intervention: A Focus Group Study

4.1 Chapter overview

This chapter will first describe the relevant background to this study, and its aims. The development of the interview schedule and the methods used in the study will then be presented. This will be followed by a discussion of the study findings which is divided into two sections: the acceptability of proposed website components and participants' perspectives on the *Know Breast Health* intervention. Finally, the results will be discussed within the context of other research in the area.

4.2 Background

The Person-Based Approach recommends conducting primary qualitative research, when necessary, as part of the planning stage when designing an intervention (Yardley et al., 2015b). To date there is no qualitative research on digital interventions to reduce the patient interval for breast cancer. The goal of qualitative research at the planning stage in the Person-Based Approach is to explore the perspectives of the people who will use the intervention, in particular, their "attitudes, understanding, needs, and situation … in order to select those intervention components that seem the most acceptable, feasible, and salient to them" (Yardley et al., 2015b, p. 4). Qualitative research, at this point in the development of an intervention, can generate novel ideas for the content of the intervention (Yardley et al., 2015b). Thus, the aim of the current study is to explore potential content of the *Know Breast Health* intervention by examining the perspectives of target users and facilitating the generation of novel ideas.

Primary qualitative work in the early stages of the development of an intervention has a number of benefits, for example, it can ensure the acceptability of the proposed intervention for its target users (Band et al., 2017; Yardley et al., 2015b). In particular, it can assess acceptability within the specific context of the proposed intervention allowing for insights that secondary qualitative work would not provide (Band et al., 2017; Yardley et al., 2015b). Interviews with target users can highlight issues that were not apparent from reviews of the literature. For example, in their qualitative work for the development of a digital intervention to reduce re-ulceration risk, Greenwell et al. (2018) found that a lack of knowledge about when to self-refer was a barrier for patients with a history of diabetic foot ulcers, something that was not evident from the research literature. Finally, conducting qualitative work before

the intervention is created is cost effective. Rather than spending resources on the creation of content that is then deemed as unacceptable by participants, this early qualitative work ensures that the initial intervention is acceptable (Yardley et al., 2015b).

Focus group interviews are an ideal method for exploring perspectives and getting guidance on intervention content selection. They have ecological validity, they allow discussion which can lead in unexpected directions, they can give participants the confidence to express views that contradict the researcher and they facilitate the development of conclusions (Braun & Clarke, 2013; Yardley et al., 2015b). Thus, focus group interviews were selected to explore the content for the *Know Breast Health* intervention.

4.2.1 Study aims

The aim of this study is to explore potential content of the *Know Breast Health* intervention by examining the perspectives of target users, assessing the acceptability of the proposed website components (v.1) and facilitating the generation of novel ideas for the intervention. The findings of this study will directly inform the content and delivery of the *Know Breast Health* intervention.

4.3 The development of the interview schedule

The interview schedule designed for this study was based on the intervention content developed in Chapter 3 and has two question 'types': *idea generation* questions and *acceptability testing* questions. *Idea generation* questions were designed to target each antecedent identified in the behavioural diagnosis. That is, *idea generation* questions aimed to get participants to discuss each antecedent and explore the kind of content that would help them to address it. Participants were presented with an antecedent and asked how they thought a website could help encourage women to address it. *Idea generation* questions were phrased as "X is what we want to encourage/change/help with, how do you think a website could do that?" (X = antecedent). *Acceptability testing* questions were designed to target each proposed website component (v.1) developed in Chapter 3. *Acceptability testing* questions aimed to facilitate discussion of the proposed components to explore their acceptability. For *acceptability testing* questions participants were presented with a proposed website component and asked to discuss it. *Acceptability testing* questions were phrased as "Y is how we are thinking of encouraging/changing/helping with X, what do you think of that?" (Y = the proposed website component, X = antecedent). Sample questions are presented in Table 4.1.

Table 4.1
Sample questions from the focus group interview schedule

Question type	Sample
Idea generation	"We want to encourage women to be able to recognise a symptom that could be breast cancer and to remember all the possible symptoms. How do you think we could do that through a website?"
Acceptability testing	"This is what we are thinking of doing to help women to be able to recognise a symptom: having graphics and/or images of breast cancer symptoms with text descriptions, what do you think of that?"

All questions aimed to facilitate discussion in order to explore the perspectives and attitudes of participants. The focus group interviews were semi-structured; while there was a list of questions to be asked there was scope for participants to raise issues not anticipated by the researcher (Braun & Clarke, 2013). The interview schedule is presented in Appendix 1a. The interview schedule was broken into three sections to provide structure for participants. The sections were based on the Pathways Model (Scott et al., 2013). The appraisal interval was addressed first, that is, antecedents relevant to the appraisal interval were discussed first. Then the help-seeking interval was addressed, that is, antecedents relevant to the appraisal interval were discussed second. The third section contained general questions relating to acceptability of the proposed website components (v.1). For example, participants were asked what they thought about goal-setting tools which are proposed to be used to address antecedents in both appraisal and help-seeking intervals.

4.4 Method

4.4.1 Ethics

This study received ethical approval from the National University of Ireland, Galway, Research Ethics Committee. All participants gave informed consent. See Appendix 2a for participant information sheet and Appendix 3 for sample consent form.

4.4.2 Design

An experiential, qualitative study was conducted with semi-structured focus group interviews (Braun & Clarke, 2013). Discussion in the focus groups centred on participants' perspectives on an internet-delivered intervention, the acceptability of the proposed website components and the generation of ideas to promote immediate help-seeking through a website. This study is reported using the *Consolidated Criteria for Reporting Qualitative Research* (see Appendix 5a). This is a 32-item checklist for interviews and focus groups to

ensure rigour in qualitative studies through explicit and comprehensive reporting (Tong, Sainsbury, & Craig, 2007).

4.4.3 Ontology and epistemology

The Person-Based Approach recommends exploring the perspectives of potential target users of the *Know Breast Health* intervention and so this study took a critical realist approach within a contextualist framework. Qualitative research can be underpinned by different ontological and epistemological assumptions. This refers to the theories about the nature of reality and knowledge. On the ontological spectrum critical realism sits in the centre. Realism posits a knowable single truth that we can accurately observe. Critical realism argues that there is a knowable world but that it is always observed subjectively, and so, there is no single truth (Braun & Clarke, 2013). On the epistemological spectrum, similar to critical realism, the contextualist approach sits in the centre. The contextualist approach posits that there are many truths but that they can only be known within the context they are researched. In the contextualist approach knowledge is always context dependent so there is no universal truth waiting to be discovered. Contextualists believe all knowledge is subjective but this does not prohibit it from being true (Braun & Clarke, 2013). Thus, a contextualist framework, with a critical realist approach is ideal for exploring the content of the *Know Breast Health* intervention by eliciting participants' views about the acceptability of proposed components and by generating discussion of novel ideas for the intervention.

4.4.4 Sample & recruitment

Purposive sampling is the typical approach taken in qualitative research. It involves selecting participants based on their ability to provide rich data that will address the research question (Palinkas et al., 2015). In this study the purposive sample is women, living in Ireland, aged 18 – 49. There are many different types of purposive sampling, in this study stratification was used. Stratification is sampling to ensure that diversity is incorporated into the data (Braun & Clarke, 2013). The aim of stratification is not to be exhaustive or generalisable, but rather to enable the inclusion of a broad range of people to contribute to the research (Braun & Clarke, 2013). Therefore, stratification was based on age, education level (primary, second, third) and residence (urban or rural). This is in keeping with the Person-Based Approach, and other studies using qualitative interviews for intervention development (Braun & Clarke, 2013; Crane, Garnett, Brown, West, & Michie, 2017; Greenwell et al., 2018; Yardley et al., 2015b).

Participants were recruited from the local community through posters, flyers and advertisements on social media. Posters were placed in community centres, employment centres, libraries and churches in the main residential areas in the west and east of Galway city and Galway city centre. The primary shopping centre in the city centre was also targeted. Flyers were handed out to customers and posters were put up in eight different staff rooms in the shopping centre. Posters were placed in community colleges, Galway-Mayo Institute of Technology and the National University of Ireland, Galway (NUIG). The NUIG campus was targeted with a focus on both students and staff. Posters were placed in staff restrooms and kitchens as well as in prominent locations throughout campus. Emails with invitations to take part were sent to administrative managers in each of the Schools and Colleges in the University, requesting that the information be shared with their staff email lists. A twitter account, Facebook page and WordPress website were all established for the study to advertise for participants on social media. Braun and Clarke (2013) recommend 2-4 focus groups for thematic analysis with 3-8 people per group as optimal.

4.4.5 Participants

Participants were 17 women with an age range of 19 – 49 years, 59% of whom lived in an urban area. The majority (76%) of participants had a third level education, 18% had second level and one participant had primary level only. Demographic details of each participant are presented in Table 4.2.

Table 4.2
Demographic variables for each participant in the Focus Group Interview Study

FG	ID	Age	Residence	Education level	Occupation
1	101	19	Rural	Third	Waitress
	102	20	Urban	Third	Student
	103	32	Urban	Third	Retail manager
	104	33	Rural	Third	Researcher
	105	43	Urban	Second	Administrator
2	106	20	Urban	Second	Waitress
	107	22	Urban	Third	Sales assistant
	108	24	Urban	Third	Sexual health educator
	109	44	Urban	Third	Lecturer
3	110	19	Urban	Third	Student
	111	21	Rural	Third	Student
	112	22	Urban	Third	Healthcare assistant
	113	24	Rural	Third	Research assistant
4	114	40	Rural	Primary	Librarian
	115	41	Urban	Third	Community development worker

FG	ID	Age	Residence	Education level	Occupation
	116	45	Rural	Third	n/a
	117	49	Rural	Second	Secretary

*FG = Focus Group number

4.4.6 Procedure

Four focus group interviews were conducted. Three of the focus groups took place on campus, in the School of Psychology building, and the fourth took place in a community centre in the west of Galway City. Five participants took part in the first focus group and each of the remaining focus groups had four participants. All focus group interviews were facilitated by EC and had a research assistant present. All focus group interviews were audio recorded and transcribed verbatim. Before the focus groups began, participants were given participant information sheets (Appendix 2a) to re-read and were given the opportunity to ask questions. Consent forms (Appendix 3) were then provided to participants. All participants consented to participation. Finally, the participants filled in a demographics form (see Appendix 4).

A general discussion about using technology in any way for healthcare was initially facilitated to get participants comfortable and relaxed. Generic focus group ground rules were outlined (see interview schedule, Appendix 1a). At this point it was made clear to participants that they were not subjects being studied but rather active contributors to the research. It was explained that their views and opinions would be incorporated into the development of the intervention. Participants were shown a basic version of the Pathways Model, outlining the primary factors associated with postponement of help-seeking. Describing the model gave the participants a basic understanding of the field of research and, importantly, it allowed the facilitator to ensure that participants understood what the focus group was *not* discussing, i.e. reasons why people postpone help-seeking. The focus group interviews focused on idea generation and acceptability testing of the proposed content for the *Know Breast Health* intervention.

The focus group interviews had three sections; the first focused on the *appraisal interval*, the second on the *help-seeking interval* and the final section focused on more general questions. Novel ideas generated in focus groups were added to the interview schedule for subsequent groups to determine their acceptability with the other participants. For each antecedent identified in the behavioural diagnosis participants were asked an *idea generation* question. Once the discussion around this was complete participants were

presented with the Website component (v.1) proposed to target that antecedent. All interviews followed this structure. Participants were invited to ask questions after each section before we moved on to the next. At the end of interviews participants were offered the opportunity to ask questions or make comments, or present any ideas they felt had not been covered. Participants were thanked for their contribution.

4.4.7 Analysis

Thematic analysis is recommended for qualitative work in the planning stage of the Person-Based Approach (Band et al., 2017; Greenwell et al., 2018). Thematic analysis is a method for identifying themes and patterns of meaning across a data set. It is a flexible method of analysis; it can combine a *top-down* approach with a *bottom-up* one, which is the method applied in this analysis (Braun & Clarke, 2013, p. 178). That is, themes were identified from the data but structured by the Pathways Model (Scott et al., 2013). The primary researcher is a novice qualitative researcher and thematic analysis is a suitable form of analysis for researchers with little experience (Braun & Clarke, 2013). Fitting with the study aim to explore the perspectives of potential target users of the intervention, and a critical realist ontology, a descriptive thematic analysis was conducted. This approach aims to "tell the story" of the data and uses participant quotes to illustrate the analysis, focusing on semantic level meaning (Braun & Clarke, 2013, p. 252). In order for the findings of this study to inform the development of the intervention it is necessary to identify the explicit meaning in the data rather than applying interpretive frameworks to explore conceptual, latent level meaning (Braun & Clarke, 2013). The seven stages of thematic analysis are presented in Table 4.3.

Table 4.3
Stages of Thematic Analysis (Braun & Clarke, 2013, p. 202)

Stages of thematic analysis
1. Transcription
2. Reading and familiarisation; taking note of items of potential interest
3. Complete coding across the entire data set
4. Searching for themes
5. Reviewing themes
6. Defining and naming themes
7. Writing and finalising analysis

During stage three of the analysis NVivo 11 was used to code transcripts and facilitate analyses and comparison of relationships between codes. The structure provided by the

interview schedule was used for complete coding. The entire data set was coded into sections, by EC, based on the appraisal and help-seeking intervals of the Pathways Model. There was overlap between sections, in these cases data points were double/triple coded. Stage 4 of the analysis involved developing themes from within the initial coding strategy. This involved coding on a sematic level where themes that were explicitly represented in the data were identified. In step 5 these themes were reviewed by AMG and EC and original transcripts were checked against them. The final stages involved refining the themes and writing up the findings.

4.5 Findings

The findings of this thematic analysis are divided into two sections; participants' perspectives and acceptability themes. The former refers to themes that explore the perspectives of participants, their attitudes to, and understating of, the proposed intervention. The acceptability themes relate directly to participants views on the acceptability of the proposed website components developed in Chapter 3. The key findings are presented in Table 4.4.

4.5.1 Participants' perspectives on the *Know Breast Health* intervention

4.5.1.1 Relationship with HCP

Participants discussed negative relationships with HCPs. Some participants expressed surprise at the idea of changing HCPs as they did not know it was possible to do so, or thought that was a prohibitively complicated procedure. Participants agreed that it was important to feel comfortable with their doctor as this would make them more likely to present with a symptom. Participants agreed that if the relationship with the HCP was a negative one, they would be less likely to engage in help-seeking. They believed that information about how to change doctor should be provided for users as they may not know that it is possible.

> *And like that, it could also be encouragement, because some people aren't happy with their doctors. Well then get out of there! Get a better doctor. You know because I was with a doctor for too long that they were just dreadful. Thankfully now, my doctor, she's fabulous you know. But I'm so much more inclined to go now because of that. So just giving people the encouragement. Because so often we're with doctors because it's from childhood, and you're just with them. It never occurs to you to change you know, until you have a really good reason to do it. I think that's definitely a massive reason why people don't go as well. It's like aw, I'm not going to them. — 103*

> *In some instances it felt like they were being dismissive, or like "oh it's nothing to worry about — 104*

> *It would be helpful to have testimony from GPs, and from people who work in breast health, to see what they're like. You know that they're not frightening monsters actually. You know people who see this all the time take it seriously, and they're not gonna be laughing at you. I think that's really important. — 309*

Key finding: Highlight to users that it is important that they should feel comfortable with their HCP and provide solutions for those who do not.

4.5.1.2 Uncertainty

Participants expressed uncertainty in four main areas: the symptoms of breast cancer, knowledge of breast cancer as a disease, self-examination and knowing what is normal for their bodies. All participants were aware of the lump as a potential symptom. Some participants knew there were other symptoms but were uncertain what they were. There was general uncertainty about what symptoms look like and what they mean. For example, for the symptom 'puckering of the skin' participants expressed confusion over what that would look like on their own breasts. There was uncertainty over breast cancer as a disease. Participants were not clear about risk factors and causes, treatments and curability. Participants expressed concern over self-examining; they did not know if they were "doing it right". There was a general agreement of being uncertain about "knowing what's normal". Participants felt uncertain that they would be able to recognise a change because they had no clear idea of what their breast were like normally.

> *You always think of the lump. […] what are the symptoms? I actually don't even know what they are — 103*

> *Maybe I'll try to see if something's wrong. But […] I don't know what it's like normally, so maybe this is normal — 111*

Key finding: Education and training are important for users to reduce uncertainty and increase confidence about symptom detection, breast cancer knowledge and knowing what is normal for them.

4.5.1.3 The diversity of real people

There are two parts to this theme; firstly, participants want to see real breasts, both with and without symptoms as they believe that graphics are not useful as they do not provide enough information and do not indicate what a symptom would look like on a real breast. Secondly, participants argued for the importance of providing a diverse variety of real bodies.

This diversity related to size, shape, age and skin colour. Participants wanted to see real people, and real people are diverse. People who are breast-feeding and transgender men were also discussed in relation to diversity.

> *I'd say on a real person with real breasts like. An actual woman. — 108*

> *I think I'd prefer the real breasts with the actual symptoms. It's kind of easier to recognise. — 115*

> *it is important to show women of different ages. — 109*

> *I think it's very important to include women who have different skin colour. — 107*

Key finding: The website content should include images of real people with examples of symptoms and should be representative of a broad range of people in terms of age, size/shape, and skin colour.

4.5.1.4 Normalising breast health

Normalising breast health on a personal level and cultural level was discussed. Participants talked about "making it normal" to self-examine. Some participants felt self-conscious or embarrassed to examine themselves. Participants stressed that making this a normal part of a person's routine was important. They felt that the intervention could help users feel like it was a normal thing to do, just like any other self-care. One participant suggested that it could be as normal as doing your eye make-up. Participants also felt it was important to normalise breast health on a cultural level. They wanted a way to make it normal to discuss breast health with friends, family and HCPs. Again some participants felt that this was not normal, that it was somehow inappropriate. Participants felt that incorporating the diversity of real people into the site would help with normalising breast health.

> *I think if it was real, like I said, it would normalise it more. — 111*

> *Just to break down I think. Not the stigma. That's not the right word. But you know. — 108*

> *Some people just wouldn't even be confident. They just try to avoid looking at themselves. — 110*

> *You could say look it up on boobs.ie or whatever it is. You know. So that it kind of becomes a social thing. — 105*

Key finding: It is important to normalise breast health by stressing that it is a standard part of a person's healthcare regime.

4.5.1.5 Fear

Fear was discussed in a number of different contexts in the focus groups. There was fear regarding a potential diagnosis based on poor understanding of breast cancer as a disease, its treatments and curability. There was fear regarding visiting a doctor due to embarrassment caused by the act of being examined or the potential of wasting the doctor's time and the shame that would cause. Participants felt that a video explaining what would happen upon reporting a symptom to an HCP would be helpful to reduce fear of this interaction. An idea that was generated in all but one of the focus groups was that possible alternative explanations of a symptom be provided to users to allay their fears. Rather than saying symptom X is a symptom of breast cancer, participants suggested that the intervention could state that symptom X could also be a symptom of some other illnesses. Participants felt that a person would be more likely to report to an HCP if she believed there was possibility of the symptom being something other than cancer.

> *It (alternative causes) might also make them a bit more confident in going to the doctor, because the fear isn't as… — 103*

> *A lot of women would think that if they get the diagnosis, it means that they're gonna have to lose their breasts. — 109*

> *It's just when you hear the word cancer […] it just scares them. That word. — 110*

> *it is the fear of the unknown like — 105*

Key finding: Reducing uncertainty around symptoms and breast cancer as a disease, as well as the HCP consultation will help reduce users fear, as will normalising talking about breast health.

4.5.2 Acceptability of website components (v.1)

4.5.2.1 Personalisation

Participants felt strongly that the experience of the website should be personalised. They believed that this would make users more engaged. This personalisation could be achieved through individual accounts, the ability to save unique information and tailored reminders. Interactive components were also talked about in his context.

> *But if it was something you could sign into and have your own account, then that kind of information could be saved, according to your profile or whatever. — 104*

> *It would be handy to have all your information in the one place so you wouldn't have to go looking through the website for it. You could just flick through it whenever. — 107*

> *Yeah. And that's making it specific to you again, so that's good. — 108*

Key finding: Make the experience as tailored to the user as possible.

4.5.2.2 Aesthetics

Participants were very clear about the importance of how the website should look and feel. Images, infographics and videos were seen as more important than text. However, participants felt the text option should always be available as well. In this way, they stressed the importance of presenting the material in multiple formats. Related to this discussion was the complexity of the site. While participants wanted multiple format types, they also wanted a site that was easy to navigate, clear and clutter free. A simple homepage was highlighted as important. Many participants discussed the experience of being overwhelmed on a homepage and immediately leaving the site as a consequence. There was discussion around colour scheme of the website, in particular, the inclusion of the colour pink. Some participants were against using any pink. Some participants felt that it was important to incorporate it as it would be good from a marketing perspective; users would see pink and know the website was about breast cancer. There was sensitivity to the fact that the website was designed to be about breast health and that pink was associated with breast cancer and that this may be a problem. Others suggested colours like blue, white and green would be more suitable to the 'health' theme of the intervention. There was a general conclusion that a limited amount of the colour pink would be acceptable. In general it was stated that the site should not be too effeminate.

> *Not blocks and blocks of text anyways — 106*

> *I do not do pink! — 110*

> *But if you think of health, and you think of wellbeing and stuff, I think of like light blues and clinical whites and stuff, and like greens. — 113*

Key finding: Provide all information in multiple formats but ensure the site is uncluttered and easy to navigate. Pink is important in a marketing context due to its association with breast cancer but participants did not see it as necessary for a breast health website.

4.5.2.3 Data protection and trust

Participants displayed a good understand of the potential hazards of health information on the internet. They discussed how often sites can be inaccurate and, or, alarmist and they were critical in their decisions to accept content as credible. Many participants had trusted websites that they regularly visited when looking for information and so did not search on Google as they believed this could provide inaccurate information. Participants believed including the University logo would provide assurance to users that the site was reputable, and the content was trustworthy. Participants were very concerned about data protection and many believed that personal information on websites is easily hacked. This was discussed in relation to potential personal accounts on the website. Participants felt strongly that any information that they stored there could easily be stolen unless stringent measures were put in place to prevent this happening.

> *There'd be certain sites I'd go to, because I can trust them, and I just know they have a reputation for good information. — 105*

> *Where would that be stored though? Would you have it locally to yourself, or would it be online? Could it be hacked, and then people see your breasts? — 109*

> *It is. It is. But it could be a target like, if it's a breast health website. I mean I know now it's not nice to think about it, and you're like who would do that? But people do do that. And you know some people can hack in scarily easily. Like I'm not tech savvy at all, but you know apparently it's not very hard to do — 108*

Key finding: Include University logos on site and ensure users are aware of the details of the security protocol put in place to protect their data.

4.5.2.4 Choice

Participants felt that choice was critical to the experience of using a website. While there was support for personalised accounts they believed that creation of such an account should not be a requirement to using the site. Users should have a choice regarding the decision to set up an account, not be forced to do so to gain access to further content. In particular, there was a strong aversion to "pop-ups" prompting participation in a particular element of the site.

> *Like when you mentioned having the pop-up at the beginning, as an internet user, I would be like yuck! — 102:*

> *Just as long as there's not any content that you can't get if you don't make an account. You know" — 107*

Key finding: Ensure choice is available at all times; do not have requirements for engagement with the site.

4.5.2.5 Interactive website components

Interactive website components are the planning tools, reminders and diary. While there was general support for these features, the effort required for their use was discussed; participants felt strongly that they did not want to have to do too much work. The tools include goal-setting, barrier identification and action planning options. There was initial uncertainty regarding these components. This was due to participants not understanding their purpose or function and as such they were unsure if they would use them. Once the reasoning behind their inclusion was explained to the participants there was general agreement as to the tools value. There was unanimous support for reminders. The reminder function was important to all participants as they clearly understood its purpose. Important here was that they could set the time as well as the date for the reminder. There was agreement that push-notifications were not necessary. Participants perceived them as intrusive and concluded that an email or message would suffice. Many participants saw push-notifications as a nuisance. It was suggested that completed action plans could serve as the reminders that users receive in the email. This was favourably accepted. In this way, rather than a generic reminder notification, users would receive their own words, their own plan, as the reminder.

The breast health diary was positively received and deemed acceptable and useful by participants. In the first focus group the idea of a breast health diary evolved into discussion about a breast health map. The map was accepted in all subsequent focus groups as a valuable aid. In all but one focus group the idea of ‘breast health selfies’ was generated by the participants. The breast health diary/map/selfies were all discussed in the context of learning what is normal for their bodies. Some of the participants struggled to be aware of what their breasts look and feel like normally and therefore did not feel confident that they would be able to identify a change if one occurred. All participants liked the idea of having a simple, time efficient way of taking note of their breasts throughout their cycle. They felt that this would increase their confidence in knowing that something was out of the ordinary. Again, it was stressed that components such as this must be designed in such a way as to be as little work as possible for users. The breast health selfies were seen by most as the ideal solution, however, all groups concurred that the data security issues around this made it impossible. They were concerned about storing images on their own phones as well as on the website.

The breast health diary and map was agreed as the best idea to help users learn what is normal for them.

> *The less work I have to do the better on anything like this. — 108*

> *I'd need to get the email alerts, something to remind me because I would just keep putting it off. — 103*

> *That's a good idea [planning tools], because it's always like if you want something, you have to set goals. You'll not do something if you don't set a goal to do it. — 110*

> *Yeah because if you get the email at work, you're gonna forget it then. — 104*

> *It [breast selfies] would be ideal like. It would be ideal. It's just hard to find a safe way of having them. — 106*

Key finding: Explaining the theory of goal-setting and action planning techniques is important so that the purpose of the task is clear to the user. Ensure the reminder function can be tailored by time and date and incorporate users action plans into prompts to maximise acceptability. Develop a low-effort technique for completion of the interactive components to ensure the workload is not too onerous on the users.

4.5.2.6 Education and training features

The education and training features proposed included videos, infographics, images and text. All were unanimously acceptable to participants. Participants were enthusiastic about content being provided in multiple formats, this made engaging with the content more interesting.

> *I think even more explicit actual photographs. Or even videos of somebody doing it in an examination. Because just like I said earlier, it describes how to do it. It depends on how you interpret that. And even those kind of cartoon pictures don't necessarily represent real life. So that's something that I have in the past searched for, and I found that hard to find. — 104*

Key finding: The education and training features including videos, infographics, images and text are acceptable.

4.5.2.7 Social support

Participants were asked if they felt a discussion forum would help them feel supported in making decisions about their breast health. All participants felt that it could potentially be helpful but that it was more likely to do harm. They felt a forum would have to be monitored by an HCP 24 hours a day, 7 days a week and believed that this was not practical.

Participants spoke about forum contributors being both intentionally and unintentionally unhelpful. They highlighted the possibility of contributors providing inaccurate information and others bulling or 'trolling' the forum. They believe that a discussion forum was not necessary for social support.

Many participants stated they would share breast health concerns with family. In particular, participants mentioned their mothers as a source of support in such cases. Participants talked about emotional support as well as practical support such as having someone drive them to the doctor's surgery.

> *A discussion forum would be good I guess in terms of support or whatever, but the first thing that comes into my mind is regulation. — 113*
>
> *I think a discussion forum could be good, as long as it's monitored. — 108*
>
> *That's what happens in real life, you're talking to your girlfriends or whatever, and it's like yeah I need to check that out or whatever. Or your parents or sisters or whatever, you know. — 104*

Key finding: The discussion forum is not necessary. Planning tools could prompt users to identify a person they would seek emotional and practical support from in the instance of discovering a breast cancer symptom.

Table 4.4
Key findings from the Focus Group Interview Study

Key findings
1. Make the experience as tailored to the user as possible
2. Key information be provided in visual/video/basic text format and that a detailed text description could be provided by a "click here for more" option
3. It is clear that pink is associated with breast cancer and participants could understand the difference between a breast cancer website and a breast health website. They therefore supported the use of other colours
4. Ensure the site is uncluttered and easy to navigate
5. University logos are sufficient to indicate the website is a credible source
6. Ensure users are aware of the details of the security protocol put in place to protect their data
7. Ensure choice is available at all times; do not require engagement in certain tasks in return for access to content
8. Explain the theory of goal-setting and action planning techniques so that the purpose/value of the task is clear to users
9. Ensure reminder function is available and can be tailored by time and date
10. Use the users own action plans as their reminders. Their own words are more effective reminders than a generic message.
11. Develop easy technique for breast health diary and/or mapping; design a visual, simple method for describing/annotating upper body

12. Ensure completion of all tasks in intervention are not too onerous on the user
13. The education and training features including videos, infographics, images and text are acceptable.
14. The discussion forum was deemed unnecessary; participants were hesitant to use it as they identified multiple issues with its management
15. It is acceptable to prompt users to identify a person they would seek emotional and practical support from in the instance of discovering a breast cancer symptom.
16. It is important to highlight to users that should they feel comfortable with their doctor and to provide solutions for those users who do not
17. Education and training are important for users to reduce uncertainty and increase confidence about symptom detection, breast cancer knowledge and knowing what is normal for them.
18. Websites content should include images of real people with examples of symptoms and should be representative of a broad range of people in terms of age, size/shape, and skin colour.
19. It is important to normalise breast health by stressing that it is a standard part of a person's healthcare regime.
20. Reducing uncertainly around symptoms and breast cancer as a disease, as well as the HCP consultation will help reduce users fear, as will normalising talking about breast health.

4.6 Discussion

This study is the first study to explore women's perspectives of an internet delivered intervention to reduce the patient interval for breast cancer. Overall, the participants found the proposed website components (v.1) acceptable and they generated some novel ideas for the intervention. Participants discussed the importance of having a positive relationship with their HCP and believed a negative one would reduce help-seeking behaviour. They discussed fear of presenting to an HCP with a breast health concern and believed having a positive relationship with their HCP would reduce this fear. Participants expressed uncertainty of the symptoms of breast cancer, of breast cancer as a disease, and of how to self-examine. In particular, participants were uncertain that they would be able to recognise a symptom if one occurred because they were uncertain about what their upper body was like normally, throughout their cycle. Participants talked about the need to *make it normal* to self-examine and to discuss breast health with friends, family and HCPs.

4.6.1 The website

In the Internet Intervention Model proposed by Ritterband, Thorndike, Cox, Kovatchev, and Gonder-Frederick (2009), the website is the primary component of the intervention. It is the means by which the intervention is delivered and has eight main elements: *appearance, behavioural prescriptions, burdens, content, delivery, message, participation* and *assessment* (Ritterband et al., 2009). These eight elements determine how the website is developed and how it functions. The discussions generated in this study map clearly onto to the Ritterband et

al. (2009) model. The *appearance* of the website in the Internet Intervention Model refers to how it looks and feels to the user and includes things like use of colour, layout and organisation of content. Participants in this study wanted a website that was easy to navigate, clear and clutter free, but that provided the same information in multiple formats: images, infographics, text, and video. They also discussed colour: blue, white and green were associated with health, pink with breast cancer. *Behavioural prescriptions* in the Ritterband et al. (2009) model instruct the user on what to do to address the problem targeted by the intervention and includes things like behavioural contracts and prompts. Participants in this study wanted personalised reminders and they were accepting of action planning and goal-setting tools for target behaviours. The *burdens* of using the website refer to navigation difficulties and intervention length (Ritterband et al., 2009). Participants in this study stressed that the website should be easy to use and be as concise as possible in all areas; brevity was key. The Internet Intervention Model states that the *content* of the website should be accurate, clear, and simple (Ritterband et al., 2009). This was mirrored by the current study's findings. The *delivery* refers to how the content is delivered, that is, for example, audio, video, text, illustrations/graphics (Ritterband et al., 2009). The participants in this study felt that having information provided in multiple formats was key and wanted minimal text and clutter. In the Ritterband et al. (2009) model *message* refers to the source and style of the website, who created it and how is it presented. The credibility and trustworthiness of the source was discussed in the focus groups, they believed the University logo would provide this. The style refers to the pitch of the content, for example, an intervention for children would have cartoons. The participants in this study addressed this element of *message* when discussing the use of the colour pink. They reported that pink is strongly associated with breast cancer, but thought that it should be combined with blues, whites and green to suggest health. They understood that the website was not pitched at cancer patients but at healthy individuals learning to manage their breast health. The *participation* component of the Internet Intervention Model relates to the website's ability to engage participants, specifically through the use of interactive elements (Ritterband et al., 2009). The participants in this study were in favour of interactive components, such as the videos and the personal account, for exactly this reason, they believed these elements would make the website more interesting to use and therefore engaging. They also stressed that any tasks to be completed needed to be concise and they did not want to have to complete something in order to obtain further information; that is they wanted choice. Finally, *assessment* refers to the websites ability to personalise the information provided to the user (Ritterband et al., 2009). Participants in the current were

supportive of the idea of tailoring. They liked the fact that tailoring would reduce the amount of information they would be exposed to and appreciated that they would only be provided with what they needed.

4.6.2 Relationship with Healthcare Professional

Focus group discussion concluded that in order to facilitate help-seeking it should be highlighted to users that they should feel comfortable with their doctor and that information on the process of changing HCPs should be provided. Participants reported that either they themselves or someone they knew had stayed with an HCP despite a negative relationship. This finding is supported by a correlational survey of women in Ireland (n= 449) by O'Mahony et al. (2013). They found that 32.1% of participants reported that their healthcare had been affected by discrimination and 19.5% reported that they had not always been treated respectfully by HCPs. Negative experiences can damage the trust relationship with a woman and her HCP which can lead to postponement of help-seeking (Heisey et al., 2011). Social cognitive theory states that low self-efficacy and poor outcome expectancies will increase the problem behaviour, that is, in this case, increase the chance of postponement of help-seeking (Bandura, 2004).

4.6.3 Uncertainty

Participants were uncertain of the symptoms of breast cancer, of breast cancer as a disease, and of how to self-examine. They were uncertain that they would be able to recognise a symptom if one occurred because they were uncertain about what their upper body was like normally, throughout their cycle. The Common-Sense Model posits that we appraise our symptoms in terms of our illness representations and our emotional response. Illness representations and emotional responses are therefore critical for help-seeking behaviour upon self-discovery of a breast cancer symptom. There are five domains of illness representations: *identity* (label for the symptom), *consequences* (beliefs about the consequences of symptom), *timeline* (beliefs about the duration of symptom), *cure/control* (beliefs about whether the symptom can be treated or managed) and *cause* (beliefs about the cause of the symptom) (Leventhal et al., 2008). Accurate knowledge of these domains, that is, accurate knowledge of breast cancer as a disease and its symptoms, understanding the consequences of postponement of help-seeking and the consequences of a diagnosis is therefore important for progression through the patient interval (Facione, 1993; Leventhal et al., 2008). Research supports the findings of this study; there is a poor understanding of non-lump symptoms of breast cancer and uncertainty around the *cure/control* domain of breast

cancer (Grunfeld, Hunter, Ramirez, & Richards, 2003). The *cause* domain of breast cancer is also often misunderstood and consequently people underestimate their risk for the disease (Jones, 1990; Kartal et al., 2014; Linsell, Burgess, & Ramirez, 2008).

For individuals to confidently interpret a bodily change as something that requires the attention of an HCP they need to be familiar with their body. Being 'Breast Aware' is understood as an individual being familiar with their own breasts and the way that they change throughout their life (Thornton & Pillarisetti, 2008). The participants in this study were uncertain about how to self-examine and about their familiarity with their bodies, they were not 'Breast Aware'. Breast awareness is considered critically important as it can lead to a reduction in postponement of help-seeking (Austoker, 2003; Parthasarathy & Rathnam, 2012). Elobaid, Aw, Lim, Hamid, and Grivna (2016) found that during the *appraisal interval* women commonly attributed symptoms to causes other than breast cancer, to the most salient contextual stimuli, such as menstrual cycle or menopausal symptoms (Jones, 1990). It is therefore important that individuals know what is normal for them, so that they can identify a change that is abnormal. This requires breast health habits such as self-exams and noticing how the body changes each month. Interventions need to target both the practical element of 'how to' self-examine but also cognitive strategies to assist individuals in becoming familiar with their breasts.

4.6.4 Normalising and diversity

Participants talked about the need to *make it normal* to self-examine and to discuss breast health with friends, family and doctors. Increasing the frequency with which individuals engage in self-examination would go some way to 'making it normal' for them. However, there was a need for the participants in this study to 'make it normal', not just for themselves, but on wider community basis. If interventions such as the one proposed, succeeded in increasing individuals' self-efficacy for self-examination, for breast cancer knowledge and for help-seeking then there would perhaps be a cultural shift whereby individuals could speak more openly and freely about breast health. This is perhaps already happening through social media with breast cancer and so it is perhaps a matter of time before it begins to be the case with breast health.

The fact that some individuals feel that it is not normal to self-examine or to discuss breast health is perhaps because individuals are not accustomed to seeing real breasts represented in a clinical or scientific way. The images used for healthcare purposes are graphical representations of breasts, images of real breasts are rarely used in this context.

This perhaps partly explains the strong preference the participants in this study had for images of real breasts in a healthcare context, both of healthy individuals and those with breast cancer. They called for a diverse range of real bodies that should be representative of a broad range of individuals in terms of age, size, shape and skin colour. There were practical reasons for this. The participants in this study had only seen graphical representations of symptoms and this negatively impacted their self-efficacy for symptom recognition. Exposing individuals to images of breasts in the healthcare context is important to help them see breasts as body parts thus 'making it normal' to self-examine and discuss breast health with others and potentially making it easier to understand/recognise symptoms.

4.6.5 Fear

Participants discussed fear of receiving a diagnosis and treatment, as well as fear of the interaction with their HCP. This finding is supported by the literature. Fear is the most studied emotion in relation to help-seeking behaviour and cancer. For some individuals fear leads to prompt presentation to an HCP while for others fear will result in postponement of help-seeking (Bish et al., 2005; Dubayova et al., 2010, p.445; Facione, 1993; Harirchi et al., 2005; Jones et al., 2014; Nosarti et al., 2000; O'Mahony et al., 2013; Otieno, Micheni, Kimende, & Mutai, 2010). In the context of this study fear was discussed as being associated with postponement of help-seeking. However, O'Mahony et al. (2013) in an Irish sample (n= 449) reported that 'being afraid on symptom discovery' was significantly associated with prompt help-seeking. Nosarti et al. (2000) found that generally, women who engaged in postponement of help-seeking expressed more fear of the consequences of diagnosis and treatment than those who did not and that postponement of help-seeking motivated by fear produced the greatest postponement. Similarly, in qualitative work with women reporting symptoms of breast cancer, Burgess et al. (2001) found that women who engaged in postponement of help-seeking were more likely to express explicit fears about the consequences of diagnosis and treatment. As discussed, the Common-Sense Model posits that we appraise our symptoms in terms of our illness representations and our emotional response. This explains why fear plays a large role in patient interval for breast cancer. An individual's knowledge about breast cancer is a critical component of the fear response; understanding the symptoms, consequence of treatment and curability of the disease will greatly reduce fear. It is therefore a vital component for any intervention to reduce postponement of help-seeking.

4.6.6 Limited resources and social support

A clear finding within the acceptability themes was that the intervention should be as effortless as possible, that is that there should be a minimum cognitive burden on individuals in using the website. They wanted clear, concise, and easy to follow pages and any interactive element to have the minimum amount of work involved as is possible. This speaks to women's limited resources due to their social role demands. This need is reflected in the research literature. Competing priorities can diminish a woman's self-efficacy for help-seeking behaviour and impact her goal setting (Bish et al., 2005; Burgess et al., 2001; Facione, 1993; Neave et al., 1990). It is difficult to prioritise a goal such as consulting an HCP if there are more proximal goals to attend to, such as doing the grocery shopping. The participants in this study did not explicitly discuss social role demands but were adamant at every opportunity that the intervention be as time effective as possible.

4.6.7 Idea generation and acceptability testing

The focus group discussions provided valuable information on the acceptability of the intervention. Overall the website components (v.1) presented were acceptable to the participants. This study has generated novel ideas for the intervention and provided practical guidance on a number of design issues. Explaining the theory behind goal-setting and action planning components greatly increases their acceptability to participants. It is clear that pink is associated with breast cancer and participants understood the distinction between a breast *cancer* website and a breast *health* website. Therefore, they supported the use of other colours. Participants suggested utilising the users own action plans as their reminders and prompts to behaviour. They believed their own words would serve as more effective reminders than a generic message. The findings also suggest that the discussion forum is not necessary, in fact, participants would be hesitant to use it as they identified multiple issues with its management. Participants suggested personal accounts would be useful for the website. Users could save the work generated from the planning tools and diary there as well as tailor their reminders. The personal accounts came with a caveat, however, it must be made clear to users how the website is protecting their data. Finally, participants suggested a breast health *map* as a means of self-monitoring. During the interviews they were presented with the breast health diary tool to help them to get to know their bodies normally look and feel. The diary was deemed acceptable by participants however, it was suggested that a more visual option would be helpful. The idea of the breast health map was acceptable to all participants.

4.6.8 Limitations

A limitation of this study is the demographics of the participants. While qualitative research does not aim to produce generalizable findings it was the goal of the study to sample a broad range of women to get as wide a range of views as possible. In terms of educational attainment, one participant had primary level only (5.9%), three had second level only (17.7%) and 13 had third level (76.5%). In the 2016 census 13% of people in Ireland had primary level only, 45% had second level only and 42% had third level (CSO, 2017). Individuals with third level education were over represented in this study.

4.7 Conclusion

The aim of this study was to explore the content of the *Know Breast Health* intervention by examining the perspectives of potential target users, assessing the acceptability of the proposed website components (v.1) and facilitating the generation of novel ideas for the intervention. Overall the website components (v.1) presented were acceptable to the participants. Participants proposed the idea of creating personal accounts on the website, where all their planning and self-monitoring tools could be stored as well as breast health maps for self-monitoring. Discussions in the interviews mapped clearly onto the Internet Intervention Model proving detailed guidance on how to create an engaging website by addressing issues of appearance, behavioural prescriptions, burden, content, delivery, message, participation and assessment (Ritterband et al., 2009). This study provides a clear mandate for the *Know Breast Health* intervention in terms of how the website should look and feel, as well as its content. The findings of this study will directly inform the next phase of development; the design stage of the Person-Based Approach. The findings will be used to create website components version two and the guiding principles of the *Know Breast Health* intervention.

5 Website Development for the *Know Breast Health* intervention

5.1 Chapter Overview

This chapter will describe the process involved in the second stage of the Person-Based Approach: *design*. It presents three major outputs: the intervention *logic model*, the *guiding principles* and version one of the intervention website. In the first section the findings from the Focus Group Interview Study will be used to update the website components to version 2. These will then be incorporated into an intervention logic model to explain the hypothesised mechanisms of action of the *Know Breast Health* intervention. In the second section, the findings from the Focus Group Interview Study will be combined with principles of digital health intervention design to create the *guiding principles* for the *Know Breast Health* intervention. The logic model and the guiding principles will be used as the building blocks for Website 1.0 and it will be described in the final section of the chapter.

5.2 Person-Based Approach stage two: Design

The second stage of the Person-Based Approach calls for the creation of the intervention *logic model* and *guiding principles* of the intervention. The logic model presents the detailed documentation of how each element of the intervention maps onto the BCTs and intervention functions to address the target behaviour (Yardley et al., 2015b). The guiding principles concisely detail the characteristics of the intervention that aim to optimise its acceptability and feasibility, and therefore, effectiveness. They are not intended to be exhaustive, rather, as the name suggests, they are guidelines for *how* the intervention is to be *delivered* (Morrison et al., 2018). Stage two of the Person-Based Approach builds on the work done in the planning stage to provide a blueprint for the intervention development. This blueprint will be used to create the website for the *Know Breast Health* intervention.

5.3 Website components

Website components are elements of the website that are active ingredients in the intervention. Website components version 1 (v.1) were developed in Chapter 3, based on the findings of the behavioural diagnosis and literature review. These were presented to participants in the Focus Group Interview Study to assess their acceptability and to see if any new website components could be generated. Table 5.1 contains website components (v.1) annotated with the findings from the Focus Group Interview Study. The Table presents each website component (v.1), stating if it was deemed acceptable to participants and outlining any

details or caveats from the findings of the Focus Group Interview Study. Website components version 2 were developed by updating website components version 1 with the results of the Focus Group Interview Study. Website components version 2 (v.2) will now each be discussed and are presented, with their corresponding BCTs in Table 5.2.

Table 5.1
Website components (v.1) annotated with findings from the Focus Group Interview Study

Website components (v.1)	**Focus Group Study findings**
Video of HCP demonstrating how to perform self-examination	Acceptable
Video of a woman performing self-exam	Acceptable
Video of a consultation	Acceptable
Video of HCP explaining the importance of immediate help-seeking	Acceptable
Text and image based information provision	Images of real bodies important; should be representative of a broad range of individuals in terms of age, size/shape, and skin colour
Goal setting, barrier identification and action planning tools	Explain the theory of goal-setting and action planning techniques so that the purpose/value of the task is clear to users
Breast health diary and map*	Develop easy visual technique for breast health mapping as well as breast health diary
Reminders*	Use the user's own action plans as the reminder.
Discussion Forum	Discussion forum not necessary, women hesitant to use it as they identified multiple issues with its management

*content proposed by participants in Focus Group Interview Study

5.3.1 Video components

All four videos were considered acceptable and helpful to participants in the Focus Group Interview Study. Therefore, no changes are necessary. The four proposed videos for the website are: an HCP demonstrating how to self-examine using a model of the female body; a woman performing a self-exam; a breast health consultation between an HCP and patient; and an HCP explaining the importance of immediate help-seeking upon self-discovery of a symptom of breast cancer.

5.3.2 Text and image-based information provision

This website will provide information, in multiple formats (text, images, infographics), about breast cancer as a disease, the importance of knowing ones' own normal bodily state and the importance of immediate help-seeking upon self-discovery of a symptom of breast

cancer. The Focus Group Interview Study participants stressed the importance of providing images of real bodies, rather than just graphical representations, as well as a diverse range of people; in terms of age, size/shape, and skin colour. Focus Group Interview participants wanted the details of the security protocol put in place to protect their data in order to feel confident using the website. Thus, information provision website components (v.2) will be in multiple formats (text, images, infographics), including images of real bodies.

5.3.3 Breast health diary

The Focus Group Interview Study found that the diary was acceptable to participants. However, they also proposed that a more visual method of self-monitoring would be useful, that is, a breast health map. They wanted this to be easy to use, with minimal time commitment required. Thus, the self-monitoring website component (v.2) will include two methods; breast health diary and map.

5.3.4 Goal setting, barrier identification and action planning tools

The goal setting, barrier identification and action planning tools were acceptable to participants but only after their purpose was explained. Thus, for interactive website components (v.2) the reasons why users are prompted to use these tools will be included in order to maximise engagement with them.

5.3.5 Discussion forum

The Focus Group Interview Study found that a discussion forum was not acceptable to participants. Participants believed that a discussion forum would only be acceptable if it was monitored by an HCP at all times. Participants thought this was necessary to prevent both intended and unintended misinformation. They did not believe it was possible for such a forum to be properly moderated and so would not use it. Thus, website components version 2 will not include a discussion forum.

5.3.6 Reminders

Reminders were acceptable to Focus Group Interview participants. They recommend using the completed action plans as the content for the reminders. Thus, the reminder component (v.2) will include the user’s own action plans as the prompt.

Table 5.2
Website Components (v.2) with intervention functions and BCTs

Website components (v.2)	**Intervention function**	**BCTs**
Video of HCP demonstrating how to perform self-examination	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal 8.3 Habit formation
	Persuasion	9.1. Credible source 15.1 Verbal persuasion about capability
	Modelling	6.1. Demonstration of the behaviour
	Education	6.3 Information about others' approval
Video of a woman performing self-exam	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal 8.3 Habit formation
	Persuasion	6.2 Social comparison 15.1 Verbal persuasion about capability
	Modelling	6.1. Demonstration of the behaviour
	Education	6.3 Information about others' approval
Video of a breast health consultation	Training	6.1. Demonstration of the behaviour
	Persuasion	6.2 Social comparison 9.1. Credible source
	Modelling	6.1. Demonstration of the behaviour
	Education	6.3 Information about others' approval
Video of HCP explaining the importance of immediate help-seeking	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source
	Education	5.1 Information about health consequences 6.3 Information about others' approval
	Coercion	5.5 Anticipated regret
Text and image based information provision	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing 15.1 Verbal persuasion about capability
	Education	5.1 Information about health consequences 6.3 Information about others' approval
	Coercion	5.5 Anticipated regret
Goal setting, barrier identification and action planning tools	Training	8.3 Habit formation
	Enablement	1.1 Goal setting (behaviour) 1.2. Problem solving 1.4. Action planning 1.9 Commitment
Reminder function	Environmental restructuring	7.1 Prompts/cues
Breast health diary/map	Enablement	2.3. Self-monitoring of behaviour

5.4 Logic Model for the *Know Breast Health* Intervention

The logic model is the culmination of the work done in Chapters 2 – 4. It incorporates the findings of the literature review, the behavioural diagnosis, the intervention functions the BCTs and the results of the Focus Group Study into a cohesive map. It is broken into three sections, one per *key target* of the intervention. The contributing factors identified in the literature review and the antecedences identified in the behavioural diagnosis can be organised into three themes, or, key targets. The key targets are a means of organising the intervention content in a cohesive and parsimonious whole. The key targets of the *Know Breast Health* intervention are 1) knowledge, 2) breast health habits and 3) help-seeking habits. Knowledge includes knowledge of breast cancer and its symptoms; knowledge of one's own normal bodily state; knowledge of how to self-examine; and knowledge of the importance of help-seeking. Breast health habits relate to the appraisal interval of the Pathways Model (Scott et al., 2013) and includes increasing self-efficacy for self-examination and the ability to notice a bodily change as well as managing negative cognitions and affect. Help-seeking habits relate to the help-seeking interval of the Pathways Model (Scott et al., 2013) and includes promoting a positive relationship with HCPs and removing barriers to help-seeking. The logic model, presented in Table 5.3, explains how each key target and its associated antecedents, will be addressed, by which website components, using BCTs. The construction of the website will be based on this logic model and the guiding principles discussed in the next section.

Table 5.3
The Know Breast Health Intervention Logic Model

Website components (v.2)	Intervention function	BCTs	Antecedents
		Key Target: Knowledge	
Video1: Expert demonstration	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal	Knowledge of how to perform self-exam
	Persuasion	9.1. Credible source 15.1 Verbal persuasion about capability	
	Modelling	6.1. Demonstration of the behaviour	

Website components (v.2)	Intervention function	BCTs	Antecedents
	Education	6.3 Information about others' approval	
Video2: Woman performing self-exam	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal	Knowledge of how to perform self-exam
	Persuasion	6.2 Social comparison 15.1 Verbal persuasion about capability	
	Modelling	6.1. Demonstration of the behaviour	
	Education	6.3 Information about others' approval	
Video3: Breast health consultation	Training	6.1. Demonstration of the behaviour	Knowledge about importance of help-seeking Knowledge about breast health consultation
	Persuasion	6.2 Social comparison 9.1. Credible source	
	Modelling	6.1. Demonstration of the behaviour	
	Education	6.3 Information about others' approval	
Video4: HCP explaining the importance of immediate help-seeking	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source	Knowledge about importance of help-seeking Knowledge about breast health consultation
	Education	5.1 Information about health consequences 6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Info1: Breast cancer and its symptoms	Persuasion	5.1 Information about health consequences 9.1. Credible source 13.2 Framing/reframing	Knowledge of breast cancer and its symptoms
	Education	5.1 Information about health consequences 6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Info2: Breast health habits	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing	Knowledge about importance of help-seeking Knowledge about importance of making

Website components (v.2)	Intervention function	BCTs	Antecedents
		15.1 Verbal persuasion about capability	time and space to perform self-exam
	Education	5.1 Information about health consequences 6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Info3: Help-Seeking Habits	Persuasion	6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing 15.1 Verbal persuasion about capability	Knowledge (optimism) about breast health consultation
	Education	6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Info4: Goal setting and action planning	Persuasion	5.1 Information about health consequences 9.1. Credible source 13.2 Framing/reframing	Knowledge about the purpose and evidence for goal setting, barrier identification & action planning
	Education	5.1 Information about health consequences 6.3 Information about others' approval	
Interactive1: Planning tools	Enablement	1.1 Goal setting (behaviour) 1.2. Problem solving 1.4. Action planning	Knowledge of barriers to breast health habits and help-seeking habits
Interactive2: Breast diary/map	Enablement	2.3. Self-monitoring of Behaviour	Knowledge of own normal bodily state
		Key Target: Breast health habits	
Video1: Expert demonstration	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal 8.3 Habit formation	Ability to perform self-exam Increased self-efficacy for performing self-exam
	Persuasion	9.1. Credible source 15.1 Verbal persuasion about capability	
	Modelling	6.1. Demonstration of the behaviour	
	Education	6.3 Information about others' approval	
Video2: Woman	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour	Ability to perform self-exam

Website components (v.2)	Intervention function	BCTs	Antecedents
performing self-exam		8.1. Behavioural practice and rehearsal 8.3 Habit formation	Increase self-efficacy for performing self-exam
	Persuasion	6.2 Social comparison 15.1 Verbal persuasion about capability	
	Modelling	6.1. Demonstration of the behaviour	
	Education	6.3 Information about others' approval	
Info1: Breast cancer and its symptoms	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing 15.1 Verbal persuasion about capability	Ability to recognise and remember symptoms Manage negative cognitions and affective reactions Increase self-efficacy for identifying symptoms Increase optimism about breast cancer curability
	Education	5.1 Information about health consequences 6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Info2: Breast health habits	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing 15.1 Verbal persuasion about capability	Normalising breast health habits Understanding importance of good breast health habits Manage negative cognitions and affective reactions Increase self-efficacy for identifying symptoms Increase self-efficacy for making time and space to perform exams
	Education	5.1 Information about health consequences 6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Interactive1: Planning tools	Training	8.3 Habit formation	Increase self-efficacy for identifying symptoms Increase self-efficacy for detecting changes Increase self-efficacy for making time and space to perform exams Identification of barriers to good breast health habits
	Enablement	1.1 Goal setting (behaviour) 1.2. Problem solving 1.4. Action planning 1.9 Commitment	

Website components (v.2)	Intervention function	BCTs	Antecedents
Interactive2: Breast diary/map	Enablement	2.3. Self-monitoring of behaviour	Self-monitoring of the upper body Knowledge of normal bodily state Ability detecting changes Increase self-efficacy for detecting changes Increase self-efficacy for knowing normal bodily state
Interactive3: Reminder	Environmental restructuring	7.1. Prompts/cues	Self-monitoring of the upper body Knowledge of normal bodily state Ability detecting changes Increase self-efficacy for identifying symptoms Increase self-efficacy for detecting changes Increase self-efficacy for making time and space to perform exams
Key Target: Help-seeking habits			
Video3: Breast health consultation	Training	6.1. Demonstration of the behaviour	Manage negative cognitions and affective reactions Optimism about interaction with HCP Understanding breast health consultation process
	Persuasion	6.2 Social comparison 9.1. Credible source	
	Modelling	6.1. Demonstration of the behaviour	
	Education	6.3 Information about others' approval	
Video4: HCP explaining the importance of immediate help-seeking	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source	Manage negative cognitions and affective reactions Optimism about interaction with HCP Knowledge about importance of immediate help-seeking Self-efficacy for making time to schedule and attend appointment
	Education	5.1 Information about health consequences	

Website components (v.2)	Intervention function	BCTs	Antecedents
		6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Info1: Breast cancer and its symptoms	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing 15.1 Verbal persuasion about capability	Manage negative cognitions and affective reactions Knowledge about importance of immediate help-seeking
	Education	5.1 Information about health consequences 6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Info3: Help-Seeking Habits	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing 15.1 Verbal persuasion about capability	Manage negative cognitions and affective reactions Knowledge about importance of immediate help-seeking Optimism about interaction with HCP
	Education	5.1 Information about health consequences 6.3 Information about others' approval	
	Coercion	5.5 Anticipated regret	
Interactive1: Planning tools	Enablement	1.1 Goal setting (behaviour) 1.2. Problem solving 1.4. Action planning 1.9 Commitment	Increase self-efficacy for making time and space to perform exams Identification of barriers to help-seeking Increase self-efficacy for help-seeking
Interactive2: Breast diary/map	Enablement	2.3. Self-monitoring of Behaviour	Increase self-efficacy for help-seeking

5.5 Guiding principles for the *Know Breast Health* Intervention

The guiding principles are the key design objectives of the intervention (Yardley et al., 2015b). They provide guidance to developers on the characteristics of the intervention that aim to optimise its acceptability and feasibility, and therefore, effectiveness. They are summary of *how* the intervention is to be *delivered* (Morrison et al., 2018). The guiding principles are an essential part of the intervention development process and will make up the

blueprint for the *Know Breast Health* intervention website, along with the intervention logic model.

The Person-Based Approach has developed generic or common guiding principles which improve the acceptability of, and engagement with, digital interventions (Yardley et al., 2015b). They are: promoting competence, promoting autonomy and promoting a positive experience and relatedness. Ritterband et al. (2009), in their Internet Intervention Model, have proposed similar guidelines on how to deliver internet interventions to increase their usability and the acceptability. These two complementary approaches to digital intervention design are presented in Table 5.4. They will be used, alongside the findings of the Focus Group Interview Study to develop the guiding principles for the *Know Breast Health* intervention. Each of the three common guiding principles from the Person-Based Approach will now be discussed in relation to the Internet Intervention Model and the findings of the Focus Group Study Interview. Finally, the guiding principles for the *Know Breast Health* intervention will be presented in Table 5.6.

Table 5.4
Internet Intervention Model elements and definitions linked to the Person-Based Approach common guiding principles

Internet Intervention Model		**Person-Based Approach features**
Appearance	How it looks and feels to the user	*Promoting a Positive Experience and Relatedness*: provide users with an enjoyable, positive, and interesting experience
Behavioural prescriptions	Instruct the user on what to do to address the problem targeted by the intervention	*Promoting Competence*: goal setting, social modelling, implementation planning, tailored feedback
Burdens	Navigation difficulties and intervention length	*Promoting a Positive Experience and Relatedness*: ensure that users can navigate and process interventions as quickly and easily as possible
Content	Accurate, clear, and simple	*Promoting a Positive Experience and Relatedness*: using short sentences, list and audio-visual formats, tailoring where appropriate
Delivery	Ways in which the content can be delivered	*Promoting Competence*: using testimonials as social modelling for overcoming obstacles
Message	Source and style of the website	*Promoting a Positive Experience and Relatedness*: using a positive autonomy-supportive (i.e., non-directive) tone and non-judgmental language at all times. Invite rather than instruct users to participate/engage, avoid words such as “should” or “must”, replace “wrong” with “surprise” etc.

Internet Intervention Model		Person-Based Approach features
Participation	Ability to engage participants	*Promoting Autonomy*: offering users a choice in how they engage with the intervention and implement the advice provided, including the goals they set, strategies they use, and aspects of the timing, order, and delivery of intervention content i.e. "self-tailoring". Caveat: too much choice can be overwhelming and so "tunnelling" can be necessary to ensure essential intervention content is received
Assessment	Ability to personalise the information provided to the user program	*Promoting Autonomy*: offering users a choice in aspects of the timing, order, and delivery of intervention content i.e. "self-tailoring"

5.5.1 Promoting a Positive Experience and Relatedness

The Person-Based Approach states that promoting a positive experience and relatedness within the design of a website is crucial to engagement with and adherence to digital interventions (Bradbury et al., 2014). Using the website must be an enjoyable, positive, and interesting experience (Yardley et al., 2015b). The Internet Intervention Model states the same objective (Ritterband et al., 2009). To achieve this the *appearance* of the website must be pleasing and the *burden* of use must be minimal (Ritterband et al., 2009). The *content* of the website should be accurate, clear, and easily understood and the mode of *delivery* should be varied (Ritterband et al., 2009). The findings of the Focus Group Interview Study clearly echoed these design recommendations from Person-Based Approach and the Internet Intervention Model. Focus Group Interview participants wanted a website that was easy to navigate, clear and clutter free but that provided the same information in multiple formats: images, infographics, text, and video. Brevity was highlighted as an important element in promoting a positive experience for participants; they wanted all content and tasks to be as concise as possible to minimise the time commitment requirement.

The Person-Based Approach stresses the importance of using a positive, non-directive, tone and non-judgmental language throughout the website. Yardley et al. (2015b) states it is critical to invite rather than instruct users to participate. Words such as "should" or "must" should be avoided and words such as "wrong" replaced with "surprise" etc. Ritterband et al. (2009) also stress the importance of the *message* of the website, incorporating the tone and the source of the website: it must appear trustworthy to ensure engagement. Yardley et al. (2015b, p. 11) outlines clear guidelines to promote trustworthiness in the source of a website, which are presented in Table 5.5. Participants in the Focus Group Interview Study stated that the NUI Galway logo would lend credibility to the website, but they would also require

information on how their data was protected (in the event of creating an individual account) to maximise the trustworthiness of the website.

Table 5.5
Person-Based Approach guidelines to promote trustworthiness in the source of a website (Yardley et al., 2015b, p. 11)

Guidelines to promote trustworthiness a website
1. Professional and consistent visual appearance
2. Error free and up-to-date content
3. Usable interface; provision of supporting evidence for the information provided
4. Details and credentials of the team responsible for developing the intervention
5. Opportunities to contact and provide feedback to the intervention team
6. Information on what data is collected from users, how that data will be used and stored

5.5.2 Promoting Competence

Promoting competence, or increasing users' sense of control and confidence, will increase the likelihood of a user engaging with, and adhering to, a digital intervention (Yardley et al., 2015b). This can be achieved through social modelling, (by demonstrating how others have overcome obstacles), goal-setting and action planning (Yardley et al., 2015b) and through *behavioural prescriptions* such as behavioural contracts or prompts (Ritterband et al., 2009). These encourage users to address the problem targeted by the intervention in a manageable and achievable way, thereby promoting competence. The Focus Group Interview Study found that participants understood the value of these kinds of tool, however it is important to explicitly state their purpose.

5.5.3 Promoting Autonomy

The goal of the common guiding principle, promoting autonomy, is to promote intrinsic motivation for the target behaviour (Yardley et al., 2015b). A key method to achieve this to provide users with choice, also known as *self-tailoring* (Yardley et al., 2015b) or a*ssessment* (Ritterband et al., 2009). This could be for example, a choice in the goals that users set, or in the content they look at. Focus Group Interview participants had strong negative feelings about being forced into a decision. For example, they made it clear that they would not like to have to complete one website section to gain access to another. Choice was paramount.

Table 5.6
Guiding Principles for the Know Breast Health intervention website

Guiding Principles
1. Multiple formats key: video, text, graphics
2. Make the experience as tailored to the user as possible
3. Keep initial interface as simple and brief as possible, site should be uncluttered and easy to navigate; include click-through options for more detailed information
4. Colour pink is associated with breast cancer, blue, white, green associated with health
5. Include University logo and details of the team responsible for developing the intervention to promote trustworthiness
6. Ensure choice is available at all times; do not require engagement in certain tasks in return for access to content
7. Ensure completion of all tasks in intervention are is not too onerous on the participant
8. Personal optional account preferable to printing/emailing options but have available for all content
9. Ensure users are aware of the details of the security protocol put in place to protect their data
10. No push-notifications, used tailored reminders, ensure user can tailor by time and date
11. Interactive components must easy to use, with minimal time commitment required

5.6 Website 1.0

The website was constructed using *WordPress Professional: Mesmerize*. All construction, design, maintenance and editing was carried out by EC. The construction of Website 1.0 followed the logic model and the guiding principles developed in this chapter. The website has three modules (see Figure 5.1) which relate directly to the three key targets of the intervention: *Module 1: Know Your Body* (key target: breast health habits), Module 2: Know Your GP (key target: help-seeking habits) and Module 3: Know Breast Cancer (key target: Knowledge). There is also a Home page and an About Us page. During website construction some of the planned website components (v.2) were edited or omitted. This process is presented in Table 5.7.

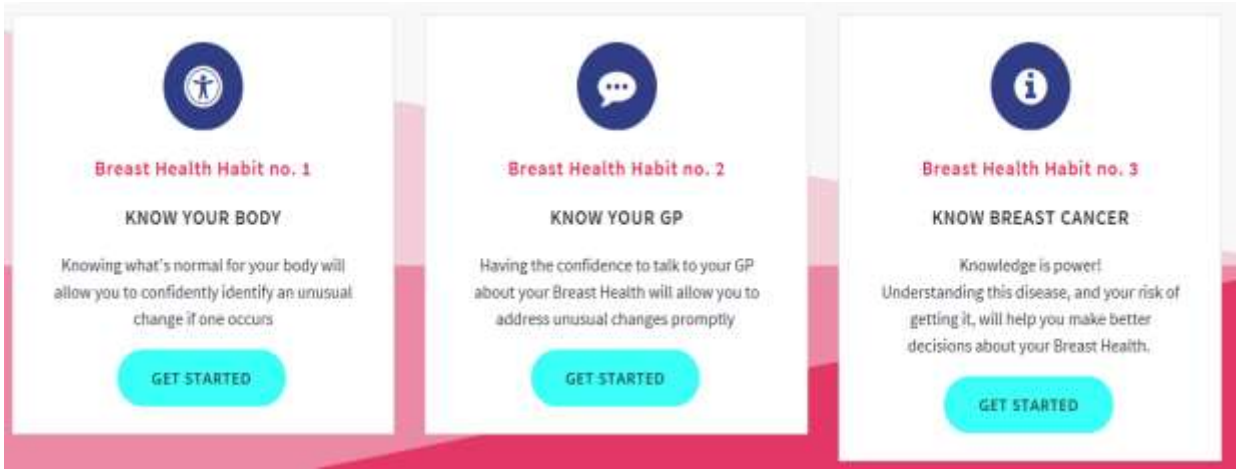

Figure 5.1. The three modules of the *Know Breast Health* intervention.

5.6.1 Video components (v.3)

Website components version 2 proposed four videos; two aimed to help users to get to know their bodies: an HCP demonstrating how to self-examine using a model of the female body and a woman performing a self-exam. As discussed in Chapter 1, breast self-examination is no longer recommended. However, the only videos available were of an HCP recommending the specific guidance of breast self-examination, rather than simply demonstrating how to self-examine. Therefore only one video to help users to get to know their bodies was included on the website. It was developed by the breast health charity *CoppaFeel* (see Figure 5.2). It is a registered charity in England and Wales (1132366) and Scotland (SC045970). A link to the video, and the transcript, are presented in Appendix 6a. The video aligns with current best practice recommendations for breast awareness. Breast awareness involves individuals having confidence to 'look at and feel' their breasts so that they know what is normal for their own body as well as the knowledge of what changes to look and feel for (O'Mahony et al., 2017). Breast awareness highlights that there is no right or wrong way to self-examine (unlike with breast self-examination) and it can be done at any time that is convenient for the individual. The *CoppaFeel* video includes individuals of different, genders, skin colours, shapes and sizes self-examining in accordance with the intervention guiding principles.

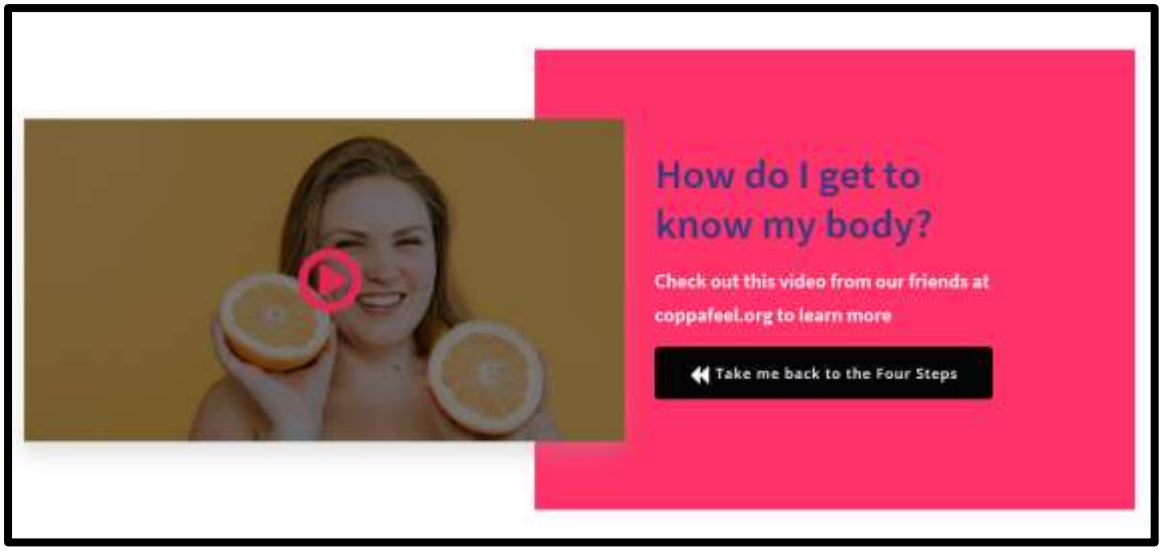

Figure 5.2. A screenshot from *Module 1: Know Your Body* of the CoppaFeel video.

Website components (v.2) included two videos to encourage immediate help-seeking upon self-discovery of a breast cancer symptom: a breast health consultation between an HCP and patient; and an HCP explaining the importance of immediate help-seeking. Due to the limited resources available this content was combined into one video on the website (see Figure 5.3). This video is a recording of a female GP in her consultation room. The GP encourages women to get to know their breasts so that any unusual change can be detected and stresses the importance of immediate help-seeking upon self-discovery of an unusual change. The GP describes in detail what occurs in a breast health consultation. Thereby combining the information from the previous proposed videos. The transcript, and link to the video, is presented in Appendix 6b.

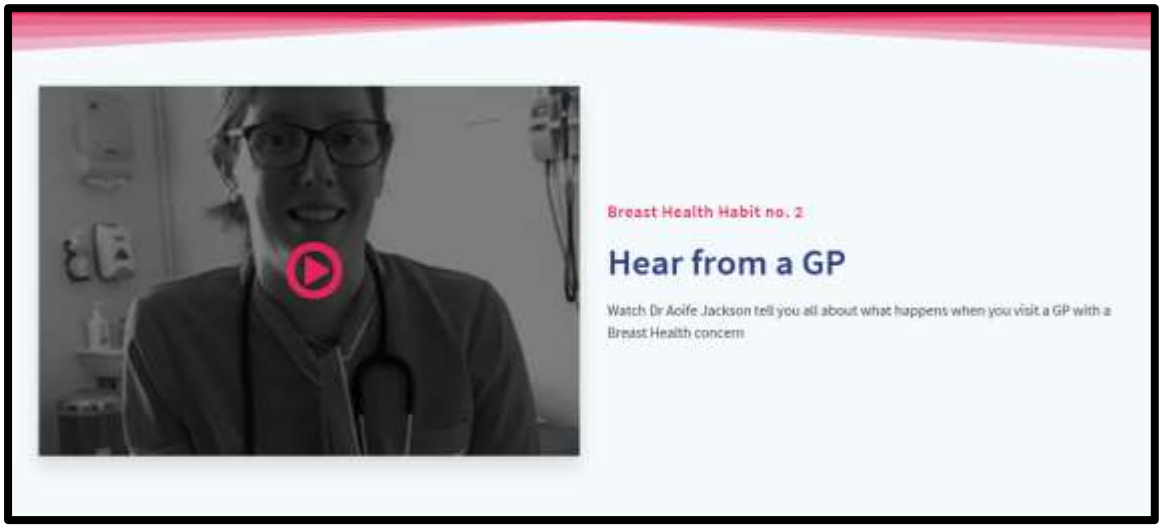

Figure 5.3. A screenshot from *Module 2: Know Your GP* of the GP video.

5.6.2 Text and image based information provision

This website provides information, in multiple formats (text, images, infographics), about breast cancer as a disease and the importance of knowing ones' own normal bodily state, the importance of immediate help-seeking upon self-discovery of a symptom of breast cancer and the importance of action planning for achieving goals (see Figures 5.4 and 5.5 for examples).

Figure 5.4. A screenshot from *Module 1: Know Your Body* explaining why goal setting is important.

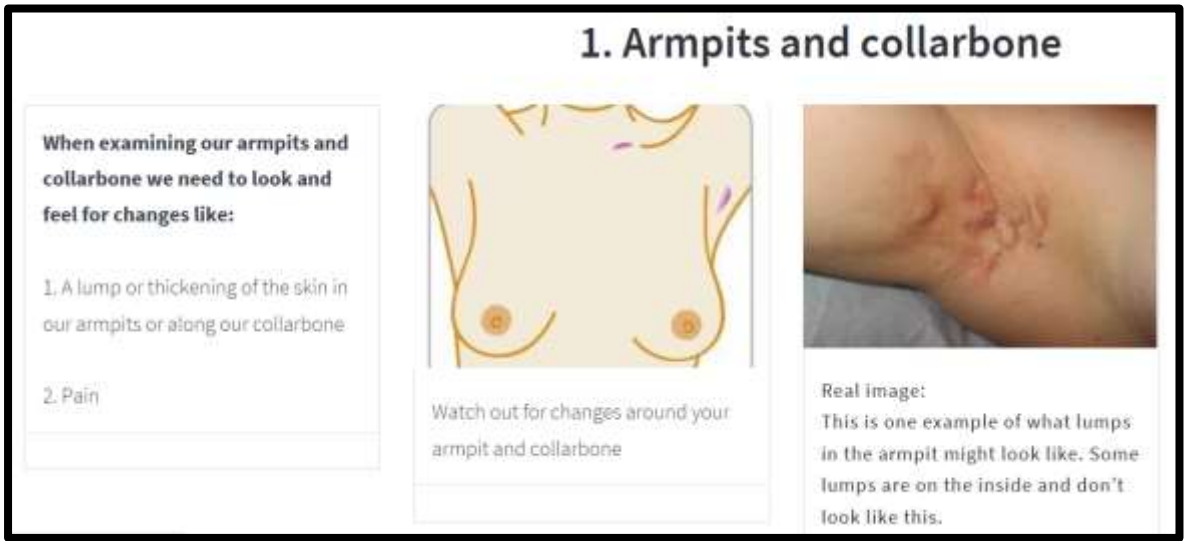

Figure 5.5. A screenshot from *Module 3: Know Breast Cancer* explaining one of the symptoms of breast cancer.

5.6.3 Breast health diary

The Focus Group Interview Study found that the diary was acceptable to participants. Breast health diary (v.1) can be seen in Appendix 7a. Participants also proposed that a more visual method of self-monitoring would be useful, that is, a breast health 'map'. They wanted this to be easy to use, with minimal time commitment required. Within the resource constraints of the *Know Breast Health* intervention a paper map was be developed. Participants has the option of printing an image that they could then annotated with details of their breast health (see Figure 5.6).

Figure 5.6. A screenshot from *Module 1: Know Your Body* of the breast health map.

5.6.4 Goal setting, barrier identification and action planning tools

Planning tools were created for *Module 1: Know Your Body* and *Module 2: Know Your GP*. They included interactive goal setting, barrier identification and action planning activities for the key targets of the intervention. Upon completion users can email their competed plans to their own email account. The *Module 1: Know Your Body* planning tool (v.1) and the *Module 2: Know Your GP* planning tool (v.1) are presented in Appendix 8a and 9a.

5.6.5 Reminders

Reminders were considered an important component of the *Know Breast Health* intervention. The website suggested to users that a reminder would be helpful tool to help them create positive breast health habits. They were provided instructions on how to set a reminder on their own phones. They were given the option to choose between instructions for

android phones or iPhones (see Figure 5.7). The Focus Group Interview Study findings recommend using the completed action plans as the content for the reminders. This was not possible in the context of the resources available for the *Know Breast Health* intervention.

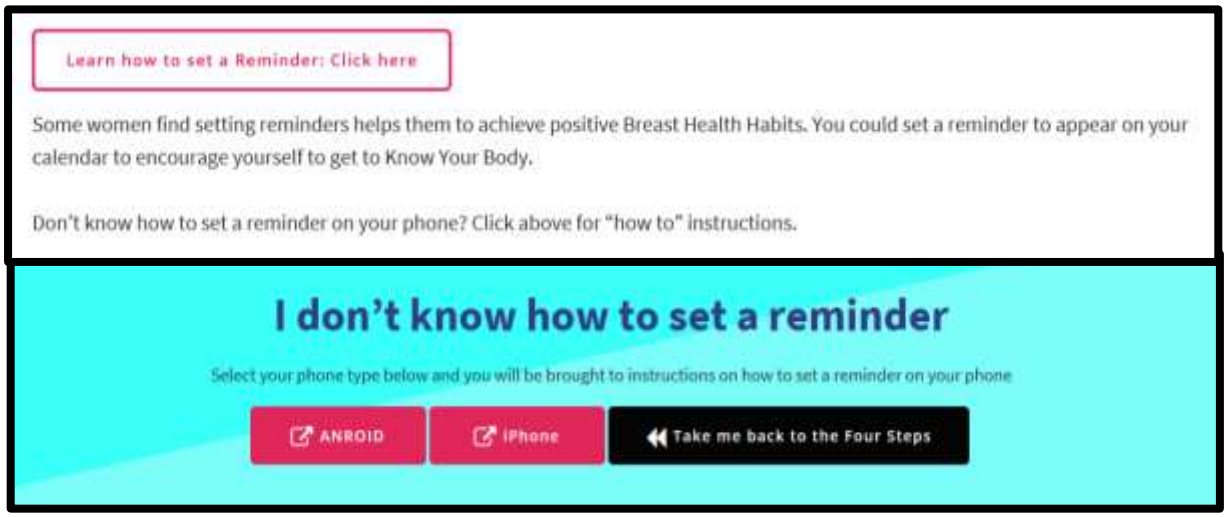

Figure 5.7. A screenshot from *Module 1: Know Your Body* of the reminder feature.

5.6.6 Tailoring

Tailoring is not a website *component* (it does not deliver any BCTs), however, it is a crucial part of the guiding principles for the *Know Breast Health* intervention and therefore a key feature of the website. Tailoring is achieved through asking users a question and directing them to content based on their answer. In *Module 1: Know Your Body*, the users are asked a series of questions designed to ascertain if they are confident that they know how their body looks and feels normally (see Figure 5.8). A negative response directs users to through *Module 1: Know Your Body*. An affirmative response sends users directly to *Module 2: Know Your GP* thereby tailoring the experience by not exposing users to content that is not relevant.

In *Module 2: Know Your GP*, the users are asked the question "Would you feel comfortable asking your GP to examine your breasts?" (see Figure 5.9). A negative response directs users to solutions (such requesting a female HCP when booking the appointment) while an affirmative response reinforces the importance of *immediate* help-seeking.

Figure 5.8. Screenshot of tailoring feature in *Module 1: Know Your Body*.

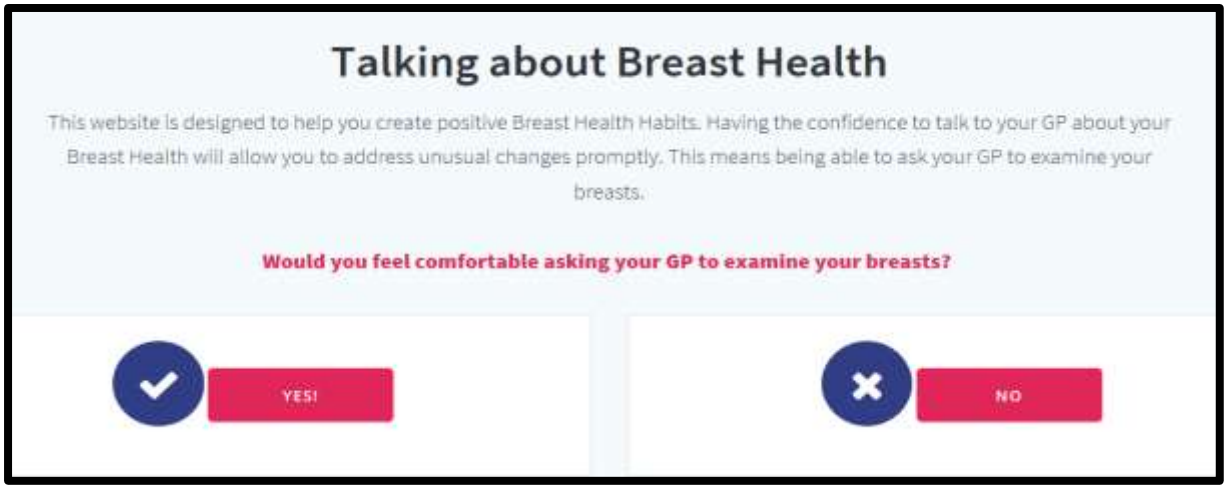

Figure 5.9. Screenshot of tailoring feature in *Module 2: Know Your GP*.

Table 5.7
Website components (v.3) of the Know Breast Health intervention

Website components (v.3)	Intervention function	BCTs
Know Your Body Video	Training	4.1. Instruction on how to perform the behaviour 6.1. Demonstration of the behaviour 8.1. Behavioural practice and rehearsal 8.3 Habit formation
	Persuasion	6.2 Social comparison 15.1 Verbal persuasion about capability
	Modelling	6.1. Demonstration of the behaviour
	Education	6.3 Information about others' approval
Know Your GP Video	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source
	Education	5.1 Information about health consequences 6.3 Information about others' approval

Website components (v.3)	Intervention function	BCTs
Text and image based information provision	Persuasion	5.1 Information about health consequences 6.2 Social comparison 9.1. Credible source 13.2 Framing/reframing 15.1 Verbal persuasion about capability
	Education	5.1 Information about health consequences 6.3 Information about others' approval
	Coercion	5.5 Anticipated regret
Goal setting, barrier identification and action planning tools	Training	8.3 Habit formation
	Enablement	1.1 Goal setting (behaviour) 1.2. Problem solving 1.4. Action planning 1.9 Commitment
Reminder function	Environmental restructuring	7.1 Prompts/cues
Breast health diary/map	Enablement	2.3. Self-monitoring of behaviour

5.7 Chapter summary

This chapter presented the design stage of the development of the *Know Breast Health* intervention. It described three major outputs: the intervention *logic model*, the *guiding principles* and Website 1.0. The logic model linked the findings from the Focus Group Interview Study with the Behaviour Change Wheel output from Chapter 3 to explain the mechanisms of action for the intervention. The guiding principles succinctly summarised the design objectives of the intervention by combining principles of digital health intervention design with the findings of the Focus Group Interview Study. Finally Website 1.0 was described. This is now ready to be presented to participants in the next stage of development: *optimisation*.

6 Optimising the *Know Breast Health* intervention: A Think-aloud Interview Study

6.1 Chapter overview

This chapter will describe the first study in the optimisation of the *Know Breast Health* intervention. It will begin by discussing the relevant background to the study, its aims and methods used. The findings will be then be presented and the iterative changes to the website described. Finally, the results will be discussed in light of other research in the area.

6.2 Background

The third stage of the Person-Based Approach is the *optimisation* stage whereby the acceptability, usability and feasibility of the intervention is enhanced. In the optimisation stage detailed user feedback is elicited that enables researchers to understand the views and experiences of those using the intervention as well as *how* they choose to use it (Morrison et al., 2018). The aim of intervention optimisation is to gain insights into every aspect of the intervention to ensure it is persuasive, acceptable and easy to use (Morrison et al., 2018). The Person-Based Approach recommends conducting think-aloud and retrospective interviews to investigate how participants use the intervention.

Think-aloud interviews require participants to vocalise their thoughts while completing a task (Branch, 2000; Jaspers, 2009). Think-aloud interviews are frequently used to assess the usability, acceptability and feasibility of digital health interventions (for examples see Bradbury et al., 2018; Crane et al., 2017; Perski, Blandford, Ubhi, West, & Michie, 2017). In think-aloud interviews participants are asked to navigate the digital intervention (e.g. a website) and provide a running commentary of their thoughts and feelings on what they were seeing and reading. Think-aloud interviews are an essential part of the Person-Based Approach as they are ideal for optimising interventions (Yardley et al., 2015b). They allow for the identification of issues of comprehension, navigation and engagement. Think-aloud interviews are not susceptible to recall biases which can occur if asking participants to reflect on an intervention they have used in the past (Branch, 2000; Yardley et al., 2016). Think-aloud interviews provide real-time reaction to every element of the intervention allowing for accurate, iterative design improvements (Jaspers, 2009; Yardley et al., 2015b).

Think-aloud interviews are effective for improving acceptability, usability and feasibility of interventions and identifying issues before going to pilot stage. For example, in

the development of a breathing-training for asthma intervention, researchers discovered that the associated imagery was not acceptable to participants (Arden-Close et al., 2019; Yardley, Ainsworth, Arden-Close, & Muller, 2015a). Based on consultation with patient stakeholders the image chosen for the intervention was a woman doing yoga. However, participants in think-aloud interviews felt that the image was too disconnected from asthma and breathing training. The researchers, therefore, changed the image to a pair of lungs. They believed that because it was medical information booklet about breathing, this would be appropriate. In further rounds of think-aloud interviews it too was found to be unacceptable to participants; they found the image of the lungs unfriendly and reported that they would be unlikely to pick up such a booklet. The researchers then changed the image to someone blowing a dandelion. This was universally accepted by participants in the next round of interviews. Participants felt the new image related to breathing but was not too clinical; it was friendly (Arden-Close et al., 2019; Yardley et al., 2015a). This work demonstrates the value that iterative rounds of think-aloud interviews can provide. Not only can issues with acceptability be identified, they can be iteratively refined (Morrison et al., 2018; Yardley et al., 2015a; Yardley et al., 2015b).

Think-aloud interviews have become the most popular qualitative method for assessing the usability of digital health interventions (Maramba, Chatterjee, & Newman, 2019). A scoping review was conducted on literature available from April 2014 to October 2017 to summarise the current methods used in usability assessment of eHealth applications. In the review, eHealth applications referred to websites, PC software and smartphone and tablet applications (apps). Of the 133 articles that met the inclusion criteria 70 used qualitative methods to assess usability; think-aloud interviews were used in 45 of those studies. A Pearson Chi-squared test ($\chi 2=11.15$, $p < 0.05$) found that the use of think-aloud interviews was significantly associated with at least one further iteration of the eHealth application being developed (Maramba et al., 2019). That is, the think-aloud interview methodology was that most often used for the *optimisation* of digital interventions.

Think-aloud interviews provide rich data and can therefore be effective with small numbers of participants. Nielsen (1994) reported that five participants are sufficient to locate between 77% and 85% of all usability problems, with progressively diminishing returns for more participants. This approach (five users) has been widely implemented in usability research since. Some researchers are critical of Nielsen's work, however, and have reported that in some cases five participants only located as little as 55% of errors (Faulkner, 2003). Nielsen (1994), however, states that when selecting the number of participants, the severity of

the outcome should any errors remain, the skill and experience of the interviewer and the number of design iterations involved should all be considered. In an experiment designed to examine this five-user estimate Faulkner (2003) assessed 60 users and randomly sampled sets of five or more from the whole. Faulkner (2003) found that increasing the number from five to ten can result in a dramatic improvement in data confidence: groups of ten found 95% of the usability problems. Faulkner (2003) concludes that given the complexity of designing for diverse user populations it is advisable to run the maximum number of participants that schedules, budgets, and availability allow.

6.2.1 Study aims

The first aim of this study is to identify issues of comprehension, navigation and engagement with the *Know Breast Health* intervention. The second aim is to rectify these issues where possible through multiple rounds of data analysis and iterative modifications to the intervention.

6.3 Method

6.3.1 Ethics

This study received ethical approval from the National University of Ireland, Galway, Research Ethics Committee. All participants gave informed consent. See Appendix 1b for participant information sheet and Appendix 3 for sample consent form.

6.3.2 Design

An experiential, qualitative study was conducted using semi-structured think-aloud interviews (Braun & Clarke, 2013). The focus of the study is the participants' point of view and their experience of using the website. This study is reported using the *Consolidated Criteria for Reporting Qualitative Research* (see Appendix 5b), a 32-item checklist for interviews to ensure rigour in qualitative studies through explicit and comprehensive reporting (Tong et al., 2007).

6.3.3 Ontology and epistemology

The Person-Based Approach recommends exploring the perspectives of potential target users of the *Know Breast Health* intervention and so this study took a critical realist approach within a contextualist framework. Qualitative research can be underpinned by different ontological and epistemological assumptions. This refers to the theories about the nature of reality and knowledge. On the ontological spectrum critical realism sits in the centre. Realism posits a knowable single truth that we can accurately observe. Critical realism argues that

there is a knowable world but that it is always observed subjectively, and so, there is no single truth (Braun & Clarke, 2013). On the epistemological spectrum, similar to critical realism, the contextualist approach sits in the centre. The contextualist approach posits that there are many truths but that they can only be known within the context they are researched. In the contextualist approach knowledge is always context dependent so there is no universal truth waiting to be discovered. Contextualists believe all knowledge is subjective but this does not prohibit it from being true (Braun & Clarke, 2013). Thus, a contextualist framework, with a critical realist approach is ideal for exploring participants experience of using the *Know Breast Health* intervention website.

6.3.4 Sample & recruitment

Purposive sampling is the typical approach taken in qualitative research. It involves selecting participants based on their ability to provide rich data that will address the research question (Palinkas et al., 2015). In this study the purposive sample is women, living in Ireland, aged 18 – 49. There are many different types of purposive sampling, in this study stratification is used. Stratification is sampling to ensure that diversity is incorporated into the data (Braun & Clarke, 2013). The aim of stratification is not to be exhaustive or generalisable, but rather to enable the inclusion of a broad range of people to contribute to the research (Braun & Clarke, 2013). Therefore, stratification was based on age, education level (primary, second, third) and residence (urban or rural). This is in keeping with the Person-Based Approach, and other studies using qualitative interviews for intervention development (Braun & Clarke, 2013; Crane et al., 2017; Greenwell et al., 2018; Yardley et al., 2015b).

Participants were recruited from the local community through posters and flyers. Posters were placed in community centres, employment centres, libraries and churches in the main residential areas in the west and east of Galway city and Galway city centre. Staff and students at NUIG were recruited through posters placed in the School of Psychology building.

6.3.5 Participants

Participants were 12 women with an age range of 18 – 49 years. The majority (75%) of participants had a third level education and 83% lived in an urban area. Demographic details of each participant are presented in Table 6.1.

Table 6.1
Demographic variables for each participant in the Think-aloud Interview Study

Round	ID	Age	Residence	Education level	Occupation
1	**201**	22	Urban	Second	Sales Assistant
	202	22	Urban	Third	Student
	203	22	Rural	Third	Student
	204	22	Urban	Third	Student
2	**205**	34	Urban	Third	Physiotherapist
	206	32	Urban	Third	Dietician
	207	37	Urban	Third	Nurse
	208	46	Urban	Third	Administrator
3	**209**	49	Urban	Second	Quality technician
	210	18	Urban	Second	N/A
	211	47	Rural	Third	Researcher
	212	38	Urban	Third	Tutor

6.3.6 Materials

ShareX was used to capture on-screen activity during the interviews. Previous research recommended that the screen activity of participants during think-aloud interviews be recorded to allow analysis of comments and actions together (Crane et al., 2017; Perski et al., 2017). ShareX was chosen as it is a free, and open-source, screenshot and screencast utility for Microsoft Windows. It is published under the GNU General Public License.

6.3.7 Procedure

The interviews were in conducted in three rounds, with four interviews held in each round. After each round was complete, that is, after four interviews were conducted, the data was analysed and modifications made to the website before the next round began (details of analysis in section 6.3.8). Eight of the eleven interviews took place on NUI Galway campus in the School of Psychology building. The remaining three took place in a community centre in the west of Galway City. All interviews were conducted by EC and were screen and audio recorded. All participants received a soft copy of the participant information sheet (Appendix 2b) a minimum of 24 hours before the interview. They were presented with a hard copy participant information sheet to re-read before the interview began and were given the opportunity to ask questions. Consent forms (Appendix 3) were then provided to participants. All participants consented to participation. Finally, the participants filled in a demographics form (see Appendix 4).

Each interview began with an explanation of the think-aloud interview technique and its purpose (see Appendix 1b for instructions and interview schedule). It was highlighted to participants that they should be as critical as possible in order to find and rectify any issues the website may have but that it was also important to share what they liked about it. Participants were told to imagine they had received the link to the website from a friend and to explore it as they would naturally. They were instructed to say everything that they were thinking out loud while they used the site. EC noted each section of the website the participants visited during natural navigation using a checklist (see Appendix 10). When they were finished they were directed to any areas they had missed. When participants had been exposed to all elements of the website they were asked general questions (see Appendix 1b for interview schedule). Finally participants were offered the opportunity to ask questions or make further comments and were thanked for their contribution. The interviews averaged 52 minutes in duration with a range of 36 to 74 minutes.

6.3.8 Analysis

An iterative, descriptive, rapid analysis was conducted (Bradbury et al., 2018). The iterative analysis followed the steps adapted from Bradbury et al. (2018), outlined in Table 6.2. Explicit meaning in the data was identified so the findings could be used to optimise the *Know Breast Health* intervention website. Transcripts were read and re-read until the researcher was familiar with them. Then each transcript was coded line by line using NVivo 12 software. Nodes were created for every website section and the data was coded into these nodes accordingly. For example, if a participant was speaking about the Home page of the website, the data was coded into the Home page node. This resulted in every website section having data assigned to it. In step three of analysis the data coded for each website section was analysed. Any data that identified potential barriers to engagement were sub-coded as such. Step four of the analysis involved tabulation of the potential barriers and problems. Following tabulation, solutions were proposed for each potential barrier and a modification code applied. Finally, selected modifications were implemented. Shorthand labels were used for each website section to make analysis easier. These shorthand labels are outlined in Table 6.3.

Table 6.2
Steps in the think-aloud interview analysis

Iterative rapid analysis protocol
1. Familiarisation with transcripts
2. Line by line coding in NVivo 12
3. Potential modifications identified and coded in NVivo 12
4. Potential modifications tabulated
5. Solutions for potential modifications proposed
6. Modification coded
7. Selected modifications implemented

EC conducted the rapid analysis, proposed the solutions, applied modification codes and implemented the changes by editing the website. This rapid iteration approach is in keeping with recommendations from previous research (Garnett et al., 2018; Morrison et al., 2015). Morrison et al. (2015) report the benefit of this approach, namely efficiency. The same researcher conducts the interviews and implements changes to the website thereby streamlining the process by removing the need to communicate feedback to a computer programmer (Morrison et al., 2015). Rapid analysis is critical when developing digital interventions as technological advancements already move faster than the speed at which interventions are typically developed and evaluated (Garnett et al., 2018; West & Michie, 2016).

Table 6.3
Shorthand labels for the Know Breast Health Intervention website

Label	**Description of website section**
KYB	Know your body (module 1)
KYB/Tailor	Tailoring component
KYB/Diary	Breast health diary
KYB/Map	Breast health map
KYB/Plan	Goal setting, barrier identification and action planning tools
KYB/Reminder	Reminder instructions
KYB/Video	Know Your Body video
KYGP	Know your GP (module 2)
KYGP/Tailor	Tailoring component
KYGP/Plan	Goal setting, barrier identification and action planning tools
KYGP/Video	Know Your GP video
KBC	Know breast cancer (module 3)
KBC/Risk	Information about breast cancer risk
KBC/Symptoms	Information about breast cancer symptoms
KBC/Survival	Information about breast cancer treatment and survival

Home	Home page
AboutUs	Information about who created and funded the website

The modification codes, adapted from Bradbury et al. (2018), and their descriptions can be seen in Table 6.4. There are three reasons a change was implemented: 1) it was important for behaviour change and consistent with the intervention logic model, 2) it was repeated by more than one participant 3) it was straightforward and feasible to implement and consistent with the intervention guiding principles. There were three reasons a change was not implemented: 1) it contradicted the logic model and/or the guiding principles, 2) it was not feasible to do so and 3) it was only supported by one participant. Once the modifications were coded the selected changes were made to the website. The iterative analysis protocol (Table 6.2) was implemented three times, after each round of interviews was complete. Following the completion of the iterative analysis and modification implementation, a general analysis was conducted. This pooled the data from all three rounds and examined the overall acceptability of the website.

Table 6.4
Modification codes and their descriptions for the Think-aloud Interview Study

Code	Reason for modification	Explanation
IMP	Important for behaviour change	The modification is likely to impact behaviour change or a antecedent (e.g. acceptability, feasibility, persuasiveness, motivation, engagement) and/or it is in line with the logic model and/or it is consistent with the intervention guiding principles
STF	Straightforward and feasible	A straightforward and feasible modification that does not involve major design changes, (e.g. simplifying or clarifying a sentence that was misunderstood) and/or changes consistent with the guiding principles
REP	Repeated	Suggestion made by more than one participant
NCF	Not changed: Feasibility	This change was not implemented because it was not feasible to do so
NCC	Not changed: Contradicts	This change was not implemented because it contradicts the logic model and/or the guiding principles and/or research literature
NCR	Not changed: Not repeated	This change was not implemented because it was only suggested by one participant

6.4 Results

6.4.1 Round 1

6.4.1.1 Important for behaviour change

There were nine modifications implemented in Round 1 that were deemed important for behaviour change. Some of these modifications were also coded as straightforward and feasible and were repeated by more than one participant. Four of the modifications related to the interactive elements; the planning tools and diary. Full details are presented in Table 6.5. Participants were unclear of the function of the planning tools (i.e. action planning, barrier identification, problem solving; goal-setting) and in general participants were unclear what would happen to their information if they completed these interactive sections. To address these issues new versions of all three forms were developed (see Appendix 7b, 8b and 9b for KYB/Diary (v.2), KYB/Plan (v.2) and KYGP/Plan (v.2)) and the pages leading to them were edited to provide simpler and clearer instruction as well as prompts for the answers.

Similar refinement was required in the KBC/Risk section. Participants were asked in the interviews if there was anything they thought was missing from the website. Participants in their twenties reported uncertainty about the relevance of the *Know Breast Health* intervention for them. That is, they thought the website was only relevant for older women. Content was therefore added to highlight that breast cancer does occur in younger women; 23% of breast cancer diagnosis in Ireland are in women aged 18 – 50.

The final two *important* modifications implemented were to do with navigation issues. When navigation is too complicated or results in the user getting lost, key components of the intervention can be missed. Ease of navigation is, therefore, important for behaviour change. The first issue was with *Home*, which required restructuring, a modification coded as straightforward and feasible. The second navigation issue related to tailoring the experience for users, an integral part of the intervention guiding principles. Completion of *Module 1: Know Your Body* is not necessary for a person who is confident that they know how their body looks and feels normally. Users are therefore asked a series of questions (see Figure 6.1) to determine this. A negative response directed users through *Module 1: Know Your Body* and an affirmative response sent users directly to *Module 2: Know Your GP*. However, this navigation for *Yes* users was disorienting and resulted in some users feeling they had missed out on valuable content. In particular, it was stated that KYB/Video had content that would be valuable for all users; even those who had answered ‘yes’ to the tailoring question.

The modification implemented to resolve this issue was to send *Yes* users directly to the KYB/Video. This way they skipped all the *Module 1: Know Your Body* content, except for the KYB/Video, allowing for a tailored experience. From there they could navigate to *Module 2: Know Your GP*.

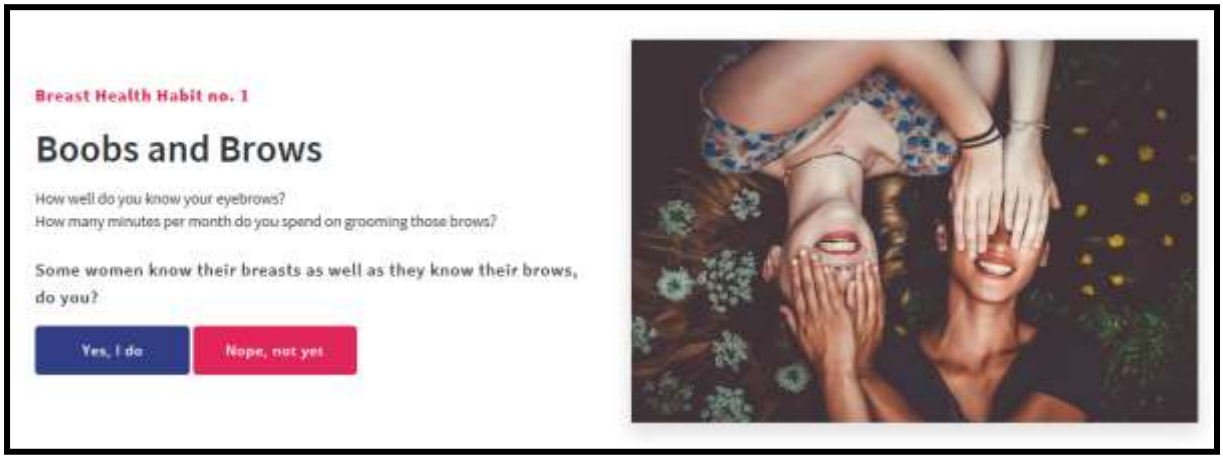

Figure 6.1. Screenshot of tailoring feature in Module 1: Know Your Body.

Table 6.5
Modification implementation Round 1: Important for behaviour change

Section	Reported barrier	Suggested change	Mod code	Notes
Home	Get started button was selected immediately directing user to KYB – no other content on home page was looked at during natural navigation. Participant agreed that the home page content was important.	Link get started button to introduction	IMP STF	
	Missed counter section completely on natural navigation – clicked on BHH. Participant agreed that the home page content was important	Restructure home page	IMP STF REP	
KYB/ Tailor	"Yes" directs straight to KYGP, missed all KYB content. This is disorienting.	Change navigation option and bring Yes users to KYB/Video	IMP STF REP	
KYB/ Diary	Unclear what would happen with the diary when completed who gets the information?	Provide clearer instruction	IMP REP	Streamlined and clarified info on page and updated KYB/ Diary to version 2
	Unclear what the *point* of the form is (participant did not read it properly)	Provide clearer, more succinct instruction	IMP	
KYB/ Plan	Only understood this tool in light of using the other one. Need to clarify	Provide clearer instruction	IMP REP	Streamlined and clarified info on

Section	Reported barrier	Suggested change	Mod code	Notes
	point of form and who will get the info			page and updated KYB/Plan to version 2
KYGP/ Plan	Confusion over the point of this exercise and how setting a goal could apply to the GP. Assumption that goal setting would be about self-examining regularly	Provide clearer instruction – highlight that it is also about barrier identification & problem solving. Provide prompts	IMP	Streamlined and clarified info on page and updated KYGP/ Plan to version 2
KBC/ Risk	This section is too complicated and text heavy – bullet points would be better and it needs to be rephrased	Rephrase and restructure with bullet points	IMP STF REP	
Missing	Information regarding relevance of breast health intervention for younger women. Participants reported being unsure if it applied to them.	Include this information	IMP STF REP	

6.4.1.2 Straightforward and feasible

A straightforward and feasible modification is one that does not involve major design changes and is consistent with the intervention guiding principles. These changes refer to rephrasing and reformatting content as well as changing navigation routes and fixing errors. There were 17 straightforward and feasible modifications made in Round 1. Six of those modifications were also coded as REP, that is, they were repeated by more than one participant. Nine of the modifications implemented were formatting changes, four were navigation changes, three involved rephrasing content for clarification purposes and one error was fixed. Full details are presented in Table 6.6.

In Website 1.0 an infographic, created by the Irish Cancer Society, on how to reduce cancer risk was included in KBC/Risk. Although risk reduction it is not a target of the current intervention, this information was included in KBC/Risk. It was deemed unethical to tell users they may be at risk of an illness and not provide them with resources on how to reduce that risk. As hypothesised this risk reduction information was important to participants for this reason but Round 1 analysis made it clear that the print on the infographic was too small. Thus, a new infographic was created which contained the same information but in a clearer format (see Figure 6.2).

Table 6.6
Modification implementation Round 1: Straightforward and Feasible

Section	Reported problem	Suggested change	Mod code	Notes
Home	"Learn more" button does not link to AboutUs	Correct link	STF	
KYB	Too complicated/cluttered to have the four steps in 2x2 square format, participant felt overwhelmed and jumped around skimming them all and clicking randomly. Would be better to have the 4 steps, in list format – vertically or horizontally	Change to left aligned	STF	
	Jumping down the page to section based on button click is disorientating	Options should open in new tabs	STF	Cannot open in new tab due to formatting restriction. Inserted "take me back" button options on all sections instead
	Buttons don't appear clickable	Change button format to match all other buttons	STF	Inserted "click here" text on button to clarify
	Button location before text introducing KYB/Video resulted in video being missed	Move button to after the line about the video	STF REP	Section removed in restructuring of page
KYB/ Reminder	Did not understand that this was just basic instruction on how to set up reminders on personal device. Thought it was a link to an app.	Provide clearer instruction	STF REP	
KBC/ Symptoms	Cover image for symptoms is lymph nodes – very scientific and potentially intimidating for some participants	Change image	STF	
	For real images explicitly state that this is *one* example of *one* woman	Make changes to clarify	STF	
	All participants missed anatomy section because navigation brought them straight past it.	Move anatomy section to end of page	STF	
KBC/ Survival	HSE links to general page, not section specific	Link to specific section on HSE website	STF	
	Participants do not understand what survival rate at 10 years means	Include more detailed explanation but keep separate	STF REP	
KBC/Risk	This info graphic is too small and cluttered	Create new infographic	STF REP	
KBC	The breast health habits headings are confusing	Remove headings	STF REP	

Section	Reported problem	Suggested change	Mod code	Notes
Overall	BHH123 at the bottom of every page would be clearer if it indicated what page user was on	Change section on each page Place 1,2,3 on top menu to reinforce that there are 3 Modules	STF REP	
	Some images rotate when hovering over them, this is off-putting	Change format	STF	
	Add indicative icons to all buttons	Add icons	STF	

Figure 6.2. Risk reduction information (v.2) in *Module 3: Know Breast Cancer*.

6.4.1.3 Not changed

There were 11 suggested modifications that were not implemented in Round 1. Full details are presented in Table 6.7. Ten of these were coded NCR; the issues were only raised by one participant. These issues were nonetheless tabulated to allow comparison with issues raised in future interviews. One suggested modification was coded as NCC i.e. it was deemed the modification would contradict the intervention logic model and guiding principles. All four Round 1 participants stated they would not use the KYB/Map, the suggested solution was to remove it as an option. Time and attention is limited and when 100% of users do not want to engage with an item it is a strong justification to remove it. However, the idea of the

KYB/Map came directly from the Focus Group Interview Study (Chapter 4) and the intervention logic model and the guiding principles stress the importance of having content in multiple formats. Thus the KYB/Map was retained at Round 1.

Table 6.7
Modification implementation Round 1: Not Changed

Section	Reported problem	Suggested change	Mod code	Notes
KYB/ Diary	Include a "how to" video in the form	Embed video in form	NCF NCR	Not possible to embed video in form
	Print version is very clinical and not in keeping with rest of website	Change format	NCR	
KYB/ Map	All participants reported they would not use it	Remove	NCC	
	Too arduous, no prompts	Add detail to map	NCR	
KYB/ Video	Video is too fast, it delivers a lot of information in a short period of time and so it too complicated.	Create new video	NCF NCR	All other participants were very positive about the video
KYGP	The circles in the boxes look like they are clickable because they pop out	Change format	NCR	
KBC/ Survival	More info on treatment required and could be emphasised more that the treatment for early stage is not mastectomy	Provide more detail	NCR	The detail is proved by the click-through option to the HSE website
KBC/ Symptoms	Would like all images to be of the same style and format	Match all images	NCR	
	More images needed for the armpits and collarbone section	Insert more images	NCR	
About us	It is impersonal/anonymous, some photos would be a positive addition	Include information about the development team	NCR	
Missing	Information about the national screening programme, eligibility and mammography	Provide this info	NCR	

6.4.2 Round 2

6.4.2.1 Important for behaviour change

There were seven modifications implemented in Round 2 that were deemed important for behaviour change. Three of these modifications were coded as straightforward and feasible and two were also repeated by more than one participant. Four of the modifications related to the interactive elements; the planning tools, diary and map. Full details are presented in Table 6.8. Participants suggested that having a selection of options to choose

from when completing the planning tools would make them easier to use. One participant also reported that selecting from a range of options made her feel “normal”, as it made her realise that she was thinking the same things as other people. Thus, options were inserted. It was suggested that both the planning tools and the diary should include a progress bar and be spread over multiple pages rather than the one-page format which felt long to participants. It was stated that this would appear less onerous to users. The participant stated that the function of the map was unclear, although she also stated that she had not properly read the description. This was, therefore, edited to be easier to read. New versions of all the planning tools and diary were developed, including multiple choice items, over many pages and including a progress bar (see Appendix 7c, 8c and 9c for KYB/Diary (v.3), KYB/Plan (v.3) and KYGP/Plan (v.3) respectively). The pages leading to them were edited to provide simpler and clearer instruction.

The homepage was again modified based on the Round 2 data. It was reported that the colours were too dark and that some of the content from the About Us page would be better on the Homepage. The Homepage sets the scene for the rest of the website and so it is important that users are exposed to it and engage with it. After Round 1 analysis counters were added to the Homepage. They are present on a number of pages on the site and proved very popular with all participants. Counters (with survival data) were therefore included on the homepage after Round 1 to add visual interest and increase engagement. However, Round 2 analysis results showed that participants did not find the homepage engaging. The modification implemented to resolve this issue was to include counters in a different style, include prevalence data rather than survival data and edit the colours and layout (see Figure 6.3).

Figure 6.3. Prevalence data counters on the Homepage

The final important modification implemented was addressing an issue tackled in Round 1: the KYB/Tailor navigation problem. In Round 1 the *Yes* participants reported that they were disorientated when brought directly from KYB/Tailor to KYGP although this was a design feature in keeping with the guiding principle of tailoring. To resolve this issue, users who answer *Yes* to KYB/Tailor were brought instead to the *Know Your Body Video*. In Round 2 it was revealed that while the participants appreciated the video, they did not know what to do after watching it. To resolve this navigation issue, a separate section was created specifically to deal with the *Yes* response at KYB/Tailor.

Table 6.8
Modification implementation Round 2: Important for behaviour change

Section	Reported problem	Suggested change	Mod code	Notes
Home	Information contained on About Us page, is compelling and would be better located on the home page	Add further information from About Us page to Home	STF IMP	
	Too text heavy	Reduce word count and insert more images/ graphics.	IMP STF	
	Hard to read: colours too dark	Reformat: change colours, in particular, make them lighter and ensure the text is clear and easy to read	STF REP IMP	Changed background, added image and used brighter colours
	Did not like counters – reasons given: too big (they didn't fit on the screen); boring or off-putting (participants liked counters where they appeared in fours)	Edit counters: increase from two to four	STF REP IMP	Changed content of counters from cancer survival statistics to prevalence data
KYB/ Diary	Wants a sense of movement and progress, not a static page to be filled in	Create new page for each section and include progress bar	IMP	
KYB/ Map	Did not understand purpose (although did not read it properly)	Clarify language	STF IMP	
KYB/ Plan	A drop-down menu would make it easier and quicker to fill in it would also let users know that other women think the same way they do	Include drop down options	IMP	Multiple choice check box options inserted for all questions and progress bar. Users can tick all that apply to them and add new ones if missing

Section	Reported problem	Suggested change	Mod code	Notes
KYB/ Tailor	"Yes" option directs to KYB/Video, this is disorientating, next step is unclear	Fix this navigation issue	IMP	Created new section for "yes" response and edited "no" section
KYGP/ Plan	Wants drop down options and a click through format – providing a sense of movement and progress, not a static page to be filled in	Include drop down options and progress bar	IMP REP	Multiple choice check box options inserted for all questions and progress bar. Users can tick all that apply to them and add new ones in if missing

6.4.2.2 Straightforward and feasible

There were 12 straightforward and feasible modifications made in Round 2. Two of those modification were also coded as REP, that is, they were repeated by more than one participant. Six of the modifications implemented involved rephrasing content for clarification purposes, three were formatting changes and three errors were fixed. Full details are presented in Table 6.9.

Table 6.9
Modification implementation Round 2: Straightforward and Feasible

Section	Reported problem	Suggested change	Mod code	Notes
KYB/ Reminder	Typo	Fix	STF	
KYB/	Image file name is not indicative	Change name of image file	STF	
KYGP/ Tailor	First option should not be leave GP, this is too extreme	Change order of suggestions	STF	
KBC/ Survival	"What is cancer" should explain *why* it is bad that cells divide and multiply uncontrollably	Rephrase	STF	
KBC/ Symptoms	The real images could be misleading, particularly the lumps (armpits and breast) important to state that lumps may be on the inside	Add detail to images	STF	
	Description on Nipple image is poor	Edit	STF	
	Anatomy section: too text-heavy, bullets point would be clearer The importance of the location of the lymph nodes is easily missed when participants scan	Edit this section to include bullet points for clarity	STF	

Section	Reported problem	Suggested change	Mod code	Notes
KBC/Risk	Risk reduction: Links to reputable web resources that could help users with behaviour change in these key areas. The information is very generic and needs to be more helpful.	Include links	STF REP	Removed infographic and created new section with clearer information and links to HSE sites for behaviour change
	The new graphic still links to the old graphic	Edit link	STF	
	KYB section of the graphic poorly phrased	Rephrase KYB section of the graphic	STF	
	More detail required for example, what hormones change? Hoe many units of alcohol		STF REP	
	Too text heavy, needs to be more graphical	Reduce word count and insert more images/graphics	STF	
Overall	Capitalisation of breast health habits is inconsistent	Make consistent	STF	

Round 2 analysis found that the information contained in KBC/Risk pertaining to how to reduce risk for breast cancer was not acceptable. Participants wanted more detailed information on what to change and how to change it, in particular, they wanted links to reputable sites where they could find more information. To resolve this issue a new section was created on the site to address risk reduction strategies and provide supporting links to the HSE websites with relevant detailed information (see Figure 6.4).

6.4.2.3 Not changed

There were 21 suggested modifications that were not implemented in Round 2. Full details are presented in Table 6.10. Thirteen of those were coded as NCR, that is, they were only reported by one participant. Eleven of them were not implemented because it was not feasible to do so. These included requests such as edits to the videos or the creation of a smartphone app to accompany the website. Seven changes not implemented were coded NCC i.e. it was deemed the modification would contradict the intervention logic model or guiding principles. Three of these referred to the removal of content that participants felt was repetitious or unnecessary. The guiding principles of the intervention state that content should be provided in as many formats as possible

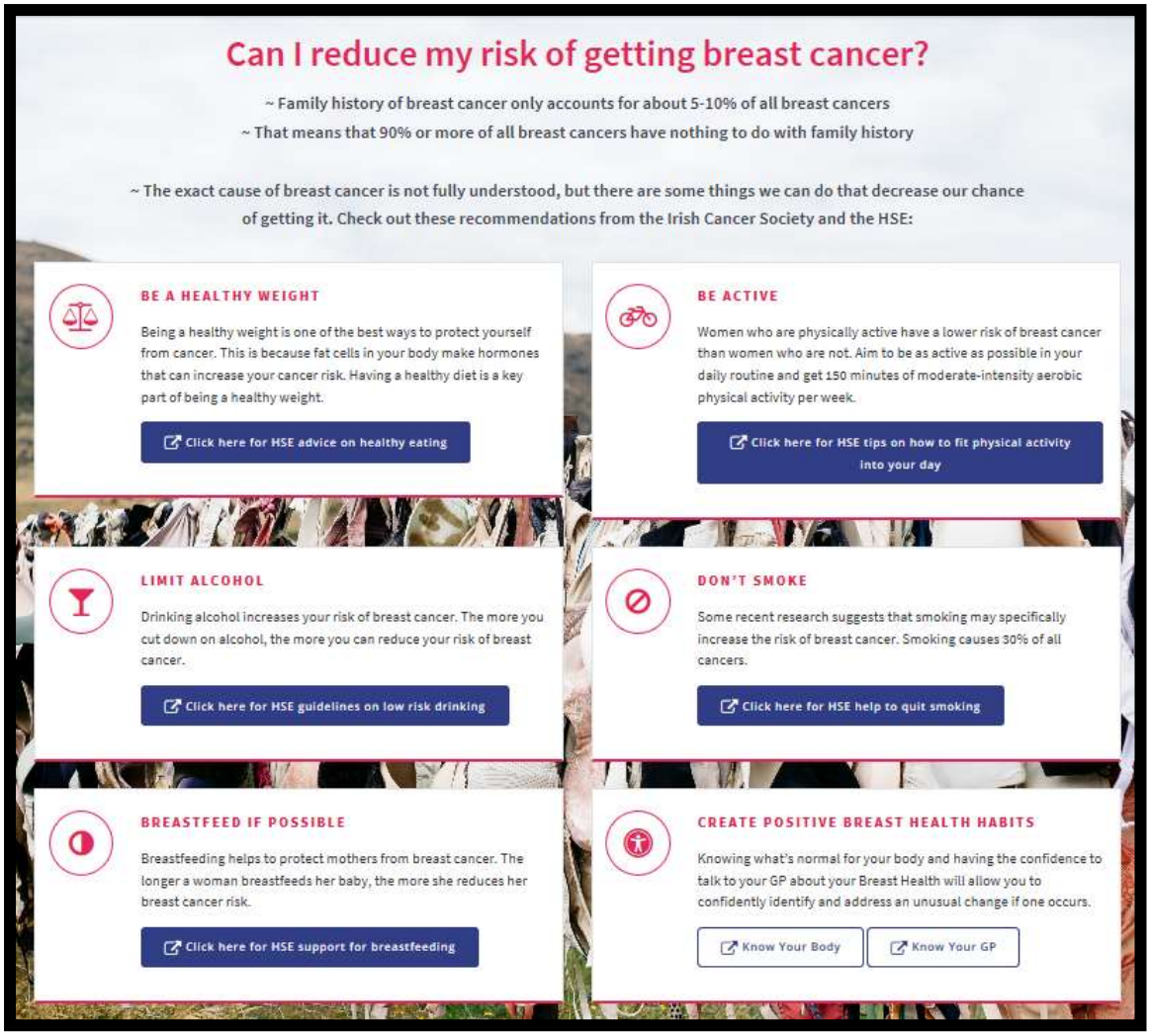

Figure 6.4. Risk reduction information (v.3) in Module 3: Know Breast Cancer.

One proposed modification coded NCF and NCC was also reported by a participant in Round 1. This modification refers to streamlining the images on the KBC/Symptoms page. Each symptom section has an array of different images, in difference formats. A single participant in both Rounds 1 and 2 suggested that the images be coordinated and in the same format. Having multiple images for all symptoms is an important component of the intervention and has been well received by participants generally. Having all images in the same format would require a reduction in the volume of images presented (NCC) or the creation of an array of original images (NCF). Thus, although repeated by two participants the change was not implemented.

Table 6.10
Modification implementation Round 2: Not Changed

Section	Reported problem	Suggested change	Mod code	Notes
Home	The logos should be at the top and there should be more information about the website creators on the homepage to lend credibility	Move logos to top of page and add further information from About Us page to Home	NCF	All participants reported they thought the site was trustworthy
KYB	Take me back option was not obvious initially, but once it was used once it was clear from then on	Create different option	NCR	All other participants found this button navigation obvious and clear
	This whole page is too text heavy , it needs more images/ graphics/ cartoons	Reduce word count and insert more images/ graphics	NCR	All other participants liked this page
	It should be clickable and provide info on whether the images shown are of healthy breasts or not	Make clickable and include this information	NCR NCF	
	This appeared very long at first which is off putting. When the participant navigated through it, she realised it was not long. But it looks like there were so many links and she was a bit overwhelmed. Participant recommended telling a user how long the section would take to complete	Add information about length of time needed to complete	NCR NCC	It would be difficult to estimate how long on average a person would take to complete. The variation would be too great and an average time could be off-putting to some users resulting in disengagement
KYB/ Tailor	Not a good analogy, because you see your brows automatically every day in the mirror so it is not the same	Remove or change	NCR	All other participants liked this feature
KYB/ Video	The video does not state that it is important to examine the upper body while lying down	Include this information	NCR NCC	Video provides best practice information
	The video does not show exactly what symptoms individuals should be looking for, showing symptoms would be valuable	Edit video to include this information	NCR NCF	This information is provided elsewhere on the website
KYB/ Diary	Would not print off	Remove print option	NCR NCC	Having multiple options is a Guiding Principle of design
KYB/Map	Wanted online version	Create online version	NCF	
KYGP/ Video	Could be a video of a patient being seen	Edit video to include this	NCR NCF	

Section	Reported problem	Suggested change	Mod code	Notes
	Could include info about what a mammogram would entail	Edit video to include this	NCR NCF	
	The video is poor quality and should be in widescreen format	Create better quality video	NCR NCF	
KBC/ Survival	This information is repetitive, the counters have been presented already, participant skimmed through it as a result	Delete the repetition	NCC	Information in multiple formats is key feature
KBC/ Symptoms	All images should be the same (except for real)- preference is for the ones with the blue outline	Use the same images across all symptom's	NCF NCC	Repeated by Round 1 participant
	Would like a video in the Anatomy section	Include video of anatomy	NCR NCF	
KBC/Risk	The info is repeated, is this necessary? Participant conclude it wouldn't negatively affect the user, and may drive the point home	Delete the repetition	NCC	Information in multiple formats is key feature
Missing	Information about next steps if a doctor finds something e.g. mammography etc.	Add info	NCC	Beyond the scope of this intervention
	An app	Create an app	NCF	
Overall	The 1,2,3 at the top navigation menu is off putting	Remove the 1,2,3 labelling	NCR	All other participants liked this feature
	Text in some parts of site was reported as being small, but readable. It was reported it could be an issue for someone who had poor sight, but no participant had difficulty	Increase size of text	NCF	

6.4.3 Round 3

6.4.3.1 Important for behaviour change

There were eight modifications implemented in Round 3 that were coded IMP, that is they were deemed important for behaviour change. Full details are presented in Table 6.11. Six of these modifications were also coded as straightforward and feasible and involved basic reformatting and simple rephrasing. The other four involved more substantial restructuring of pages. Once again the KYB/Tailor was problematic. Although navigation problems were resolved the participants misinterpreted some of the content and were not enticed to watch the KYB/Video. The section was, therefore, restructured and rephrased (see Figure 6.5).

Table 6.11
Modification implementation Round 3: Important for behaviour change

Section	Reported problem	Suggested change	Mod code	Notes
KYB	"take me back" button not visible when Reminder button is selected from KYB	Change location of "take me back" button	IMP STF	
KYB/ Tailor	One participant did not watch video on natural navigation, was not enticed to do so	Rephrase so this appears more interesting	IMP	
	Thought they had to actually answer the question, or pick an option, like it was a test	Restructure and rephrase this section	IMP	
KYB/ Video	Missed the video	Change button colour so it stands out more	IMP STF	
KYB/ Diary	Participant scanned and missed that there was an online option	Change order of buttons; put online version first	IMP STF	
KYB/ Plan	Additional option: being afraid of what you might find	Update options	IMP STF	
KYGP/ Plan	Missed KYGP/Plan because navigated from KYGP/Video straight to KBC,	Insert "take me back" button	IMP STF	
	Unclear what would happen to information saved in plans	Rephrase	IMP STF	

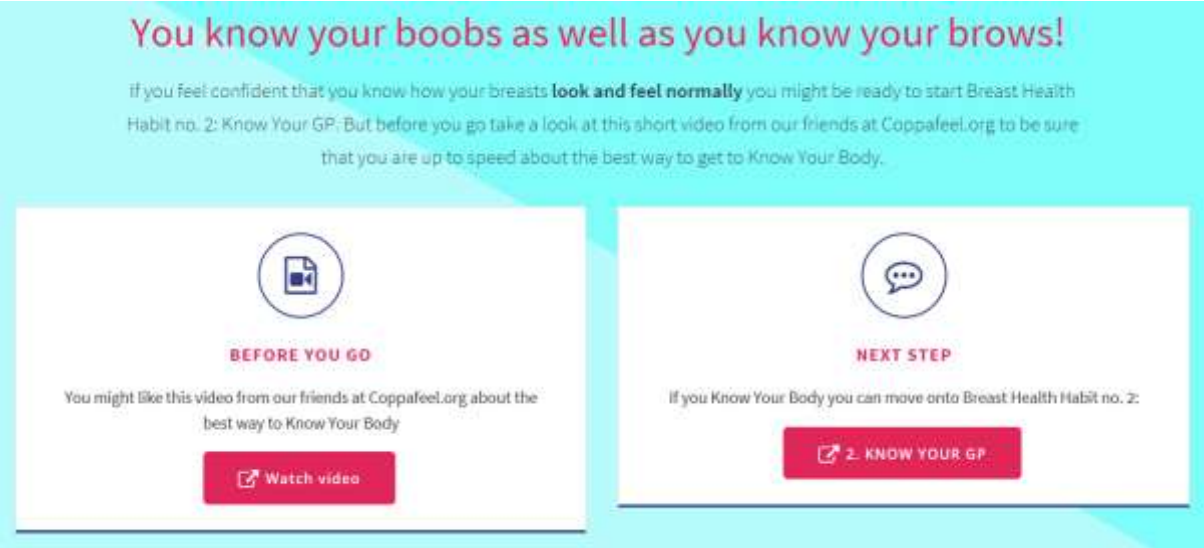

Figure 6.5. Screenshot of tailoring feature in Module 1: Know Your Body.

6.4.3.2 Straightforward and feasible

There were 10 straightforward and feasible modifications made in Round 3. There were four formatting changes, four involved rephrasing content for clarification purposes and two errors were fixed. Full details are presented in Table 6.12.

Table 6.12
Modification implementation Round 3: Straightforward and Feasible

Section	Reported problem	Suggested change	Mod code	Notes
Home	Counters symbol looks like a play button, giving the impression they are clickable	Change symbol	STF	
	Phrasing on counter is not clear	Rephrase	STF	
KYB/ Reminder	The external links with instructions on how to set reminder are very hard to follow, not user friendly	Link to better quality instructions	STF	
KYB/Plan	Typo on page one	Correct	STF	
KYGP	It is not clear what cancer *stage* actually means.	Provide more detail	STF	Additional detail was also added to KBC/Survival
KBC	In the intro it is not obvious the images are clickable	Restructure in new format to make it clear they are clickable	STF	
KBC/Risk	Give BMI information so user knows what a healthy weight is	Add detail	STF	
	Is there an alternative to 30mins 5 days a week?	Add detail	STF	
	Not clear that the links go to external pages	And external link symbol Add that it is HSE	STF	
About Us	Typo	Correct	STF	

6.4.3.3 Not changed

There were 11 suggested modifications that were not implemented in Round 3 (see Table 6.13). Five modifications were not implemented because it was not feasible to do so. Three were coded as NCR, that is, they were only reported by one participant and three were coded NCC i.e. it was deemed the modification would contradict the intervention logic model or guiding principles. Three of these referred to the removal of content that participants felt was repetitious or unnecessary. The guiding principles of the intervention state that content should be provided in as many formats as possible.

Table 6.13
Modification implementation Round 3: Not Changed

Section	Reported problem	Suggested change	Mod code	Notes
Home	Skimmed homepage: was driven by the "Get started now!" banner at bottom of page so skimmed content to get there. However, didn't report being confused or disoriented during natural navigation. On directed navigation when she read the Homepage she stated there was no new information there; she felt she hadn't missed anything	Remove "get started" banner to encourage better engagement with the Homepage	NCC	This was not changed because the various "get started" options have been welcomed by other participants. It provides structure and a clear starting point. Participants appreciate when it is obvious what they are required to do.
	Skipped homepage completely, went straight to navigating tabs. Found the "get started" option was too much of a commitment, thought it was off-putting and wanted to know what the site was about before committing.	Remove "get started" button to encourage better engagement with the Homepage	NCC	
KYB/Map	Would not print, would like online version	Create online version	NCF	
KYB/Plan	Would like printable option	Create print option	NCR	
KYGP	One participant reported "we don't say 'GP' we say 'Doctor'	Change to doctor	NCR	
KYGP/ Video	The GP is not very engaging, but what she says is	Create new video	NCF	
	The video would appear more professional if it was trimmed: didn't like that you could see the GP turn on and off the camera	Trim video	NCR	
KBC/ Survival	The repetition of these counters made the participant think she had already visited this page	Change counters	NCC	
KBC/ Symptoms	Text on some images too small	Increase size of text	NCF	The content in small text is also provided in larger text
Missing	Provide some examples of the many explanations for a change in the breast	Provide examples	NCF	
Overall	On completion of plans and diary have a "close" or "end" option, currently just has "back" and "submit"	Add button option	NCF	

6.4.4 Website components (v.3)

This section presents the pooled data from all three interview rounds for each of the website components. It presents the overall findings of participants' experiences using the website.

6.4.4.1 Video

All participants were complementary of the KYB/Video. They thought it is was engaging and provided practical advice while keeping a light hearted, entertaining tone.

> *Engaging and like, enjoyable to watch. Practical tips, good, things like that. — 204*

> *That's a great little video. It's kind of upbeat and it's like, it's not too serious and it's making it kind of normal, normalising checking your boobs, I suppose and it's a kind of, it's positive I like how it's positive. — 207*

> *That [KYB/Video] was good. I feel like I want to check my boobs right now! — 212*

The content of the KYGP/Video was supported by participants. They found the words of the GP reassuring and particularly like that the GP explained in detail what would happen if they were to ask their GP for a breast exam. There was some criticism of the quality of the KYGP/Video and more than one participant mentioned that the GP was not very engaging. However, those who did also said that the GP was friendly and reassuring.

> *I also liked how she literally went step by step through what you will expect because a lot of the time if you aren't comfortable it's because you don't know what's going to happen. — 201*

> *Like I know like, I would have said "no I won't!" [have a Breast Health consultation with my GP] but then when I saw that [GP video] I was like "wait, no sure, I know what's going to happen now so it's not as scary". — 203*

> *She's not the most engaging. But it doesn't matter, what she says is great. — 211*

6.4.4.2 Information provision

By Round 3, all the information provided to participants on the site was deemed acceptable. Some participants found the information provided about cancer risk and survival "scary". However, they believed the fear was important to motivate them to engage in the behaviour.

It is [scary] but it kind of needs to be though because as soon as I'm after reading that I'd be going straight into Know Your Body [Module 1] because you'd be wanting to check like. — 201

That's Scary. But like it's kind of like making you more like oh, like you'd want to do it sooner rather than later. — 210

6.4.4.3 Interactive elements

The KYB/Plan involved setting a goal, barrier identification, problem solving and action planning. The participants struggled to answer the questions in the first two rounds and many suggested having a selection of options to choose from would be helpful. All participants found it easy to use once the suggestions were supplied for them, although not all participants said they would use it.

I think that's good to have it really specific and make people think so yeah, I think that would work; I would use that. — 206

Yeah and as well sometimes drop downs make me think that I'm normal or if there's options, that I'm thinking of, I'm reminded that other people that might be answering this as well and, oh that's ok that's what most people do. — 205.

I'm not sure how I'd answer that question for example, what would stop you from getting to know your body. Only if you didn't want to know I suppose […] Maybe even give suggestions there might be a thing to trigger people to think of what they might think of. — 208.

The KYGP/Plan involved setting a goal, barrier identification and problem solving. The participants experience with the KYGP/Plan was similar to the KYB/Plan in that they struggled to answer the questions in the earlier rounds. As prompts and the selection of options was supplied they found it straightforward and useful.

I don't know how much I would use that […]I think that [prompts]actually would be good, that might be a wee bit more helpful. — 201

Making you actually write the goal down is really good because you could just click through the site and not do anything. But to actually write it down and then see the email I think would make me, anyway……act on it a bit more. — 206

The KYB/Diary was seen as helpful and participants particularly appreciated how prescriptive it was, the prompts made it very clear what they were meant to look and feel for.

I find it helpful it tells you, you know, one, two, three, four or what to look at, what to look for, yeah I definitely find that helpful because I don't really know myself. — 202

> *Oh that's very good you can fill it in online or print it off for people who don't like online stuff. Oh that's very good, and takes you through it step by step. I really like that checklist. Yeah I think it's very helpful because I think a lot of people just don't know what they're looking for. — 207.*

The majority of participants said they would not use the KYB/Map. This could be because it was "*not that pretty*" (204) and it was not available online, it had a print-only option. A more aesthetically pleasing option, which was interactive and online could have been more acceptable.

KYB/Reminder was generally accepted by all participants. While participants would prefer an app or email reminder function, they were happy with the directions to set up a reminder on their own phone.

> *Ok yeah. Yeah and that's helpful like if you're going to set reminders. — 205*

> *If I sent one email reminder would you be sending out reminders like in a month or two? like you know if I've given in my email address would you send in a reminder? — 206*

6.4.5 Design Features

This section presents the pooled data from all three interview rounds for each of the design features. It presents the overall findings of participants' experiences using the website.

6.4.5.1 Aesthetics

The colour theme, images and overall format of the website was positively received by all participants.

> *It's very, I love the colours, just the way it looks is very pleasing. — 202*

> *I think that was very nice [main background image] and the colour, the whole scheme of it, the little boxes; you know the lay out of it generally along the way you know. — 208*

> *I like it, I like the colour scheme it's bright, it's kind of eye catching. — 207*

6.4.5.2 Content

Overall, participants found the content acceptable, educational and engaging.

> *I liked the figures, I liked the, I just liked the information of it all to be honest. — 201*

> *No, like I kind of expected it to be a bit more boring, like when I went into HSE ones, but like this one and the video, I was like…that was fun. — 210*

Yeah, it is good. There's not too much. You're not overloaded with information, which is good. — 212

6.4.5.3 Navigation

Participants, overall, found the navigation of the site easy, they particularly liked that there were three main sections and that this was constantly reiterated and sign-posted throughout the site.

I really liked the way that there was three different habits and that was sort of like kept throughout. — 203

I thought it was good, accessible, easy to navigate for everyone, all this big writing and everything like it's just, it's easy like it actually is. — 201

...yeah easy enough to navigate. One, two, three yeah and even if I hop in, what I like is, if I hop into any of them, it's like their modularised kind of. — 205

6.4.5.4 Trustworthiness

Participants reported that the site appeared trustworthy. Although they were cognisant of their own biases due to the fact they were taking part in a research study they believed that if they received the website from a friend on social media they would think it was credible. They reported three reasons for trusting in the website: the quality, the association with NUIG and the links to the HSE.

Like I think [it's trustworthy] because it's like quite high quality and it's got like these [IRC and NUIG logos] here, so it's like the real deal. — 210

Yeah, you know it did, it did strike me [as trustworthy], just first reaction, that it is, it does look really credible. — 204

Yeah definitely [it's trustworthy] especially when I go into the About Us and it's like on about the college like once you see something like that you know…but yeah I definitely would. Even the way it looks like you'd know. — 203

Yeah especially because it links in the HSE. — 209

6.4.5.5 Real images

Participants were very positive about the inclusion of images of real breasts, both healthy and symptomatic. Being exposed to different types of breasts provided reassurance that there is a huge variety and diversity of breasts, and that their own breasts were normal. Secondly participants found having real images of breasts with symptoms was very helpful for understanding what was meant by the different symptoms.

I think that's good. I think that's kind of good you never see different… you always just see perfect ones. — 206

But this I think well that's very helpful for me to see an image like that. Yeah I find it helpful to see like yeah, like a real breast and I mean obviously you should know, I mean it won't look the exact same but even for women to get comfortable like it would make me feel more comfortable. — 202

It's good, yeah, because it's kind of like, when they say, like when you just read it, and it's just like oh, like what's a lump. It's kind of good to like have an example of what it could look like. — 210

6.4.5.6 Breast health versus cancer

Participants were cognisant that the focus of the website was breast health rather than breast cancer. They appreciated this, preferring a health centred resource rather than an illness centred one.

But, yeah, yeah, it was nice, because I think when you see cancer, it's just "oh, I don't want that now", and this [website] didn't focus on it, so, it was engaging for that reason. — 204

I actually don't feel like checking my breasts because I'm worried. I feel like checking my breasts because I'm like oh, let me get to know my body better. — 212

Yeah I definitely think that like obviously there's information about cancer, who gets breast cancer, what is breast cancer, but I think it does definitely come across as being you know making these health habits. — 202

6.4.5.7 Empowered

Participants felt empowered by the website and saw it as a helpful resource. They compared this to other health related sites that are more instructional, directive and overbearing.

And then like it wasn't too in your face almost, it's kind of making you think about it, making you do it, making you set the reminders, it's making you kind of take the ownership rather than any of the other websites, whether it's a breast check or the other ones, where it's "do this and do that", they're kind of……"you should do it"…whereas this one is about…take ownership of yourself, so I like it. — 206

It wasn't intimating, like it was proactive which I liked and everything. And, yeah, you know, it was like feminist in that way of like you know, it's your body…have a look at it, that kind of thing. You know, and there's nothing no, nothing wrong with having a look! — 204.

Anything I liked about it? It was, it didn't scare you. So it was more of a positive, taking control kind of a website as opposed to "if you don't do this you're going to die". — 209.

I'm informed, I am educated after it. — 205

6.5 Discussion

This study aimed to optimise the *Know Breast Health* intervention through think-aloud interviews. This aim was achieved. These interviews identified issues of navigation, comprehension and engagement. The iterative process of interview-analyse-edit maximised the amount of useful data gained from the study. In Round 1 blatant issues of navigation were resolved. If using a traditional non-iterative approach, these navigation issues would have been present throughout all interviews as changes to the intervention would not be possible until all data was collected and analysed. Navigation issues are disorienting and distracting for users. When faced with these issues, participants are less able to address issues of acceptability. Comprehension issues were systematically fine-tuned in each round arriving at an optimum level at the end of the study. In a traditional approach the initial comprehension issue would have been identified and changed but there would be no opportunity to refine the changes. Engagement issues were identified and modified throughout all three rounds. The iterative process allowed multiple variations to be trialled across different sections of the website. Once again if the iterative process were not employed in this study the modifications implemented after the initial engagement issues were identified would not have been assessed and enhanced. A traditional approach would have produced the *Know Breast Health* intervention Website 2.0, the iterative approach employed here has allowed more advanced development of the *Know Breast Health* intervention, producing Website 4.0.

Participants reacted positively to the aesthetics of the *Know Breast Health* intervention. The appearance of a website is critical to the success of the intervention it is delivering (Ritterband et al., 2009; Yardley et al., 2015b). If a website is not pleasing to look at, the user will not engage with its content (Ritterband et al., 2009; Yardley et al., 2015b). This study found that good aesthetics also improved the trustworthiness of the site. This is another important component to a successful digital intervention (Yardley et al., 2015b). If the user does not think the information provided is credible, they will not engage with it. Participants' in the current study trusted the *Know Breast Health* website and stated that if they were to receive it as a link on social media, they would consider it a credible source. They referred to

the quality and professionalism of the aesthetics, as well as the University logo as indicators of trustworthiness and reliability.

The ease of use of a website strongly impacts on the extent of user engagement (Ritterband et al., 2009; Yardley et al., 2015b). This relates to how easy it is to navigate and how much time and effort, or burden, is required to digest information presented and complete sections. The content must be simple, concise and presented in multiple formats and navigation must flow easily, so that the user does not have to consciously think about it. The iterative design allowed the navigation difficulties be addressed and refined in the *Know Breast Health* intervention. Areas where the burden on participants was high were identified in Round 1 and improved in subsequent rounds. The interactive components, a crucial part of the website both for delivery of BCTs and for promoting engagement, felt onerous to the participants at the beginning. The participants struggled to answer the questions in the first two rounds and many suggested having a selection of options to choose from would be helpful. Website 4.0 now has multiple choice checkboxes in the two planning tools. This allows for an interactive, tailored experience without the burden of work being high. There is an 'insert text' option for those users who have additional suggestions but generally users are only required to tick boxes.

Multiple formats were used to present information: text (including bullet points and short sentences), images, video, infographics and animated counters, and it was deemed acceptable, educational and engaging by participants. In particular, participants responded positively to the inclusion of images of real breasts. This was a finding from the Focus Group Interview Study; those participants wanted the *Know Breast Health* intervention to include real images for two reasons 1) to make it easier to understand breast cancer symptoms by seeing real world examples and 2) to represent the diversity of women's bodies. Participants in this study had the same reaction to the real images complaining that ordinarily "*you always just see perfect ones*" and that it is easier to comprehend what a symptom is when provided with an example.

The language used, or the *message*, of the website is another important area for maximising engagement (Ritterband et al., 2009; Yardley et al., 2015b). A positive, non-directive, tone is important and it is critical to invite rather than instruct users to participate (Yardley et al., 2015b). This was achieved with the *Know Breast Health* intervention. Participants reported feeling empowerment by the website, rather than having a sense that they were being instructed. This was also fostered through the use of *behavioural*

prescriptions which instruct the user on what to do to address the target problem (Ritterband et al., 2009). These were delivered in the interactive components, KYB/Plan, KYB/Reminder, GP/Plan and the two videos. Increasing confidence and competence is important for engagement with, and adherence to digital interventions generally (Yardley et al., 2015b). The *Know Breast Health* intervention achieved this.

Behaviour change interventions aim to promote intrinsic motivation for the target behaviour, and according to Yardley et al. (2015b), promoting autonomy is the best way to achieve this in a digital intervention. This requires the ability to personalise the information provided to the user, to provide choice to users or the option to "self-tailor" their experience. This was achieved in the *Know Breast Health* intervention by asking participants' questions and tailoring the content they were exposed to based on their answer and through the interactive components. These elements were deemed acceptable to participants.

6.5.1 Strengths

This study used ShareX an open-source screencast utility for Microsoft Windows. This software was used to capture the on-screen activity of participants during the interviews. Similar think-aloud interview studies in the behavioural sciences recommended that future researchers record the screen activity of participants during think-aloud interviews to allow analysis of comments and actions together (Crane et al., 2017; Perski et al., 2017). The video recording was essential to fully comprehend the data collected in this study and greatly aided analysis,

6.5.2 Limitations

A limitation of this study is the lack of diversity in the participants. Although there was a good age range, 75% of the participants had a third level education and 83% were from an urban area. One of the benefits of digital intervention is their ability to access hard to reach populations or those who have limited access to in-person interventions. The current sample had limited input from individuals from these groups. However the think-aloud interview format is primarily designed to tackle issues of usability. As discussed think-aloud interviews provide rich data and so can be effective with small numbers of participants. It is widely held that five participants are sufficient to locate between 77% and 85% of issues and, more recently, it has been established that 10 participants will find 95% of problems (Faulkner, 2003; Nielsen, 1994). It is, therefore, likely that with the 12 participants in the current study the majority of usability issues have been identified.

EC conducted the interviews and implemented the changes to the website. This could have resulted in social desirability bias in participant data. However, this rapid iteration approach is in keeping with recommendations from previous research (Garnett et al., 2018; Morrison et al., 2015). The resulting efficiency is critical for the development of digital interventions as technological advancements already move faster than the speed at which interventions are typically developed and evaluated (Garnett et al., 2018; West & Michie, 2016). Having to communicate feedback to a computer programmer would greatly slow down, and potentially impede, development (Morrison et al., 2015). In accordance with previous research using this methodology, social desirability bias was directly targeted in the procedure for the interviews (Morrison et al., 2015). Participants were asked to be as critical as possible and told that the aim of the think-aloud interviews was to find problems so they could be fixed. It is hoped that this framing prevented social desirability bias from impacting participants' thoughts and opinions as they were told it was their job to highlight issues. The number of problems and barriers identified by participants suggest this strategy was successful.

6.6 Conclusion

This study provided rich insights into participants' perceptions of the *Know Breast Health* intervention. It allowed for the optimisation of the *Know Breast Health* intervention through identifying potential barriers to engagement and systematically removing them. This study demonstrates the value of the iterative design followed. Using a traditional design, with the same amount of participants, the intervention would only be at Website 2.0. It facilitated the incremental optimisation of all aspects of the intervention, thereby maximising how engaging the *Know Breast Health* intervention is. Website 4.0 is now ready for the next stage in the Person-Based Approach development process.

7 Optimising the *Know Breast Health* Intervention: A Retrospective Interview Study

7.1 Chapter overview

This chapter will describe the second study in the optimisation of the *Know Breast Health* intervention: a retrospective interview study. It will begin by discussing the relevant background to the study, its aims and methods used. The findings will be then be presented and the iterative changes to the website described. Finally, the results will be discussed in light of other research in the area.

7.2 Background

The third stage of the Person-Based Approach is the *optimisation* stage whereby the acceptability, usability and feasibility of the intervention is enhanced. In the optimisation stage detailed user feedback is elicited that enables researchers to understand the views and experiences of those using the intervention as well as *how* they choose to use it (Morrison et al., 2018). The aim of intervention optimisation is to gain insights into every aspect of the intervention to ensure it is persuasive, acceptable and easy to use (Morrison et al., 2018). The value of optimising interventions is that issues can be rectified before examining the intervention in a trial. For example, Muller et al. (2017) developed a brief web-based intervention to promote physical activity in people with type 2 diabetes. During intervention optimisation they found that participants were incorrectly using the physical activity planner; they were overestimating their physical activity. This resulted in them receiving inaccurate tailored feedback. Through iterative modifications based on rounds of participant feedback the planner was edited and refined so that participants used it correctly. The optimisation phase greatly enhanced the physical activity intervention (Muller et al., 2017).

The Person-Based Approach recommends conducting retrospective interviews, for optimisation, to understand the experience of participants using the intervention (Morrison et al., 2018; Yardley et al., 2015b). A retrospective interview is one that takes place after a participant has been given the opportunity to use the intervention in their own time (Bradbury et al., 2014; Branch, 2000). When using the intervention independently, participants may interact with an intervention differently than they would in the presence of a researcher, for example, as they would in think-aloud interviews (Bradbury et al., 2014; Branch, 2000). Participants may engage with some elements of the intervention while ignoring others. This is different to a think-aloud interview where the participant is guided through every element of

the intervention by the researcher (Yardley et al., 2015b). In particular, retrospective interviews allow the participant to engage in behaviour that would not be possible with the researcher present, for example, in the case of the *Know Breast Health* intervention, self-examination. Retrospective interviews, therefore, act as a complementary methodology to think-aloud interviews. They can optimise interventions by gathering data on the participant experience (Morrison et al., 2018; Yardley et al., 2015b).

7.2.1 Study aims

The aim of this study is to explore participants' experience of using the *Know Breast Health* intervention independently. The study will examine participants' perspectives of Website 4.0 in order optimise the *Know Breast Health* intervention by enhancing acceptability, usability and feasibility.

7.3 Method

7.3.1 Ethics

This study received ethical approval from the National University of Ireland, Galway, Research Ethics Committee. All participants gave informed consent. See Appendix 2c for participant information sheet and Appendix 3 for consent form.

7.3.2 Design

An experiential, qualitative study was conducted with semi-structured retrospective interviews (Braun & Clarke, 2013). Discussion in the interviews was guided by participants' experience of using the *Know Breast Health* intervention independently and their thoughts and opinions about the website's usability, acceptability and feasibility. This study is reported using the *Consolidated Criteria for Reporting Qualitative Research* (see Appendix 5c). This is a 32-item checklist for interviews to ensure rigour in qualitative studies through explicit and comprehensive reporting (Tong et al., 2007).

7.3.3 Ontology and epistemology

The Person-Based Approach recommends exploring the perspectives of potential target users of the *Know Breast Health* intervention and so this study took a critical realist approach within a contextualist framework. Qualitative research can be underpinned by different ontological and epistemological assumptions. This refers to the theories about the nature of reality and knowledge. On the ontological spectrum critical realism sits in the centre. Realism posits a knowable single truth that we can accurately observe. Critical realism argues that there is a knowable world but that it is always observed subjectively, and so, there is no

single truth (Braun & Clarke, 2013). On the epistemological spectrum, similar to critical realism, the contextualist approach sits in the centre. The contextualist approach posits that there are many truths but that they can only be known within the context they are researched. In the contextualist approach knowledge is always context dependent so there is no universal truth waiting to be discovered. Contextualists believe all knowledge is subjective but this does not prohibit it from being true (Braun & Clarke, 2013). Thus, a contextualist framework, with a critical realist approach is ideal for exploring participants' experience of using the *Know Breast Health* intervention independently and eliciting their views about its usability, acceptability and feasibility.

7.3.4 Sample & recruitment

Purposive sampling is the typical approach taken in qualitative research. It involves selecting participants based on their ability to provide rich data that will address the research question (Palinkas et al., 2015). In this study the purposive sample is women, living in Ireland, aged 18 – 49. There are many different types of purposive sampling, in this study stratification is used. Stratification is sampling to ensure that diversity is incorporated into the data. The aim of stratification is not to be exhaustive or generalisable, but rather to enable the inclusion of a broad range of people to contribute to the research (Braun & Clarke, 2013). Therefore, stratification was based on age, education level (primary, second, third) and residence (urban or rural). This is in keeping with the Person-Based Approach, and other studies using retrospective interviews for intervention development (Braun & Clarke, 2013; Crane et al., 2017; Greenwell et al., 2018; Yardley et al., 2015b). Participants were recruited through advertisements on social media. A twitter account, Facebook page and WordPress website were all established for the study to advertise for participants on social media.

Published retrospective interview studies using the Person-Based Approach have a range of seven to thirteen participants (e.g. Bradbury et al., 2018; Crane et al., 2017; Foster et al., 2015; Morrison et al., 2014). Braun and Clarke (2013) recommend six to ten participants for interview studies using thematic analysis. Data saturation is a typical method of determining sample size in qualitative research (Braun & Clarke, 2013). Bradbury et al. (2018) state that when conducting qualitative research for intervention development, data saturation is reached when participants do not identify any new significant modifications to the intervention. The current study therefore sought to achieve this form of data saturation and aimed to recruit 12 participants.

7.3.5 Participants

Participants were 12 women with an age range of 18 – 49 years. The majority (67%) of participants had a third level education and 58% lived in a rural area. Demographic details of each participant are presented in Table 7.1.

Table 7.1
Demographic variables for each participant in the Retrospective Interview Study

ID	Age	Residence	Education level	Occupation
301	26	Urban	Second	Administrative assistant
302	47	Rural	Second	n/a
303	47	Rural	Third	Teacher
304	27	Urban	Third	Nutritionist
305	37	Urban	Third	Researcher
306	40	Rural	Third	Practice nurse
307	36	Rural	Second	Unemployed
308	39	Rural	Third	Teacher
309	27	Urban	Third	Assistant psychologist
310	18	Rural	Second	Student
311	29	Rural	Third	Teacher
312	49	Urban	Third	School principal

7.3.6 Procedure

All contact with participants was online and over-the-phone. Participants completed an online expression of interest form (Appendix 11) and were then sent the participant information sheet (Appendix 2) and online consent form (Appendix 3) by email. Once participants had given informed consent, they completed a demographics form (see Appendix 4), selected a time and date for their phone call interview and were provided with a link to the website. All interviews were conducted by EC, were audio recorded and transcribed in full.

Each interview began with an explanation of the purpose of the interview (see Appendix 1c for interview schedule). It was highlighted to participants that criticisms of the website were welcomed as it would allow problems to be identified and rectified. Participants were asked a series of general questions at the beginning and end of the interview. Specific questions were asked about each section of the website. Finally, participants were offered the opportunity to ask questions or make further comments and were thanked for their contribution. The interviews averaged 29.5 minutes in duration with a range of 19 – 46 minutes.

7.3.7 Analysis

A descriptive thematic analysis emphasising semantic themes was chosen for this research. This approach was taken because the focus of this study is the participant experience. In order for the findings of this study to inform the development of the intervention it is necessary to identify the explicit meaning in the data rather than applying interpretive frameworks to explore conceptual, latent level meaning (Braun & Clarke, 2013). Thematic analysis is a flexible method of analysis that allows the combination of a "top-down" approach with a "bottom-up" one (Braun & Clarke, 2013, p. 178). In the current analysis themes were identified from the data but coded within the structure of the *Know Breast Health* intervention website, thereby combining top-down with bottom-up analysis. The seven stages of thematic analysis are presented in Table 7.2.

Table 7.2
Stages of Thematic Analysis for the Retrospective Interview Study (Braun & Clarke, 2013, p. 202)

Stages of thematic analysis
1. Transcription
2. Reading and familiarisation; taking note of items of potential interest
3. Complete coding across the entire data set
4. Searching for themes
5. Reviewing themes
6. Defining and naming themes
7. Writing and finalising analysis

Transcripts were read and re-read until the researcher was familiar with them. Then each transcript was coded line by line using NVivo 12 software. Nodes were created for every website section and the data was coded into these nodes accordingly. For example, if a participant was speaking about the Home page of the website, the data was coded into the Home page node. This resulted in every website section having data assigned to it. NVivo 12 was used to facilitate analyses and comparison of the relationships between nodes in Stage 4 of the analysis. This involved searching for themes from within, and across, the different nodes. This meant coding on a semantic level, where themes that were explicitly represented in the data were identified. In step 5 these themes were reviewed by AMG and EC and original transcripts were checked against them. The following stages involved reviewing and refining themes until finalised.

A separate descriptive analysis was conducted on each website section node. Any data that identified potential barriers to engagement or suggested edits to the intervention were sub-coded as such. These were then tabulated and solutions were proposed for each. Shorthand labels were used for each website section to make analysis easier. These shorthand labels are outlined in Table 7.3.

Table 7.3
Shorthand labels for the Know Breast Health Intervention website

Label	Description of website section
KYB	Know your body (module 1)
KYB/Tailor	Tailoring component
KYB/Diary	Breast health diary
KYB/Map	Breast health map
KYB/Plan	Goal setting, barrier identification and action planning tools
KYB/Reminder	Reminder instructions
KYB/Video	Know Your Body video
KYGP	Know your GP (module 2)
KYGP/Tailor	Tailoring component
KYGP/Plan	Goal setting, barrier identification and action planning tools
KYGP/Video	Know Your GP video
KBC	Know breast cancer (module 3)
KBC/Risk	Information about breast cancer risk
KBC/Symptoms	Information about breast cancer symptoms
KBC/Survival	Information about breast cancer treatment and survival
Home	Home page
AboutUs	Information about who created and funded the website

7.4 Findings

Overall, the *Know Breast Health* intervention Website 4.0 was acceptable to participants. It was described as helpful and motivating and participants particularly liked the tone of the website. It was described as friendly and light-hearted rather than serious and clinical. It was seen as educational without being directive or scare-mongering. This led to participants feeling encouraged and supported to engage with their breast health. The descriptive analysis identified 13 suggested edits to the *Know Breast Health* intervention. This will be presented first followed by the thematic analysis which identified four themes: approachable, educational, motivating and acceptable.

7.4.1 Descriptive analysis

Participants suggested 13 edits to the *Know Breast Health* intervention. These can be divided into edits regarding information provision and edits related to functionality of the website. Eight of the suggestions are novel and the remaining five were also suggested in the Think-aloud Interview Study (Chapter 6). All suggested edits were tabulated and potential solutions proposed; a selection of edits will now be discussed in detail (see Table 7.4).

Two participants (305 and 308) were current/recent breastfeeding mothers and reported that a section specifically aimed at breastfeeding parents would be helpful. They discussed the many changes the body goes through during pregnancy, breastfeeding and thereafter and felt that a section dedicated to this information would be valuable. *Module 3: Know Breast Cancer* contains a section on reducing risk of breast cancer and states that breastfeeding is a protective factor for breast cancer. This section provides a link to the HSE support pages for breastfeeding parents. The participants thought that more detail about this on the *Know Breast Health* intervention website would be preferable, as well as information about breast health throughout pregnancy and breastfeeding.

> *They can be a bit sore at times or tender at times and is it the feeding? Or is it something else that's going on? And I suppose you don't want to ignore it because of the amount of time that you're feeding. — 308*

Participant 304, a nutritionist, identified a problem with the language used in KBC/Risk. The participant highlighted that the phrasing “be a healthy weight” could contribute to weight stigmatisation (see Figure 7.1). The content was taken from the *Irish Cancer Society* and the Irish *Health Service Executive*, both credible sources. Nonetheless, the nutritionist recommended a change to the language to keep in line with current best practice. In discussion with EC it was established that “have a healthy diet” would be a better recommendation, one more in keeping with people-first language. The guidance by the *Irish Cancer Society* ultimately recommends a healthy diet, and so the recommendation remains unchanged, but the focus is now on a modifiable behaviour (making changes to diet) rather than a vague goal of “be a healthy weight”.

> *...for a lot of patients that we'll see they'll never be a “healthy weight”, you know so it's kind of saying “ok so what does that mean about me” — 304*

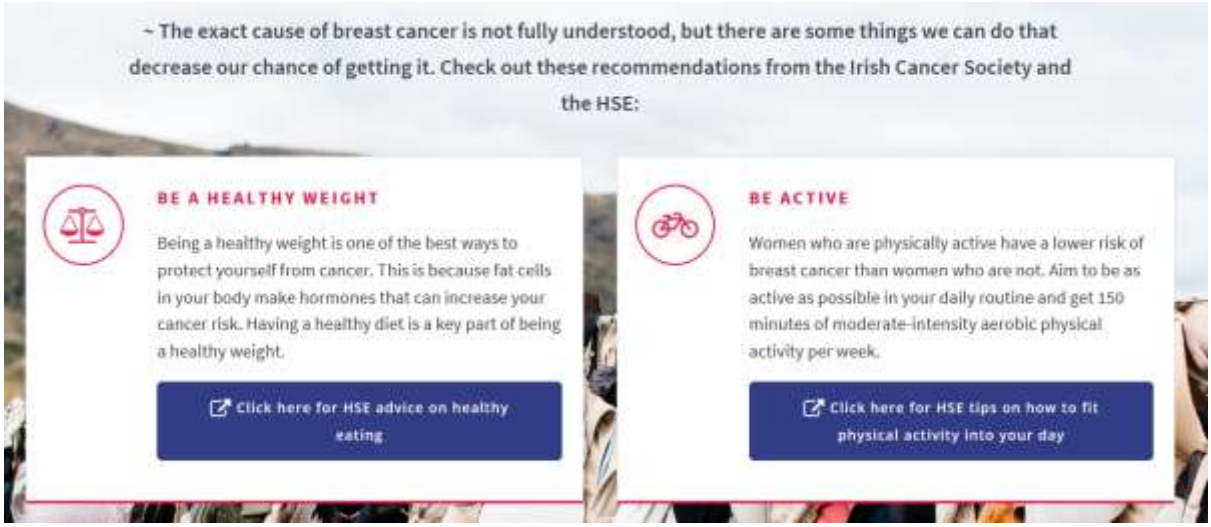

Figure 7.1 Screenshot from the Reduce Risk section of *Module 3: Know Breast Cancer*.

Numerous participants suggested that the interactive elements would be better suited in an app, or a personal account on the website. Participants believed that emailing themselves with their plans or diaries, would not be effective. They reported that they would lose track of the documents amongst all their other emails. Participants, therefore, preferred a single location (app or account) to save all their plans and diaries in. They believed they would be more likely to use them in this situation. One participant suggested that with individual accounts the reminder functions could be personalised and incorporate the users' own plans.

> *Kind of in the same way as the diary. Like if it [KYB/Plan] was on a separate app that was away from it, away from your email. Or maybe… Yeah. I'm not really sure. Just I wouldn't fill it out just to email it to myself because as I say, I would probably end up just deleting it. Or I don't know, if you could have an account on the website and it would save there. — 310*

> *Because when I emailed the thing off, it was emailed back to me. I wasn't sure whether that was going to be emailed back like on a reminder type basis … because it would, like with the best will in the world, you kind of set your own goals or whatever, but I know myself that you might do that for a couple of months. And then you forget about it again, whereas if you were getting an external reminder. It would help: a reminder of what you signed up for yourself. — 312*

Table 7.4
Modifications for implementation in next iteration of the Know Breast Health intervention

Mod type		Suggested edit	Potential solution	Section
Information	N	Specific information on pregnancy and breastfeeding lacking	Include section on pregnancy and breastfeeding	–
	N	No information on how to tell a partner they have a symptom of breast cancer	Include section with guidance on how to tell a partner they have a symptom	–
	N	Video recommends that men should also be aware of breast cancer symptoms but contains no information about prevalence	Include this information, including prevalence data, in the KBC section	KYB/ Video
	N	Recommendation to 'be a healthy weight' could contribute to weight stigmatisation	Change language to "have a healthy diet"	KBC/ Risk
	N	Participant queried what stage of the disease was represented in all the images provided	Label each image with its corresponding cancer stage	KBC/ Symptoms
Functionality	N	There are no subtitles on videos	Include subtitles on videos	Videos
	N	There is no search bar	Include search bar	–
	N	The website was optimised for desktop use and did not work equally as well on all devices. The counters move too slowly on mobile devices. New sections opened into new tables too often. New tabs are helpful on desktop but very cumbersome on mobile devices.	Optimise interface on all devices	–
	R	Bypass navigation style was disorienting for some participants. They felt like they had missed something as a consequence of this form of navigation.	Change navigation style	–
	R	Participant reported that KYB/Plan appeared as though it would be too much work. They did not click into it for this reason.	Include an indicator of how long it takes to complete	KYB/ Plan
	R	Participants did not like the email function	Create individual accounts on the website (or app) so that plans etc. can be save there	Email function
	R	Some participants wanted the Interactive elements in an accompanying app	Make these available in an accompanying app	Interactive elements
	R	The GP video is poor quality; specifically the sound is poor and the lighting changes	Edit video	KYGP/ Video

R = Repeated
N = Novel

Table 7.5 presents participant navigation records. The navigation records were calculated based on self-report data from the participants. During interviews participants were asked if they had visited the various website sections and this was noted by the interviewer. Each column represents a participants activity on the website and each row represents a

website section. A tick indicates that the participant visited that website section. The total column represents the total number of participants that visited each section. The bottom section of the table reports the device type used by participants and the number of times they visited the website. Finally, the Table presents data on the percentage of the website each participant was visited: on average 74.5% of the website was visited with a range of 47% – 100%.

Table 7.5
Participant navigation records for Retrospective Interview Study

	Participant number												**Total**
	301	302	303	304	305	306	307	308	309	310	311	312	n
Website section													
Home	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
AboutUs	✓	x	✓	✓	x	x	x	✓	x	✓	x	✓	6
Module 1: Know Your Body													
Tailor*	R	Y	N	R	R	R	Y	N	N	N	N	R	12
Step 1	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	11
Video	✓	x	✓	✓	x	✓	x	✓	✓	✓	✓	✓	9
Diary/Map	✓	x	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	10
Reminder	✓	x	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	10
Plan	✓	x	✓	x	✓	x	x	✓	x	✓	✓	✓	7
Module 2: Know Your GP													
Tailor**	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	12
Why	✓	✓	✓	✓	x	x	✓	✓	✓	✓	✓	✓	10
Video	x	x	x	x	x	x	✓	✓	✓	x	x	✓	4
Plan	✓	x	x	x	x	x	✓	x	x	x	x	✓	3
Module 3: Know breast cancer													
Risk	✓	x	✓	✓	x	x	✓	✓	✓	✓	✓	✓	9
Symptoms	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	11
Survival	✓	✓	✓	✓	x	x	x	x	✓	✓	✓	✓	8
Usage information													**Mean**
Mobile	✓	x	✓	✓	x	✓	✓	✓	x	✓	✓	✓	
Desktop	x	✓	x	✓	✓	x	✓	✓	✓	x	x	x	
No. of visits	3	2	2	3	1	3	3	5	3	3	2	1	2.58
% website used	93	47	87	80	53	47	53	87	80	87	80	100	74.5

Total n = total number of participants who visited that website section
Y = participant answered yes to the question
N = participant answered no to the question
R = participant read the question but did not select an answer
* Do you know your breasts as well as your brows?
** Would you feel comfortable asking your GP to examine your breasts?

The participant navigation records demonstrate that the tailoring options are working for users. In KYB/Tailor users who answer Yes (i.e. Yes, I know my body well) are directed

to the next module (Know Your GP) after receiving a prompt to watch KYB/Video. The KYB/Tailor section was visited by all participants, however, only seven answered the question and received tailored navigation. Of the participants who did not answer the question (301, 304, 305, 306 and 312), two of them used 100% of the module and the remaining three used 75% of the module. This usage is equivalent to those participants that answered No to the KYB/Tailor question, (i.e. No, I do not know my body well). Five of the participants who answered No used 100% of the section while the remaining No participants used 75%. Only two participants said Yes to the question, they had 25% and 0% usage thereby demonstrating that the tailoring option was working for the participants. In *Module 2: Know Your GP* all participants answered yes to the question *would you feel comfortable asking your GP to examine your breasts?* and only two participants completed the module, again demonstrating that the tailoring option worked.

7.4.1.1 Data saturation

Participants made 13 suggested edits for the intervention, eight of which were novel. These novel suggestions were not significant modifications, and so, data saturation was achieved as per the criteria presented in Bradbury et al. (2018). Three of the eight suggestions were only made possible by the retrospective interview format: include subtitles on videos, a search bar option and optimise interface on all devices. Participants in the Think-aloud Interview Study (Chapter 6) only used the intervention on a desktop, had sound for all videos and did not have to search for anything.

7.4.2 Thematic analysis

7.4.2.1 Approachable

This theme represents participant attitudes towards the website; it felt warm and friendly, with a welcoming air. This differed from their expectations for, and their experiences of, cancer and health related websites. Participants expected a cold, clinical and dull website to address the topic of breast cancer. Instead participants found the website colour palette "*bright*" and "*vibrant*" (309), and the images were seen as "*quirky and funny and engaging*" (305). For participants the tone was determined through the design and the content of the website.

> *Yeah, and it's not even like really clinical and like cold, do you know…it feels welcoming. — 309*

> *And I really liked the design. Like I liked the colours and layout that were used. I think it kind of made it more approachable, like especially since it's kind of a, yeah, slightly scary topic. — 310*

Participants found the *Know Breast Health* intervention suggestive rather than directive. They reported that it prompted them to think about their breast health in a way they had not before, and motivated them to engage with it. The website did this through encouraging and supportive content rather than authoritative commands.

> *It's kind of gentle and the "try and make this a habit" and that kind of thing, it's not like "do this" and "you should do" or whatever. — 309*

For example, participants were encouraged to think about the time they give to other activities in their lives, such as grooming their eyebrows and compare this to the time they give to their breast health. One participant remarked "*you'd know when there's a hair out of place in your flipping eyebrows, whereas, like I mean, would you know that there's something wrong in your breasts!*" (303). The structure of the website, in particular, the click-through options also supported the idea that the website wass suggestive not directive. Participants felt that they were being invited to look at more detailed information rather than being forced to.

> *If someone can just make the choice to go and get further information if they want, I think that's better, I like that. I'm sort of the type of person if I see too much I just get put off. — 304*

> *I like that kind of the most important information is given and then you can click on for further advice and further tips. I think that's good. — 311.*

At times the intervention content was deemed to be "shocking" or "scary". This related to the prevalence and survival statistics for breast cancer. Participants had not encountered this information before. Participants reported that while the information was inherently frightening, it was presented in such a way as to minimise a fear response. They reported feeling that the website was not trying to use scare tactics to make them change their behaviour but rather it was trying to provide them with important facts so that they would be properly informed. There was general consensus that individuals need to know this potentially fear-inducing information and that the intervention was not trying to use the fear against them.

> *The way that the information is conveyed and the way it's laid out you don't, although you're getting the scary information, you don't feel the fear because it's all very, it's quite "this is what you can do" kind of thing… Yeah again it's that*

> *thing of something that you think will be scary or intimidating they make it, yeah they just make it much more, I don't know what the word I'm looking for; it's the opposite of scary and intimidating it's … accessible. — 301*

> *I think once you break something down, it makes it much easier for somebody not to be fearful of it. Yeah. … it is sort of removing the fear factor of all of it. — 302*

> *It was making a point without being, what's the word? You know, scaremongering type of thing, you know. Like it was telling me what I needed to know, being how important it was, but without, you know, kind of, without me feeling at the end of it "oh my God!". — 308*

Participants believed the website to be a trustworthy source. There were four reasons given by participants for viewing the website as a credible source of information. The quality of the design (how the website looked) and the content (for example, real images of symptoms and a video of a GP) indicated to participants that it could be trusted.

> *It looks very professional you can tell that it's, you know there's expert led, and it just looks, I don't know, I don't know how to explain it, but it does look credible. It's tidy and it's neat and every part of it is finished you know complete looking so that's kind of all of those little clues. — 304*

> *It looked like it was well-produced. It wasn't a shoddy thing. I think, you know, the embedding of the videos, you know, the GP video and different things like that, so no, overall, I don't know about such things but to me, it seemed very credible. — 308*

A second indicator for participants of the website's credibility was the website creators. The National University of Ireland, Galway and Irish Research Council logos were cited as key to this, as was the description on the About Us page. Finally, one participant described that her trust in the website came from the person who shared it on social media. This participant had faith in her friend and assumed anything that they shared would be of good quality.

> *I think it [trust in the website] comes from, you know, once somebody else who you feel is sort of reasonably credible as well and who's kind of, you know they've a degree of sense, posted it on their page, you sort of end up looking at it. — 302*

> *Now I would definitely look at it and I suppose yeah, once I read it then, it did say that it was NUIG and that it was based on research. So yeah, yeah you'd know that it was a trusted source. — 312*

7.4.2.2 Educational

All participants were asked if they found the website helpful, they all responded yes. Participants identified two key manners in which the website was helpful: it offered practical guidance and it provided new information and learning opportunities. The practical help provided by the website came from *Module 1: Know Your Body* from the video and interactive elements and from *Module 3: Know Breast Cancer*, specifically the symptoms page. This information helped the participants understand what they should be looking for and how they should look for it. The planning tools helped them to set goals, identify barriers and facilitators and make specific plans for engaging with their breast health.

> *Yeah, I thought that [KYB/Video] was excellent. Now, again, like it's just good to see, you know, real photos and videos and, you know, how exactly to do these things. I thought yeah, I like that. — 307*

> *So yeah, I picked my time and place. Yeah. I suppose making me commit to a particular time it's just about making the commitment, so that would be, yeah, my intention going forward. — 308*

Participants reported learning helpful information in *Module 3: Know Breast Cancer*. Participants were unaware of the prevalence of breast cancer, their personal risk and the survival statistics for the disease. *Module 3: Know Breast Cancer* also presented the symptoms of breast cancer in detail with textual descriptions, graphics and photos of symptoms. Participants were surprised by the array of symptoms as well as the locations that can be affected i.e. the armpit and collarbone. Information on the treatment of breast cancer was also provided and identified as new and valuable information by participants.

> *I actually thought that [symptoms page] was really good, yeah I'd no idea what it could look like and how different it can look. I just thought it was lumps so I actually thought the visual was actually really informative. — 309*

> *I think what doesn't get across sometimes is it's not just the lump, there's so many other things. — 304*

A key component of the success of the guidance and learning provided by the website was how accessible and engaging it was. The content was described as easy to read and understandable, straightforward and simple, not overwhelming and lacking in jargon. When asked what she liked best about the website one participant responded "*the simplicity of it, I think, is…That's probably the best, you know, aspect of it*" (302). Participants liked that the website was divided into three modules. It was seen by participants as a manageable amount that made the information easily digestible.

> *I liked the way it was broken down to just three topics. Like it just was broken down into small manageable pieces. It didn't seem like it was never-ending. — 307*

> *Yeah like I loved the way there's just the three kind of key messages and the three sections. — 304*

Information was presented in "*bite-sized*" (304) sections and this was seen as key for comprehension and keeping participants' attention. For example, details such as the font style and spacing used in text boxes was just as important as the actual words to the comprehensibility of the information.

> *This might sound really simplistic, but I like how everything's put into a different box. It's not just a big paragraph of writing. — 311*

Participants were prompted to think about when would be the best time to perform an exam and discussed the importance of associating the exam with something else. One participant (308) discussed how "*I have a lot of boys in my house, you know, with football on an evening*" and that matches would be a good cue for her to engage with her breast health.

> *You say it's good to set a goal, well you can just do one right now! Here it is! So yeah, before I knew it I had made a plan. And yeah just to sort of get that ball rolling is really good. — 301*

Participants also thought about their relationship with their GP and whether they would feel comfortable being examined. One participant (303) discussed how she has a male GP, who she has a good relationship with, but that she nonetheless felt she would be uncomfortable asking to examine her breasts. She realised through using the intervention that she could ask for the practice nurse to perform the exam instead. Participants were prompted to think about barreirs that prevented them from being engaged with their breast health, which ranged from uncertainty to time management. Participants reported discovering that there were no legitimate barriers to engagement with their breast health after completing the barrier identification tasks.

> *The way that everything is presented and communicated it kind of broke down a lot of barriers for me personally that I didn't even know that I had. — 301*

> *I think it just makes you aware of the things that might stop you doing it and makes you realise, well actually, why should they stop me? — 312*

7.4.2.3 Motivating

The intervention motivated participants to engage with their breast health. It did this by being engaging, supportive and providing important information. The content and design was engaging for participants. The animated counters for example, were very positively received by participants. Participants felt the counters were "*eye-catching"* and "*effective*"; they made reading statistics more engaging. For the survival statistic counters one participant remarked "*...you were sort of willing the little round thing to, you know, willing it to go round a little bit more*" (308). Presenting information in an engaging way allows for users to connect with it, without that connection the information cannot have the intended impact on behaviour.

> *I thought that [animated counters] was really… It got a really strong message across. Without being too cumbersome, you know. If you're reading statistics, it's really boring. I thought that was very eye-catching and very effective. — 312*

> *Well, especially nowadays, eyebrows are such a big thing, aren't they? Do you know, so it is. It's a very true question. How much time do you spend on your eyebrows? Do you know your breasts as well as your brows? So it was just a way, it just caught my eye, you know. Boobs and brows, even just the title…And well, my honest answer was no, I don't. I don't know my breasts as well as my eyebrows, so yeah, I thought that was effective. — 311*

> *But I thought it was, yeah, I really liked how it was kind of bringing a little bit of humour in because again, that engaged me and made me want to continue on. — 310*

Participants found the intervention supportive and encouraging; this motivated them to engage with their breast health. The content was not overwhelming and there was practical tips and guidance on how to improve their breast health habits.

> *Yeah it's broken down in a very manageable way. Yeah again it's just sort of nice that it's not everything at once, it's like ok "step one" that's ok I can do that, "step two" oh ok I can watch the video yeah, "step three" yeah it's just it's all manageable. — 301*

> *Oh yeah. I did think that whole notion of tagging it on to something, I'm definitely doing that. Pick a time, after training or whatever. I thought that was a great idea. — 312*

> *I did think of 'oh where will I do it and how often will I do it and how will I remember'...yeah it definitely, it did like make me think about how I would put the habit into practice. — 309*

Information about breast cancer the disease, in particular, prevalence and survival statistics was deemed motivating to the participants. For example, a person with a stage one diagnosis has a 94% survival rate at ten years, compared to 10% for someone diagnosed with stage four breast cancer. While this information was shocking for most women, it was recognised as very important. It highlighted the seriousness of the illness and in particular the importance of an early diagnosis. Participants were motivated by this information to self-examine and the seek help immediately if they noticed any changes. Thus this information was deemed "*a good scary*" (311).

> *And I suppose seeing those figures would make you decide, you know, I'd better go now rather than later. — 307*

> *It's kind of shocking, but at the same time, kind of hopeful that like it would motivate you to keep checking so that you can be sure that if you did catch it, that you would catch it early. — 310*

> *It's [survival statistics] probably the most memorable part of the website, most memorable statistics from the website. Yeah it's really important information and it's the motivator for people to take their breast health more seriously. — 301*

7.4.2.4 Acceptable

Overall the *Know Breast Health* intervention was acceptable to participants. Many of the participants enquired as to when and how the website would be available to the general public and stated that they believed it was an important resource for people to have access to. Participants strongly supported the use of real photos of symptoms of breast cancer. Participants found them educational and there was consensus that they had not seen anything like that before. Some participants also noted, positively, the individual diversity represented on the website. Both male and female bodies were represented as well as bodies of different colours, sizes and shapes.

> *It's very inclusive it's not just like all white bodies and it's not all women but it's quite good, it's very inclusive. — 309*

> *I thought the real photos were fantastic. Because you know, you can actually see them in real life. Because it doesn't matter how well something is described in text or, you know, what type of little animated diagram you have. You know, there's nothing like actually seeing a photo of something to realise oh right, that's, you know, what you're looking for. — 307*

Participants found all the content acceptable but varied in how they engaged with the information provided on the website. The interactive elements, such as the diary, map, reminders and planning tools, in particular, resulted in different responses. Many participants stated that while they could see the point of a certain component or function and they could see how it might be helpful to others, they would not personally use it.

> *I love, the reminder thing because that's definitely something I would need. — 304*

> *And then the reminder function. I guess this all depends on the person, but for me, I have, you know, a busy job and I have a baby and I have reminders for everything and I've apps for everything and having to add another task, you know, another reminder, I just thought oh God, no! I don't want to do that. — 305*

All participants, with one exception had a positive reaction to the KYB/Tailor question (*Some women know their breasts as well as they know their brows, do you?*). Participant 305 thought the question was pointless, although, she reported that it caught her attention.

> *What has eyebrows got to do with boobs? Which I guess caught my attention, which is maybe what it's meant to do. ... It's just a quirky thing and there's nothing really to it. It's not really about eyebrows. There's no like clinical link ... so I thought that was a bit, yeah, there's no aim, I think." - 305*

All other participants understood the point of the question; to make them think about how much time they give to their breast health compared to time they give to, for example, their eyebrows. For the majority of participants the question prompted them to think about this disparity. Some participants stated the question wasn't relevant to them, that they did not give much time or thought to their brows and that they did not know their brows well, but they nonetheless understood the point of the question.

> *I think it is a good question because it does make you think and say, 'Ok, yeah. Well, hold on for a second. I do spend more time on my brows than I do on my breasts! so yeah. — 303*

> *I like the idea, but it doesn't really work for me personally because I don't, I wouldn't say I know my brows too well. And so, do I know my breasts as well as my brows? well I probably don't really know my brows that well and I certainly don't know my breasts that well. But I get, I totally get the idea. — 301*

7.5 Discussion

7.5.1 Summary of findings

The participants in this study found the intervention welcoming, encouraging and supportive. They appreciated that it had a suggestive rather than commanding tone. Participants thought the website was trustworthy and found the content and structure acceptable. In particular, participants liked the practical guidance and knowledge it provided to them. This study generated some novel ideas for the optimisation of *Know Breast Health* intervention and reiterated some findings from the Think-aloud Interview Study (Chapter 6). This study shows that, overall, Website 4.0 is acceptable to participants and the modifications implemented upon completion of the Think-aloud Interview Study were successful. However, it makes clear that participants want increased functionality in future iterations of the website.

7.5.2 The acceptability of the *Know Breast Health* intervention website

Overall, the *Know Breast Health* intervention was acceptable to participants. However, there were 13 edits suggested by participants to enhance the acceptability and feasibility of the intervention. Five of these were also suggested in the Think-aloud Interview Study (Chapter 6). They were not implemented then due to financial constraints (n = 4) and because it was not repeated by any other participant (n = 1). These will now be discussed.

In Round 2 of the Think-aloud Interview Study one participant reported that the Four Steps section in *Module 1: Know Your Body* appeared very long and arduous, which was off-putting. When the participant did navigate through it, she realised it did not take long, and so, she recommended a time-to-complete indication should be given to users. This change was not implemented. It was decided that it would be difficult to calculate how long users took to compete because it is a large section, with many components (KYB/Diary, KYB/Map, KYB/Plan. KYB/Reminder, KYB/Video). The time variation across users would be large and an average time could be off-putting to some users resulting in disengagement. A participant in the current study, also requested time-to-complete information. The request was for just one component; the KYB/Plan. This is a more feasible edit than the one suggested in the Think-aloud Interview Study. It would be possible to get accurate information about how long each participant takes to complete the KYB/Plan and include an average time as well as a range. A recommendation for Website 5.0 is to include time-to-complete indicators to all individual components where possible. Thus, while there will be no indicators for entire sections users will be able to estimate how long individual sections will take to complete, thereby improving the intervention's acceptability.

There were four suggested edits that were not implemented during the Think-aloud Interview Study due to financial constraints, which were repeated by participants in the current study. These addressed issues of functionality: bypass navigation can be disorienting, individual accounts and/or an accompanying app is desirable, quality of GP video. The current study also identified three new issues of functionality: missing a search bar, optimised for desktop, subtitles required on all videos. These issues impact the acceptability and feasibility of the *Know Breast Health* intervention.

Many of these issues were expected and are limitations of the intervention due to financial constraints. For example, the *Know Breast Health* intervention is optimised for desktop use. It was expected that this would be an issue for some users in this study, however, it was unavoidable given the budget limitations. Participants would prefer to save their completed plans and diaries in an account or in an app. This is evidenced by the usage data from the current study; 100% of participants recommended to complete the breast health diary did so, but only one used the email function. Similarly, seven of the 10 participants recommended to use the Know Your Body planning tool did so, and only two used the email function. This provides strong justification for including individual accounts or an accompanying app in Website 5.0.

The remaining edits suggested by participants relate to information provision. In some cases more detail in existing content was required (e.g. breast cancer in men), in others new sections were requested (e.g. breast health during pregnancy and breastfeeding). These additions will not necessarily enhance the acceptability or feasibility of the intervention, although they may perhaps improve engagement for certain participants. There was one suggested edit in the information provision category that was important for acceptability. The language used in the Know Breast Cancer, Reduce Risk section was weight stigmatising. The feedback received from the participant allowed for the proposal of an alternative, acceptable, non-stigmatising text for the next iteration of the website.

7.5.3 Promoting engagement

The Person-Based Approach states that promoting a positive experience and relatedness within the design of a website is crucial to engagement with and adherence to digital interventions (Bradbury et al., 2014). Using the website must be an enjoyable, positive, and interesting experience (Yardley et al., 2015b). To achieve this, the language used in the intervention must be non-directive and non-judgmental; users must be invited, rather than instructed, to participate (Yardley et al., 2015b). This has been further supported by empirical

evidence from digital intervention developers. The findings of a retrospective interview study assessing the usability of a digital intervention to reduce alcohol consumption reported that the intervention must be visually appealing, easy to use and have a non-judgemental tone (Crane et al., 2017). The *Know Breast Health* intervention Website 4.0 promotes a positive experience and relatedness. Participants reported that the website was approachable, in particular, they liked the tone of the website which they found suggestive and supportive rather than directive and judgemental. This differed from their expectations for, and their experiences of, cancer and health related websites and motivated them to engage with their breast health.

The Person-Based Approach states that in order for an intervention to be engaging, it must be trustworthy (Yardley et al., 2015b). Participants in the current study trusted the website and many of them based this solely on how it looked. Some participants were aware of the About Us section of the website and cited the logos and descriptions therein as important for establishing credibility. However, the majority of participants were convinced that the intervention was trustworthy by the quality of the website and its contents, for example, the video of the GP. This is in keeping with the Person-Based Approach recommendations to promote trustworthiness in the source of a website. They state it must have a professional and consistent visual appearance and usable interface (Yardley et al., 2015b).

Maximising intervention users' sense of control and competence will increase the likelihood of a user engaging with, and adhering to, a digital intervention (Yardley et al., 2015b). This involves encouraging users to address the problem targeted by the intervention in a manageable and achievable way. The *Know Breast Health* intervention promotes competence in its users by providing practical guidance and providing helpful information. Participants reported that the intervention content was manageable and easy to understand. It made them feel supported and encouraged to engage with their breast health. The intervention did not overwhelm participants and the practical tools, such as barrier identification and action planning made them feel like their goals were achievable. While the content of the intervention is important, how it is presented it essential to participants experiencing a sense of control and competence. These findings are reflected in similar studies addressing acceptability and feasibility of digital interventions. Perski et al. (2017) report that when participants were choosing health promoting apps the most important criterion was the "look and feel" of the app. In a longitudinal qualitative study on experiences using digital

interventions for physical activity Baretta, Perski, and Steca (2019) found that simplicity and ease of use are "essential prerequisites" to engagement with the intervention.

7.5.4 Limitations

The participant navigation records are based on participant self-report. A benefit of digital interventions is the ability to gather data on participant usage (Michie et al., 2017). That was not possible in the current study. Due to budget limitations back-end data analytics was not a feature of the website. It is possible that participants experienced recall bias when reporting if they had visited a website section (Bradbury et al., 2014; Yardley et al., 2016). However, because the usage data was collected as part of an interview, it was possible to ascertain if participants had seen website sections. Participants discussed their experiences using the website, so it was clear to the interviewer if they had not seen a section, because they were unable to discuss it, thereby limiting the chance of error.

All participants had a positive relationship with their GP. Thus, all participants answered yes to the tailoring question "Would you feel comfortable asking your GP to examine your breasts?". Therefore, only 25% of participants saw all of the content in *Module 2: Know Your GP*. While this provided limited information about user experience of that module, it did highlight that the tailoring was successful in the intervention.

7.5.5 Recommendations for Website 5.0

This study has produced clear guidance on how to enhance the acceptability, usability and feasibility of the *Know Breast Health* intervention. Website 5.0 must maintain a supportive and non-judgemental tone and ensure that information provided is practical and easy to understand. Improved functionality is important for the acceptance of future iterations of the *Know Breast Health* intervention. In particular, participants want individual accounts where they can save their breast health diaries and plans. The aesthetics of the website are paramount to user experience; they determine if the website is perceived as friendly, trustworthy and interesting.

7.6 Conclusion

The aim of this study was to enhance the acceptability and feasibility of the *Know Breast Health* intervention by interviewing participants about their experiences of using it independently. The retrospective interview design allowed participants to describe their perspectives of the intervention. It allowed for an in-depth understanding of how participants use the website independently and, therefore, identified areas that participants enjoyed and

those they would change. The findings show that overall, the *Know Breast Health* intervention Website 4.0 is acceptable and feasible. However, the findings indicate clearly how the intervention can be further optimised through improving issues of functionality. The *Know Breast Health* intervention has a clear mandate for the next phase of development.

8 General Discussion

8.1 Discussion overview

This chapter will firstly present a summary of the overall findings of this research. The contributions this research has made to the early diagnosis literature as well as the science of intervention development will then be discussed. Implications for future research and policy will be addressed. Limitations of the research will be outlined, followed by concluding remarks.

8.2 Summary of research findings

The overall aim of this research was to develop an intervention to target step one of the WHO strategy for cancer early diagnosis, *awareness and accessing care*, for breast cancer (WHO, 2017). The objective was to use health psychology methodologies to create a usable, acceptable and engaging intervention by incorporating target user perspectives and grounding it in theory and evidence. Finally, this research aimed to develop the intervention in a transparent and systematic way in order to contribute to the science of intervention development.

Planning is the first stage in the Person-Based Approach to intervention development (Yardley et al., 2015b). The Pathways Model highlights the role of patient, healthcare and disease factors in progression through the patient interval (Scott et al., 2013). The literature review for the planning stage of the *Know Breast Health* intervention identified the contributing factors for the patient interval for breast cancer. These many factors can be grouped under four main headings; social factors, knowledge, healthcare habits and cognitions and affect. These findings were used to specify the content of the *Know Breast Health* intervention by following the Behaviour Change Wheel (Michie et al., 2014). The first stage, the behavioural diagnosis, used the findings of the literature review to understand the target behaviour: immediate help-seeking upon self-discovery of a symptom of breast cancer. Stages 2 and 3 identified the intervention functions and the BCTs most likely to impact the target behaviour. By following the Behaviour Change Wheel APEASE criteria, website components (v.1) were developed (Michie et al., 2014). Website components are how the BCTs are operationalised in the *Know Breast Health* intervention. They are the mode of delivery for the active ingredients of the intervention. The Behaviour Change Wheel was used to develop proposed content for the intervention.

The next step in the planning stage of development was to explore potential content of the *Know Breast Health* intervention with target users. Focus group interviews were conducted to assess the acceptability of the proposed website components (v.1) and facilitate the generation of novel ideas for the intervention. Overall the website components (v.1) as presented were acceptable to the participants. Discussions in the focus groups mapped clearly onto the Internet Intervention Model providing detailed guidance on how to create an engaging website by addressing issues of appearance, behavioural prescriptions, burdens, content, delivery, message, participation and assessment (Ritterband et al., 2009). The Focus Group Interview Study provided a clear mandate for the *Know Breast Health* intervention in terms of how the website should look and feel, as well as its content.

Stage 2 of the Person-Based Approach to intervention development is *design* (Yardley et al., 2015b). In the design stage of the development of the *Know Breast Health* intervention the *logic model* and *guiding principles* were produced in order to provide a blueprint for the *Know Breast Health* intervention Website 1.0. The findings from the Focus Group Interview Study were used firstly, to create website components version 2. These were then combined with the Behaviour Change Wheel work to create the logic model which details the hypothesised mechanisms of action of the *Know Breast Health* intervention. Secondly, the findings from the Focus Group Interview Study were combined with principles of digital health intervention design to create the guiding principles of the *Know Breast Health* intervention.

The third stage of the Person-Based Approach is *optimisation* (Yardley et al., 2015b). In the *optimisation* stage of the development of the *Know Breast Health* intervention the usability, acceptability and feasibility of the intervention was enhanced in order to maximise user engagement. The Think-aloud Interview study did this through iterative modification based on target user feedback. Participant reactions to every intervention component was elicited, observed and analysed to optimise it from the user perspective. The think-aloud interviews identified issues of navigation, comprehension and engagement. Three rounds of *interview-analyse-edit* were conducted to maximise the amount of useful data gained from the interviews. The iterative process allowed multiple variations to be tested across different sections of the website. While traditional approach would have produced the *Know Breast Health* intervention Website 2.0, the iterative approach employed here allowed more advanced development of the *Know Breast Health* intervention, producing Website 4.0. The Retrospective Interview Study enhanced the usability, acceptability and feasibility of the

website through a thematic analysis of participants' experience of using the intervention in their own time. Overall the *Know Breast Health* intervention Website 4.0 was acceptable to participants; they found it welcoming, motivating and supportive. Participants thought Website 4.0 was trustworthy and found the content and aesthetics engaging. In particular, participants liked the provision of practical guidance and knowledge. The full website can be seen here: http://digital-health-uiot.datascienceinstitute.ie

This research has developed an intervention to promote immediate help-seeking to an HCP upon self-discovery of a symptom of breast cancer. It is recommended that interventions be described using an intervention *ontology structure* (Michie, West, Sheals, & Godinho, 2018; West & Michie, 2016). The intervention ontology structure is a method for organising evidence about interventions (Michie et al., 2018; West & Michie, 2016). It is a conceptual structure for representing the key elements of interventions: the content, features of delivery, mechanisms of action, target behaviour, target population, setting, uptake and engagement (West & Michie, 2016). The idea of the *ontology structure* is to promote a common language for intervention developers in order to advance the science (Michie et al., 2018). In the *Know Breast Health* intervention the *target population* is women, living in Ireland, aged 18 – 49. The target *behaviour* of the intervention is immediate help-seeking to an HCP upon self-discovery of a symptom of breast cancer. The many and complex antecedents to this behaviour were identified in the behavioural diagnosis. The intervention acts on these antecedents through training, persuasion, modelling, education, enablement, coercion and environmental restructuring. The *content* of the intervention which is described in detail and classified with BCTs is *delivered* through a website. The planning, design and optimisation of the *Know Breast Health* intervention has aimed to maximise future *uptake* and *engagement*.

8.3 Contribution of this research

8.3.1 A transparent development process

The process of intervention development has been referred to as a "black box" due to lack of reporting on the methods and procedures involved (Hoddinott, 2015). There are frequent calls for better and more detailed descriptions of the content of behaviour change interventions (Fredrix, McSharry, Flannery, Dinneen, & Byrne, 2018; Knittle, 2015; Michie, Fixsen, Grimshaw, & Eccles, 2009; Morrissey et al., 2017; Peters & Marques, 2014; Presseau et al., 2015; Riley et al., 2008; West & Michie, 2016). Without adequate reporting of intervention content, researchers, practitioners and patients must guess how best to use them

(Hoffmann et al., 2017). Furthermore, without the proper reporting, the time and resources invested in the conduct of research is wasted (Garnett et al., 2018; Glasziou et al., 2014; Macleod et al., 2014). It is estimated that 85% of research activity can be classified as 'research waste' (Bleijenberg et al., 2018; Macleod et al., 2014). Adequate reporting and descriptions of interventions have been highlighted as areas to target to reduce research waste (Bleijenberg et al., 2018; Ioannidis et al., 2014). In addition, incomplete intervention descriptions prevent replication (Hoffmann et al., 2014; Hoffmann et al., 2017; Webster et al., 2015). In order to advance the science of intervention development generally, and improve the effectiveness of individual interventions specifically, researchers must be able to build on the research findings of others (Garnett et al., 2018; Greenwell et al., 2018; Hoffmann et al., 2017; O'Cathain et al., 2019; Webster et al., 2015). The current research is reported in transparent detail, which is necessary to advance the science and to reduce research waste.

Despite this, there are still shortcomings in the published descriptions of interventions (Greenwell et al., 2018; O'Cathain et al., 2019b; Rousseau et al., 2019). There are two important facets of interventions that need to be explicated in the scientific literature: the *content* of the intervention and the *process* of how that content was developed, including how decisions were made and how the intervention is hypothesised to work (Greenwell et al., 2018). In recent years, guidance has been produced to help intervention developers better report their work. For example, the Template for Intervention Description and Replication (TIDieR), is a checklist and guideline developed to "improve the completeness of reporting, and ultimately the replicability, of interventions" (Hoffmann et al., 2014, p. 10). However, Bleijenberg et al. (2018) argues that while reporting standards are perhaps improving, not enough attention is given to the development process of complex interventions and, specifically, how interventions can be improved before proceeding to a full clinical trial. Those without a clear development process fail to contribute to the scientific literature in a meaningful way. This is because, irrespective of the outcome of an intervention trial, without a clear understanding of the active ingredients and the proposed mechanisms of action, the findings have limited impact (Garnett et al., 2018; Greenwell et al., 2018; Webster et al., 2015).

The *Know Breast Health* intervention has been systematically and transparently reported. This thesis provides a clear description of both the intervention content and the development process that created it. Furthermore, an intervention logic model has been

produced which outlines the hypothesised mechanisms of action. Consequently, this research makes a valuable contribution to the growing science of intervention development and facilitates an effective use of research resources thereby reducing research waste.

8.3.2 A focus on engagement

A key objective of the Person-Based Approach is to create interventions that are *engaging* for target users (Morrison et al., 2018; Yardley et al., 2015b). Accordingly, this was also a goal for the *Know Breast Health* intervention. But what is engagement? Engagement is used in varying ways in the digital intervention development literature (Yardley et al., 2016). It is most often understood in terms of the usability and usage of an intervention and the factors that influence these (Yardley et al., 2016). Usability can be defined as "being easy to use, easy to understand, efficient to complete, and acceptable" (Jibb et al., 2017, p. 285) or "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" (Maramba et al., 2019, p. 96). Other researchers would describe usability and acceptability as necessary preconditions to engagement, rather than indicators of engagement (Triberti, Kelders, & Gaggioli, 2018). Perski et al. (2016) distinguish between engagement as a *behaviour* and engagement as a *subjective experience*. Engagement as a behaviour refers to the extent of usage of a digital intervention with a focus on concepts such as dose, duration, frequency and depth of usage. Engagement as a subjective experience refers to the *interaction* with a digital intervention, with a focus on concepts such as attention, interest and affect (Perski et al., 2016). Another explication of engagement comes from Yardley et al. (2016); within a multidisciplinary, international working group tasked with providing an overview of the important issues with engagement and digital health interventions. They report that engagement should be understood at two "intimately linked" levels; the micro and macro (Yardley et al., 2016, p. 834). The micro level involves the "moment-to-moment" engagement with the intervention and the "macro" level involves target user "identification with the wider intervention goals" (Yardley et al., 2016, p. 834).

There are many reasons to place engagement as a central goal of intervention development. In the first instance, engagement is necessary for effectiveness (Yardley et al., 2016). Interventions that are carefully designed and tested to maximise engagement are acceptable and feasible, and are therefore more likely to be effective (Bleijenberg et al., 2018; Macleod et al., 2014; O'Cathain et al., 2019). Bleijenberg et al. (2018) purport that the reason so many trials have negative or inconclusive results is that they lack a systematic

development process that carefully examines issues of engagement and feasibility. If an intervention is not used by the target user, it cannot be effective; therefore, engagement should be a priority for the intervention development process (Jibb et al., 2017; Yardley et al., 2016). Focusing on engagement also represents sound ethical practice. Resources in healthcare are limited and should be used in the most effective way possible. Additionally, ensuring an intervention is engaging increases the potential benefits for the patients and public who use it. An engaging intervention will improve productivity, enhance user well-being, reduce user stress, increase accessibility and reduce the risk of harm (Maramba et al., 2019).

The importance of engagement for both the ethics of health research and the effectiveness of research has been identified by policy makers. The National Institute for Health and Care Excellence (NICE) in the UK has published an Evidence Standards Framework for Digital Health Technologies to provide guidance for policy makers on digital health intervention (NICE, 2019). In this guidance the minimum accepted level of evidence is that representative target users were involved in the design, development or testing of the intervention and that user satisfaction was assessed (NICE, 2019). Further evidence of the focus policy makers have on user engagement is the inclusion of *usability* as a criteria for digital interventions seeking to be included in the United Kingdom National Health Service (NHS) Apps Library (NHS, 2019). The NHS Apps Library helps members of the public to find trusted health and wellbeing apps and digital tools that have been assessed to be clinically safe and secure to use (NHS, 2019). Digital intervention developers must complete the Digital Assessment Questionnaire to have their digital intervention added; usability is one of the seven sections that require evidence (NHS, 2019). Thus, when submitting interventions for adoption into policy and practice researchers will be required to provide evidence that their intervention is engaging (Garnett et al., 2018; Maramba et al., 2019).

Despite its importance, evidence shows that digital interventions typically have poor target user engagement (Baretta et al., 2019). That is, they suffer from low usage and high levels of dropout or “non-usage attrition” (Baretta et al., 2019; Kohl et al., 2013; Yardley et al., 2016). It is estimated that 74% of health and fitness apps are discarded after their tenth use and that 26% are only used once (Baretta et al., 2019). In order to improve engagement with digital interventions, the target users must be included in their development (Kohl et al., 2013; Michie et al., 2017; Yardley et al., 2015a; Yardley et al., 2015b).

Following the Person-Based Approach, the current research developed an engaging intervention. The *Know Breast Health* intervention has focused on usability; it is easy to use, easy to understand and acceptable, but it also focused on engagement as *a subjective experience* (Jibb et al., 2017; Perski et al., 2016). The qualitative studies addressed participant experiences using the website; their attention, interest and affect (Perski et al., 2016). Throughout the current research engagement has been understood at two linked levels (Yardley et al., 2016) . The Think-aloud Interview Study focused more on the micro level or the "moment-to-moment" engagement with the website. While the Retrospective Interview Study took a more "macro" level approach and explored participants experience of engaging the wider intervention goals (Yardley et al., 2016). This research, therefore, contributes to the literature on how best to promote engagement with digital interventions.

8.3.3 A breast health intervention

8.3.3.1 The patient interval for breast cancer

Research demonstrates that there are many barriers to individuals progressing through the patient interval for breast cancer. The current research contributes to this evidence base. The literature review conducted in chapter 2 identified four key domains in the patient interval for breast cancer: knowledge, healthcare habits, social factors, and cognitions and affect. Participants in the current research, in keeping with both the qualitative and quantitative evidence (for example O'Mahony et al., 2011; Quaife et al., 2014), demonstrated knowledge gaps in relation to the symptoms of breast cancer and understanding of breast cancer as a disease. Participants in the Focus Group Study also reported a lack of knowledge regarding self-examination and knowing what is normal for their bodies, which is a novel finding. Participants expressed concern over self-examining; they did not know if they were "doing it right" and they felt uncertain that they would be able to recognise a change because they had no clear idea of what their breasts were like normally.

The importance of attitudes to HCPs and the role of fear and embarrassment to the patient interval for breast cancer is well documented in both the qualitative and quantitative research literature and is replicated in the current research expanding the evidence base of the importance of these factors (Bandura, 2004; Bish et al., 2005; Burgess et al., 2001; Facione, 1993; Forbes et al., 2014; Heisey et al., 2011; Khakbazan et al., 2014; Neave et al., 1990; Niksic et al., 2015; O'Mahony et al., 2013; Scott et al., 2013). The current work also found that some participants felt self-conscious or too embarrassed to perform self-exams. This is a novel finding. Finally participants in the current research highlighted social norms as an

important factor in their progression through the patient interval for breast cancer. Normalising breast health on a personal level and cultural level was discussed. Participants talked about the importance of "making it normal" to self-examine and to discuss breast health with friends, family and HCPs because, currently, to do so feels somehow inappropriate. The current research contributes to our understanding of the patient interval for breast cancer. It highlights that appraisal processes are key for an individual to perceive a reason to discuss a symptom with an HCP, and that factors associated with help-seeking are essential for prompt presentation. Interventions to date have focused on the *appraisal* interval only (Anastasi & Lusher, 2019; Austoker et al., 2009; O'Mahony et al., 2017). The *Know Breast Health* intervention targets the whole patient interval, addressing both appraisal and help-seeking processes. Thus, the *Know Breast Health* intervention is a comprehensive intervention to promote timely help-seeking to an HCP upon self-discovery of a symptom of breast cancer.

8.3.3.2 Women aged 18 – 49

The *Know Breast Health* intervention was designed for women aged 18 – 49, although it is suitable for use by women of all ages. In Ireland, the National Screening Service invites all women at age 50 into *BreastCheck*, the national breast screening programme (HSE, 2019). This is a successful screening programme; in 2016/17 186,181 women were invited to screen and 139,839 women were screened (HSE, 2019). Women in the *BreastCheck* programme are supported and encouraged to engage with their breast health. Women aged 18 – 49 have no such supports, despite the fact that 23% of breast cancers in Ireland are found in this age group (Registry, 2013, 2018). Participants in the Focus Group Interview Study expressed concerns about their uncertainty regarding breast cancer as a disease, its symptoms and self-examination. Participants across all three qualitative studies strongly supported the *Know Breast Health* intervention website and believed it was an important resource for women in Ireland. Similarly, a Cochrane review on interventions for raising breast cancer awareness called for interventions that addressed the needs of younger women (O'Mahony et al., 2017). The *Know Breast Health* intervention has addressed this by delivering an intervention that is acceptable and engaging to women ages 18 – 49.

8.3.3.3 WHO guidelines for Cancer Early Diagnosis

The WHO, in their *Guide to Cancer Early Diagnosis* outline interventions to promote early diagnosis (WHO, 2017). For the patient interval it recommends three interventions: (i) empower and engage people and communities, (ii) improve health literacy and reduce cancer

stigma, and (iii) facilitate access to primary care (WHO, 2017). The WHO states that these interventions must involve people in communities, improve knowledge and awareness and identify barriers to attendance (WHO, 2017). The *Know Breast Health* intervention, by following the Person-Based Approach has adhered to the WHO guidelines. Women participated at three separate stages of development of the intervention and the qualitative findings show that participants found the intervention supportive, encouraging and empowering, addressing the first recommendation.

In terms of the second recommendation, public health literacy is defined as "the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions" (Freedman et al., 2009, p. 448). The *Know Breast Health* intervention aims to increase the health literacy of the target user. The iterative development approach resulted in an intervention that is easy to understand and provides information that users can process and act upon. The mode of delivery of the *Know Breast Health* intervention means that it has the potential to be obtainable by all individuals with an internet connected device. A website was chosen as it is a low-cost option, with the potential for great reach. Given the large target population (women aged 18 – 49) this was an important consideration. Unlike in-person and/or paper-based interventions, once developed, the costs of implementation will be limited and it can be accessed by an infinite number of users (Yardley et al., 2015b). By removing geographic and time-based constraints the *Know Breast Health* can increase access to healthcare information for users (Bradbury et al., 2014; Kohl et al., 2013).

The third recommended intervention from the WHO is to facilitate access to primary care (WHO, 2017). This refers to ensuring populations engage with their health by removing obstacles to primary care (WHO, 2017). While the *Know Breast Health* intervention cannot address system level barriers to care, such as accessibility, it does facilitate identification of individual level barriers to care, such as fear or embarrassment. By following the Person-Based Approach and using the Behaviour Change Wheel the *Know Breast Health* intervention is context-sensitive, that is, tailored to the Irish healthcare system. Thereby facilitating, as much as possible, the reduction of barriers to primary care.

The current research has adhered to the WHO guidelines, and developed an intervention that targets the first step of the WHO strategy for cancer early diagnosis; *awareness and accessing care.*

8.3.3.4 Replicability

A Cochrane review on interventions for raising breast cancer awareness in women recommended that future research provide detailed descriptions of interventions and their mode of delivery as well as measurement tools and outcome assessments (O'Mahony et al., 2017). The *Know Breast Health* intervention has been systematically and transparently developed and reported. The systematic and transparent reporting employed in the current research, with clearly described intervention content and mechanisms of action, will enable replication, and the development of a high quality trial that will contribute to the development of a strong evidence base for early cancer diagnosis research.

8.4 Implications for research and policy

8.4.1 Design versus development

The development phase of an intervention can be described as the period from when an intervention is initially conceived to when it is ready for formal evaluation (Craig et al., 2008; Hoddinott, 2015). This is a complex process. O'Cathain et al. (2019) conducted a systematic methods overview and identified 18 actions in the intervention development process and synthesised them into seven domains: conception, planning, designing, creating, refining, documenting and planning for future evaluation. In the intervention development literature the *design* process receives insufficient attention (Rousseau et al., 2019). This could be due to the limited detail provided on design in the widely cited Medical Research Council guidance on the development and evaluation of complex interventions (Craig et al., 2008; Rousseau et al., 2019). O'Cathain et al. (2019) in their review found a number of elements made up the design stage of development: idea generation for solutions, components and features of an intervention; making decisions about the content, format and delivery of the intervention; and creating implementation plans and re-evaluating where to intervene (O'Cathain et al., 2019). Rousseau et al. (2019) conducted a qualitative interview study with intervention developers and associated stakeholders to investigate how design occurs in health intervention development. Participants reported that the design stage posed more challenges than other parts of the development process. The results also showed substantial variation in approaches to design (Rousseau et al., 2019). Evidently, the design phase of intervention development is critical and challenging, and yet, detailed guidance and adequate reporting is lacking (Rousseau et al., 2019).

In the Person-Based Approach the *design* phase comprises identifying the key intervention design objectives and the distinctive features of the intervention needed to achieve those objectives (Yardley et al., 2015a; Yardley et al., 2015b). However, the most recent Person-Based Approach overview paper omits the design stage, so too does the guidance on the Person-Based Approach website (Morrison et al., 2018; Southampton, 2019). In the newest version, the Person-Based Approach is a three step process of planning, optimising and implementing. The design stage has been absorbed by the planning stage and so, technically, the Person-Based Approach specific guidance remains the same. However, it could be argued, that this reduction in focus on design is problematic given the complexity of the design stage of development (O'Cathain et al., 2019).

In the current research, the Person-Based Approach failed to provide adequate guidance to address the various actions involved in the design stage of the development of the *Know Breast Health* intervention. The Behaviour Change Wheel guide to intervention development was therefore incorporated into the development process. This addition is in keeping with Person-Based Approach guidance, which recommends conducting "complementary theory-based activities", such as behaviour analysis, in parallel with the Person-Based Approach (Morrison et al., 2018, p. 465). The Behaviour Change Wheel provides a list of options to select at each stage of the development process allowing for a clear and systematic means of development. However, there is limited guidance on translating chosen BCTs into intervention content. This is reflected in the new INDEX guidelines which state that *principles of creativity* are required to actually bring intervention content to fruition (O'Cathain et al., 2019a). As also reported by other researchers (Garnett et al., 2018; Webster et al., 2015), personal judgement and imagination were required to make the leap from recommended BCTs to the possible website components of the *Know Breast Health* intervention. Such a leap would not have been possible if only using the Person-Based Approach. The broad description of the stages of development provided by the Person-Based Approach does not guide the user to intervention *content* creation. However it does guide the user in other ways. The website components, developed using the Behaviour Change Wheel, began as ideas that were presented to participants in the Focus Group Interview Study and, if deemed acceptable by participants, they were brought to life in the website. The Focus Group Interview Study also encouraged participants to generate ideas for the intervention. This process, of presenting the proposed website components to relevant stakeholders for

feedback, is a key step in the Person-Based Approach. Thus, combining these two approaches was effective.

There is insufficient discussion and reporting of the design process involved in intervention development in the healthcare literature (Rousseau et al., 2019). This may be a consequence of the *leap* described above; the moment where imagination must play a role in the development process. As discussed, intervention development science is advocating for more transparent and systematic reporting and this *leap* is difficult to account for in that environment. It is, however, a necessary step in the development of interventions, particularly in this age of rapid technological advancement. Imagination and creativity are all the more important now, if we are to take advantage of the ever expanding range of possibilities for digital health interventions (Bazzano, Martin, Hicks, Faughnan, & Murphy, 2017; Rousseau et al., 2019). Future research must place a spotlight on the design stage of the development process in order to support the expansion of the science and exploit technology for healthcare gains.

8.4.2 Breast cancer in low and middle income countries

There are substantial global inequities in cancer survival for women. Breast cancer survival is lower for indigenous women in high-income countries and is lower in most low- and middle-income countries than in high-income countries (Ginsburg et al., 2017b). In the last 25 years breast cancer mortality rates have decreased in many high-income countries due to a combination of awareness, early detection, and effective treatments (Denny et al., 2017). Mammography is effective at reducing breast cancer mortality among women aged 50 – 74 years, but is only possible in high-resource settings (Denny et al., 2017). Higher mortality rates in low- and middle-income countries are due to advanced stage at diagnosis or limited access to treatment, or both (Denny et al., 2017).

In a 2017 Lancet Series on health, equity, and women's cancers, Denny et al. (2017, p. 866) highlighted *breast awareness* as a "universally feasible approach" to improve early detection of breast cancer and reduce the disparities between low- and middle-income countries and high-income countries. They called for public information or education campaigns to reduce postponement of help-seeking and promote breast awareness (Denny et al., 2017). In particular, interventions that reduce stigma, dispel myths (such as, that cancer is inevitably fatal), break down barriers to access and encourage women to seek care early in the disease course are recommended as necessary (Denny et al., 2017).

Digital health interventions have the potential to improve access to, and quality of, healthcare in low- and middle-income countries (Naslund et al., 2017). The WHO *Global Strategy on Digital Health 2020 – 2024* aims to harness the potential of digital health to achieve their vison of "health for all" (WHO, 2019, p. 6). The Global Strategy states that digital health interventions should be "people-centred, evidence-based, effective, efficient, sustainable, inclusive, equitable, and contextualized" (WHO, 2019, p. 6). Recommendations for best practices in applying digital health interventions in low- and middle-income countries involve engaging target users in their development and keeping simplicity, interoperability and adaptability as design features (Bazzano et al., 2017; Clifford, 2016; Holeman et al., 2014; Labrique et al., 2018).

Health psychology methodologies, such as those used in this research, are ideally suited to developing digital interventions to improve breast health in low- and middle-income countries. The current research provides a template for the development of a digital intervention to target the patient interval for breast cancer. Using health psychology approaches, a people-centred and evidence-based intervention was created, tailored to the Irish healthcare system. Similar approaches could be used to develop an intervention to target the patient interval for breast cancer in low- and middle-income countries. By following the approach outlined in the current research (the Person-Based Approach and Behaviour Change Wheel), future research could produce culturally sensitive, digital interventions in low- and middle-income countries for a limited cost. Digital interventions, such as the *Know Breast Health* intervention, do not require large capital investment and have potential to aid breast cancer control in low resource settings (Denny et al., 2017; Ginsburg et al., 2017a; Murray, May, & Mair, 2010; WHO, 2017).

8.5 Next steps for intervention development

The next step in the development of the *Know Breast Health* intervention is the final stage of the Person-Based Approach: *implementation*. This stage involves the use of a mixed methods study to identify further modifications to improve the acceptability, feasibility, and effectiveness of an intervention (Yardley et al., 2015b). This process evaluation approach allows for the examination of the fully deployed intervention to make it more effective in changing behaviour or more suitable to a real-world context (Morrison et al., 2018). The guiding principles can be edited and the intervention further optimised by triangulating qualitative and quantitative data (Morrison et al., 2018; Yardley et al., 2015b).

The Medical Research Council guidance on developing and evaluating complex interventions would recommend a feasibility or pilot study as the next step (Craig et al., 2008). There is some confusion about what these studies entail and how they can be distinguished from each other (Hallingberg et al., 2018). A systematic review of the guidance for pilot and feasibility studies in complex interventions in public health found 25 unique sources of guidance or recommendations for feasibility or pilot studies (Hallingberg et al., 2018). A useful framework was developed by Eldridge et al. (2016) to define pilot and feasibility studies using expert consensus and a systematic review. The framework defines feasibility as an overarching concept which incorporates three distinct types of study: randomised pilot studies, non-randomised pilot studies, and feasibility studies that are not pilot studies. All feasibility studies address the question 'can it be done, should it be done and how should it be done?' (Eldridge et al., 2016). A randomised or non-randomised pilot study could be used as the next step in development of the *Know Breast Health* intervention.

The Medical Research Council guidance then calls for developers to evaluate the effectiveness of their intervention (Craig et al., 2008). The guidance recommends randomised experimental designs (e.g. RCTs) to yield reliable estimates of effect (Craig et al., 2008). Is such a path warranted or, indeed useful, in the case of the *Know Breast Health* intervention? A crucial aspect of the evaluation of an intervention in an experimental trial is the choice of outcome measures (Craig et al., 2008). The aim of the *Know Breast Health* intervention is to promote timely presentation of self-discovered breast cancer symptoms to an HCP. This outcome cannot practicably be assed in an experimental trial; proxy measures must be employed instead. For example, self-examination is necessary to identify a bodily change that could be breast cancer, therefore, a measure to determine self-efficacy for self-exams could be delivered before and after intervention use. If a statistically significant increase in self-efficacy was detected, we could determine the intervention is successful at increasing self-efficacy for self-examination. Such measures could be delivered to participants for all of the active ingredients of the intervention thus determining if the intervention (or which components of it) is effective. A multiphase optimisation strategy (MOST; Collins, 2018) could be implemented to do this. MOST has been recommended as a method to assist developers in deciding what are the most effective or important components of an intervention given certain constraints (Levati et al., 2016; Pellegrini, Steglitz, & Hoffman, 2014). MOST is a three phase process: preparation, optimisation and evaluation (Collins, 2018). The optimisation phase in MOST refers to a process using fully powered, efficient,

randomized experimentation to gather information about the individual and combined performance of intervention components (Collins, 2018). The aim is to identify the best possible combinations of intervention components that is effective at addressing the target behaviour (Collins, 2018; Kugler, Balantekin, Birch, & Savage, 2016). In the case of the *Know Breast Health* intervention using MOST would involve each website component having two levels: on (included in the website) and off (not included). In this way the fractional factorial design allows for examination of all website components to determine what is effective. An additional benefit of MOST is far less participants are required than a traditional experimental design (Collins et al., 2016). Using MOST would allow for the evaluation of the effectiveness of relevant proxy indicators for future prompt presentation to a HCP upon self-discovery of a symptom of breast cancer.

The causal chain in the *Know Breast Health* intervention is complex, as is the case with most public health and health promotion interventions (Victora, Habicht, & Bryce, 2004). These complex causal chains are understood using theoretical modelling and empirical evidence. For example, an increase in self-efficacy to perform a breast self-exam will make it more likely an individual will perform self-exams and therefore more likely they would notice a bodily change if one occurs and therefore more likely to promptly present to an HCP. A long causal chain does not negate the value of an intervention; this information is a valuable resource for women but perhaps it negates the value of a traditional approach to effectiveness testing. A primary benefit of the *Know Breast Health* intervention is its cost to reach ratio, a consequence of its mode of delivery: a website. Once developed, minimal expense is required to maintain it and the potential reach is exponential with no extra cost per user. This benefit is cannot be considered in an experimental trial to test effectiveness. Finally, the process of running an experimental trial is lengthy and expensive. Significant funding would be required to embark on this process for the *Know Breast Health* intervention. In the context of interventions such as this conducting an experimental trial could transform a reasonably cheap intervention, tailored to the specific healthcare context, into a prohibitively expensive one. .

There have been calls from researchers and regulatory bodies, including the World Health Organization, for a universal standard for evaluating the quality of online health information (Devine, Broderick, Harris, Wu, & Hilfiker, 2016; Robillard, Jun, Lai, & Feng, 2018). Robillard et al. (2018) reviewed the literature for existing health information evaluation tools; 36 articles were included. The tools identified ranged from generic

assessments, intended for use across multiple domains of online health information, to assessments targeted to a specific conditions (Robillard et al., 2018). From this evidence they created and validate a quantitative measure of the quality of online health information. The QUality Evaluation Scoring Tool (QUEST) measures six aspects of the quality of online health information: authorship, attribution, conflict of interest, currency, complementarity, and tone yielding an overall quality score between 0 and 28 (Robillard et al., 2018). It is proven to be reliable and valid across a wide range of health topics and can inform a universal standard of online health information (Robillard et al., 2018). Assessing the *Know Breast Health* intervention using independent observers and the QUEST may be a more pragmatic next step in its development than an experimental trial approach. The *Know Breast Health* website is a systematically developed intervention based in health psychology theory and evidence and informed by members of the public. If it were deemed to meet international standards for health information it could legitimately be rolled out without traditional effectiveness testing. The *Know Breast Health* intervention, once certified as meeting QUESTS standards could be hosted by national cancer organisations or public health bodies and be promoted on social media. This model of determining the quality of the intervention rather than its efficacy may be suitable for public health and health promotion interventions with lengthy causal chains. Such an approach may make the delivery of such interventions more feasible and more likely to be implemented in general, and in particular, in low- and middle-income countries.

8.6 Limitations of the current research

8.6.1 Diversity of participants

Forty-two women participated in this research, with 61% living in an urban area. The majority of participants (73%) had a third level education, 24% had second level and one participant had primary level only. The age range of participants was 18 – 49 years: 10% were under 20, 37% in their twenties, 24% were in their thirties and 29% were in their forties. The purposive stratification sampling employed in the current research did not aim to be exhaustive or generalisable but rather aimed to include a broad range of people to contribute to the research (Braun & Clarke, 2013; Palinkas et al., 2015; Yardley et al., 2015b). This was successfully achieved with the age and residence (urban or rural) stratification but individuals with third level education were over-represented in the study. This research also failed to recruit any Irish Traveller women, a minority group who experience health inequalities on the Island of Ireland. Travellers experience a higher mortality than the general population at all

ages and for all causes of death. The life expectancy of Traveller women is 70.1 years compared to 81.6 years for women in the general population (Abdalla, Quirke, Daly, Fitzpatrick, & Kelleher, 2010).

The *Know Breast Health* intervention aims to increase the health literacy of women. However, it is optimised for use by well educated, non-Traveller women and may not be appropriate for other, at-risk groups. Key components of health literacy are the degree to which individuals can process and understand the information provided (Freedman et al., 2009, p. 448). Inclusion of individuals with low literacy and from minority groups in the development process is essential to facilitate this. There are well documented difficulties in recruiting individuals from minority populations to participate in research (Yardley et al., 2016). Future research on the *Know Breast Health* intervention should conduct an optimisation study with a targeted recruitment strategy: purposively sample Traveller women and women with low literacy levels and stratify based on age and residence. This approach will ensure a sample that can enhance the interventions acceptability to all groups.

8.6.2 Public and patient involvement

The involvement of patients and members of the public in the development of health interventions is now considered best practice (Armstrong, Herbert, Aveling, Dixon-Woods, & Martin, 2013; de Wit, Abma, Koelewijn-van Loon, Collins, & Kirwan, 2013; INVOLVE, 2012). Public and patient involvement (PPI) in research occurs "when individuals meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarising, distributing, sharing, and applying its resulting knowledge" (Walsh et al., 2018, p. 3) . PPI can improve research design, intervention development and delivery as well as the recruitment and retention pf participants (Andrews, Allen, Sheppard, Baylis, & Wainwright, 2015; Bagley et al., 2016; Crocker et al., 2015). The current research included members of public as research participants formally and systematically throughout the planning, design and optimisation process. Involving members of the public in this way allowed for the collection and analysis of data to aid design and development. However, the incorporation of a PPI panel could have further enhanced the development of the *Know Breast Health* intervention. In particular, incorporating a PPI panel could have addressed the diversity issues discussed above by improving recruitment from minority groups. The key Person-Based Approach guidance paper (Yardley et al., 2015b) does not refer to PPI, however, the more recent update does (Morrison et al., 2018). (Morrison et al., 2018) argues, in keeping with best practice, that PPI can further complement

the Person-Based Approach to intervention development. Future iterations of the *Know Breast Health* intervention should include a PPI representative.

8.6.3 Financial constraints

Financial constraints resulted in not all of the desired website components were included in the intervention. There were several ideas suggested by multiple participants across the studies that were not translated into website components. Namely, individual accounts on the *Know Breast Health* intervention website and an app to accompany the website. These components were not possible due to financial constraints. This issue has been reported by other researchers (Simons et al., 2018). However, the Person-Based Approach states that the optimisation phase of digital intervention development can be done with prototypes rather than completed products. The work done to date for the *Know Breast Health* intervention demonstrates a clear requirement for added features and can therefore be used to source more funding for the next phase of research.

8.6.4 Social desirability bias

Social desirability bias was a potential problem throughout the qualitative work in the current research as participants may have felt reluctant to be critical of the intervention in the presence of a researcher involved in its development (Morrison et al., 2015). Accordingly, social desirability bias was directly targeted in each study. In the Focus Group Interview Study participants were told that they were active contributors to the research. They were asked to try to think of ideas for the intervention and share them with each other for discussion. They were told that their advice was needed on the content proposed for the intervention, that their input would guide how the website looked and what was included in it. In the think-aloud and retrospective interviews participants were encouraged to be as critical as possible, they were told that their job was to find problems with the website so that they could be fixed. They were asked to help to improve the website by sharing their thoughts and opinions about how it looked and what it said. These instructions were well received by participants. Participants were critical of both the proposed website components and the actual website. For example, participants in the Focus Group Interview Study were critical of the idea of a discussion forum and concluded it should not be included in the website. In the Think Aloud Study participants were critical of navigation issues and the in the Retrospective Interview Study they criticised the quality of the GP video. This demonstrates that the instructions to the participants to minimise social desirability bias were successful.

8.7 Conclusion

This research developed an intervention to target step one of the WHO strategy for cancer early diagnosis, *awareness and accessing care*, for breast cancer (WHO, 2017). Health psychology methodologies were used to create a usable, acceptable and engaging intervention by incorporating target user perspectives throughout the development process, and grounding it in theory and evidence. This research was conducted and reported transparently and systematically to contribute to the growing science of intervention development. Furthermore, this work provides a template for the development of engaging, context-sensitive, digital interventions for future research. The *Know Breast Health* intervention targets the whole patient interval, addressing both appraisal and help-seeking processes. Thus, the *Know Breast Health* intervention is the first comprehensive intervention to promote timely help-seeking to an HCP upon self-discovery of a symptom of breast cancer. With development and optimisation complete, this intervention is now ready for piloting and implementation.

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Appendices

Appendix 1: Interview Schedules

Appendix 1a: Interview Schedule for Focus Group Interview Study

Appendix 1b: Interview Schedule for Think-aloud Interview Study

Appendix 1c: Interview Schedule for Retrospective Interview Study

Appendix 1a: Interview Schedule for Focus Group Interview Study

Warm up and ground rules

Purpose

- The purpose of this focus group is to get your opinions.
- The purpose of my PhD is to help women to make quicker/better decisions about their breast health.
- Designing a website to do that.
- This is the first step in the design process- your opinions.
- You are active participants in this research- more than that you are contributors to this research
- This website will be designed using theory, scientific evidence and women's voices

Warm up

- Tell us your NAME and if you have ever used a website/app or any kind of technology to help you manage your health.
- Do you have an app for health on your phone right now?
- Last time you googled something about health?
- What do you like about technology helping you with your health?
- Do you have an interest in using a website to manage your breast health?

Guidelines

1. You do not need to speak in any particular order. When you have something to say, please do so.
2. Please try not to interrupt each other.
3. Remember that there are many people in the group and it is important that we obtain the point of view of each one of you.
4. Because we have limited time together, I may need to stop you and to redirect our discussion. Does anyone have any questions?

My model

You are part of this research now, you are contributing so it's important you understand the context of what we are doing

ONE final guideline

This is about a website- how it can help us manage our breast health. It would be interesting to chat about *why* women delay but that is not why we're here. As you've just seen we know what can cause women to delay. We're here to talk about the website and how it can help women to make quicker decisions. I will be ruthless in keeping ye on track to talk about that!

Any questions?

Appraisal interval

This is what we want to encourage - how do you think we could do that through a website?

This is what we're thinking of doing - what do you think of that?

1. **Being sure and confident about how to examine yourself**
   - Video: Expert (e.g. doctor) demonstrating how it's done using a demonstrator mould
   - Video: women examining her own breasts
2. **Being sure and confident about how to recognise a symptom that could be BC**
3. **Being able to remember all the symptoms**
   - Education: text description and Pictures of symptoms- real images, sketches…
   - Print: list of symptoms &/ pictures of symptoms
   - Testimony: personal descriptions of symptoms
4. **Good understanding of BC as a disease; it's causes, risk factors, curability & treatment needed**
   - Education: video, text, infographics, images
   - Testimony: positive remarks about curability
5. **Being able to remember what's normal for you**
6. **Being confident that you would notice a change- Self-monitoring your breasts**
7. **Making time to notice breast**
   - Misc.: online diary (printable); Breast Map; Breast Selfie
   - Misc.: Notifications/reminders
   - Print: visual cue- to stick up somewhere
   - Worksheet (w print/email options): Action planning
8. **Any questions?**

Help-seeking interval

This is what we want to encourage - how do you think we could do that through a website?

This is what we're thinking of doing - what do you think of that?

9. **Make and attend the appointment as soon as a change is noticed**
10. **Being confident that you can make time to see a doctor**
    - Education: this is what will happen; step by step
    - Testimony: best €50 I ever spent
    - Worksheet (w print/email options):
      - Identify Practicalities: where it is, how much it will cost
      - Identify barriers and solutions – list of common barriers and solutions
      - Action planning- goal setting
11. **Being sure and confident that I can show my doctor my breasts and talk about my concerns**
12. **Understanding that my doctor will not think it is a waste of time to talk about my breast health, that it is not an embarrassing thing to do**

- Misc.: question: are you happy to **show** your doctor your breasts and have she/he examine them in detail?
- Video: woman talking to doctor/being examined
- Testimony/Video: testimony from Doc about importance of patient disclosure
- Education: the practicalities of changing GP/how to do it

13. Any questions?

General

14. These are some general questions/ideas for the website - what are your thoughts on these?

15. Feeling supported to make the right decisions

16. Feeling confident that you have the right information

- Video: Social comparison through video/ vignettes
- Misc.: Discussion Forum; comments section; option to submit Qs and have them published with answers

17. Setting goals

- BC symptoms/disease & recognition
- Making and attending appointment
- Worksheet (w print/email options): Setting goals

18. What should the website look like?

- Breast *health*?
- NUIG logo?
- Pink?

19. Your breast health plan

- Create an account?
- Booklet of all your worksheets combined together into one (w print/email options)

20. Any questions?

Wrap up

21. Final question

Do you have an interest in using a website to manage your breast health?

22. Themes

Identify and organise the major themes from the participant's responses

Determine how each member perceives them

23. Any final questions?

24. Thank you

Appendix 1b: Interview Schedule for Think-aloud Interview Study

Opening

The purpose of this interview is to get your thoughts about this website. The goal is to interview many different women and to use what they tell me to make this website the best it can be! So don't worry about being critical- in fact **the more critical the better**! I want to find all the problems and fix them.

Complete website

Allow participant to navigate through naturally, then guide through sections they missed

Questions

1. What are your overall views toward the website?
2. Was there anything you particularly disliked?
3. Was there anything you found particularly hard to use?
4. Was there anything you particularly liked?
5. Was there anything you found particularly easy to use?
6. Anything you wanted to see there/expected to see there but didn't?
7. Do you have any suggestions for how the website could be improved?
8. Are there any other comments you would like to make?
9. Trustworthiness of the site?
10. Breast health versus breast cancer?
11. Would you use it?

Conclusion

- Do you have any comments, thoughts or questions?
- Thank you for your contribution to this research.

Appendix 1c: Interview Schedule for Retrospective Interview Study

Purpose of interview

1. The purpose of this interview is to get your opinions on the website.
2. These interviews are to find problems with the website so that they can be fixed, so please don't be afraid to be critical- the more critical the better!
3. You can also tell me what you did like
4. We are looking for both positive and negative feedback

Format

1. We'll start with your general impressions, by asking dome general questions
2. Then we'll go through each section of the site so we can get a bit more specific
3. As we discuss each section I'll tell you what we were trying to achieve in that section and ask you if you have any ideas about how we could do it better.

Any questions?

General Questions

1. How many times did you visit the site?
2. Do you think you saw it all/used it all?
3. What device did you use? Phone, Tablet, desktop
4. What are your overall views/ impressions / thoughts about the website?
5. Trustworthiness of the site?
6. Was there anything you particularly disliked, or found hard to use?
7. Was there anything you particularly liked?
8. How did you find navigating the site? Did you understand that there were 3 key sections?
9. Anything you wanted to see there/expected to see there but didn't?

Home Page

1. How important was the home page to your experience?
2. Did you read all the content? Does it matter?

Module 1: Know Your Body

Some women know their breasts as well as they know their brows, do you?

What did you think of that question?

Can you remember what you answered?

Follow our Four Steps:

What did you think of the four steps?

Step 2: KYB/video:

What did you think of that?

Step 3: KYB/Diary + KYB/Map

What did you think of the diary?

What did you think of the map?

Step 3: KYB/Reminder

What did you think of that?

Step 4: Make a plan

Module 2: Know Your GP

Would you feel comfortable asking your GP to examine your breasts?

What did you think of that question?

Can you remember what you answered?

KYGP/Yes + No

What did you think of that?

Why it's important

What did you think of that?

KYGP/Video

What did you think of that?

Purpose:

Set your Goal for Breast Health Habit no.2 now!

What did you think of that?

About Us

What did you think of that?

Module 3: Know breast cancer

Introduction

What did you think of that?

KBC/WhoGetsIt/

What did you think of that?

KBC/WhoGetsIt/ReduceRisk

What did you think of that?

KBC/Symptoms + KBC/Symptoms/Anatomy

What did you think of that?

KBC/How Serious/Counters + Explanations

What did you think of that?

KBC/How Serious/WhatIs cancer +treatments

What did you think of that?

General questions

1. Breast health versus breast cancer?
2. Did you think it was helpful?
3. Do you think it helped you build confidence to get to know your body?
4. Do you think it helped you build confidence for taking to your GP?
5. Do you think you know more about breast cancer?
6. Would you use it? Would you share it?
7. Any general comments or thoughts you would like to share?
8. Do you have any suggestions for how the website could be improved?
9. Do you have any questions for me or about the website?

THANK YOU!

Appendix 2: Participant Information Sheets

Appendix 2a: Participant Information Sheet for Focus Group Interview Study

Appendix 2b: Participant Information Sheet for Think-aloud Interview Study

Appendix 2c: Participant Information Sheet for Retrospective Interview Study

Appendix 2a: Participant Information Sheet for Focus Group Interview Study

Participant Information Sheet

Can a website help manage your breast health

Overview
You are being invited to take part in a study exploring the idea of website focused on helping you manage your breast health

Before you decide to take part, it is important that you understand why the research is being done and what it will involve. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read this information. You should only consent to participate in this research study when you feel you understand what is being asked of you, and you have had enough time to think about your decision.

Who is doing the research?
The research is being conducted by Emma Carr, a PhD Candidate from the School of Psychology at the National University of Ireland, Galway. The research team also includes Dr Jane Walsh and Dr AnnMarie Groarke lecturers in the School of Psychology in NUI, Galway.

What is the research about?
Lots of women delay seeking help when they discover a bodily change that could be a symptom of breast cancer. This research is investigating women's thoughts and opinions about using a website to help them to make prompt decisions about their breast health.

What you will be asked to do
You will be invited to take part in a group discussion.
The group will consist of you, the researcher and 3-5 other participants. You will have an opportunity to discuss your thoughts and opinions about using a website to help make decisions about your healthcare e.g. do you think it's a good idea. You will also be able to make suggestions about what you think would be good to include in a website to help women to make prompt decisions about their

breast health. It will be a casual environment and refreshments will be provided. Each session is scheduled to last approximately one hour.

Your data

In order to accurately capture the group discussions, the researcher will record audio of the session. Selective quotes may be used to illustrate points in any resulting publications. However these quotes will be completely anonymous; your name will not be used.

What's next?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to keep this *Information Sheet* and to read a *Consent Form*. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way. Although we hope you will join us, participation is voluntary.

Contact

If you have any queries about the project, you can contact the lead researcher –
Emma Carr – e.carr2@nuigalway.ie
Alternatively the following people can also be contacted –
Dr. AnnMarie Groarke – annmarie.groarke@nuigalway.ie
Dr. Jane Walsh – jane.walsh@nuigalway.ie

If you have any concerns about this study and wish to contact someone in confidence, you may contact Prof Gary O'Donohoe, Established Professor of psychology, National University of Ireland, Galway (091-495 5122)

Appendix 2b: Participant Information Sheet for Think-aloud Interview Study

Participant Information Sheet

Can a website help manage your breast health?

Overview

You are being invited to take part in a study to explore a newly developed website designed to help women manage their breast health

Before you decide to take part, it is important that you understand why the research is being done and what it will involve. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read this information. You should only consent to participate in this research study when you feel you understand what is being asked of you, and you have had enough time to think about your decision.

Who is doing the research?

The research is being conducted by Emma Carr, a PhD Candidate from the School of Psychology at the National University of Ireland, Galway. The research team also includes Dr Jane Walsh and Dr AnnMarie Groarke, Senior Lecturers in the School of Psychology in NUI, Galway.

What is the research about?

Unfortunately, some women don't notice an unusual change in their breasts when one occurs, and some women put off going to the doctor about a change. Losing this time could be detrimental to their health. By creating positive breast health habits women can identify a change if one occurs, and have the confidence to promptly make an appointment with their GP. The goal of this research is to build a website that will help women to create positive breast health habits.

What you will be asked to do

You will be asked to use our website in the presence of a researcher. While using the website you will be asked to "think-aloud" or, tell the researcher what you are thinking while you use the website. You will be audio recorded and the computer screen will be recorded. We are interested in your thoughts and opinions of the site, so we will also ask you some questions about what you think of it. We are doing this so we can identify problems and make the website better.

Your data

The researcher will use an audio and screen recorder during the session. Selective quotes may be used to illustrate points in any resulting publications. However these quotes will be completely anonymous; your name will not be used.

What's next?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to keep this *Information Sheet* and to read a *Consent Form*. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way. Although we hope you will join us, participation is voluntary.

Contact

If you have any queries about the project, you can contact the lead researcher –
Emma Carr – e.carr2@nuigalway.ie
Alternatively the following people can also be contacted –
Dr. AnnMarie Groarke – annmarie.groarke@nuigalway.ie
Dr. Jane Walsh – jane.walsh@nuigalway.ie

If you have any concerns about this study and wish to contact someone in confidence, you may contact Dr John Bogue, Head of School, Psychology, National University of Ireland, Galway (091-495 5124).

Appendix 2c: Participant Information Sheet for Retrospective Interview Study

Participant Information Sheet

The Know Breast Health Study

Overview

You are being invited to take part in a study to explore a newly developed website designed to help women manage their breast health

Before you decide to take part, it is important that you understand why the research is being done and what it will involve. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read this information. You should only consent to participate in this research study when you feel you understand what is being asked of you, and you have had enough time to think about your decision.

Who is doing the research?

The research is being conducted by Emma Carr, a PhD Candidate from the School of Psychology at the National University of Ireland, Galway. The research team also includes Dr Jane Walsh and Dr AnnMarie Groarke lecturers in the School of Psychology in NUI, Galway.

What is the research about?

Unfortunately, some women don't notice an unusual change in their breasts when one occurs, and some women put off going to the doctor about a change. Losing this time could be detrimental to their health. By creating positive breast health habits women can identify a change if one occurs, and have the confidence to promptly make an appointment with their GP. The goal of this research is to create a website that will help women to create positive breast health habits..

What you will be asked to do

You will be asked to use our website over the course of a week. You can use it as often or as little as you like. You will then be asked to take part in a phone interview to discuss your thoughts and opinions of the website. This is so that we can make changes to the website to make it better.

Your data
The researcher will audio record the phone interview. Selective quotes may be used to illustrate points in any resulting publications. However these quotes will be completely anonymous, that is, your name will not be used.

What's next?
It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to keep this *Information Sheet* and to complete a *Consent Form*. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way. Although we hope you will join us, participation is voluntary.

Contact
If you have any queries about the project, you can contact the lead researcher –
Emma Carr – e.carr2@nuigalway.ie
Alternatively the following people can also be contacted –
Dr. AnnMarie Groarke – annmarie.groarke@nuigalway.ie
Dr. Jane Walsh – jane.walsh@nuigalway.ie

If you have any concerns about this study and wish to contact someone in confidence, you may contact Dr John Bogue, Head of School, Psychology, National University of Ireland, Galway (091-495 5124)

Appendix 3: Consent Form

Queries

If you have any questions regarding this consent form or any other questions about this study, please contact Emma Carr (e.carr2@nuigalway.ie) or one of her supervisors:
Dr AnnMarie Groarke – annmarie.groarke@nuigalway.ie
Dr Jane Walsh – jane.walsh@nuigalway.ie

If you have any concerns about this study and wish to contact someone in confidence, you may contact Dr John Bogue, Head of School of Psychology, National University of Ireland, Galway (091 495124).

PARTICIPATION IS STRICTLY VOLUNTARY

Please initial EACH box and sign your name in the space below

1. I confirm that I have read the document entitled 'Participant Information Sheet' and have had the opportunity to ask questions ☐
2. I am satisfied that I understand the information provided and have had enough time to consider the information ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected ☐
4. I agree to take part in the above study ☐

Name: _____ (Please use block capitals)

Signature: _____

Date: _____ / _____ / _____

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Appendix 4: Demographics Form

NUI Galway
OÉ Gaillimh

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

1. Name:

   _____

2. How old are you? _____

3. Do you live in an urban or rural area? Urban Rural

4. What is your level of education?

   Primary Secondary Third level

5. What is your occupation/previous occupation? _____

Appendix 5: Consolidated Criteria for Reporting Qualitative Research

Appendix 5a: Consolidated Criteria for Reporting Qualitative Research: Focus Group Interview Study

Appendix 5b: Consolidated Criteria for Reporting Qualitative Research: Think-aloud Interview Study

Appendix 5c: Consolidated Criteria for Reporting Qualitative Research: Retrospective Interview Study

Appendix 5a: Consolidated Criteria for Reporting Qualitative Research: Focus Group Interview Study

Item	Description
Domain 1: Research team and reflexivity	
Personal characteristics	
Interviewer/ facilitator	EC
Credentials	B.A., H.Dip., MSc.
Occupation	PhD candidate
Gender	Female
Experience and training	Trained in qualitative research methods and design
Relationship with participants	
Relationship established	Two participants were known to EC prior to the focus group. All other participants contacted EC through one of the social media sites, email or telephone to discuss arrangements for the focus groups.
Participant knowledge of the interviewer	Participants new that the researcher was a PhD student developing a digital intervention to reduce postponement of help-seeking in individuals who self-discovered a breast cancer symptom. Participants were informed that EC's goal was to hear their thoughts and opinions about the proposed content and that the results would be incorporated into the design of the intervention.
Interviewer characteristics	Participants were informed that EC felt strongly that target users of interventions should be involved in their development in order to improve their usability and acceptability.
Domain 2: Study design	
Theoretical framework	
Methodological orientation and Theory	This study took a critical realist approach within a contextualist framework. A descriptive thematic analysis emphasising sematic themes was therefore chosen.
Participant selection	
Sampling	This study had a purposive sample of women, living in Ireland, aged 18 – 50, stratified by age, education level and residence (urban or rural).
Method of approach	Social media, email, posters and flyers
Sample size	17
Non-participation	0
Setting	

Setting of data collection	Three focus group were held on campus and one was held in a community centre in Galway city
Presence of non-participants	There was a research assistant present at all focus groups
Description of sample	See section 4.4.5
Interview guide	See appendix 1a for the complete interview schedule.
Data collection	
Repeat interviews	n/a
Audio/visual recording	Audio recording
Field notes	n/a
Duration	The interviews lasted an average of 1.5 hours
Data saturation	EC and AMG discussed data saturation and concluded it had been reached
Transcripts returned	Transcripts were not returned to participants for comment
Domain 3: analysis and findings	
Data analysis	
Number of data coders	EC coded the data
Description of the coding tree	Open coding or data derived coding was firstly performed. This consisted of transcripts being read thoroughly and sections of text being assigned to descriptive codes that reflected the semantic content of the data and the Model of Pathways to Treatment intervals. Content of transcripts was constantly compared to codes that were already established. After forming the codes, they were grouped into categories, which were then grouped into themes.
Derivation of themes	EC developed the initial themes from the data. These emerging themes were reviewed by AMG and checked against transcripts
Software	NVivo 11
Participant checking	Participants did not provide feedback on the findings
Reporting	
Quotations presented	Participant quotations were presented to illustrate the themes and findings. Each quotation was identified with a participant number
Data and findings consistent	There was consistency between the data presented and the findings
Clarity of major themes	Major themes are clearly presented in the findings
Clarity of minor themes	Minor themes are clearly presented in the findings

Appendix 5b: Consolidated Criteria for Reporting Qualitative Research: Think-Aloud Interview Study

Item	Description
Domain 1: Research team and reflexivity	
Personal characteristics	
Interviewer/ facilitator	EC
Credentials	B.A., H.Dip., MSc.
Occupation	PhD candidate
Gender	Female
Experience and training	Trained in qualitative research methods and design
Relationship with participants	
Relationship established	One participant was a family member of EC.
Participant knowledge of the interviewer	Participants knew that the researcher was a PhD student involved in the development of the intervention. Participants were informed that EC's goal was to hear their thoughts and opinions about the website and that the results would be used to improve the website.
Interviewer characteristics	It was made clear to participants that EC wanted to find any problems with the website so that it could be improved. Participants were informed that EC felt strongly that target users of interventions should be involved in their development in order to improve their usability and acceptability.
Domain 2: Study design	
Theoretical framework	
Methodological orientation and Theory	This study took a critical realist approach within a contextualist framework. A descriptive thematic analysis emphasising sematic themes was therefore chosen.
Participant selection	
Sampling	This study had a purposive sample of women, living in Ireland, aged 18 – 50, stratified by age, education level and residence (urban or rural).
Method of approach	Email, posters and flyers
Sample size	12
Non-participation	0
Setting	

Setting of data collection	Three interviews were held in a community centre in Galway city and the remainder took place on campus in the School of Psychology
Presence of non-participants	EC was the only non-participant present
Description of sample	See section 6.3.5
Interview guide	See Appendix 1a for the complete interview schedule.
Data collection	
Repeat interviews	n/a
Audio/visual recording	Did the research use audio or visual recording to collect the data? Audio and visual recording was used to collect data. ShareX was used to capture on-screen activity during the interviews. See section 6.3.6. for further details.
Field notes	n/a
Duration	The interviews lasted an average of 50 minutes, ranging from 36 to 74 minutes
Data saturation	Yes
Transcripts returned	Transcripts were not returned to participants for comment
Domain 3: analysis and findings	
Data analysis	
Number of data coders	EC coded the data
Description of the coding tree	No
Derivation of themes	A thematic analysis was not conducted.
Software	NVivo 12
Participant checking	Participants did not provide feedback on the findings
Reporting	
Quotations presented	Participant quotations were presented to illustrate the findings. Each quotation was identified with a participant number
Data and findings consistent	There was consistency between the data presented and the findings
Clarity of major themes	Major themes clearly presented in the findings
Clarity of minor themes	There is a description of minor themes

Appendix 5c: Consolidated Criteria for Reporting Qualitative Research: Retrospective Interview Study

Item	Description
Domain 1: Research team and reflexivity	
Personal characteristics	
Interviewer/ facilitator	EC
Credentials	B.A., H.Dip., MSc.
Occupation	PhD candidate
Gender	Female
Experience and training	Trained in qualitative research methods and design
Relationship with participants	
Relationship established	One participant was known to EC prior to the interviews.
Participant knowledge of the interviewer	Participants knew that the researcher was a PhD student involved in the development of the intervention. Participants were informed that EC's goal was to hear their thoughts and opinions about using the website independently and that the results would be used to improve the website..
Interviewer characteristics	It was made clear to participants that EC wanted to find any problems with the website so that it could be improved. Participants were informed that EC felt strongly that target users of interventions should be involved in their development in order to improve their usability and acceptability.
Domain 2: Study design	
Theoretical framework	
Methodological orientation and Theory	This study took a critical realist approach within a contextualist framework. A descriptive thematic analysis emphasising sematic themes was therefore chosen
Participant selection	
Sampling	This study had a purposive sample of women, living in Ireland, aged 18 – 50, stratified by age, education level and residence (urban or rural).
Method of approach	Social media
Sample size	13
Non-participation	0
Setting	
Setting of data collection	Data was collected through online surveys and over-the-phone interviews

Presence of non-participants	The interviews were conducted by phone.
Description of sample	See section 7.3.5
Interview guide	See appendix 1 for the complete interview schedule.
Data collection	
Repeat interviews	n/a
Audio/visual recording	Audio recording
Field notes	n/a
Duration	On average interviews lasted 30 minutes, ranging from 19 to 46 minutes
Data saturation	Yes
Transcripts returned	Transcripts were not returned to participants for comment
Domain 3: analysis and findings	
Data analysis	
Number of data coders	EC coded the data
Description of the coding tree	Open coding or data derived coding was firstly performed. This consisted of transcripts being read thoroughly and sections of text being assigned to descriptive codes that reflected the semantic content of the data. Content of transcripts was constantly compared to codes that were already established. After forming the codes, they were grouped into categories, which were then grouped into themes.
Derivation of themes	The analysis combined a "top down" approach with a "bottom up" one. Thematic analysis was chosen as it facilitates this approach (Braun & Clarke, 2013). Themes were identified from the data but framed by the *Know Breast Health* intervention modules
Software	NVivo 12
Participant checking	Participants did not provide feedback on the findings
Reporting	
Quotations presented	Participant quotations were presented to illustrate the findings and each quotation was identified with a participant number
Data and findings consistent	There was consistency between the data presented and the findings
Clarity of major themes	Major themes were clearly presented in the findings
Clarity of minor themes	There was a description of diverse cases and minor themes

Appendix 6: Video transcripts

Appendix 6a: KYB/Video transcript

Appendix 6b: KYGP/Video transcript

Appendix 6a: KYB/Video transcript

https://www.youtube.com/watch?time_continue=3&v=a3R1CqqJKbY

There are no rules for boob checking, just do whatever feels comfortable. The key is getting to know what normal feels like for you. All you need are your hands, your boobs and some handy pointers. You can check anywhere; in the shower; on the sofa; even when you're getting dressed, just make it part of your normal routine.

Everybody has breast tissue, all genders, so we should all be checking. You spend more time with your body than anyone else so you're the best person to know how your boobs usually feel. All boobs are different and they'll naturally change throughout your life, even each month, so get to know their natural rhythm.

Note anything that changes, or seems unusual, if one area feels thicker, or any new lumps appear, or if you notice a sudden change in size or shape. It's normal for boobs to hurt around your period but if the pain is different or there more often then get it checked out. Keep an eye out for changes to the skin like dimpling or puckering, or any unexplained rashes or redness, and don't forget your nipples. Look to see if they've become pulled in, changed position or changed shape, or if there's any crusting or liquid coming out. Make sure you're feeling everywhere there's breast tissue not just your boobs, but right up to your collarbone and under your armpits in case there's any swelling. We recommend coppin’ a feel once a month and if you notice anything that doesn't feel normal book an appointment with your doctor.

Appendix 6b: KYGP/Video transcript

https://www.youtube.com/watch?v=erDfOdvmiqk

Hello, I'm Dr Aoife Jackson and I'm a GP. Today I want to talk to you about Breast Health. Firstly I want to encourage you to get to know your upper body; your breasts, armpits and collarbone. You can do this by having a look and feel wherever is comfortable and convenient for you- in the shower- when you're getting undressed- on the couch! It doesn't matter how or when you do it, all that matters is that you know what your breasts normally look and feel like. If you do, you will be able to notice an unusual change if one occurs.

If you do notice a change, make an appointment with your GP straight away and have it checked out. Your GP is always happy to talk to you about your breast health. It is very important. While most breast changes are harmless some can be symptoms of cancer. In this case, the quicker your GP sees you, the better. That's why we are always happy to talk about Breast Health.

If you do talk to your GP about your Breast Health, what can you expect in that appointment?

Well, your GP will ask you about your medical history and if you have a family history of breast cancer and they will ask you about your period. Then they will perform a clinical breast exam. You will be given some privacy and asked to expose the upper part of your body and when you are ready, to lie down on the exam bed. Your GP will inspect the breasts visually first, carefully looking at shape and size, the skin and nipples. They will then examine you manually. They will feel all around both of your breasts and up to your armpit and collarbone.

So, make sure you get to Know Your Body, and that you are confident that you can talk to your GP about your Breast Health. If you notice an unusual change, go see your GP straight away. Thanks for listening.

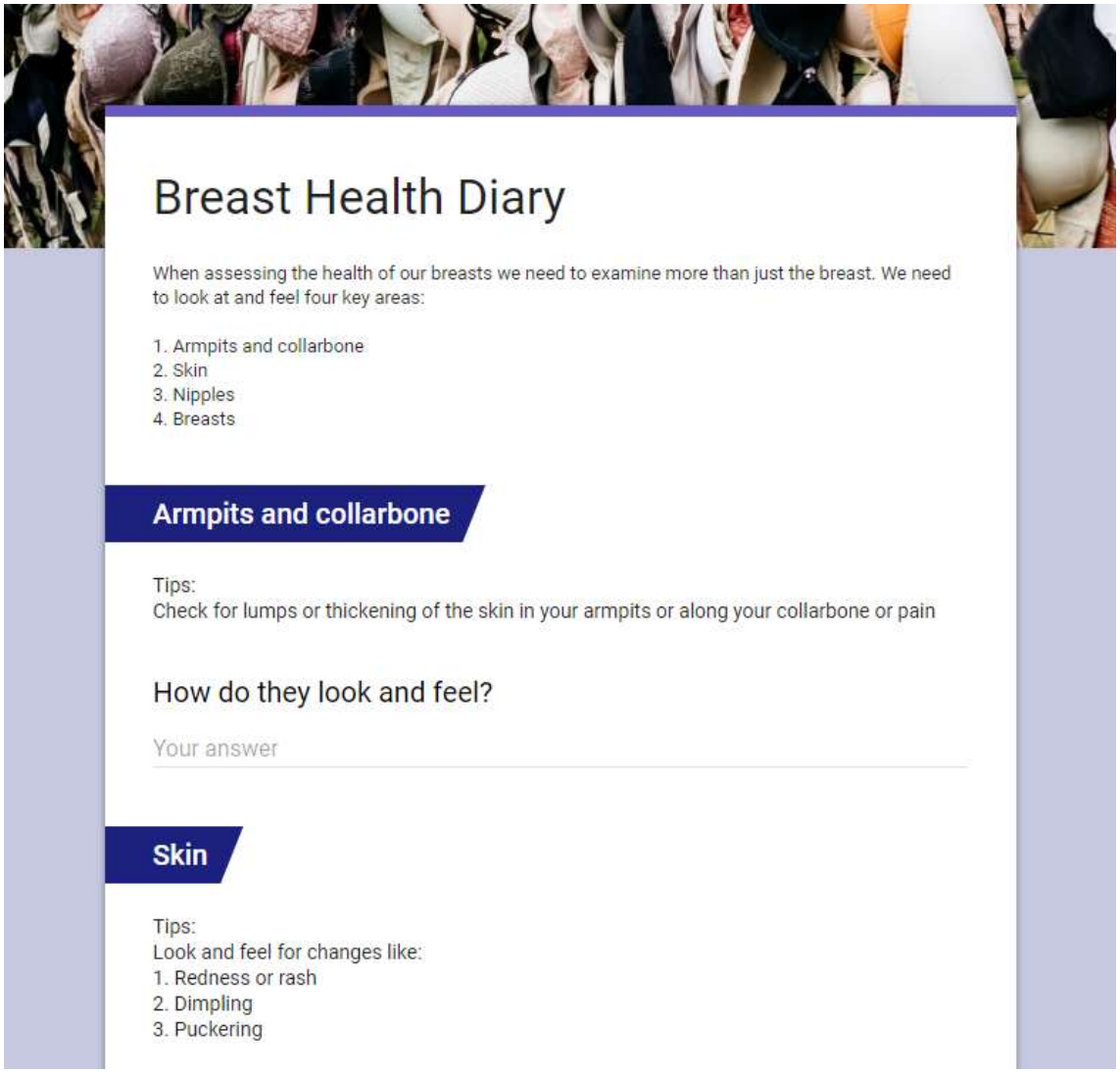
Appendix 7: KYB/Diary

Appendix 7a: KYB/Diary v.1

Appendix 7b: KYB/ Diary v.2

Appendix 7c: KYB/ Diary v.3

Appendix 7a: KYB/Diary v.1



Breast Health Diary

When assessing the health of our breasts we need to examine more than just the breast. We need to look at and feel four key areas:

1. Armpits and collarbone
2. Skin
3. Nipples
4. Breasts

Armpits and collarbone

Tips:
Check for lumps or thickening of the skin in your armpits or along your collarbone or pain

How do they look and feel?

Your answer

Skin

Tips:
Look and feel for changes like:
1. Redness or rash
2. Dimpling
3. Puckering

How does it look and feel?

Your answer

Nipples

Tips:
Look and feel for changes like:
1. A rash on or around the nipple
2. Discharge or bleeding from the nipple
3. Change in size or shape of the nipple
4. Change in direction or position of the nipple

How do they look and feel?

Your answer

Breasts

Tips:
Look and feel for changes like:
1. Change in Size
2. Change in Shape
3. Lump or thickening
4. Unusual pain

How do they look and feel?

Your answer

Any other thoughts?

Your answer

Would you like a copy of this form?

If so, please enter your name and email address below and we will send it to you.
We will not save your email address or use it for any other purpose.

Name

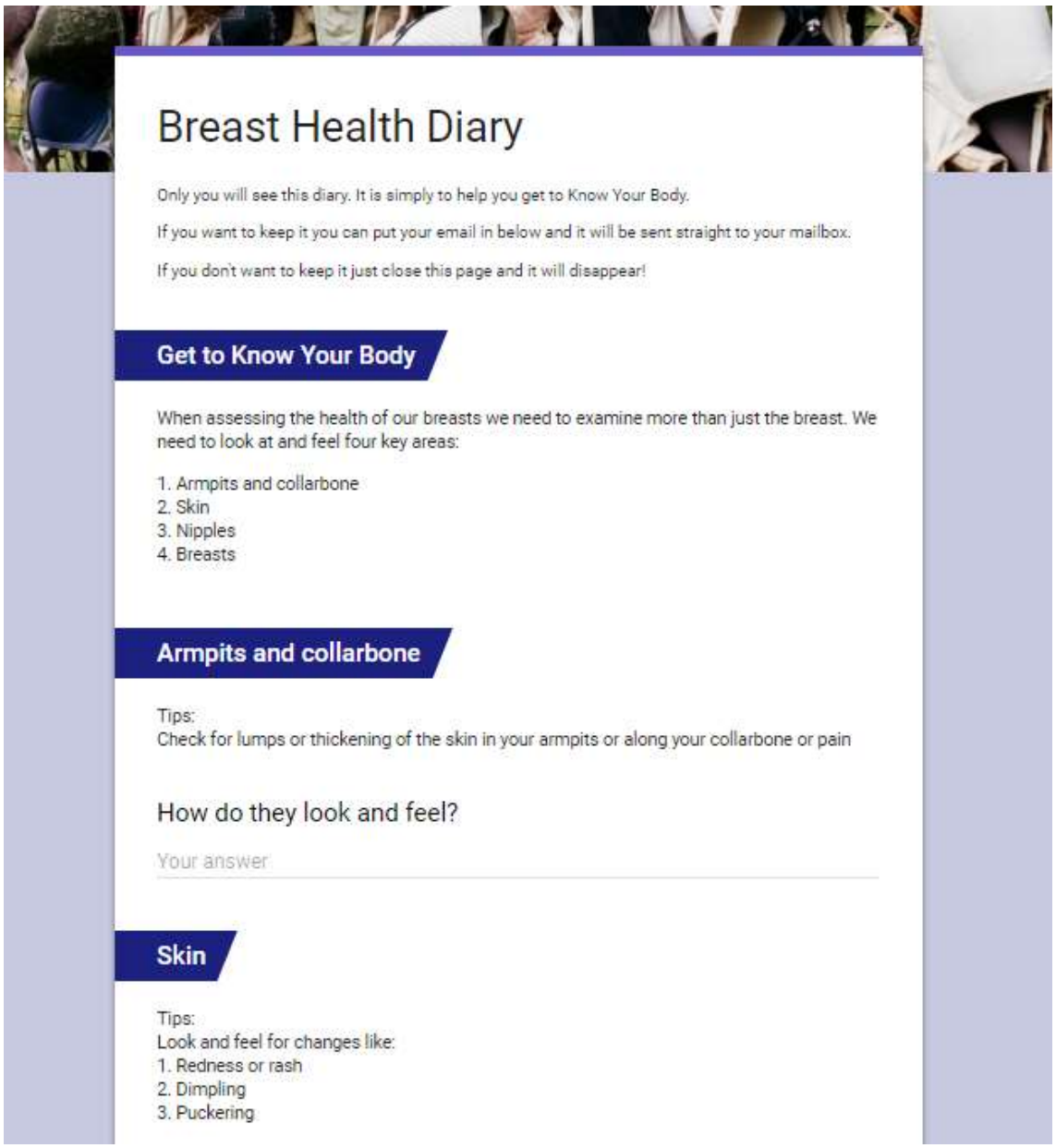
Your answer

Email

Your answer

SUBMIT

Appendix 7b: KYB/Diary v.2



Breast Health Diary

Only you will see this diary. It is simply to help you get to Know Your Body.

If you want to keep it you can put your email in below and it will be sent straight to your mailbox.

If you don't want to keep it just close this page and it will disappear!

Get to Know Your Body

When assessing the health of our breasts we need to examine more than just the breast. We need to look at and feel four key areas:

1. Armpits and collarbone
2. Skin
3. Nipples
4. Breasts

Armpits and collarbone

Tips:
Check for lumps or thickening of the skin in your armpits or along your collarbone or pain

How do they look and feel?

Your answer

Skin

Tips:
Look and feel for changes like:
1. Redness or rash
2. Dimpling
3. Puckering

Nipples

Tips:
Look and feel for changes like:
1. A rash on or around the nipple
2. Discharge or bleeding from the nipple
3. Change in size or shape of the nipple
4. Change in direction or position of the nipple

How do they look and feel?

Your answer

Breasts

Tips:
Look and feel for changes like:
1. Change in Size
2. Change in Shape
3. Lump or thickening
4. Unusual pain

How do they look and feel?

Your answer

Any other thoughts?

Your answer

Would you like to keep this?

If so, please enter your name and email address below and we will send it to you.
We will not save your email address or use it for any other purpose.

Appendix 7c: KYB/Diary v.3

Breast Health Diary

Only you will see this.

If you don't want to keep it just close the page and it will disappear!

If you want to keep it you can insert your email when you're finished and it will be sent straight to your inbox.

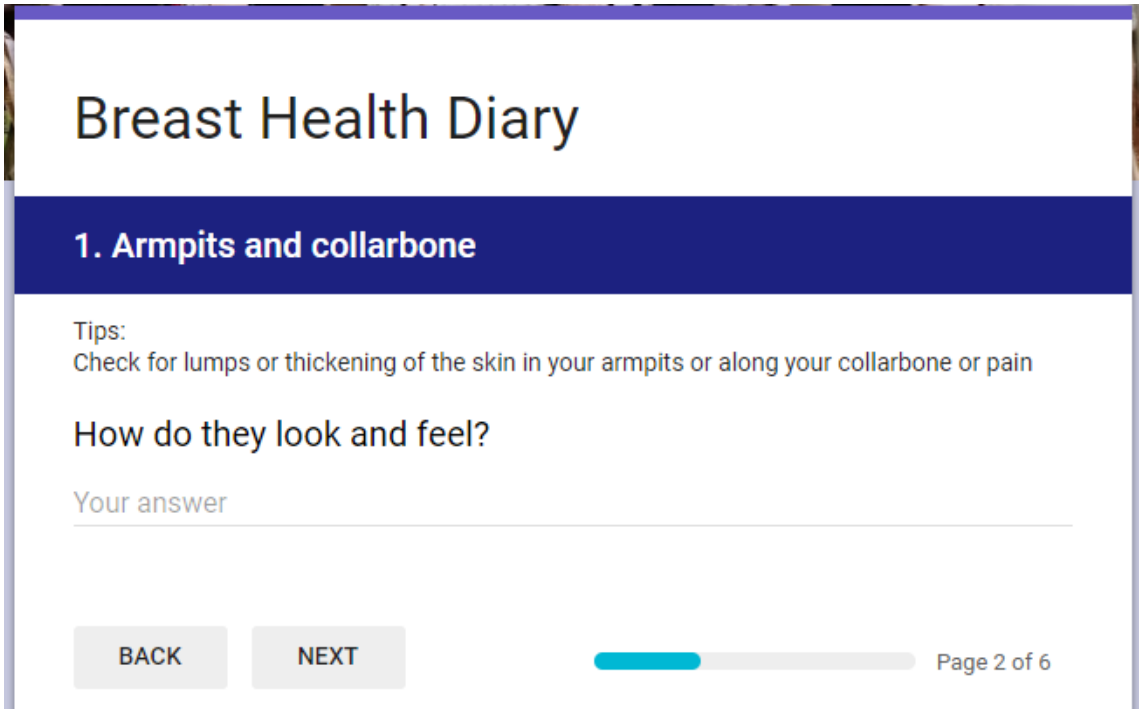
Get to Know Your Body

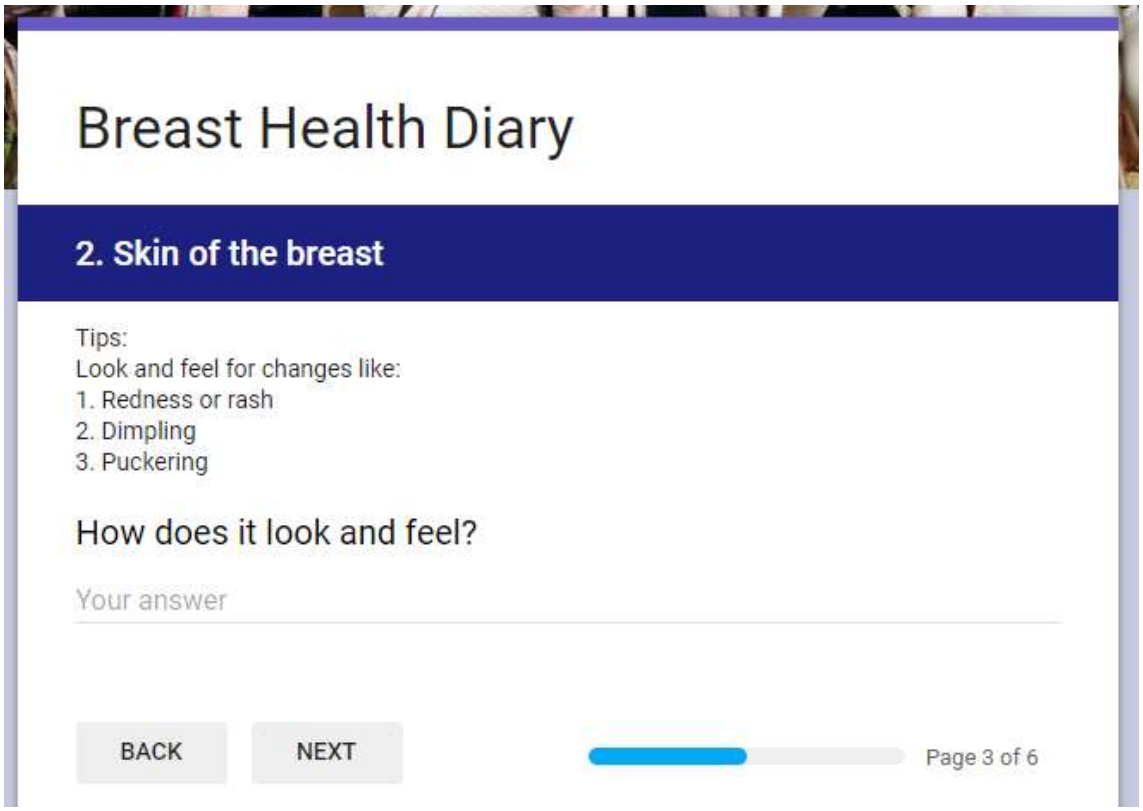
When assessing the health of our breasts we need to examine more than just the breast. We need to look at and feel four key areas:

1. Armpits and collarbone
2. Skin
3. Nipples
4. Breasts

NEXT

Page 1 of 6


Breast Health Diary
1. Armpits and collarbone
Tips:
Check for lumps or thickening of the skin in your armpits or along your collarbone or pain
How do they look and feel?
Your answer
BACK
NEXT
Page 2 of 6


Breast Health Diary
2. Skin of the breast
Tips:
Look and feel for changes like:
1. Redness or rash
2. Dimpling
3. Puckering
How does it look and feel?
Your answer
BACK
NEXT
Page 3 of 6

Breast Health Diary

3. Nipples

Tips:
Look and feel for changes like:
1. A rash on or around the nipple
2. Discharge or bleeding from the nipple
3. Change in size or shape of the nipple
4. Change in direction or position of the nipple

How do they look and feel?

Your answer

BACK NEXT

Page 4 of 6

Breast Health Diary

4. Breasts

Tips:
Look and feel for changes like:
1. Change in Size
2. Change in Shape
3. Lump or thickening
4. Unusual pain

How do they look and feel?

Your answer

BACK NEXT

Page 5 of 6

Breast Health Diary

Finished!

Would you like to keep your Breast Health Diary?

REMINDER: Only you will see this.

If you don't want to keep it just close the page and it will disappear!

If you want to keep it, , please enter your name and email address below and we will send it to you.

Name

Your answer

Email

Your answer

Appendix 8: KYB/Plan

Appendix 8a: KYB/Plan v.1

Appendix 8b: KYB/Plan v.2

Appendix 8c: KYB/Plan v.3

Appendix 8a: KYB/Plan v.1

Breast Health Habit no. 1: Know Your Body

* Required

Set your goal:

I want to get to know my body so that I will notice an unusual change if one occurs *

- ◯ Yes, I do
- ◯ No, I don't

NEXT

Breast Health Habit no. 1: Know Your Body

Know Your Body

Making a plan can help make sure that getting to Know Your Body doesn't get lost among all the other important things going on in your life.

What would stop you from getting to Know Your Body?

Your answer

What would help you to get to Know Your Body?

Your answer

When and where will you get to know your body?

Be really specific. The more specific you are, the more likely you are to remember.

When?

Your answer

Where?

Your answer

I need help answering these questions

If you don't know how you will get to Know Your Body please click here:
http://digital-health-uiot.datascienceinstitute.ie/know-your-body/#how

Do you feel confident you will get to Know Your Body?

- ◯ I WILL get to know my body
- ◯ I'm not sure if I will get to know my body

BACK NEXT

Would you like a copy of this form?

It might be helpful to look back on it when you are thinking about your Breast Health

If so, please enter your name and email address below and we will send it to you.
We will not save your email address or use it for any other purpose.

Name

Your answer

Email

Your answer

Appendix 8b: KYB/Plan v.2

Breast Health Habit no. 1: Know Your Body

Only you will see this. It is simply to help you get to Know Your Body.

If you want to keep it you can put your email in below and it will be sent straight to your mailbox.

If you don't want to keep it just close this page and it will disappear!

* Required

Set your goal:

I want to get to know my body so that I will notice an unusual change if one occurs *

- ○ Yes, I do
- ○ No, I don't

NEXT

Know Your Body

Making a plan can help make sure that getting to Know Your Body doesn't get lost among all the other important things going on in your life.

When and where will you get to know your body?

Be really specific. The more specific you are, the more likely you are to remember.

When?

Your answer

Where?

Your answer

What would stop you from getting to Know Your Body?

Your answer

What would help you to get to Know Your Body?

Your answer

I need help answering these questions

If you don't know how you will get to Know Your Body please click here:
http://digital-health-uiot.datascienceinstitute.ie/know-your-body/#how

Do you feel confident you will get to Know Your Body?

- ◯ I WILL get to know my body
- ◯ I'm not sure if I will get to know my body

Breast Health Habit no. 1: Know Your Body

Would you like to keep this?

If so, please enter your name and email address below and we will send it to you.
We will not save your email address or use it for any other purpose.

Name

Your answer

Email

Your answer

BACK SUBMIT

Appendix 8c: KYB/Plan v.3

Breast Health Habit no. 1: Know Your Body

Only you will see this.

If you don't want to keep it just close the page and it will disappear!

If you want to keep it you can insert your email when you're finished and it will be sent straight to your inbox.

* Required

Set your goal:

My goal is to get to know my body so that I will notice an unusual change if one occurs *

- ○ Agree
- ○ Disagree

NEXT

Page 1 of 5

Know Your Body

What would stop you from getting to Know Your Body?

Tick all that apply to you and fill in the "other" option if you can think of other reasons

- [ ] Feeling uncomfortably or thinking it's weird to examine myself
- [ ] Forgetting to do it
- [ ] Thinking it isn't important
- [ ] Not making a specific plan
- [ ] Being afraid of what I might find
- [ ] Other:

What would help you to get to Know Your Body?

Tick all that apply to you and fill in the "other" option if you can think of other reasons

- [ ] Picking a specific time and place so that I remember to do it
- [ ] Knowing it is normal to look at and feel my body
- [ ] Knowing why it's important to be aware of my Breast Health
- [ ] Setting a reminder on my phone
- [ ] Filling in the Breast Health Diary (do that here: http://digital-health-uiot.datascienceinstitute.ie/know-your-body/#diary)
- [ ] Watching instructional videos (do that here: http://digital-health-uiot.datascienceinstitute.ie/know-your-body/#how)
- [ ] Other: _____

BACK NEXT

Page 2 of 5

Know Your Body

Making a plan can help make sure that getting to Know Your Body doesn't get lost among all the other important things going on in your life.

When and where will you get to know your body?

Be really specific. The more specific you are, the more likely you are to remember.

When?

Examples:
1) After yoga
2) Whenever I wear my red bra

Your answer

Where?

Examples:
1) In the shower
2) In my bedroom

Your answer

BACK NEXT

Page 3 of 5

Breast Health Habit no. 1: Know Your Body

Would you like to keep this?

REMINDER: Only you will see this.

If you don't want to keep it just close the page and it will disappear!

If you want to keep it, , please enter your name and email address below and we will send it to you.

Name

Your answer

Email

Your answer

BACK SUBMIT

Page 5 of 5

Appendix 9: KYGP/Plan

Appendix 9a: KYGP/Plan v.1

Appendix 9b: KYGP/Plan v.2

Appendix 9c: KYGP/Plan v.3

Appendix 9a: KYGP/Plan v.1

Breast Health Habit no. 2: Know Your GP

* Required

Set your goal:

If I notice a change I will make and attend an appointment with my GP straight away *

- ◯ Yes, I will
- ◯ No, I won't

NEXT

Never submit passwords through Google Forms.

Breast Health Habit no. 2: Know Your GP

Know Your GP

If you notice a change you will make and attend an appointment with your GP without hesitating

What would stop you from doing this?

Your answer

What would help you to do this?

Your answer

I need help answering these questions

If you don't know how to answer these questions please click here:
http://digital-health-uiot.datascienceinstitute.ie/know-your-gp/#timing

Would you like a copy of this form?

If so, please enter your name and email address below and we will send it to you.
We will not save your email address or use it for any other purpose.

Name

Your answer

Email

Your answer

Appendix 9b: KYGP/Plan v.2

Breast Health Habit no. 2: Know Your GP

Only you will see this.

If you want to keep it you can put your email in below and it will be sent straight to your mailbox.

If you don't want to keep it just close this page and it will disappear!

* Required

Set your goal:

My goal is to see my GP straight away if I notice a change *

- ○ Agree
- ○ Disagree

NEXT

My goal is to see my GP straight away if I notice a change

What would stop you from doing this?

Example: "I'm too embarrassed to ask my doctor to examine my breasts"

Your answer

What would help you to do this?

Example: "Asking for a female doctor when I make my appointment"

Your answer

I need help answering these questions

If you don't know how to answer these questions please click here:
http://digital-health-uiot.datascienceinstitute.ie/know-your-gp/#no

Would you like to keep this?

If so, please enter your name and email address below and we will send it to you.
We will not save your email address or use it for any other purpose.

Name

Your answer

Email

Your answer

BACK SUBMIT

Appendix 9c: KYGP/Plan v.3

Breast Health Habit no. 2: Know Your GP

Only you will see this.

If you don't want to keep it just close the page and it will disappear!

If you want to keep it you can insert your email when you're finished and it will be sent straight to your inbox.

* Required

Set your goal:

My goal is to see my GP straight away if I notice a change *

- ○ Agree
- ○ Disagree

NEXT

My goal is to see my GP straight away if I notice an unusual change

What would stop you from doing this?

Tick all that apply to you and fill in the "other" option if you can think of other reasons

- [ ] Not feeling comfortable with my GP examining my breasts
- [ ] Being too embarrassed to ask
- [ ] Being afraid of what they might find
- [ ] Thinking my GP will think I'm wasting their time
- [ ] Being too busy with other things to make time for an appointment
- [ ] Other: _____

What would help you to do this?

Tick all that apply to you and fill in the "other" option if you can think of other reasons

- [ ] Bringing a loved one with me to the appointment
- [ ] Asking for a GP or Nurse that I am comfortable with examining my breasts (for example a female)
- [ ] Knowing that GPs will never think Breast Health is a waste of time
- [ ] Changing my GP
- [ ] Knowing that it is likely the change will not be cancer – there are many other explanations for a change in the breast
- [ ] Understanding that early diagnosis of breast cancer has 94% survival rates
- [ ] Other: _____

Would you like to keep this?

REMINDER: Only you will see this.

If you don't want to keep it just close the page and it will disappear!

If you want to keep it, , please enter your name and email address below and we will send it to you.

Name

Your answer

Email

Your answer

BACK SUBMIT

Appendix 10: Think Aloud Interview Website Navigation Checklist

Website section	Visited	Notes
Home		
AboutUs		
Module 1: Know Your Body		
Tailor*		
Step 1		
Video		
Diary/Map		
Reminder		
Plan		
Module 2: Know Your GP		
Tailor**		
Why		
Video		
Plan		
Module 3: Know breast cancer		
Risk		
Symptoms		
Survival		
Usage information		
Mobile		
Desktop		
No. of visits		
% website used		

Appendix 11: Online expression of interest form

NUI Galway
OÉ Gaillimh

Know Breast Health

Thank you for your interest in the Know Breast Health website.
Please complete this form and a member of the team will get back to you.

We ask you some basic questions about yourself. This is because our aim is to get women from different age groups and different walks of life to give us feedback on the newly developed website.

1. Name *

Enter your answer

2. Email *

Enter your answer