

Title:

An Investigation into the Information Deficits experienced by Breast Cancer patients in Ireland.

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Declaration Statement

I hereby certify that the material, which I now submit for assessment on the programme of study leading to the award of Masters of Arts, is entirely my own work and has not been taken from the work of others except to the extent of such work which has been cited and acknowledged within the text of my own work. No portion of the work contained in this design report has been submitted in support of an application for another degree or qualification to this or any other institute.



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Cancer Terminology

The cancer process is described in most research and literature as a journey which is broken down into stages of being a patient or a survivor. There has been controversy around these staged descriptions in cancer, for example, The National Cancer Control Program (NCCP) Strategy 2017-2026 states that ‘survivorship’ commences at a person’s diagnosis and continues until the end of life [29]. This term is used in medical circles but many people affected by cancer find fault and do not endorse the term “cancer survivor” [4, 41, 42].

Also, many reject the use of war metaphors to label the cancer trajectory [30, 32]. War metaphors imply that people affected by cancer should think of the disease as a ‘battle’, that they are somehow responsible for their cancer. It divides people affected by cancer into categories of winner’s v’s losers and those who do not recover are more likely to feel guilty [29, 30, 41, 65].

The Irish Cancer Society uses the phrase ‘people affected by cancer’ when referring to anyone who has had a cancer diagnosis [76]. In the interest of inclusivity, the terms ‘people affected by cancer’ (PaC) and “people affected by Breast Cancer” (PaBC) are used throughout this report when referring to cancer patients and survivors.

The following page provides a glossary of terms used throughout this report.

Glossary

ACS	American Cancer Society
BCNA	Breast Cancer Network Australia
BC.org	BreastCancer.org (USA)
BCNZ	Breast Cancer Foundation New Zealand

BCR	Breakthrough Cancer Research
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BCR has funded this masters research project.

BRCA	BRCA1, BRCA2 mutations or alterations.
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BRCA1 (BReast CAncer gene 1) and BRCA2 (BReast CAncer gene 2) are genes that produce proteins that help repair damaged DNA. Everyone has two copies of each of these genes—one copy inherited from each parent. Sometimes people carry a mutated version of this gene which can be harmful, these variants increase risks of several cancers—most notably breast and ovarian cancer.

CA	Competitive Analysis
CBCN	Canadian Breast Cancer Network
DP	Design Process
DT	Design Thinking
HC	Human-Centered
ICS	Irish Cancer Society
ILC	Invasive Lobular Carcinoma
NCCP	National Cancer Control Program
NCR	National Cancer Registry

MET	Metastatic / Stage 4 Breast Cancer
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A metastatic diagnosis means that the primary cancer has spread to another part of the body. It is a terminal diagnosis or called stage four cancer. It is still recognised as a Breast Cancer diagnosis, but the secondary tumours are located elsewhere, to clarify; a Breast Cancer which has spread to the liver would not be diagnosed as Liver Cancer.

MKF	Marie Keating Foundation
MM	MacMillan UK
SD	Service Design
TN	Triple Negative Breast Cancer
PAR	Participatory Action Research
PaC	People affected by Cancer
PaBC	People affected by Breast Cancer
PPI	Patient and Public Involvement

“I live with cancer, and cancer is manageable... it’s not actually the cancer, it’s the issues around cancer.”

Participant 6, Interview, November 2021

Chapter 1: Introduction

1.1 Background

Cancer is the second leading cause of death globally and is responsible for an estimated 9.6 million deaths in 2018 [8, 14, 84]. Globally, this equates to one in every six deaths being due to cancer [14, 85]. Before 2020 it was predicted that 1 in 2 people in Ireland would develop cancer during their lifetime [9, 10, 11]. Currently 200,000 people in Ireland are living with or after a cancer diagnosis, which equates to 1 in every 25 of the population [10, 34, 58]. This number is expected to more than double by 2045 [58].

More than 3,500 women and around 34 men are diagnosed with Breast Cancer (BC) annually in Ireland [11]. In total there are 12 types of BC, the two main groups are invasive and non-invasive. This study focused on three of those subtypes of BC and the BRCA genetic alteration. 5-10% of BC cases are BRCA/hereditary. One in every eight BC diagnosis is Triple Negative. About one in ten women are diagnosed with Invasive Lobular Carcinoma. 30% of primary diagnoses will metastasise to stage III/IV BC [13].

1.2 My Lived Experience

In 2017 at the age of 39, I was diagnosed with Breast Cancer. I was living in New Zealand at the time. The diagnosis came as a complete shock. Post surgeries I returned to live in Ireland in November 2017. I continued my adjuvant therapy here; I found the transition difficult. As a person affected by BC, I have lived experience

of the information deficit in the Irish Healthcare System.

This ontological master’s research is an investigation into the Information Deficits experienced by people affected by Breast Cancer (PaBC) in Ireland. It is an initial ethnographic exploration of PaBC experiences of the health care system, how they access information, their modes of acquisition, and how and when they are communicated with by their healthcare team.

1.3 The Breast Cancer Information Deficit

The Information Deficit, is one of the top five unmet needs facing people affected by cancer in Ireland today [47, 49]. The information needs of PaBC do not significantly decrease over time, however, the type of information people seek does change over the cancer trajectory [72, 63]. Their need for information and access to resources, services, and support remains high throughout diagnosis, treatment, and post treatment [9, 29, 55, 63, 87].

Over 70% of PaC are said to experience psychological distress, with up to 25% experiencing a diagnosable form of depression [90] while many report feelings of “anxiety and abandonment” when they transition to life after treatment [5].

People who feel more connected to a support system of care are more likely to know signs and symptoms of diseases, be better able to assimilate information and are less likely to drop out of the system [21,

62, 81]. There is a growing need for better information sharing and care coordination for people affected by BC [31, 70], these improvements are hindered by lack of research in terms of cancer survivorship care [87]. Over half of PaC are dissatisfied with the information they received from their healthcare team [9, 16, 24, 89]. Other factors which impact their dissatisfaction include the level of communication and time allocated during appointments [2]. Good communication helps improve patients' well-being and quality of life [51, 57, 61, 88].

Timing of information is important [46, 56, 63, 72]. Important life changing decisions need to be made. PaC need to be able to communicate their concerns, question options being presented to them, understand their situation, and make sense of their diagnosis [9, 16, 24, 57, 89]. Research has shown that unfortunately, it is not uncommon for PaC to complete their treatment without knowledge of further risks [59]. Crawford (2012) argued that PaC failed to act because they did not realise the significance of their symptoms [21]. Vento (2015) stated that a shortfall in knowledge will impair a person's judgement and their ability to notice signs and symptoms which negatively impacts their diagnosis at presentation [81]. If a person cannot efficiently interpret health information it can have negative impacts on the lives of the patient and those closest to them [62].

Traditionally, primary sources of health-related information have included the GP, family and friends and the media. The internet has created another source of medical information [17]. BC is the most common cancer searched for on the internet [26]. Out of 1000+ people affected by BC, 91% wished for more information on

their illness [61, 63]. A 2019 study by de Frutos et al showed that there has been a rapid increase in the number of PaC using the internet on a daily basis for health related information. The study found the number had jumped from 8%–15% in the 1990's to the current figure of 70%–97% [51].

A 2018 National Cancer Control Program (NCCP) report on cancer survivorship services in Ireland found that an online source of information was important to PaC, their families and healthcare professionals [29]. The report proposed a “one-stop-shop website” as part of its ALLIES for survivorship care model [29].

1.4 Mission, Vision + Problem Statement

The **vision** of this study is to reduce the information deficit in order to improve the quality of life for people affected by cancer. The **mission** is to identify the Information Deficits experienced by Breast Cancer patients in Ireland by exploring patients' use of information services. The **problem statement** is the Information Deficit greatly contributes to the distress caused by a cancer diagnosis and adds pressure to an already disjointed service.

The research findings from this study will contribute towards a doctoral study focused on developing a digital platform or “one-stop-shop” website. The PhD project will also explore the most appropriate communication channels to connect users to trustworthy sources of content, advice, resources, services and support. Developing a design solution like this could potentially reduce the negative impact of the information deficit on cancer patients' lives in the future.

Chapter 2: Design Methods

The Design Process for research was used throughout this study and applied to gathering and examining data. Design Thinking provided a methodological approach and enabled Human Centered insights when analysing findings.

Service Design is relevant because of the aims of the study to contribute to enhancing services. The Service Design process was not used for this study but would be used for the doctoral study focused on developing a digital platform or “one-stop-shop” website.

2.1 The Design Process

In 2004 the Design Council UK set about defining and visualising the design process. The result was the Double Diamond *Figure 2*, the methodology has become a main point of reference in the design world [23]. Separated into four phases — **Discover**, **Define**, **Develop** and **Deliver** — it is probably the most popular visualisation of the design process methodology used around the globe [48]. The two diamonds represent the design process using divergent thinking then applying convergent thinking [23]. At the moment this research study is in the Discovery and Define phase of the Double Diamond, see *Figure 2*.

2.2 Design Thinking

Design Thinking (DT) has made design accessible to non-traditional designers, it enables those without design backgrounds to play an integral part in defining design problems and developing design solutions [26, 86]. DT takes the principles

of the design process of diverging and converging to explore problems [80]. DT permits the formation of multi-disciplinary teams, allows for many experts to collaborate, and optimises resources and production [34, 86]. It encourages debate, changes mindsets, and enables user-centric problem solving [80]. The DT approach provides a five-step solution-based methodology to problem solving [33, 86]. The five phases of DT are **Research**, **Analyse**, **Ideate**, **Prototype** and **Test**. Design Thinking is an iterative process where each round is repeated multiple times, the aim being that every iteration improves the previous [36].

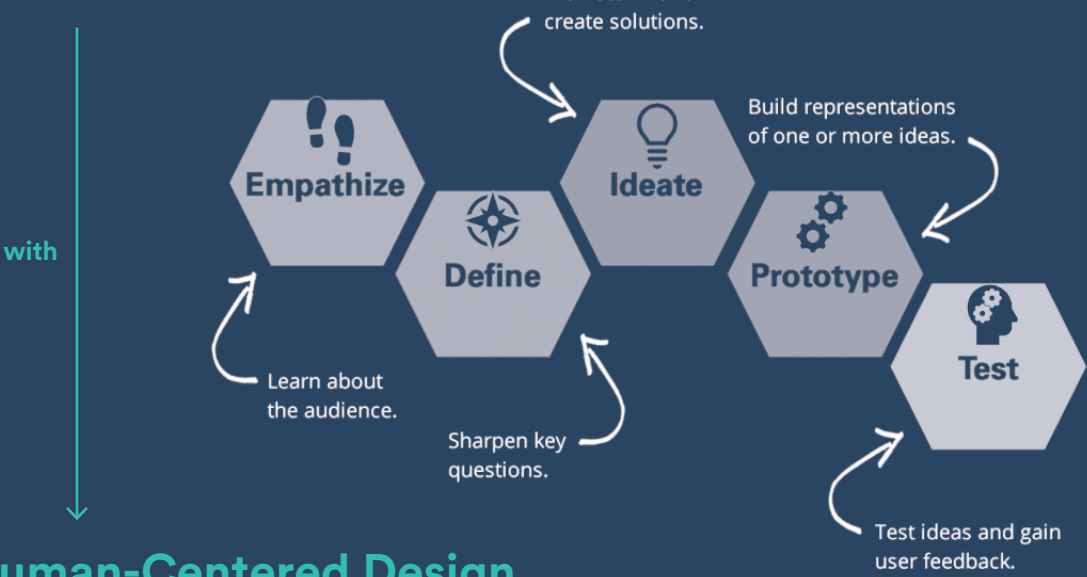
2.3 Human-Centred Design

The DT process is fundamentally a human-centred (HC) mindset [33, 36, 40]. It is a tool that encourages building empathy of the target users through design research and analysis [33, 86]. It promotes re-framing the problem through brainstorming and co-creation and a hands-on approach to prototyping and testing phases [36, 40]. The DT method combines with a HC mindset in its problem-solving [33]. In the corporate world this method of problem-solving leads to innovation which creates a competitive edge [40]. Research that combines DT methodologies with a HC approach can enable societal change [33], see *Figure 1*.

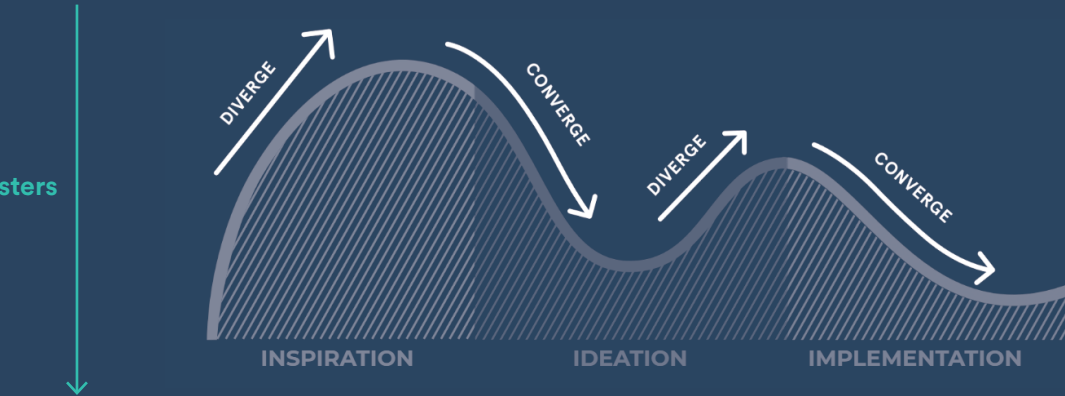
The HC process is divided into three steps. In the **Inspiration** phase **Observational Research** is performed by facilitating workshops and conducting interviews. The **Ideation** stage involves **Visual**

Figure 1: Using Design Thinking and Human-Centered Design Together

Design Thinking



Human-Centered Design



Social Enterprise Thinking

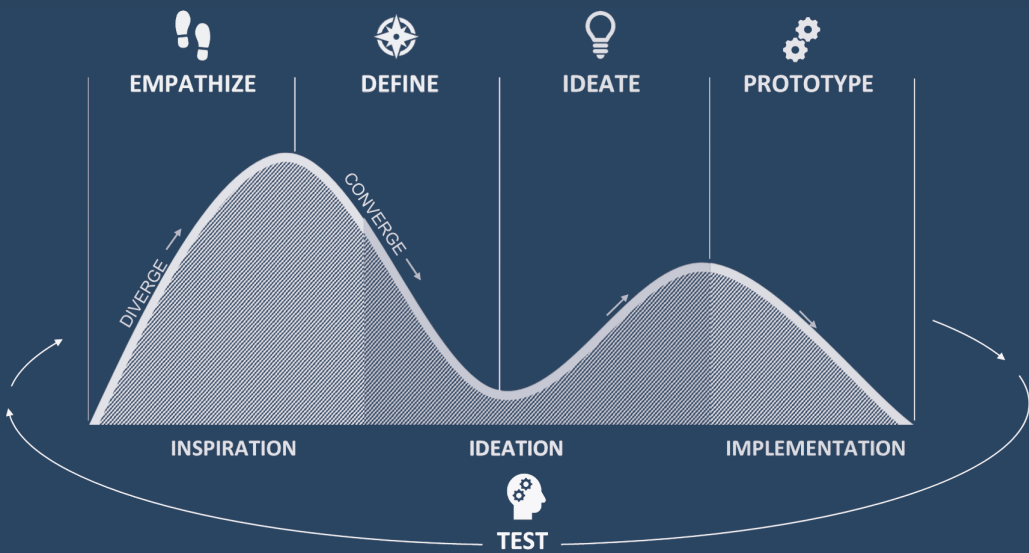


Figure 2: Double Diamond

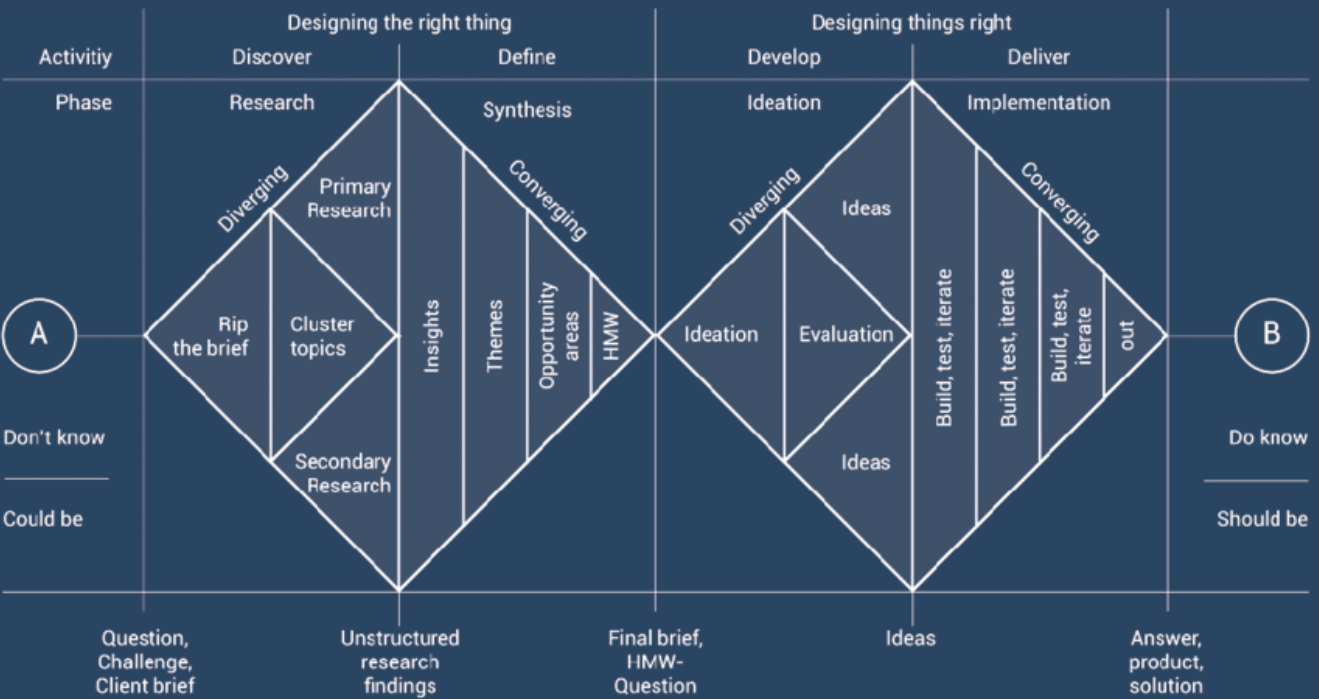


Table 1: The Design Process, Design Thinking + Human-Centered Approach in relation to this Study

DP Stage	Discover	Define	Develop		Deliver
DT Stage	Research	Analyse	Ideate	Prototype	Test
HC Phase	Inspiration		Ideation		Rapid Prototyping
Research + Data Gathering	- 10 x Interviews - 3 x Workshop		- Patient Journey - Personas - Stakeholder Map - Support Map - Feedback Grid - Brainstorm		
			To be explored as part of PhD research		

Sensemaking that allows the researcher to make sense of the observational research to identify relationships between variables and start ideation with stakeholders. The final **Implementation** phase allows for **Rapid Prototyping** which provides insights into what users are looking for and if the designs align with users' goals [40].

The DT and HC approach were applied to this research, *please see Table 1 on previous page* for how each stage relates to the data collection performed during this study.

2.4 Service Design

Service Design is a process mainly used by designers to improve and develop services by understanding all the connections between the facets of an organisation and optimising the systems operation to better support user journeys [80]. The results of SD improve experiences for both users and staff [85]. In many systems teams work independently, do not communicate with each other, and do not consider how the user experiences the system across multiple encounters. [40, 85]. This leads to gaps in service, knowledge, and information. These gaps are known as user pain points. Service design helps identify misalignment between service and business models and proposes initiatives to bridge them.

Service Design analyses the workflows and procedures performed throughout a service. It examines the people involved in the service and how they navigate it and looks at touch-points like physical spaces or digital environments. It removes redundant processes and/or proposes completely new services to enable efficiency [40, 80].

Chapter 3: Research Methodologies

Kelly (2021) argued that a multi-disciplinary and co-creation research approach is required to tackle the Information Deficit experienced by people affected by cancer (PaC) in Ireland [47]. A pragmatic approach was considered appropriate given the context of the research. People affected by Breast (PaBC) Cancer worked with the researcher. Participatory Action Research is an appropriate methodology as it facilitated the involvement of the public and patients in the study.

3.1 Pragmatism

Pragmatism is used within an actual real-world situation [25] and it employs an empirical approach to analysing the real-world data [19, 64] by inductive and deductive reasoning, testing, evaluation, and observation. Knowledge is gained through one's own direct experience and by understanding the indirect experience through other people's situation [64]. Mixed method studies are best suited to this methodology, using qualitative research methods alongside quantitative techniques to analyse human experience and behaviour [25]. The four main goals of a Pragmatic examination are focusing on understanding human experience, recognising that there will be multiple factors and variables which are interdependent and unpredictable, understanding the big picture by taking a holistic view, and contributing a unique perspective by challenging the status quo [25].

3.2 Participatory Action Research

The Participatory Action Research (PAR) approach aims to involve the public in generating knowledge about issues and problems of concern to them, through their generated insights they can promote personal and societal change [71]. In 1997 McTaggart discussed the difference between 'participation' and 'involvement' in PAR [75]. Many forms of research work 'to' inform or involve people 'about' the research 'for' people. In PAR the work is done 'by' participants who work 'with' the researcher [52].

3.3 Public Participation in Research

There have been many studies around public alienation regarding science. A common assumption in the scientific community is that the public does not have the basic knowledge of how scientific processes work, understand scientific facts, and lack the ability to use rational thinking [6, 73]. One of the most pivotal reports on this topic was The Public's Understanding of Science published by the British Royal Society in 1985, where Bodmer concluded that a greater understanding of scientific issues would substantially improve the ability of the public to make the right decisions when needed [6].

3.4 Patient Public Involvement in Ireland

Patient Public Involvement (PPI) is making great strides in Ireland towards the engagement of the public and PaC in

Figure 3: A comparison of the Reiterative Process in PAR and DT

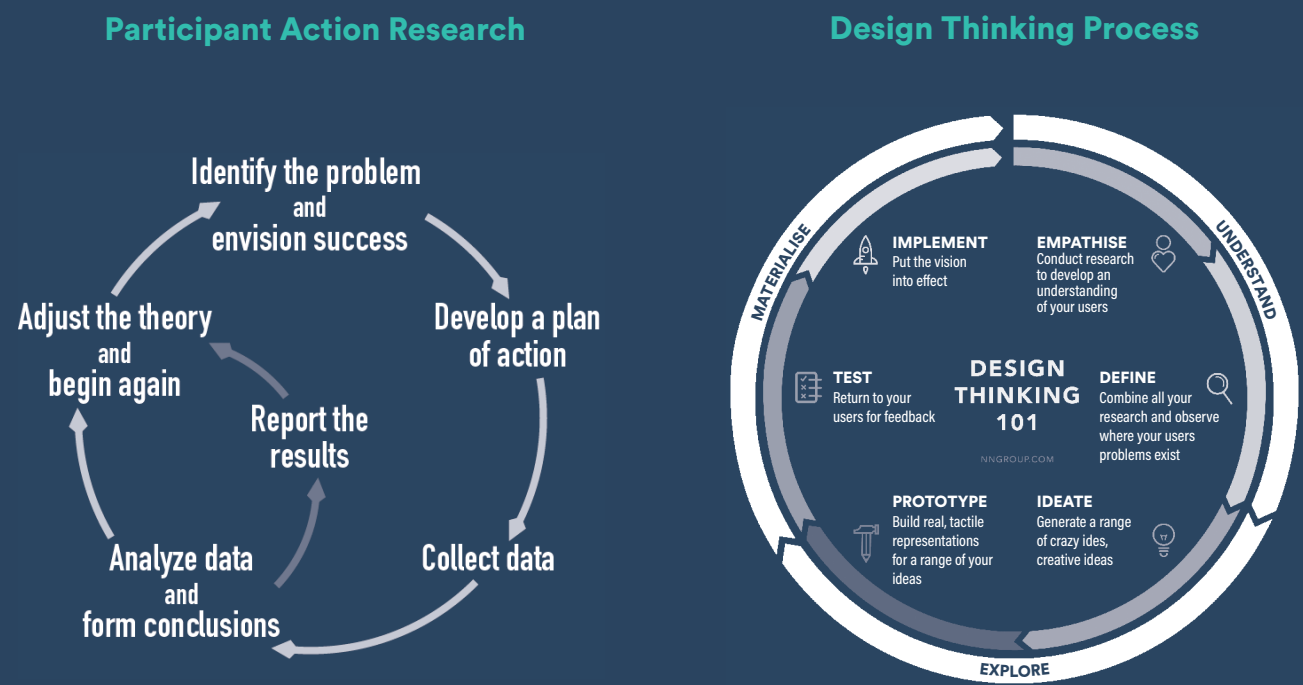


Table 2: How PAR+PPI relate to the Design Thinking Process of this Study

DP Stage	Discover	Define	Develop		Deliver	
DT Stage	Research	Analyse		Ideate	Prototype	Test
HC Phase	Inspiration		Ideation		Rapid Prototyping	
Research + Data Gathering	- 10 x Interviews - 3 x Workshop	- Patient journey - Personas - Stakeholder Map - Support Map - Feedback Grid - Brainstorm		To be explored as part of PhD research		
Methodologies	- DT+HC. PAR/PPI Involvement					
Analysis	- Thematic Analysis - Competitive Analysis					
Output	- MA Design Report					

cancer research but it is still a relatively new approach in Ireland. PaC struggle to get their voices heard; scientists find it difficult to distil their research into lay terms. The 2014 Hannigan report highlighted the low rate of patient involvement and the underdeveloped area of PPI in health research in Ireland [54]. In response to this report the Irish Health Research Forum (IHRF) was assembled, its first meeting in 2015 focused on the topic of PPI and highlighted the need for a culture change [37] and supported the value of researchers engaging with the public. The Irish Cancer Society website explains PPI in the Irish context using the PAR terminology. Allowing people to **participate** in research, **engagement** with the public through events or promoting research through the media and **involving** people in any stage of the process where they work ‘with’ the researcher.

3.5 Patient Public Involvement, Participation Action Research + Design Thinking

PPI, PAR and DT complement each other and are very similar. *Figure 3* outlines the similarities in the processes. *Table 2* outlines how PAR and PPI relate to the Design Thinking Process of this research. People’s level of participation is significant to the PPI, PAR and the DT processes. In all cases the research involves HC and a reiterative process. Collaboration between experts and PaC is required to move forward in a positive way, at the moment findings are fragmented and influenced by basic science [47]. PPI, PAR and DT permit the formation of multi-disciplinary teams, allow for many experts to collaborate, and optimises resources and production [34, 80, 86]. These methodologies encourage debate, change mindsets, and enable user-centric problem solving [80].

This process draws on ethnographic and ontological research. It takes a qualitative and quantitative approach through interviews and workshops. The study employs pragmatism and uses thematic analysis to gain insights from data. The process incorporates phases 1 + 2 of the human-centered (HC) methodology, and uses both PAR and PPI guidelines for engaging with PaBC.

I'd never had any mental
I kind of had an acute sort
have been for where my i
mean, rolling panic attack
weeks, from when I was d

But I think that when you
when I had my kind of p
in that time, like, by the t
grand, like, in a lot of wa
needed some kind of he
have been effective but t

it resolved around when I
much what is the plan? W
It had just thrown me into
with. You know, granted it
got through the chemo, an

It's always is that I, I kept
Yeah details. And then be
times, I would go through
bang, bang, bang bang q
elaboration, she elaborate
the way she communicate
communicator, I feel, thou
with without having every

I get given a leaflet from r
was on a4 paper. But you
tried to read it. Yeah. I ha
three times.

Then I was back into then
cannot read it. They said
they told me, as much as
all that kind of thing. But i
Yeah. But would it have m
doesn't happen to everyb
may not happen. Rightly c
if it had been explained to
for months, you're going t
shoulder.

If you compare that to how
you process your way thro
fix. There is no bullets tha
go through and get out the

Chapter 4: Present Study

4.1 Study Design

This ontological and ethnographic study took an empirical-analytical approach [78] using pragmatic methodologies and participation action research. This mixed method exploratory research aimed to explore the main aspects of this under-researched problem [74] by using qualitative and quantitative methods. Data was collected through interviews and workshops which used collaborative design thinking tools. The DT tools enabled dynamic interaction between researcher, patients, and stakeholders and espoused a PPI approach [78]. Ten interviews were semi-structured and included a mini survey component. The three workshops employed a Design Thinking approach and used Design Research tools to gather data. The study focused on the specific information deficits experienced by participants and aimed to highlight the issues that contribute to these gaps.

4.2 Aims

The first aim of this study was to highlight issues to identify information deficits from a patient's perspective. Why is the information not getting through to patients? What are the communication breakdowns and where do they happen in the cancer journey? Do they have suggestions as to what may work in the future?

The second aim of this study was to perform a Competitive Analysis to examine the User Experience and Interface Design of websites dedicated to supplying cancer information and to assess the Quality of

Information found by participants. What information is out there for patients online? What's available to them on Irish Cancer related websites, compared to those in the UK, US, Canada, New Zealand, Australia? How do the Irish cancer websites stack up against international websites? Where do improvements need to be made?

4.3 Research Focus and Rationale

This study focused on information from participants with the following subtypes of Breast Cancer. PaBC with Triple Negative, Invasive Lobular Carcinoma, Metastatic Stage Four Breast Cancer and individuals with BRCA genetic alterations were recruited.

4.4 Project Objectives

- Create a design report which presents the gathered data from desktop research, interviews and workshops
- Create visual artefacts to reflect findings in the design report; a map of the identified national services, support and resources and a patient journey map detailing the information gaps and how PaBC acquired information.

4.5 Personal Objectives

This final MA project affords the opportunity to integrate design and academic skills on a research topic that I am very passionate about. It also allows me to acquire expert knowledge and transferable skills necessary for my professional development.

4.6 Recruitment

Participants were recruited using a combination of Purposive, Convenience and Snowball sampling via social media and my own cancer network. Participants were recruited using a flyer advert and information pack which included consent forms, *please see Appendix 1.1*. These were circulated by email to cancer researchers, PPI, cancer charities and support groups who forwarded the invitation and uploaded content to their social media channels. Several of the researcher's social media channels were used (Facebook, LinkedIn, WhatsApp, and Twitter) to engage with PaBC, researchers, healthcare, and media professionals. Those interested were asked to refer to the Inclusion and Exclusion Criteria before application. If they met the criteria and wished to participate they were asked to contact the researcher directly by email. All participants signed the information pack and provided signed consent forms prior to taking part in the study. Each individual was sent an acknowledgement of their expression of interest files. Times and dates for interviews and workshops were selected by the researcher between 26/10/2021 – 29/11/2021. Participants were given a choice to select their preference, see *Appendix 3.2 + 3.3*.

(1) Inclusion Criteria

- **Age:** 18–75
- **Gender:** An open call to people affected by BC regardless of gender.
- **Patients + Stakeholders:** The recruitment call included PaBC and stakeholders who had experience of/with Breast Cancer, it included but was not limited to carers, healthcare professionals, peer groups, support groups, charity organisations, cancer researchers.
- **Creative Mindsets:** Those who worked in media, design and communications

were recruited to perform Direct and Indirect Competitive Analysis of cancer focused websites.

- **Computer Literacy:** Participants needed to have a good level of computer literacy.

(2) Exclusion Criteria

Breast Cancer is a sensitive topic, and every effort was made to reduce the potential for distress for those involved. For this reason, the following exclusion criteria was specified: Those who have been diagnosed in the past 12 months with a serious mental illness, brain disorder, alcoholism, drug addiction or substance abuse were excluded from this study.

(3) Recruitment Call

Between 07/10/2021 and 26/10/2021 the recruitment flyer and information pack were circulated to recruit participants.

4.7 Participants

(1) Interviews

Ten Female participants and 0 Males took part in interviews. They resided in the east, south and midlands of Ireland. The participants fell into two age categories, 4 were between 40-50, while the remaining 6 were 51-61 on their last birthday. Diagnosis were: Triple Negative (n=2), Invasive Lobular Carcinoma (n=6), Metastatic (n=4) and BRCA1 mutation (n=1).

(2) Workshops

In total 30 individuals participated in three workshops:

(a) Workshop A

Eight people affected by Breast Cancer (PaBC) participated in Workshop A. Their diagnoses included Triple Negative (n=2), Invasive Lobular Carcinoma (n=4), Metastatic (n=2) and BRCA1 mutation (n=1). They resided in the east, south and midlands. These eight participants were

also interviewed and are included in the 10 interviewees mentioned above.

(b) Workshop B

Nine participants took part in this workshop. Their backgrounds were varied and included a Registered Genetic Counsellor, BC nurse and MSc student, Lecturer in Medical Education, Clinical Lecturer and Surgical Trainee specialising in Breast Surgery, Nurse PhD and Assistant Professor, Social Liaison Officer for a Cancer Support Group and two Patient Advocates.

(c) Workshop C

A total of 12 participants took part in Workshop C, five were learning experience experts, this group comprised of two researchers, two designers and one adult educator. The remaining individuals included a web developer, an architect/lecturer, a mechanical engineer with a specialisation in BC research, a client director, a department of education civil servant, a communications officer, and a senior business analyst.

4.8 Data Collection

(1) Literature Review

Peer reviewed papers were sourced from scholarly databases including Google Scholar, Pub.med, IADT Library etc. Chosen papers investigated communications in cancer care, the geographical, literacy and cultural barriers experienced by patients in accessing resources and the information deficit experienced by people affected by BC internationally and nationally, see *Appendix 2.1 + 5.1*.

(2) Interviews

An interview schedule was developed, with eight questions and prompts included which were used when necessary, see

Appendix 2.4. Interviews were one hour in length, were recorded by video or phone and transcribed using Otter.ai application.

(3) Online Workshops

In total 3 workshops were facilitated online. PaBC and stakeholders were facilitated using design thinking tools and frameworks. All workshops took place using video, Google applications and MIRO software for teamwork. Workshops were recorded and transcribed using Otter.ai application. Each workshop followed a similar agenda starting with an Introduction and Icebreaker session, this was followed by the Data Collection exercises and ended with a Playback Discussion where participants provided feedback on their insights. *Table 3* on the next page outlines the agenda of each workshop.

» **Workshop A - Communication Timeline**
Focused on information and communication from the PaBC perspective.

» **Workshop B - Map Resources + Services**

Focused on stakeholder perspectives of the BC experience and on compiling a list of national services, supports and resources.

» **Workshop C - Website Competitive Analysis**

Performed a Direct and Indirect Competitive Analysis of cancer focused websites. A Competitive Analysis (or competitive research) is a research approach that specialises in the review of competitor information and finding out what competitors strengths and weaknesses.

Please see Appendix 3.2 for Agenda and Info Documents and 2.2 Design Tools Used.

Table 3: Overview of Workshop Agendas

Workshop A Communication Timeline	Workshop B Map Resources + Services	Workshop C Competitive Analysis
Welcome + Agenda		
Intro to Miro		
Icebreaker Session		
Data Collection Tools - Patient Timelines - Personas - Feedback Grid - Communication Timelines	Data Collection Tools - Stakeholder Maps - Support List - Brainstorm	Data Collection Tools - Direct + Indirect Competitive Analysis
Playback Discussion		
Finish		

Table 4: Overview of Workshop Objectives

	Workshop A Communication Timeline	Workshop B Map Resources + Services	Workshop C Competitive Analysis
Participant Description	People affected by Breast Cancer (PaBC)	PaBC and peers, members of support groups, allied health professionals and cancer researchers	Creative Mindsets, Designers, Developers, Media Students and Professionals
Aim of Workshop	We focused on details, creating a timeline of how, when and where PaBC source information, highlighting where gaps and pain points	The aim was to pool their collective knowledge to map out the current national services, support and resources	The participants provided observations and insights to create an initial overview of websites in direct and indirect categories

4.9 Procedure

a) Interviews

In total 10 Interviews were conducted over the month of November 2021 with BC patients. A Google form was created with multiple date choices and preferred interview type – phone/zoom. This form was distributed to participants on 18/10/2021. Individuals chose a preferred date and time for the interview. Follow up emails were sent seven days later. Confirmation emails were sent with a digital file containing interview questions and zoom links where applicable. *Please see Appendix 3.1 for Email Correspondence + 3.3 for Google Forms.*

b) Workshops

Three workshops were held over the month of November, each had different participant types and objectives. *Please see Table 4 which outlines the objective of each workshop.*

Online workshops were prepared in Miro, *see Appendix 2.3 for workshop templates.* Google forms with date choices were created for each Workshop, these were distributed to participants, *see Appendix 3.3.* The Google forms allowed people to select multiple options. The majority vote decided the date selection. Emails were sent to confirm the date selection to each group. Before the workshop a reminder email was sent to participants along with relevant links - Zoom/Miro Workshop/Miro Onboarding Video/Google Applications - and the Workshop Agenda PDF, *see Appendix 3.1 and 3.2.*

4.10 Ethics

Ethical issues such as informed consent, anonymity and security of data issues were key considerations. IADT Ethics Form B was completed and supporting documentation was supplied to the IADT Ethics Committee in July 2021. Ethics approval was granted, and consent was given to proceed, *see Appendix 4.1 + 4.2.*

4.11 Data Analysis

This study uses inductive analysis working from the ‘bottom up’ and deductive reasoning working from the ‘top down’ while analysing the data [22]. Divergent and convergent thinking were used while gathering qualitative and quantitative data, analysing literature and performing competitive analysis. Thematic Analysis was used to uncover patterns and insights in qualitative research by identifying and organizing data [17, 43, 69]. Interpretive and descriptive codes were assigned to the data and used to summarise the content, significant patterns began to emerge which described meanings and experiences, these patterns are referred to as themes. There were two sets of data – Interviews and Workshops – that needed to be analysed and each used a different thematic approach.

» Interviews

Thematic Analysis of interviews was conducted by repeatedly reading transcripts and by listening to interviews constantly while journaling. Patterns and codes were identified, content was mapped out in Miro, a concept map developed and themes were assigned accordingly.

» Workshop A: Communication Timeline

Thematic Analysis of Workshop data was organised by using Affinity Diagrams, a design research tool which helps identify themes in content. Themes were assigned to groups of content and comments were ordered into relevant categories. It was cross referenced with interview thematic analysis and contributed to Chapter 5 - Findings: The Patient Perspective.

Due to time constraints and the volume of data collected during the research phase decisions were made to prioritise the data to be analysed. The intention was to analyse the data from Workshop A and create a Patient Journey visual artefact. This data will be examined and presented at a later date, see *Appendix 5.5 for workshop images*.

» Workshop B: Mapping Resource + Services

Due to time constraints and the volume of data that needed to be examined the decision was made to prioritise the research to be analysed. The findings from this workshop will be examined and presented at a later date.

» Workshop C: Competitive Analysis

The quantitative data from the Likert Scales and Traffic Light System were analysed using Simple Metrics and Adjusted Wald Completion Rate Calculations. Simple Metrics were used to for given tasks e.g. 0=Fail, 1=Pass. Net Promoter Scores were calculated based on mean scores. The findings were analysed, insights were gained by comparing quality of information and the dimensions of user experience and interface design.

4.12 Technology Challenges

The Participatory Action Research (PAR) approach was applied to the research by adjusting the workshops and interview procedures. The process continually evolved based on ongoing participant feedback. Issues with Miro in Workshop A were eliminated by Workshop C, simply by the researcher using Miro as a communal space while screen sharing, this saved time and confusion. For Workshops B and C participants used Google and Microsoft tools, these were more familiar to them and saved much confusion and eliminated time wasting issues. After feedback from Workshop A individuals were supplied with the interview document prior to the session to allow them to be familiar and prepare for questions prior to interview sessions. There were issues with internet coverage during interviews so the decision was made to switch to interviews over the telephone.

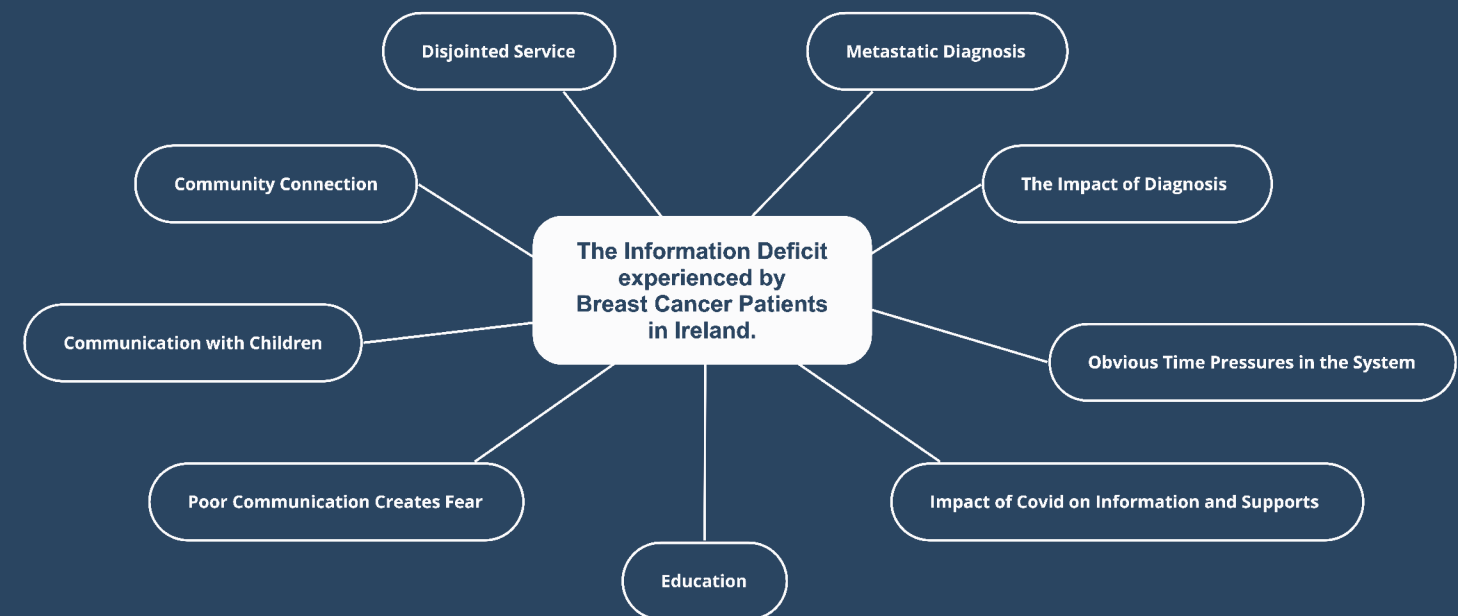
Please see Appendix 7.2 for a full account of Technology Challenges.

Chapter 5 – Findings: The Patient Perspective

To identify the most common themes in the data a thematic analysis was performed. Insights were gained using deductive and inductive analysis of interview and workshop transcripts and the participant comments from Workshop A.

Nine key recurring themes were identified and illustrated in *Figure 5*. The findings are presented in this chapter with an explanation of what each theme represents and some quotes from participants to illustrate. *Please note this chapter is a summary of Appendix 7.1.*

Figure 5: Nine Key Themes identified in Thematic Analysis



5.1 The Impact of Diagnosis

A cancer diagnosis has a vast negative impact on PaBC mental health. There is a significant need for support at this point. The research highlighted a lack of understanding around the shock of a cancer diagnosis and how this impacted the capacity of PaBC to process information and ask for help.

Participants were overwhelmed by their cancer diagnosis citing feeling shock (P5, 6, 7, 8, 9), terror (P1, 9, 10), fear (P1, 6, 9), vulnerability (P2, 6), trauma (P1, 10) and anger (P6, 8) at this point of the journey. “I'd never had any mental health problems at all, but I was just literally freaking out... I think that when you're diagnosed is the worst, it was the worst time for me” (P1) and “in truth, the physical part of it is nearly the easier it is really the easier because in many ways, it's the mental, the psychological. But that's so much harder” (P3). Workshop participants felt that “support was required from the first abnormal test result- this is the most traumatic time and there is no support”.

Participants felt that there was a gap in understanding how the impact of a diagnosis impeded a PaBC capacity to know how to ask for help. There is a “mismatch between information given and ability to process that information” (P10) and P9 stated “I think I could have benefited from counselling during diagnosis at that stage and heading into double mastectomy, because I remember being really quite traumatized and not able to find out information at that stage” (P9). While P3 said “I didn't have the mental capacity I don't think... I think when I was in the thick of things was not the time for me personally to go and look for support”.

5.2 Poor Communication Creates Fear

This theme focuses on the fear and uncertainty that comes from a lack of or poor communication of relevant and timely information about the next steps. The absence of information leaves a gap for anxiety to flourish. Participants spoke about poor communication styles. They needed to know what the treatment plan was. Poor bedside manner and packages of leaflets that were not relevant or specific enough for their situation contributed to their negative experiences.

What's the plan?

For all participants the not knowing was the hardest thing to deal with, it had a negative impact on their mental health “nobody can prepare you for that. And it hits everybody differently... To me, that was the worst part of the whole procedure. It is the hardest part of the whole thing” (P5).

Issues around uncertainty were alleviated once participants knew the treatment plan “it resolved around when I saw my surgeon and he told me what the plan was... It was that uncertainty of what's going to happen. It had just thrown me into total spiral... [the plan] was actually something concrete that I could deal with” (P1). Participants felt anxiety could have been avoided with better communication around what the next steps were “it could have reduced a lot of trauma, if I had known that there was a plan” (P6).

Communication styles of healthcare teams were important as were the forms of communication. The level of information that was communicated was important, PaBC were critical of the volume of generic of generic content given to them,

they needed specific information on their diagnosis

(a) Bedside manner

Communication styles of their healthcare team seemed to be the luck of the draw and was hard for individuals to deal with. Contrary to popular belief, the quality of communication did not depend on public v's private system. Participant 9 was diagnosed in the public system where, “My surgeon was terrific, but Breast Cancer Nurse was tough which was difficult as [I] felt so vulnerable” her oncology care was in the private system where “I was with an oncologist he's a great man, but just doesn't have good communication skills...I was very alone at that stage.” Her account was in direct contrast to a fully public patient “I had a great oncologist; he was at the end of the phone when needed. Nothing was a problem... I never felt I was taking up his time” (P5).

(b) Leaflet packs

Participants agreed that leaflets and booklets were important at every stage of the cancer trajectory. However, the approach of handing a patient a pack of leaflets from different sources was met with negative responses “when I came home with the big brown envelope of all the booklets. I couldn't look, it actually made my stomach turn looking at it” (P5), and “this leaflet thing just really bugged me” (P4). Interestingly P5 reflected back to before her own diagnosis when her aunt who had being diagnosed with cancer came home and refused to look at the leaflet pack “I thought well, I'll read it and see what it says. But it's a different story. When it's for you. I was like, get me away from that. You know, and I'm not the only person to say that” (P5).

(c) Less generic information more specific content

Participants found that the amount of information given in leaflets, booklets and even online was too general and insufficient for their needs. Participant 4 stated the brochure “was a bit of a mixed bag, I have to say, and I looked at it a few times. And felt, yeah, it doesn't really tell the whole story” and P1 said “it's not going to be specific to me. So how helpful can it be?”

Specific details to their diagnosis were important to the participants however too much information was scary. Some participants found the literature they were given overwhelming “I got given a leaflet from my surgeon about the mastectomy... I never read that, because I had a panic attack every time I tried to read it” (P1). Others were put off by the quantity of information “I would find it hard to read along a really detailed information leaflet, or all at once” (P6) and “I did eventually look at it. I just, there's just too much information I kind of just didn't” (P10).

What participants felt they needed:

(a) A list or directory

Packs of leaflets were seen as “a complete waste of time” (P5) but a list or directory was seen as helpful. “... every single patient regardless of their age, should be given the resources, services and support that are available” (P2). Workshop suggestions included: a “website where you can filter information”, a “National database of patients, their illnesses and links to Clinicians, GPs and Patients”, “a list of good information and websites to access” and “a list of alternative treatments while having chemo. like physio, nutritionists etc”.

(b) Patient navigator

Participants felt outreach should be available to PaBC during all stages of the BC journey. Ideally a person who could help them navigate the system and point them in the right direction. “I think if somebody was just to say to you, how are you doing? Have you any questions? Is there anything that you need support wise... Is there anything I can do to help? and point you the right direction” (P3).

5.3 Disjointed service

Although three People affected by Breast Cancer (PaBC) experienced a holistic approach to their care. Most participants referred to the lack of coordination between the various systems which showed up as low levels of communication within and between systems resulting in inconsistent experiences, mixed messages and a consequent lack of trust.

Poor Coordination of Care

The Workshop A Feedback Grid comments stated, “Some staff need training around communication” and there was a lack of “Referrals to Counselling/Social Worker/ Nutritionist/ Trials on Diagnosis”. The workshop participants spoke about the “breakdown of sharing information between the hospital and GP” and “a gap in treatments for GMS (General Medical Services) patient’s vs private patients”. Only two out of ten participants interviewed mentioned that their oncologists, (one private, one public) referred them to complementary therapies at cancer support centers. There are eight designated cancer center’s in Ireland, two out of eight were mentioned for taking a holistic approach to patient care.

While this theme highlights poor coordination of care there were 2 sub-themes, one referring particularly to the

gap in accessibility to Breast Cancer Nurses and the other to the experience of receiving mixed messages due to lack of coordination of care.

(a) Breast Care Nurses

The role of a Breast Care Nurses (BCN) is to provide continuity of care to PaBC, they are a key point of contact between patients and the healthcare team [15, 21]. BCN were only available in the public setting, two participants mentioned that they did not have this dedicated person after they transferred to private care. “I lost access to the breast liaison nurse or other relevant (person) through the private clinic” (P6) and “I had a breast care nurse in public but once moved to private that ended” (P1). BCN are not accessible to PaBC after the primary treatment phase ends and are also not accessible to Metastatic patients “I am always asking and saying I need a private nurse. And he did assign me to a nurse, but she never contacted me... I now have her contact if I need her now, but it was really really from asking” (P6) and “You know, where you had the liaison nurse with the primary. I got the name like, face-to-face with an introduction. And I never saw her after that” (P2). BCN were also mentioned in Workshop A, where participants noted; a “nurse needed in private rooms” and that there is a “need for Liason Nurse throughout Secondary Diagnosis not just Primary”.

(b) Mixed Messages

In the public system people affected by Breast Cancer (PaBC) spoke of seeing a new doctor at each appointment and receiving mixed messages. Participant 4 commented “you get your surgical cancer nurse specialist (CNS). And then you have your medical oncology CNS. And there isn't a whole heap of coordination between those two people... I found that sometimes some of the information contradicted each

other.” One participant blamed herself for the contradictions in answers “I find they have a different way of answering things, or maybe I'm not asking the questions right?” (P2). This confusion impacted their trust in their team. Questions were also raised about the doctor's credibility “he referred to Google twice with my questions, and I'm kind saying, well how can they say not to look at Dr. Google, if the doctor in the room with me has looked up two of my questions?” (P2).

In the private system individuals saw the same healthcare professionals at each appointment however, this did not guarantee good communication. As mentioned earlier participant 9 struggled with her oncologist, “he showed no empathy... information was communicated badly, I felt a nuisance if I asked anything” compared to participant 1 “I trusted her implicitly, I would never second guess, or I would never research anything... I didn't look anywhere else for any more information” (P1).

5.4 Obvious Time Pressures in System

Issues around time were noted in many aspects of this research and are visible in both the public and private systems. Time continuously presented participants with dilemmas. They constantly observed the time pressure on their healthcare team and witnessed the impact on other PaBC. They experienced first-hand limited time on their own care while long wait times increased psychological issues.

All participants mentioned the limited time they had with their consultants “I think, you know, [they are] too busy. That's the impression I get” (P4), and “I had access to her... It could be only for five minutes. But that was the five minutes that counted” (P1).

Participants spoke of wanting to make the best use of the little time they had “I literally, you know, kept diaries of my symptoms of everything... I would go through the last two weeks of notes. And I would make a list of questions. I was like bang, bang, bang, bang questions. And she just answered every question. And if it needed more elaboration, she elaborates. And it was very efficient for her. And it was also for me, I found” (P1).

They were conscious of the impact of delays but they also wished they had more time to ask more questions “he's after walking into the room and saying, sorry for the hour and a half delay, we're up to our eyes. And you kinda think I can't delay him... you want to be fast, you're thinking, I'm kinda in a dilemma here” (P2), and “there's not, there's just not enough time in the clinics to be honest. And my consultant gives me the time. He'd give me an extra 10 minutes or whatever. But it's just you just don't feel appropriate” (P6).

Workshop responses noted the “need for specialists to make more time available to patients” and that the “current wait time for tests” and “genetic appointments” needed to change.

5.5 Education

Gaps were highlighted around educating patients about their diagnosis and its consequences. In particular there was a lack of education about the signs and symptoms of cancer recurrence. In the absence of education PaBC performed their own online research to find information and support.

(a) Knowledge is power

Being educated about their diagnosis brought a sense of control over their situation and empowered them to act

in a proactive way. In the absence of information and support participants used their own self initiative and performed their own research. Participant 4 stated “I don't think being passive in this regard, particularly with health information is the way to behave, and, you know, then what happens with people, I've seen it time and time again, they're either one thing or the other, that they do nothing, or they overreact, and neither of those is where you want people to go, right?”

(b) Signs and Symptoms of Recurrence

The theme of education was mentioned by participants in the primary diagnosis setting, but it was the Metastatic patients who brought this issue to the fore. The biggest gap was the lack of education around recurrence, many did not know signs and symptoms or what to look out for. In hindsight they felt that there should be better education about their diagnosis and how it could spread. “It was just really strange. I didn't understand the way I had to know, like, they don't really tell you what to look out for or anything. I didn't really understand how it spreads, cancer spreads when it does leave the primary site breast or whatever it is, I had no understanding of it but I knew that if it was in my organs, it was not good” (P3). Another stated “... in terms of the information provided when I left, medical information, that was never made available to me, and it was never made clear” (P4).

The participants felt that this information should have been made clear at the end of their primary treatment as it would enable PaBC to be proactive and would avoid unnecessary panic when they experienced pains in the future. “You know, even, it's about giving control back to the patient. Right? And that's what information does, and letting them like I did you know, watch for stuff but not in an irrational way but I

had the information to make those choices” (P4).

5.6 Community Connection and Peer Support

Participants felt there should be more available peer support “they've been through it all, like, some of the cancer support centers don't have that. They have brilliant counsellors and everything, but they haven't people that have been through it” (P5), and “The nurses were good, but they weren't counsellors, or they weren't experienced people, or peers” (P9).

The importance of peer support and presence was also mentioned in Workshop A, participants felt there should be “a way to link up with people who have a similar diagnosis to you” and “a breast cancer survivor should be employed on the medical team - nothing like talking to someone who has been there”. They also noted the need for “a designated person like a nurse who can take phone calls or meet with you if you have any problems from treatments. Rather than trying to see your Oncologist”.

Peer groups on Facebook and WhatsApp were mentioned as a point of reference and a place where they felt safe to ask questions. In this study group the most popular Facebook Groups mentioned were Breast Friends, Breast Cancer Survivors Ireland and Lobular Ireland.

5.7 Communicating with Children

All the participants were parents. They all voiced concerns around talking to children about their diagnosis, they worried how their diagnosis would impact their children's mental health and struggled to find support and communication approaches that could help them. “When

you have children, the first thing you think about is your children. And how is it gonna affect that?” (P1) another said “I have to this day not told my kids that I have a metastatic diagnosis... how do I now start that conversation. So I think I think the piece around support and communication like it just It's absolutely disgraceful” (P3). P1 stated “in the UK, Maggie centers, they have all this set up for children where they can go and they can have art therapy. They literally function like creches... we have zero here, like, absolutely zero.” P7 spoke about trying to find support for her daughter “the resources out there, actually they're very, very scarce on the ground. And then the ones that are there, like your CAN, or TUSLA, places like that, they're so overwhelmed. And under-resourced and underfunded. The waitlists were crazy” (P7).

They were worried about timing, the amount of information and its source; “I wanted to tell them but not tell them too soon. So you always have to have the timing right when it comes to the kids because they were, you know, getting to the age where they do understand and they'd hear and you'd have people you know, kind of whispering” (P6).

5.8 The Impact of Covid on Information and Supports

Covid was seen to have positive and negative impacts on the breast cancer experience and access to information and support. Participants spoke of the delays and postponements of treatments and closures of supports due to COVID “I would have had three treatments... I think you're entitled to six. COVID hit in the middle of it so they closed” (P5). For others it compounded their mental health issues “between the stress of trying to get over my treatment and then trying to deal with

COVID... there was a time I felt very, you know, dark and you know not good” (P10). This participant also compared online classes to how she felt when she had visited her cancer support centre, “the stress lifted off your shoulders, and I've really missed like, it's not the same when it's up online. Oh, my God, I want to go back” (P10).

5.9 A Metastatic Diagnosis

This theme refers to the high level of trauma associated with this type of diagnosis which is compounded by the lack of information and support available to Metastatic patients. “As bad as a primary diagnosis is, as tough as that is to come to terms with it, it's like, nothing in comparison to metastatic diagnosis. I mean, you don't know that at the time [primary diagnosis] it is very traumatic, but a metastatic one is just on a different level altogether” (P3).

(a) Gaps in information, support, and resources

The Metastatic participants did not want to belittle the gaps experienced by anyone with a primary cancer diagnosis. The first time round they admitted they had some support but after their secondary diagnosis, ‘there's not the same support there, not, definitely not, for metastatic’ (P6), and “I definitely found a big, big difference in the communication with the metastatic diagnosis. And the attention just wasn't there” (P2).

Their disillusionment was palpable, they had expected the same level of support second time round “You know, there's, there's, there's breast care nurses, but they only deal with primary patients. Why is there nothing like that for a metastatic patient?” (P3). They described feeling abandoned after their diagnosis and not

knowing who to turn to. “Nobody checked in with me after that, nobody rang me a week later, nobody checked in... I had nothing. I had no, I didn't know where to go” (P3).

Participant 5 spoke more about supporting her friend who had received a Metastatic diagnosis while she herself was recovering from a primary diagnosis “I feel looking on. She was just left... she was waiting for somebody to come back to her with a procedure like a plan, which would definitely have happened with [primary] breast cancer... but they didn't the second time, they didn't” (P5).

(b) Lack of communication and information

The negative psychological impact of a Metastatic diagnosis was exacerbated by the lack of education, communication and support received by the participants. The need for clear communication and relevant information in relation to treatments is even more important for those with a stage four diagnosis, they want to understand their life expectancy and need to know the plan. “I got nothing. Like none, like no information. And I was too traumatised to go look for it. I couldn't. I was just in survival mode.” (P3). Another stated “...I know primary, you had a plan. But you know, there's so much frustration with, am I forgotten about? Do they care? You know what I mean? ...If someone kind of went through that psychological part” (P6).

5.10 Key Takeaways

The breakdowns in communication create fear and exasperate mental health issues which are related to a cancer diagnosis and its treatments. The quality of communication greatly impacted the development of patient and practitioner relationships and ultimately determined

whether people affected by Breast Cancer trusted their healthcare teams.

There is also a mismatch between the information given to patients and their ability to process it. All interviewees rejected the generic leaflets packs given to them and expressed the desire for specific information at different stages in relation to their diagnosis.

Those who struggled to get the answers and support looked online for guidance. Learning how to navigate the information online is a steep learning curve. It leads to further feelings of frustration, disillusionment, and exposure to misinformation.

Gaps in online information for PaBC in Ireland are discussed in the next chapter.

Chapter 6 – Findings:
Gaps in Online Content

The aim of Workshop C was to highlight gaps in national and international online information available to People affected by Breast Cancer (PaBC). PaBC were excluded from this workshop as they would already have experience of using the chosen websites and their answers would not be impartial. Workshop C participants had no cancer diagnosis, their backgrounds included media, communications, and education.

Direct and Indirect Competitive Analysis, see 6.1 for explanation, of BC information was performed on national and international cancer focused websites. Websites were analysed based on the available content to highlight information gaps, the quality of information found by participants and the User Experience (UX) and Interface Design (UI) ratings. Participant insights from the workshop are also noted at the end of the chapter.

This chapter is a summary of Appendix 6.1 Workshop C Competitive Analysis Research Findings Document. Please refer to this for more details on all points.

6.1 Competitive Analysis

Eight websites were chosen and equally divided into two categories.

**Direct Competitive Analysis:
All Cancer Types Websites**

These websites were direct sources of online information mentioned by PaBC. They are general cancer information websites and supply a broad range of information. Two of these websites were

Irish – the Irish Cancer Society and Marie Keating Foundation, one is UK based – MacMillan, and the fourth is in the US – American Cancer Society.

**Indirect Competitive Analysis:
Breast Cancer Specific Websites**

These websites were online information sources that are specific to BC, they were not mentioned by PaBC but these nations were held up in literature sources as the four international key players in cancer care and survivorship – the US, Canada, Australia and New Zealand. The websites analysed were BreastCancer.org (US), Canadian Breast Cancer Network, Breast Cancer Network Australia, and Breast Cancer Foundation New Zealand.

Table 5 on page 28 provides an overview of the categories and websites chosen for the competitive analysis.

It is worth mentioning that there is no website focused specifically on Breast Cancer information for PaBC in Ireland. The charity “Breast Cancer Ireland” is primarily a research funding organisation. This website provides limited information on the assigned tasks and was not mentioned by PaBC, for these reasons it was excluded from the study.

Table 5: Tasks and Scenes developed from Research Insights

#	Insights from Research		Scene Setting	Task	Sub Task	Information Search
1	Education: Participants spoke of a lack of specific information in relation to their diagnosis. Understanding specifics e.g. their pathology (G1 T1b NO) and BC type (Invasive Lobular Carcinoma) relates to prognosis can educates them in terms of recurrence		You have been diagnosed with Breast Cancer, specifically Invasive Lobular Carcinoma. You read your pathology results, it said your tumour was G1 T1b NO. You want to understand these terms. Please see if you can find out what they mean.	1	a	Explanation of G1 T1b NO
					b	Explanation of Invasive Lobular Carcinoma
					c	A glossary on terms for results/ a graph
2	Impact of Time: Waiting times have a negative impact on patients mental health. Understanding normal waiting times helps PaBC to understand how long they should expect to wait and know when to follow up on something if it is taking too long.		You're still reeling in shock from your diagnosis, you're very anxious and worried about what will happen next. You've been waiting for over a week since your diagnostic tests were done and don't know how long is 'normal' to wait for these test results.	2	–	On average, how long should a patient expect to wait between having a diagnostic test and getting the results?
3	Communication between teams: PaBC could have a better understanding of people in their medical team. Who is involved in their care and who should they approach with issues of concern?		You've met a couple members of your team – your surgeon and the breast care nurse. You would like to know who else is involved in your care and what they do.	3	–	Please list the people who would be involved in a Multidisciplinary Team (MDT).
4	Children: Communication with children and supports were was cited as a big gap for participants.		You have three children, they are 15, eleven and seven who are struggling to come to terms with your diagnosis. Can you find:	4	a	Advise on how to talk to children about your diagnosis
					b	Supports that could help you
5	Communication: What's the plan? All PaBC struggled not knowing a treatment plan. The not knowing had a significant impact on their mental health. Having an example treatment plan and knowing options could allow patients to know what options to consider based on their diagnosis.		You've been waiting to see your consultant to know what your treatment plan is, you are concerned about the options you have and wondering what are the best options for you. Can you find:	5	a	An example of a Breast Cancer patient treatment plan
					b	A treatment options comparison sheet
					c	Questions to ask your doctor/ nurse
6	A list or directory: Participant feedback suggested a need for a national list/directory to connect existing services and help them find supports easily. They also spoke of importance of peer support and patient navigators to help point them in the right direction.		You have left the hospital and no longer have a team looking after you. You were not given any information on what to do next. You feel very isolated and scared and disillusioned. Reality is setting in. Everyone thinks you're over it now and you know you are only beginning to comprehend the rollercoaster. You would like to connect with other patients who have gone through what you have gone through. You would like to find some supports close to where you live. Can you find:	6	a	Supports - A detailed list of nationwide supports
					b	Peers - An online community with a members section
					c	Programs - Courses that could help
7	Education: Understanding side effects of medication can prevent unnessecary concerns but also educates PaBC on what to look out for.		You are experiencing some side effects from the drugs you are taking. You decide to find information on Breast Cancer drugs and their side effects.	7	a	Breast Cancer Drug List
					b	Breast Cancer Drug Side Effects
8	Education: In the absence of information patients perform their own research online. PaBC have developed ways to access credbility of information, but many fall prey to disinformation and misinformation.		Your friends keep sending you different natural remedies and information on the best diets for cancer. You're very confused as to what to believe. Can you find:	8	a	Tips on how to access information
					b	Cancer myth busters

Table 6: Overview of Competitive Analysis Categories

Direct Competitive Analysis	Indirect Competitive Analysis
A general cancer website that supplies information on all cancer types	A Breast Cancer specific website that supplies information on the disease
<div>- Irish Cancer Society</div> <div>- Marie Keating Foundation</div> <div>- American Cancer Society</div> <div>- MacMillan UK</div>	<div>- BreastCancer.org (USA)</div> <div>- Canadian Breast Cancer Network</div> <div>- Breast Cancer Foundation New Zealand</div> <div>- Breast Cancer Network Australia</div>
Why the websites were chosen:	
These four websites were cited by interview and workshop participants as their key websites for sourcing information.	These nations are considered key players in cancer and prioritise cancer survivorship care [29].

6.2 Content Available on Websites

Based on the findings from the interviews and workshops several information search tasks were composed for the competitive analysis. Scenes were developed in relation to those insights, see *Table 6 on previous page*. Each participant was assigned eight tasks, some of which had sub tasks. The scene provided context before they performed their information search tasks, see *Table 6*.

Each website was checked for available information based on the assigned tasks. Please see *Table 7* for the comparisons of the information available across the eight websites.

Direct Analysis:

All Cancer Type Websites

These websites contained a large amount of information in relation to the assigned tasks. Mac Millan (MM) covered the highest amount of content at 16 out of the 17 (16/17) search items. The Irish Cancer Society (ICS) and American Cancer Society

(ACS) were both a close second with answers to 15/17 items while Marie Keating Foundation (MKF) scored 10/17.

Indirect Analysis:

Breast Cancer Specific Websites

Again, these websites contained a lot of content relevant to the assigned tasks. Both the Breast Cancer Network Australia (BCNA) and the Canadian Breast Cancer Network (CBCN) scored the highest at 16/17 search items. Breast Cancer Foundation New Zealand (BCNZ) had answers to 15/17 items while BreastCancer.org (BC.org) scored 10/17.

Table 7: Information Available on Analysed Websites

Task	Sub Task	Information Search	Direct Comp Analysis: All Cancer Types				Indirect Comp Analysis: Breast Cancer Specific			
			ICS	MKF	ACS	MM	BCNZ	BC.org	BCNA	CBCN
1	a	Explanation of G1 T1b NO	✓	X	✓	✓	✓	✓	X	✓
	b	Explanation of Invasive Lobular Carcinoma	✓	X	✓	✓	✓	✓	✓	✓
	c	A glossary on terms for results/ a graph	✓	X	✓	✓	✓	X	X	✓
2	–	On average, how long should a patient expect to wait between having a diagnostic test and getting the results?	✓	✓	✓	✓	X	✓	X	X
3	–	Please list the people who would be involved in a Multidisciplinary Team (MDT).	X	X	✓	✓	✓	✓	✓	✓
4	a	Advise on how to talk to children about your diagnosis	✓	✓	✓	✓	✓	✓	✓	✓
	b	Supports that could help you	✓	✓	✓	✓	✓	✓	✓	✓
5	a	An example of a Breast Cancer patient treatment plan	✓	✓	✓	✓	X	✓	✓	X
	b	A treatment options comparison sheet	X	X	X	X	X	X	X	X
	c	Questions to ask your doctor/nurse	✓	X	✓	✓	✓	✓	X	✓
6	a	Supports - A detailed list of nationwide supports	✓	✓	✓	✓	✓	✓	✓	✓
	b	Peers - An online community with a members section	✓	✓	✓	✓	✓	✓	✓	✓
	c	Programs - Courses that could help	✓	✓	X	✓	✓	X	✓	✓
7	a	Breast Cancer Drug List	✓	X	✓	✓	✓	✓	✓	✓
	b	Breast Cancer Drug Side Effects	✓	X	✓	✓	✓	✓	✓	✓
8	a	Tips on how to access information	✓	X	✓	✓	✓	✓	✓	✓
	b	Cancer myth busters	✓	X	✓	✓	✓	✓	✓	X

6.3 Information Quality

Participants were asked to grade any content they found by choosing one of three descriptions: Informative = 3, Basic =2 or Scientific = 1. The content quality results were analysed in terms of the number of descriptions assigned to each task item. Individual task quality scores were also compared to ascertain which category (Direct v's Indirect) contained better quality information. The average of Individual Task Quality scores from the eight websites were ranked in terms of highest to lowest. Below is a summary of the findings.

(1) Content Quality

(a) Basic

This rating was based on whether an item was given a basic rating by one or more users.

» Direct Analysis:

All Cancers Type Websites

The largest number of basic responses was on the ICS website at 8/17 task items. The ACS rated 6/17 while MKF and MM scored 5/17. Across all the Direct websites 0/17 results were unanimously rated as basic by users.

» Indirect Analysis:

Breast Cancer Specific Websites

The largest amount of basic information responses was on the CBCN website at 11/17 task items. BCNZ scored 7/17, BCNA 6/17 while BC.org scored 4/17. There were 0/17 that were unanimously rated as Basic by users.

(b) Informative

This rating was based on whether an item was given an informative rating by one or more users.

» Direct Analysis:

All Cancers Type Websites

The largest amount of informative content as on the MM website at 12/17 tasks. The lowest score was MKF at 6/17 with the ICS 9/17 and ACS 11/17. Users also agreed on several tasks where they unanimously rated the content as informative – ICS 1/17, MKF 0/17, MM 2/17 and ACS 4/17.

» Indirect Analysis:

Breast Cancer Specific Websites

The highest rating of informative content was found on the BC.org website at 14/17 tasks. The lowest was 9/17 on BCNZ, with CBCN 10/17 and BCNA 11/17. Users also agreed on several tasks where they unanimously rated the content found as informative – BCNZ 4/17, BC.org 2/17, BCNA 4/17 and CBCN 0/17.

(c) Scientific

A scientific rating indicates that the content contained scientific jargon that was too complicated for the user to understand.

» Direct Analysis:

All Cancers Type Websites

0 out of 17 items were given a scientific rating by participants on the Direct websites.

» Indirect Analysis:

Breast Cancer Specific Websites

Only one Indirect website contained information that was considered scientific by users BC.org 3/17.

(2) Individual Information Quality Scores

Table 8 shows the comparison in information scores from each task between Direct and Indirect categories. The higher amount of quality information was found on Indirect Breast Cancer Specific websites with over double (11/17) tasks compared to Direct All Cancer Type websites (5/17).

Table 8: Individual Task Information Quality Total Scores – Direct v's Indirect Competitive Analysis

Task	Sub Task	Information Search	Direct Scores All Cancer Types	In Direct Scores BC Specific	Difference*
1	a	Explanation of G1 T1b NO	7	14	7
	b	Explanation of Invasive Lobular Carcinoma	20	27	7
	c	A glossary on terms for results/ a graph	11	12	1
2	–	On average, how long should a patient expect to wait between having a diagnostic test and getting the results?	12	5	7
3	–	Please list the people who would be involved in a Multidisciplinary Team (MDT).	16	26	10
4	a	Advise on how to talk to children about your diagnosis	24	33	9
	b	Supports that could help you	27	32	5
5	a	An example of a Breast Cancer patient treatment plan	14	11	3
	b	A treatment options comparison sheet	0	0	0
	c	Questions to ask your doctor/nurse	16	20	4
6	a	Supports - A detailed list of nationwide supports	34	28	6
	b	Peers - An online community with a members section	35	28	7
	c	Programs - Courses that could help	12	9	3
7	a	Breast Cancer Drug List	10	16	6
	b	Breast Cancer Drug Side Effects	15	28	13
8	a	Tips on how to access information	19	24	5
	b	Cancer myth busters	5	11	6

* Higher scoring category indicated by number colour

(3) Website Rankings for Content Quality

As illustrated in *Figure 6* The ACS (American Cancer Society) ranked the highest while MKF (Marie Keating Foundation) scored the lowest for content quality. The Irish Cancer Society and Canadian Breast Cancer Network were in joint 6th place. The lowest rankings included both Irish sites – Irish Cancer Society and Marie Keating Foundation.

On average the results showed that the Direct Analysis websites contained more Basic information at 50% (8.5/17) compared to 41% (7/17) of Indirect analysis results. The ratings found that 55% (9.5/17) of Direct Analysis contained 9% less Informative content than 64% (11/17) Indirect Analysis. There were no Scientific content ratings on the Direct Analysis compared to one website in the Indirect Analysis. BC.org results showed 3/17 were considered scientific.

(4) Information Quality Key Takeaways:

The Irish websites rated below average in terms of Information Quality. Direct Analysis websites had more basic, less informative content and no scientific information when compared with the Indirect Analysis websites.

6.4 Biggest Gaps in Information Based on Assigned Tasks

(1) Combined overall gaps

The 17 task items were ranked according to the combined total users scores from each CA category. See *Table 9*, rankings from largest gap – *A treatment options comparison sheet*, to smallest gap – *Peers: An online community section*.

(2) Gap Comparison between Direct and Indirect Competitive Analysis Categories

The total user scores were calculated on each of the task items. *Figure 7* shows the differences between CA categories and the total overall gaps.

Figure 6: Website Rankings based on Content Quality

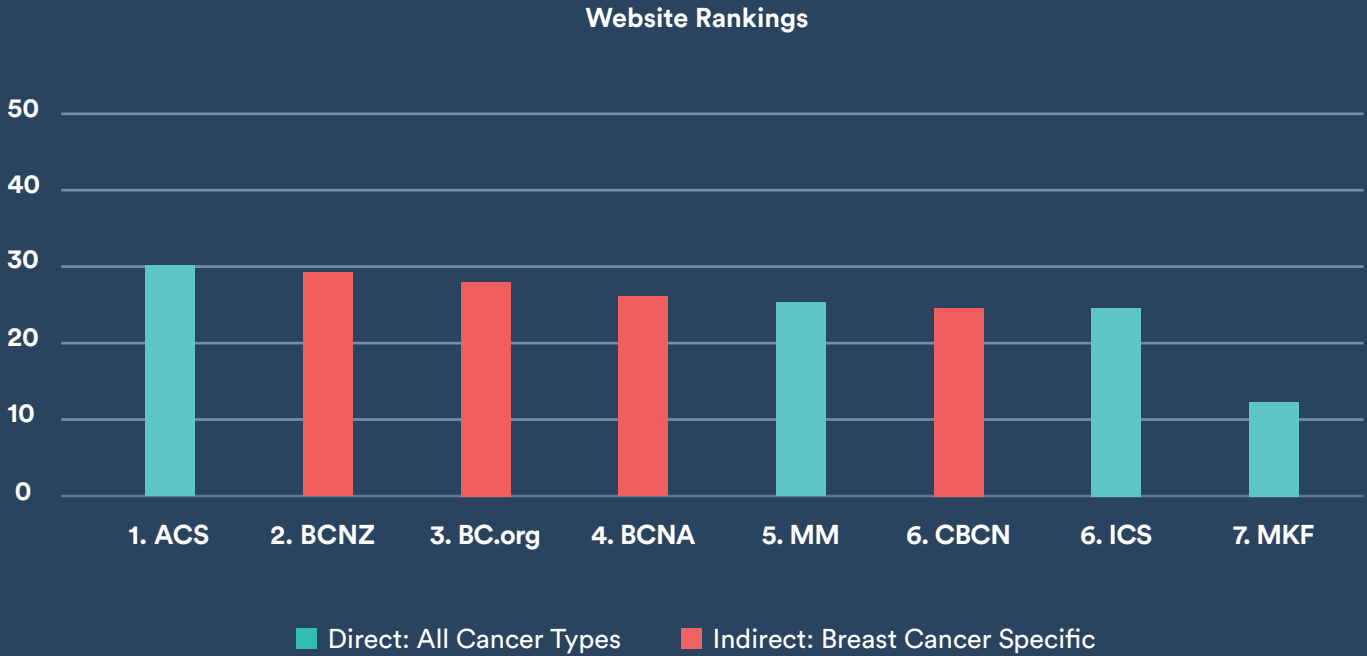


Figure 7: A comparison of the the Information Quality for Individual Tasks

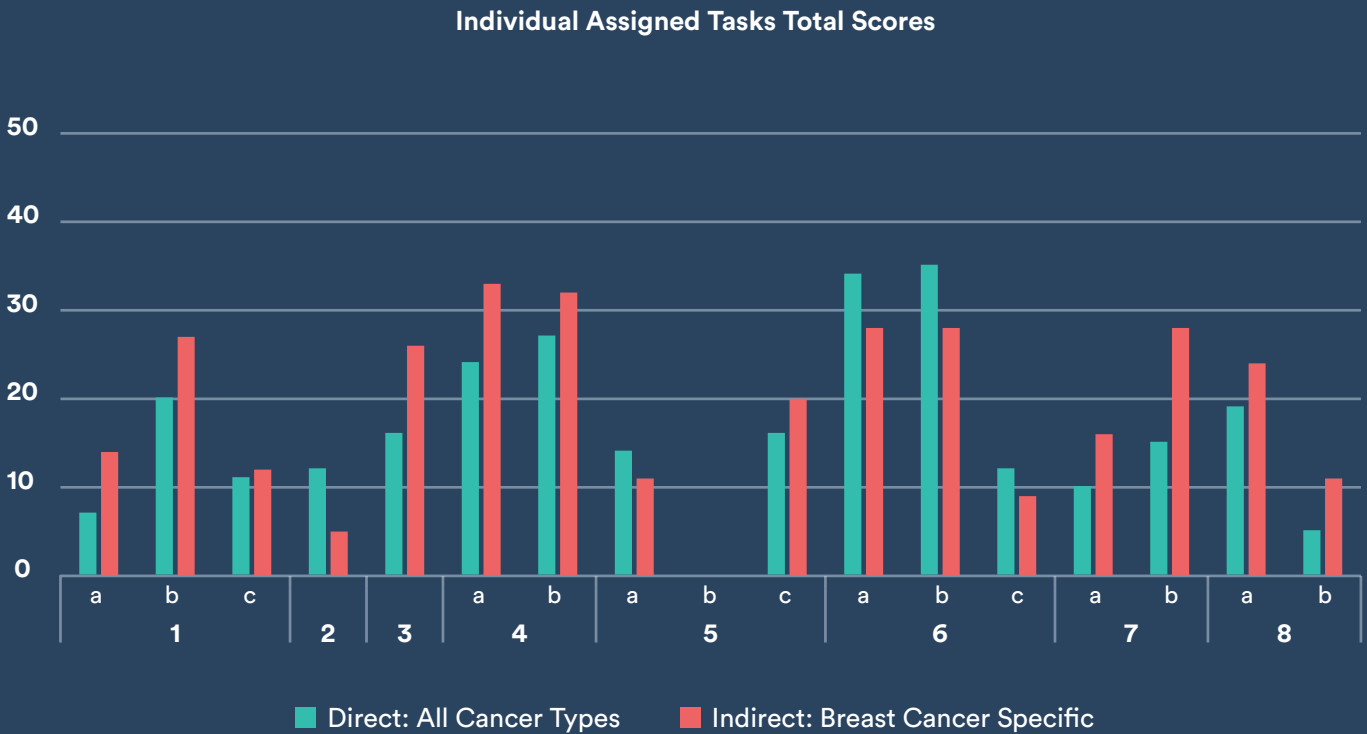


Table 9: Gaps in Information based on Tasks – ranked from Largest to Smallest

Rank	Task	Sub Task	Description	Total Score*
1	5	b	A treatment options comparison sheet	0
2	8	b	Cancer myth busters	16
3	2	–	On average, how long should a patient expect to wait between having a diagnostic test and getting the results?	17
4	1	a	Explanation of G1 T1b NO	21
5	6	c	Programs - Courses that could help	21
6	1	c	A glossary on terms for results/ a graph	23
7	5	a	An example of a Breast Cancer patient treatment plan	25
8	7	a	Breast Cancer Drug List	26
9	5	c	Questions to ask your doctor/nurse	36
10	3	–	Please list the people who would be involved in a Multidisciplinary Team (MDT).	42
11	7	b	Breast Cancer Drug Side Effects	43
12	8	a	Tips on how to access information	43
13	1	b	Explanation of Invasive Lobular Carcinoma	47
14	4	a	Advise on how to talk to children about your diagnosis	57
15	4	b	Supports that could help you	59
16	6	a	Supports - A detailed list of nationwide supports	62
17	6	b	Peers - An online community with a members section	63

*Total Score = Two CA Categoires (All Cancer Type + BC Specific) User Scores.
Max score for a single task was 51, when taking total score of two CA categories Max Score = 102

6.5 User Experience and Interface Design

User Experience and Interface Design of each Direct and Indirect Analysis was assessed based on:

- 1. **Effectiveness** - was the user able to achieve their goals?
- 2. **Satisfaction** - was the user satisfied with the website?
- 3. **Task Success** - was the user complete the given task?

(1) Effectiveness

For a website to be considered effective companies should aim or try to exceed a completion rate average of 78% [77].

» **Direct Analysis:**
All Cancer Type Websites
The ACS Completion Rate Calculation scored approximately 46.6% to 87.0% which is 9% higher than the European counterparts. MM and the ICS marginally succeeded in achieving the 78% competitive rate calculation. MKF failed in achieving the rating by over 20%.

» **Indirect Analysis:**
Breast Cancer Specific Websites
All the Indirect Analysis Breast Cancer Specific websites exceeded a completion rate average of 78% indicating that these websites have been designed with the end user in mind. BCNA scores ranked as 41.2% to 82.8% while BCNZ, BC.org and CBCN all scored approximately 52.5% to 91.0%.

(2) Satisfaction

To rate participant satisfaction levels each participant was asked eight questions overall. Seven related to different dimensions of User Experience (UX) and User Interface (UI) design and rated on (a) Accessibility, (b) Appearance and (c)

Usability. Question eight related to (d) Website Referral as a user who is satisfied with their user experience is more likely to refer a product to another person.

Please see Table 10 for a summary of mean scores from UI/UX Questions.

(a) Accessibility:

» **Direct Analysis:**
All Cancer Type Websites
In all cases the content was text heavy with a lack of informative imagery, diagrams and videos used to communicate content, there was poor use of videos by all the websites. A wider variety of visual tools is needed to explain information to users. ICS and MKF scored an average content chunking rating which indicates that improvements need to be made to content divisions to help people digest content. ACS and MM information was divided in a clearer manner.

» **Indirect Analysis:**
Breast Cancer Specific Websites
These websites achieved average or higher scores for accessibility. BCNA and BC.org scored above average, while BCNZ and CBCN achieved high accessibility scores. A wider variety of visual tools - informative imagery, diagrams, and videos - is needed on all websites to explain information to users. In all cases the users unanimously agreed that the content information was broken down into digestible chunks.

(b) Appearance:

» **Direct Analysis:**
All Cancer Type Websites
MKF scored poorly in this regard, users found the advertisements and fundraising visuals distracting. This was the ICS

strongest dimension, a higher-than-average score. MM scored lower than average while the ACS scored the highest overall. In all cases if the accessibility issues were addressed, the appearance scores would increase.

» **Indirect Analysis:**
Breast Cancer Specific Websites
Overall these websites scored highly in terms of appearance. BC.org ranked highest in this category with all users unanimous in their scores. BCNZ and BCNA presented some contradictions between user opinion but still achieved an above average score. CBCN scored high in terms of appearance.

(c) Usability:

» **Direct Analysis:**
All Cancer Type Websites
The Irish websites scored poor (ICS) and below average (MKF) in terms of Usability. An examination of information architecture is needed to align navigation with user mental models. Overall, the MM website scored highly, an above average ranking. The ACS website scored highest

in this category with all users unanimously rating the fonts with the top score.

» **Indirect Analysis:**
Breast Cancer Specific Websites
Overall, these websites scored higher than average usability scores. BCNA and BC.org scored above average, while BCNZ and CBCN achieved high usability scores.

(d) **Website Referral**
To calculate each Website Referral rate participant Loyalty ratings were compared with the Net Promoter Scores. All of the answers within the Direct and Indirect Analysis categories were examined and then compared against each other.

» **Direct Analysis:**
All Cancer Type Websites
One out of three users gave the ICS, MKF and ACS a Promoter score on their NPS and Loyalty Rating, therefore highly likely to refer others to this website. They also scored one Passive rating each, which indicated these users were on the fence in terms of referral. The ICS, MKF and MM all received one Detractor rating. MM

scored the highest referral rating with two out of three users giving a promoter score on both counts, they did not receive a Passive score, but one user gave them a Detractor rating on both counts.

» **Indirect Analysis:**
Breast Cancer Specific Websites
BCNZ and BCNA both achieved two Promoter ratings with their third rating as Passive. The BC.org and CBCN scored one Promoter rating and two Passive ratings. None of these sites were given a Detractor rating.

(3) **Task Success**
One of the biggest issues facing People affected by Breast Cancer is not being able to find or access the information they need. *Table 3* illustrates the amount of content provided by the Direct and Indirect websites. The task failure rates indicate that better understanding of user mental models is needed across the board. Information architecture needs to be redesigned to match user expectations.

(a) **Partial Failed Tasks**
Some users found information on the items when others did not, in these cases the results were considered a Partial Failed Task.

» **Direct Analysis:**
All Cancer Type Websites
MKF website had the highest score for 15/17 partial failed tasks. MM was close at 13/17, followed by ICS at 11/17, the ACS results were the best at 10/17.

» **Indirect Analysis:**
Breast Cancer Specific Websites
BC.org had the highest score for 12/17 partial failed tasks, BCNA was close at 11/17, followed by BCNA and CBCN with 9/17.

(b) **Complete Failed Tasks**
In cases where users unanimously could not find a task item it was considered a Complete Failed Task .

» **Direct Analysis:**
All Cancer Type Websites
MKF website had the highest score 10/17 complete failed tasks, the ICS and MM indicated 3/17 complete failed tasks each, the ACS had only 1/17.

» **Indirect Analysis:**
Breast Cancer Specific Websites
BCNA website had the highest score 5/17 complete failed tasks. CBCN results indicated 4/17 while BCNZ and BC.org had only 1/17.

6.6 Participant insights from Workshop C

Barriers
Some of the participants reported having to sign up and become a member of the website to get more information. This presented barriers to finding relevant information. They found it annoying. What if the user does not want to register and hand over their own data? Participants also noted that they needed to have a national address relevant to these websites in order to become a member.

Emotions
Participants spoke of how they had emotional responses while performing the tasks. Several participants were parents and two individuals reported “being brought to tears” when they considered the physiological strain PaBC would be under. Many of the participants stated they found the amount of content on websites “overwhelming” while also stating that if they felt like that without a diagnosis they had no idea how someone with a diagnosis would deal with it. A few

Table 10: Summary of Mean Scores from Competitive Analysis UX/UI Questions

	Direct Comp Analysis: All Cancer Types				Indirect Comp Analysis: Breast Cancer Specific			
Website	ICS	MKF	ACS	MM	BCNZ	BC.org	BCNA	CBCN
Accessibility	7	8	8	12	11	11	12	13
Appearance	9	2	11	5	8	9	8	11
Usability	4	6	10	10	11	9	9	11

participants spoke of wanting to get their breasts checked and planning to book an appointment with their doctor.

6.7 Key Takeaways

The Effectiveness, Satisfaction and Task Success key findings indicate that all Direct (All Cancer Type) websites were less user friendly than the Indirect (Breast Cancer Specific) websites. Interestingly the analysis also showed that the International websites (ACS, BCNA, BC.org, BCNZ, CBCN) scored higher than the European (ICS, MKF, MM) counterparts.

Overall, the Irish websites (ICS, MKF) ranked lowest in every category. More work needs to be done in understanding PaBC mental models and their information needs. Also, better User Experience and Interface Design would help increase Satisfaction, Effectiveness and Task Success.

Chapter 7: Conclusion

7.1 Study Conclusion

By taking an ontological approach to understanding the information deficit experienced by people affected by BC, their methods of information acquisition and the channels used to communicate with them we can have a better understanding of how to inform and engage PaC [5, 28]. The 2019 NCCP Living with and Beyond Cancer in Ireland Report implementation plan outlines its Priority Action 3: Provide Information for cancer patients and families, the first recommendation being Identify information needs across the patient pathway [56]. Information searching behaviour is associated with better cancer related health outcomes, with higher rates of awareness, knowledge, preventative behaviours, and screening adherence [83].

Study Aim One

The first aim of this study was to highlight issues to identify information deficits from a patient's perspective. Why is the information not getting through to patients? What are the communication breakdowns and where do they happen in the cancer journey?

The thematic analysis from interviews and data from Workshop A found nine key themes in the data. These key themes highlighted poor communication and the lack of information for patients in an already disjointed service of care. The quality of communication greatly impacted the development of patient and practitioner relationships. The breakdowns in communication created fear and exasperated mental health issues which

are related to a cancer diagnosis and its treatments.

PaBC want to be easily guided to specific information in relation to their diagnosis as much time is wasted by them trying to find answers, support, and guidance. It affects their mental health and quality of life. Not knowing is the hardest thing for PaBC to deal with, by becoming better educated about their own disease they know signs and symptoms and can make better informed life changing decisions. This knowledge has the potential to reduce the prognosis stage rates and limit metastatic recurrence. It could also reduce the level of treatments needed by PaBC and therefore free up the health system backlog.

Study Aim Two

The second aim of this study was to perform a Competitive Analysis of online cancer information. It examined the User Experience and Interface Design of websites dedicated to supplying cancer information and assessed the Quality of Information found on those websites. What information was online for PaBC? What's available to them on Irish Cancer related websites, compared to those in the UK, US, Canada, New Zealand, Australia? How do the Irish cancer websites stack up against international websites?

The Competitive Analysis (CA) tasks showed more needs to be done in terms of usability, accessibility, and appearance of online platforms. The gaps become more apparent when a user's search criteria is specific to diagnosis, pathology prognosis, treatment plans etc. The CA also showed that over half the information on Irish

websites was considered too generic and basic by participants. The differences in content quality indicated that standards are lacking in Breast Cancer information and that there is a need for some form of criteria in terms of content streaming.

The Irish websites performed poorly in User Experience (UX) and this was highlighted even more when they were compared to their international counterparts. The UX issues highlighted how the information gap is impacted by the lack of understanding of patient mental models. The findings showed that one Irish website had a high available information score (15/17) but users struggled to locate it.

There is a need for better understanding of how the information deficits happen, what information people are searching for, how they go about looking for it and where they expect to find it. More also needs to be done in terms of analysing usability, accessibility, and appearance of cancer information websites. Ideally anyone, not just PaBC, should be able to locate a higher quality of relevant information on Irish based websites.

Participant suggestions for what could work in the future:

PaBC felt that there should be a patient navigator assigned to them at diagnosis. This person could be a peer “someone who had been through it” or a patient advocate. A trained outreach individual who could help them navigate their disease and point them in the right direction when needed. This solution could help fill the Breast Cancer Nurse gap mentioned by many participants.

They also suggested a website with a list where users could filter and find specific information. Both of these suggestions

correlate with the findings from the 2019 NCCP Reports [55, 56].

In conclusion:

The research showed that the quality of offline and online information for PaBC in Ireland was lacking and that information was poorly communicated and distributed. The standards of information quality and communication pathways need to be raised for people affected by Breast Cancer in Ireland. These insights highlight how this under researched problem needs to be analysed using a Service Design perspective.

7.2 Strengths and Limitations of the Study

(1) Competitive Analysis Barriers

Some of the participants reported having to sign up and become a member of the website to get more information. This presented barriers to finding all the relevant information available.

(2) Impact of COVID

Covid restricted the opportunity for the researcher and participants to meet face-to-face. On site workshops would have created a different atmosphere however I do not feel it had a negative impact on the research. The participants were engaged and responsive during all exercises. If anything I feel it reduced geographical barriers, travel time and costs and allowed for a greater variety of participants to be involved.

During interviews many PaBC commented on how technology had helped them feel more connected, less isolated and better informed because of their ability to attend conference webinars, fireside chats and online discussions without having to leave their own homes. *Please see Appendix 7.1 for more details.*

(3) Researcher Experience

Having no previous experience of performing research at this level the timings to perform analysis and write findings was greatly underestimated. That being said, the length of time to create a high quality of work can only be learned by the process of going through it. It is unfortunate that a quantity of data has not been examined, it has not gone to waste and will be relevant to the next stages of research. In hindsight this project alone was four projects in one, two of which have been presented in this design report.

(4) Time Constraints

Due to time constraints and the vast quantity of data produced from 10 interviews and 3 workshops, further time is needed to analyse research and develop a patient timeline, and to create a map of national services and support.

7.3 Next Steps:

(1) Workshop Analysis

Further analysis from workshop A and B will be added to this Design Report and will be submitted for poster presentation at the 58th Irish Association for Cancer Research Annual Conference in March 2022.

(2) Doctoral Research

The findings from this research will contribute to the next step, a doctoral study on this topic.

7.4 Reflections:

My experience of Breast Cancer and the needs I identified lead me to this study. I believe in co-creating solutions and working with multi-disciplinary experts to create positive change. In the last 18 months I have gained invaluable experience by committing to this MA

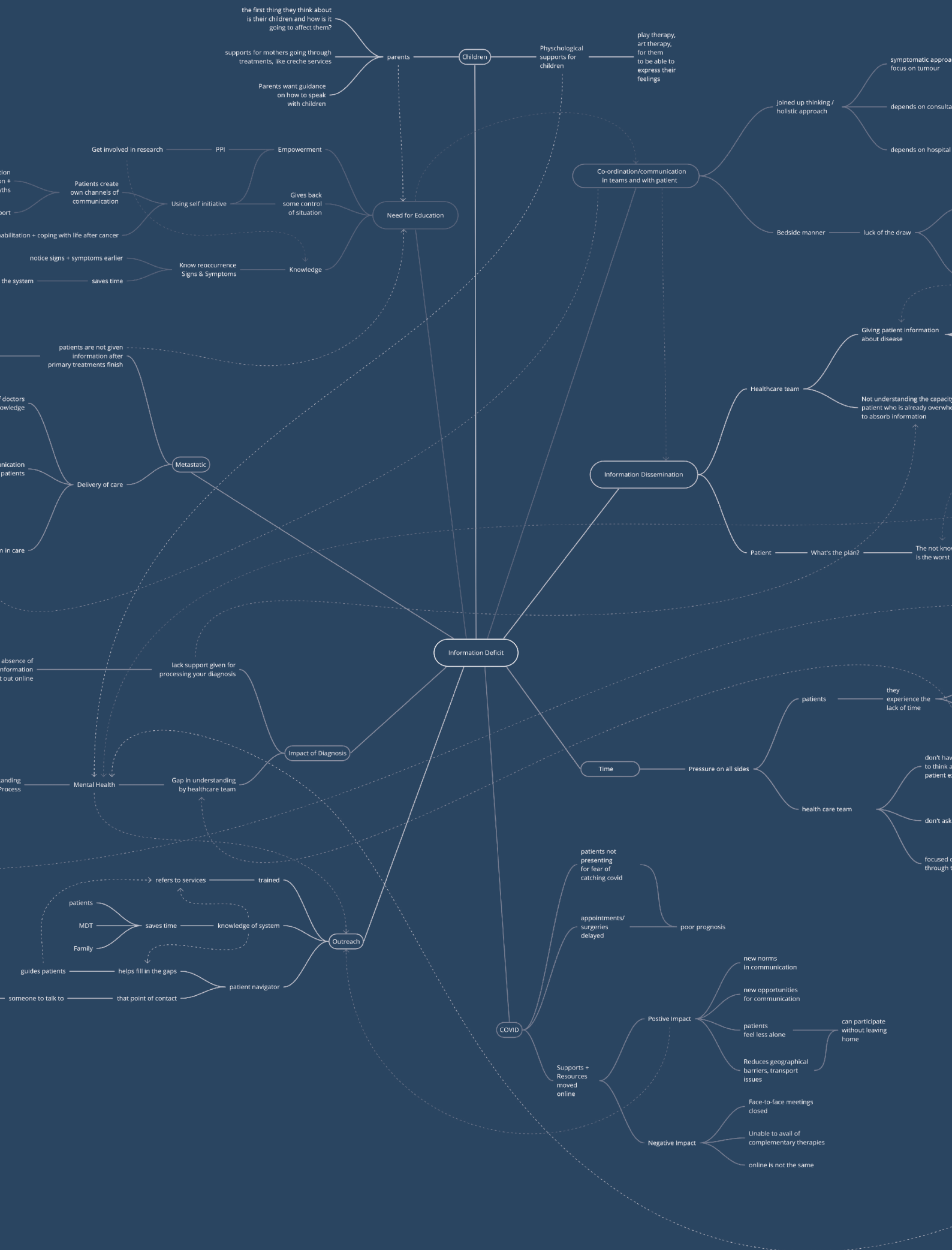
Design for Change. Through project-based learning I have worked with research tools, participated in, and created design charrettes, facilitated workshops, interviewed participants, written design reports, and analysed findings. This MA research has allowed me to recruit a wide range of stakeholders and patients affected by Breast Cancer. I have continued to build my network of connections with Cancer Charities across the island of Ireland including Cancer Researchers, Patient Support and Peer Groups, the Patient Voice in Cancer Research (PVCR).

Being aware of bias I briefly outlined my own lived experience in the Introduction and the steps I took to counteract my own perceptions are outlined in my Ethics Application, *Appendix 4.1*. Before I commenced the study I was concerned that listening to PaBC stories might bring old emotions to the surface and I pondered how this study might affect my own mental health. Being aware of this issue I availed of free counselling from the Irish Cancer Society for the duration of the study. My fears of potential negative impact did not happen, instead I found I was even more motivated to continue researching the topic. It was a cathartic process. Working with participants who were actively engaged was hugely refreshing. I found more friends through the process, as I gasped, empathised, and laughed with participants.

I look forward to diving deep into the research again and continuing to follow my passion for this topic.

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Figure References

Figure 1 **Using Design Thinking and Human-Centered Design Together**

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Figure 2 **Double Diamond**

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Figure 3 **Participant Action Research**

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Design Thinking Process

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