

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

K McKeon¹, C Doyle¹, S Casey¹, C Pandolfi², M Ivers³, ¹Design + Visual Arts, Dun Laoghaire Institute of Art, Design + Technology, Dublin, ²School of Design, George Brown College, Toronto, ³School of Psychology, UCD, Dublin.



Background

The Information Deficit (ID), is one of the top five unmet needs facing people affected by cancer in Ireland today [1, 2]. Patients who feel more connected to a support system are more likely to know signs of diseases, better able to assimilate information and less likely to drop out of the system [3, 4, 5]. The information needs of Breast Cancer Patients (BCP) do not significantly decrease over time, however, the type of information BCP seek does change over the cancer trajectory [6, 4]. There is a growing need for better information sharing and care coordination for BCP [14, 15]. Their information and support needs remains high throughout diagnosis, treatment, and post treatment [7, 8, 9, 10, 11].

Aims

The first aim was to identify ID from a BCP perspective through Thematic Analysis (TA). Why is the information not getting through? What and where are the communication breakdowns? The second aim was to perform a Competitive Analysis to (a) examine the User Experience (UX) and User Interface (UI) Design of dedicated cancer information websites and to (b) assess the Quality of Information found. What's available to BCP on Irish Cancer websites, compared to the UK, US, Canada, NZ, Australia? How do the Irish websites stack up against international sites? The study focused on the specific information deficits experienced by participants and aimed to highlight the issues that contribute to these gaps.

Steps Taken

This mixed method exploratory research aimed to explore the main aspects of this under-researched problem [12] by using qualitative and quantitative pragmatic methodologies and participation action research. Data was collected through 10 semi-structured interviews and three workshops. Design Thinking tools enabled interaction between researcher, patients, stakeholders and espoused a Patient and Public Involvement (PPI) approach [13]. TA was used to uncover patterns and assign codes which highlighted key themes in qualitative research.

Insights

The Nine Key Themes identified in the TA (Figure 1) showed that 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 BCP trusted their healthcare teams. All interviewees and patient participants 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.

The differences in online content quality highlighted by the Competitive Analysis (Figure 2-5) indicated that standards are lacking in BCP information criteria across the board. Over half the content found on Irish website was considered too generic and basic by participants. The Irish websites performed poorly in UX+UI and this was highlighted even more so when they were compared to their international counterparts (Figure 4). Overall the UX+UI Design issues on all websites highlighted how information gaps are further impacted by the lack of understanding of patient mental models (Figure 5).

Conclusion

BCP need specific levels of tailored information at different stages. There is a mismatch between the information given to patients and their ability to process it. There is also a need for a 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 needs to be done in terms of usability, accessibility, and appearance of websites for BCP in Ireland. Better UX+UI Design would increase Task Success and Effectiveness and have a positive impact on BCP Satisfaction in relation to their online information seeking behaviours.

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Figure 1: Nine Key Themes identified in Thematic Analysis

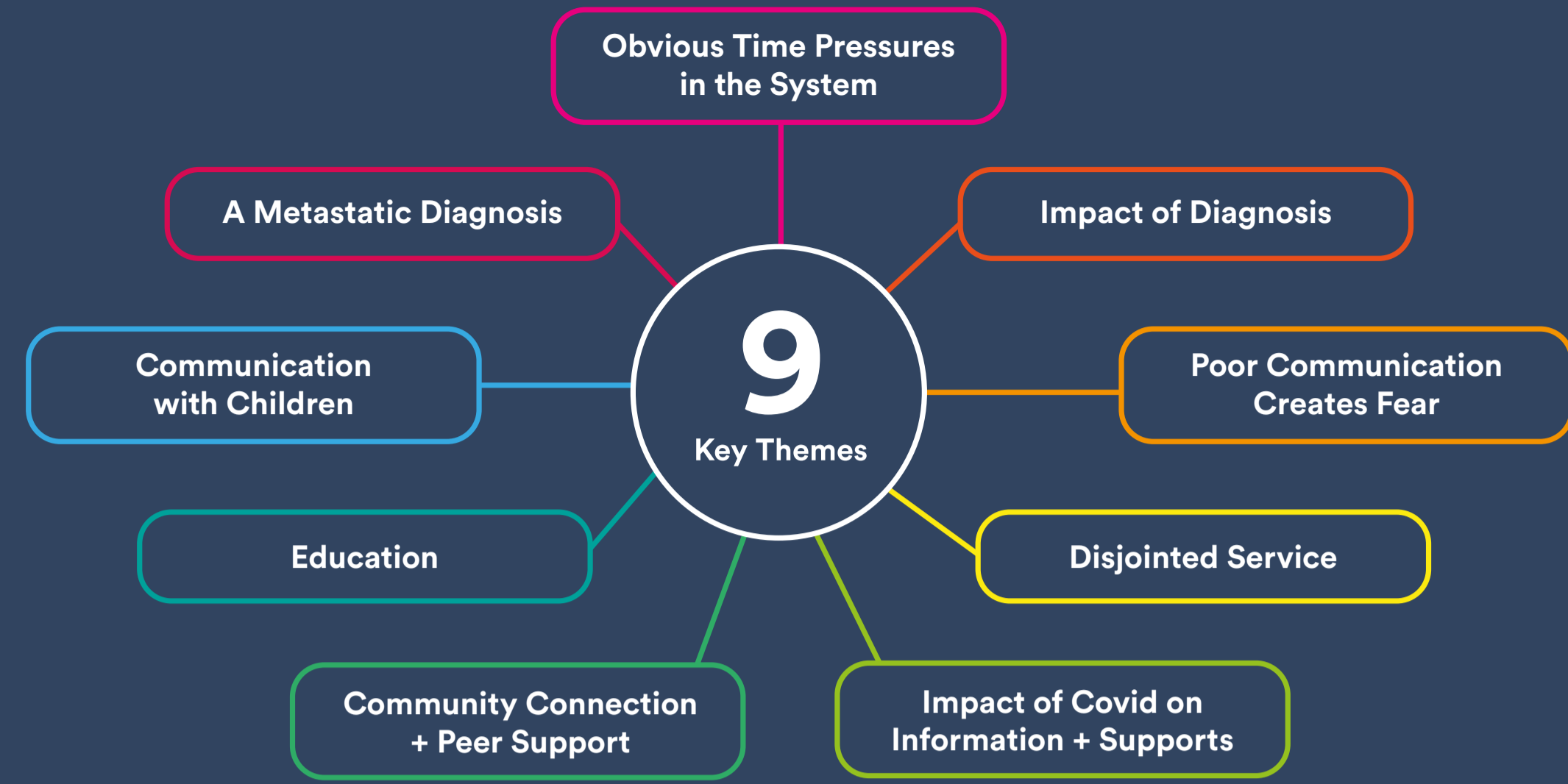


Figure 2: Tasks based on TA + Information Found on Analysed Websites

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	
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 BC patient treatment plan	✓	✓	✓	✓	X	✓	X	
	b	A treatment options comparison sheet	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	BC Drug List	✓	X	✓	✓	✓	✓	✓	
	b	BC Drug Side Effects	✓	X	✓	✓	✓	✓	✓	
8	a	Tips on how to access information	✓	X	✓	✓	✓	✓	✓	
	b	Cancer myth busters	✓	X	✓	✓	✓	✓	X	

Figure 3: 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
- Irish Cancer Society (ICS) - Marie Keating Foundation (MKF) - American Cancer Society (ACS) - MacMillan UK (MM)	- BreastCancer.org (BC.org) - Canadian Breast Cancer Network (CBCN) - Breast Cancer Foundation NZ (BCNZ) - Breast Cancer Network Australia (BCNA)
Why the websites were chosen to be analysed:	
These websites were direct sources of online information mentioned by BCP.	These websites are online information sources that are specific to Breast Cancer, they were not mentioned by BCP 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 [16].
They are general cancer information websites and supply a broad range of information.	

Figure 4: Website Rankings based on Content Quality

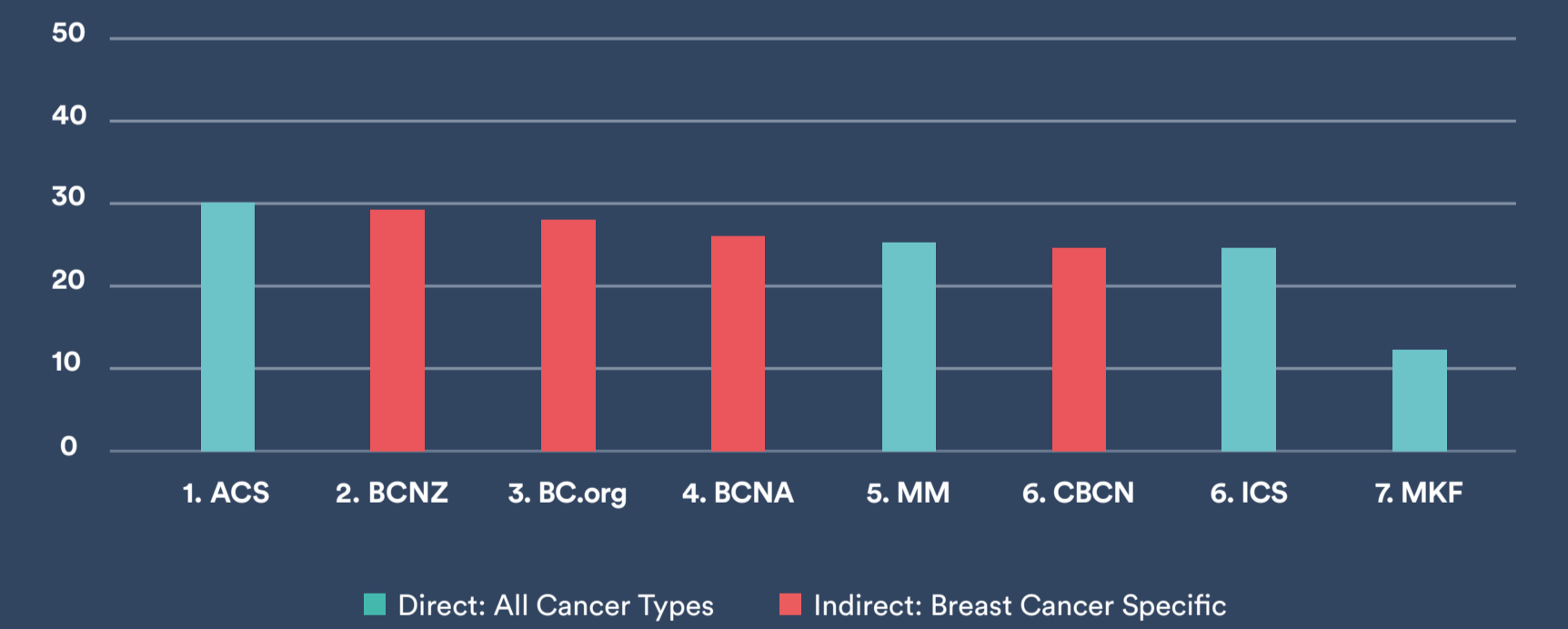
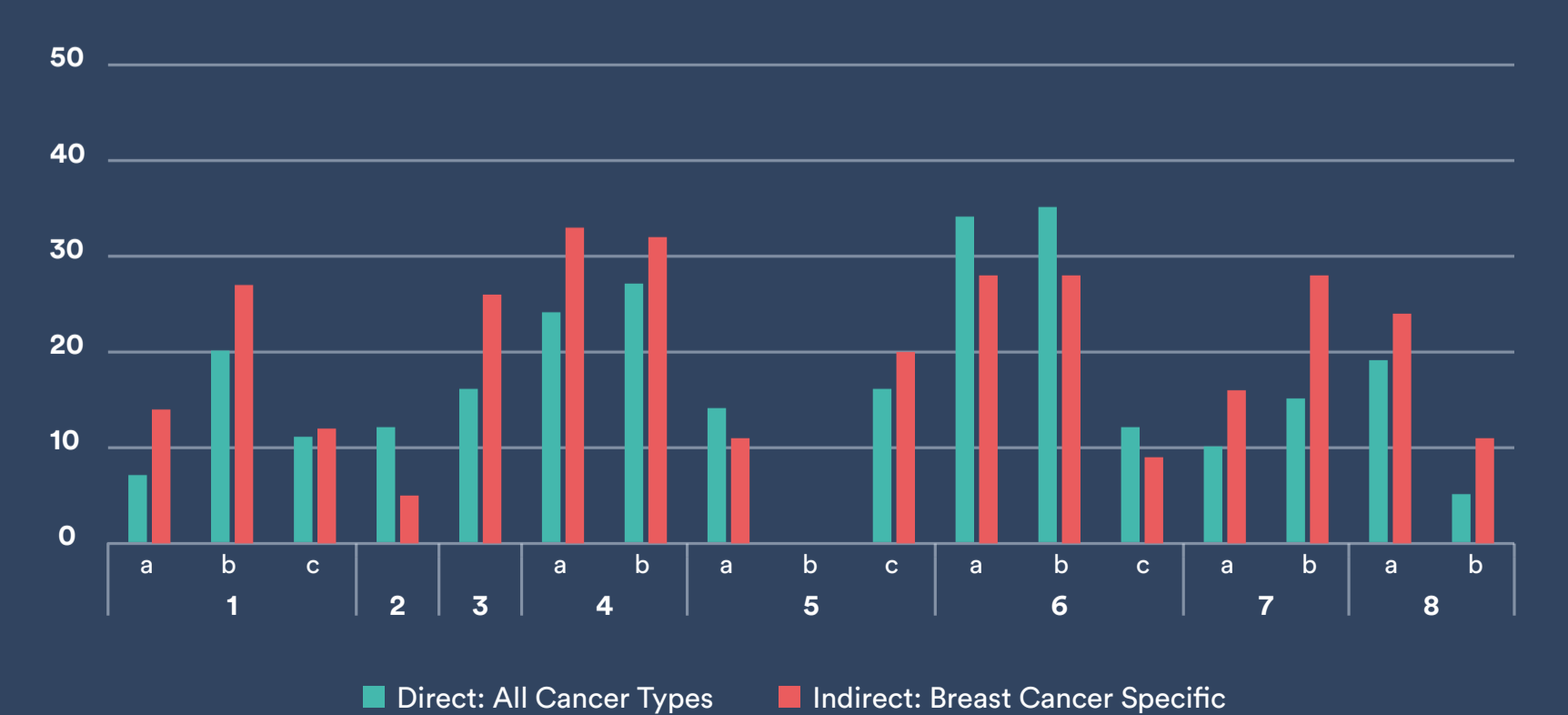


Figure 5: A Comparison of the Information Quality for Individual



In total 17 information searching tasks were assigned and each user ranked the content they found as Basic, Informative or Scientific. The highest possible score for information was 51 (17x3 = 51). Scores were calculated as 0 = Fail, 1 = Scientific, 2 = Basic, 3 = Informative.