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

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## 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 the signs of diseases, are better able to assimilate information, and are less likely to drop out of the system [3, 4, 5]. The information needs of Breast Cancer Patients (BCPs) do not significantly decrease over time. However, the type of information BCPs seek does change over the cancer trajectory [6, 4]. There is a growing need for better information sharing and care coordination for BCPs [14, 15]. Their information and support needs remain high throughout diagnosis, treatment, and post treatment [7, 8, 9, 10, 11].

## Aims

The first aim of the investigation was to identify ID from a BCP perspective through Thematic Analysis (TA). Why is 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 BCPs on Irish cancer websites, compared to the UK, US, Canada, NZ and 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 investigate the main aspects of this under-researched problem [12] by using pragmatic methodologies through qualitative and quantitative participation action research. Data was collected through 10 semi-structured interviews and three workshops. Design Thinking tools enabled interaction between researcher, patients and stakeholders and espoused a Patient and Public Involvement (PPI) approach [13]. TA was used to uncover patterns and assign codes that 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 exacerbate mental health issues 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 BCPs 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 were looking for additional answers and support looked online for guidance. Navigating the information online is a steep learning curve. It leads to further feelings of frustration, disillusionment, and exposure to misinformation.

Figures 2–5 illustrate the range in quality of online content and indicate that no standard criteria exist for BCP information. Over half the content found on Irish websites was considered too generic or basic by participants. The UX+UI component of Irish websites performed poorly initially, and this was exaggerated further when compared to their international counterparts. (Figure 3). Overall, the UX+UI Design issues on all websites highlighted how the information gaps are influenced by poor understanding of patient mental models (Figure 4).

## Conclusion

BCPs 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 BCPs in Ireland.

Better UX+UI Design would increase Task Success and Effectiveness and have a positive impact on BCPs Satisfaction in relation to their online information-seeking behaviours.

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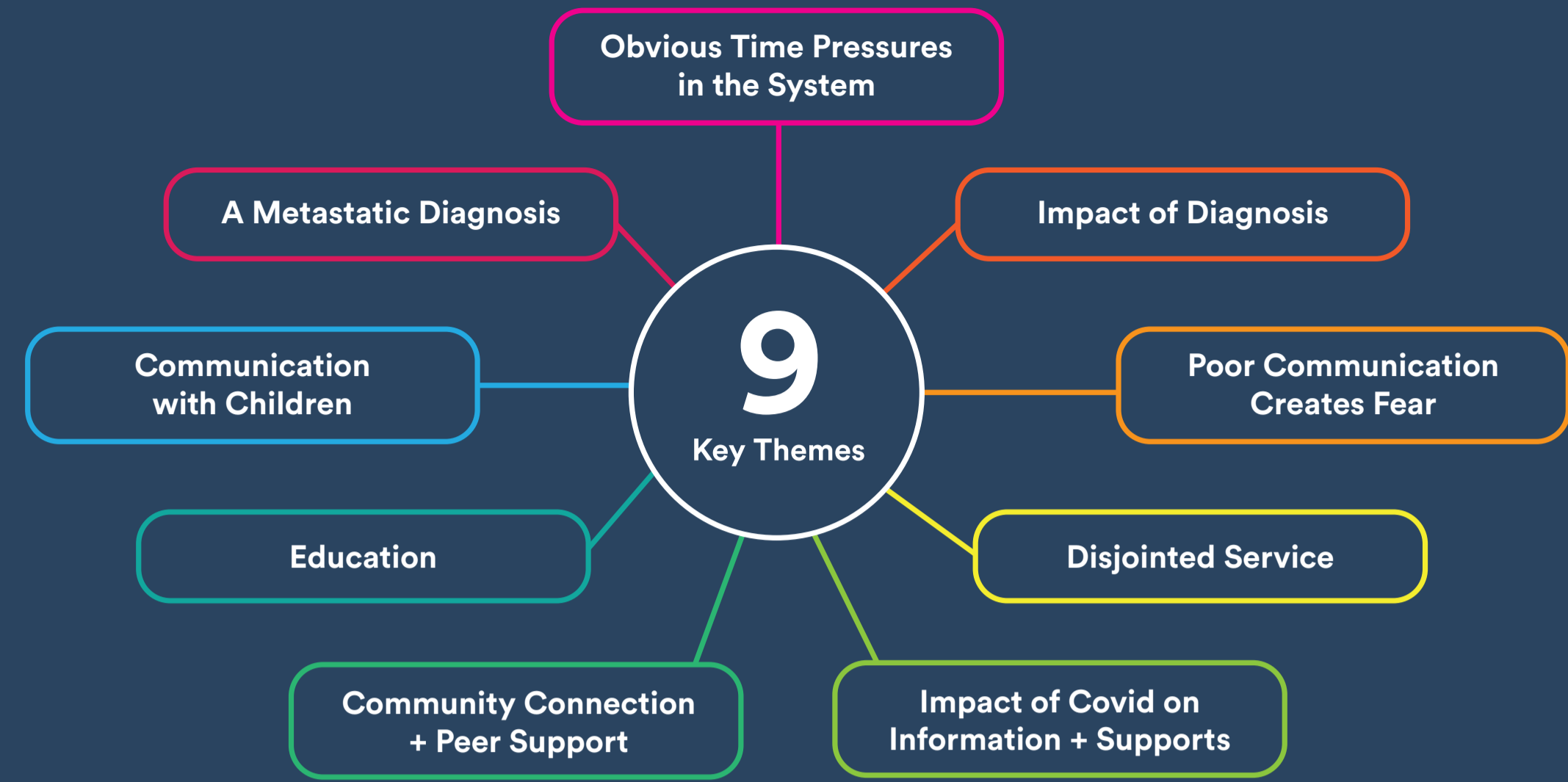
Figure 1: Nine Key Themes identified in Thematic Analysis



Figure 1: Nine Key Themes identified in Thematic Analysis — 9 Key Themes: Obvious Time Pressures in the System; A Metastatic Diagnosis; Impact of Diagnosis; Communication with Children; Poor Communication Creates Fear; Education; Disjointed Service; Community Connection + Peer Support; Impact of Covid on Information + Supports

## Figure 2: Competitive Analysis Categories

| Direct Competitive Analysis: All Cancer Types | Indirect Competitive Analysis: Breast Cancer Specific |
|---|---|
| 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)<br>- Marie Keating Foundation (MKF)<br>- American Cancer Society (ACS)<br>- MacMillan UK (MM) | - BreastCancer.org (BC.org)(USA)<br>- Canadian Breast Cancer Network (CBCN)<br>- Breast Cancer Network Australia (BCNA)<br>- Breast Cancer Foundation NZ (BCNZ) |
| Why the websites were chosen for analysis; | |
| These websites were direct sources of online information mentioned by BCP.<br><br>They are general cancer information websites and supply a broad range of information. | 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]. |

## Figure 3: Website Rankings based on Content Quality



Figure 3: Website Rankings based on Content Quality — 1. ACS, 2. BCNZ, 3. BC.org, 4. BCNA, 5. MM, 6. CBCN, 6. ICS, 7. MKF. ■ Direct: All Cancer Types ■ Indirect: Breast Cancer Specific
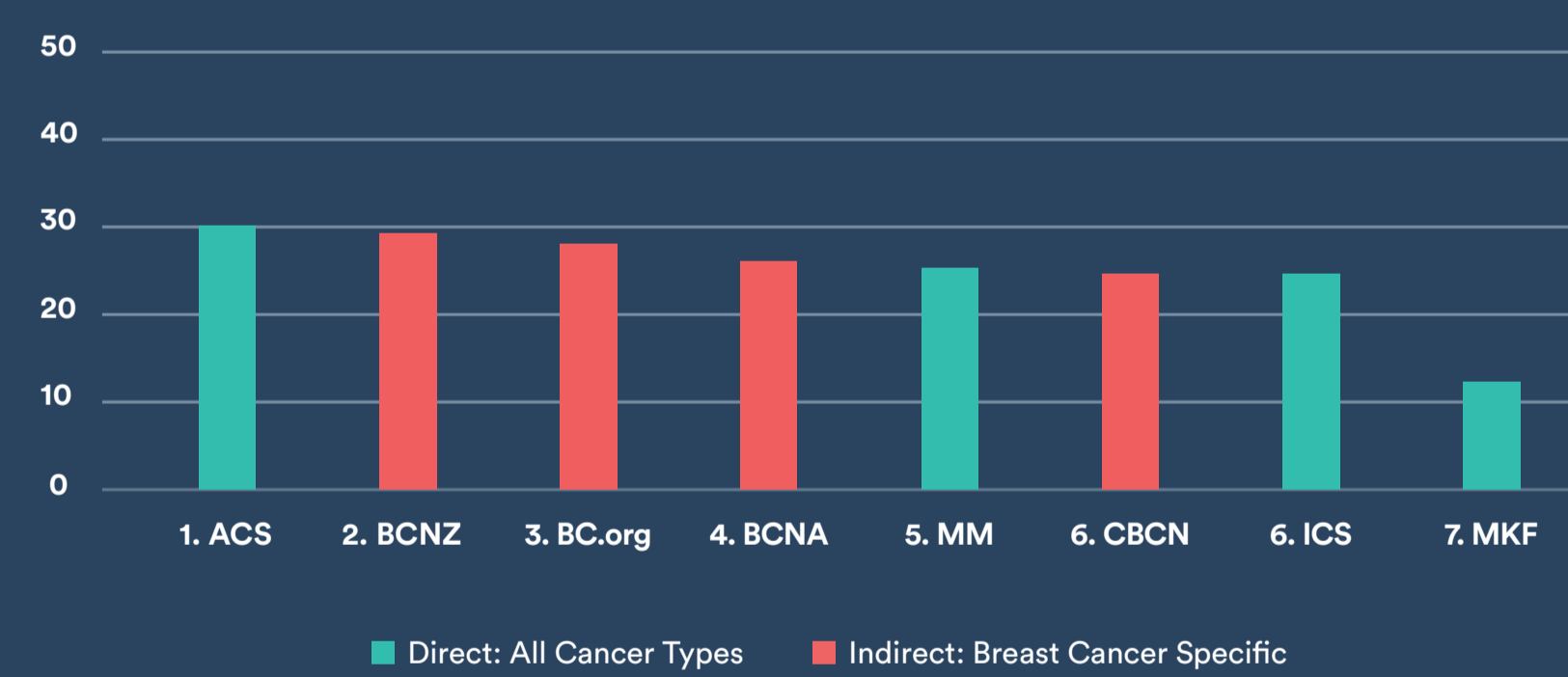
## Figure 4: A Comparison of the Information Quality for Individual Tasks



Figure 4: A Comparison of the Information Quality for Individual Tasks — Tasks 1–8, subtasks a/b/c. ■ Direct: All Cancer Types ■ Indirect: Breast Cancer Specific
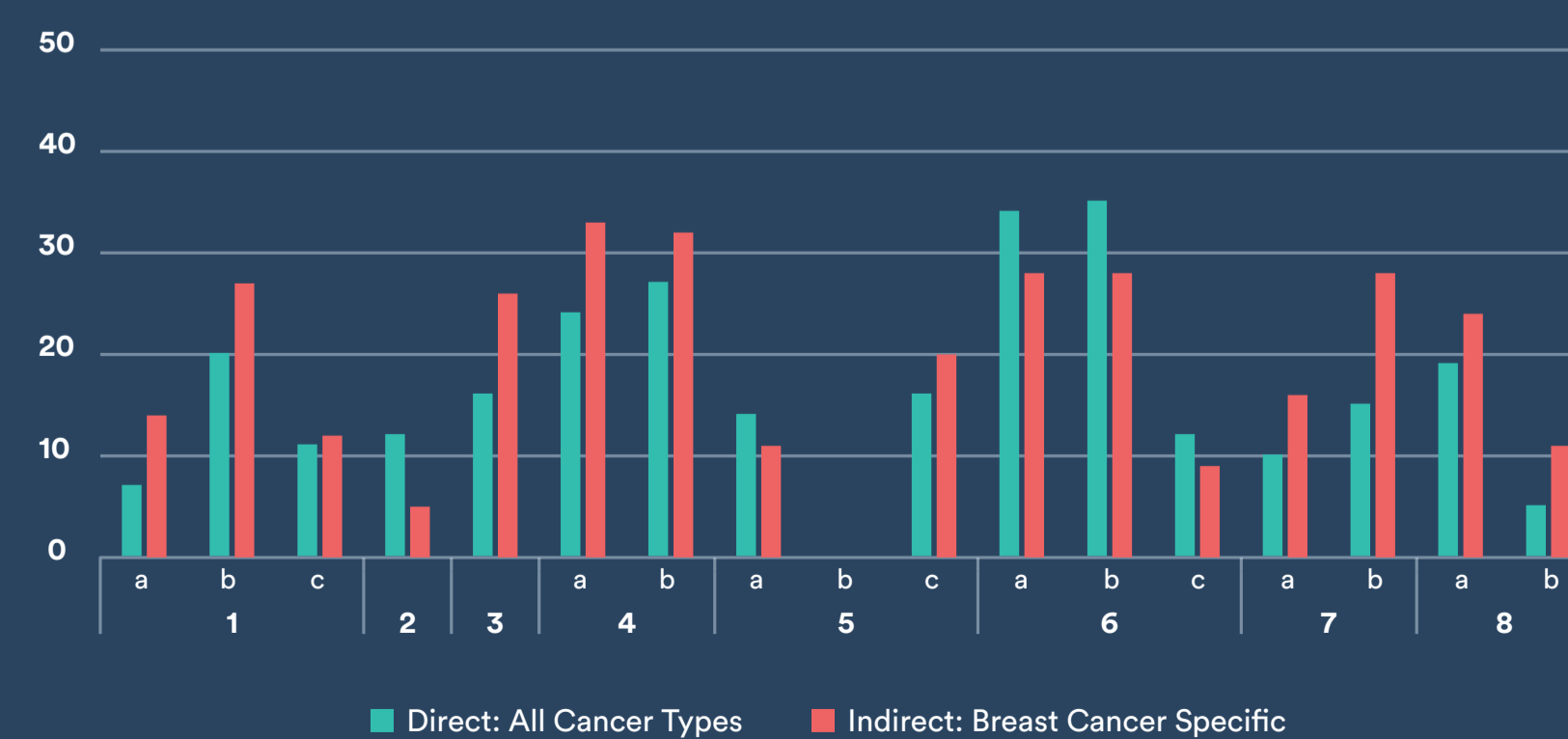
## Figure 5: Tasks based on TA + Information Found on Analysed Websites

| Task | Sub Task | Information Search | Direct Comp Analysis: All Cancer Types ICS | MKF | ACS | MM | Indirect Comp Analysis: Breast Cancer Specific BCNZ | BC.org | BCNA | CBCN |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | a | Explanation of G1 T1b NO | ✓ | X | ✓ | ✓ | ✓ | X | ✓ | ✓ |
| 1 | b | Explanation of Invasive Lobular Carcinoma | | | | | | | | ✓ |
| 1 | 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 | Advice on how to talk to children about your diagnosis | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 4 | b | Supports that could help you | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 5 | a | An example of a BC patient treatment plan | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | X | X |
| 5 | b | A treatment options comparison sheet | X | X | X | X | X | X | X | X |
| 5 | c | Questions to ask your doctor/nurse | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | X | ✓ |
| 6 | a | Supports - A detailed list of nationwide supports | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 6 | b | Peers - An online community with a members section | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 6 | c | Programs - Courses that could help | ✓ | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 7 | a | BC Drug List | ✓ | X | ✓ | ✓ | ✓ | ✓ | X | ✓ |
| 7 | b | BC Drug Side Effects | ✓ | X | ✓ | ✓ | ✓ | ✓ | X | ✓ |
| 8 | a | Tips on how to access information | ✓ | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 8 | b | Cancer myth busters | ✓ | X | ✓ | ✓ | ✓ | ✓ | ✓ | X |

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