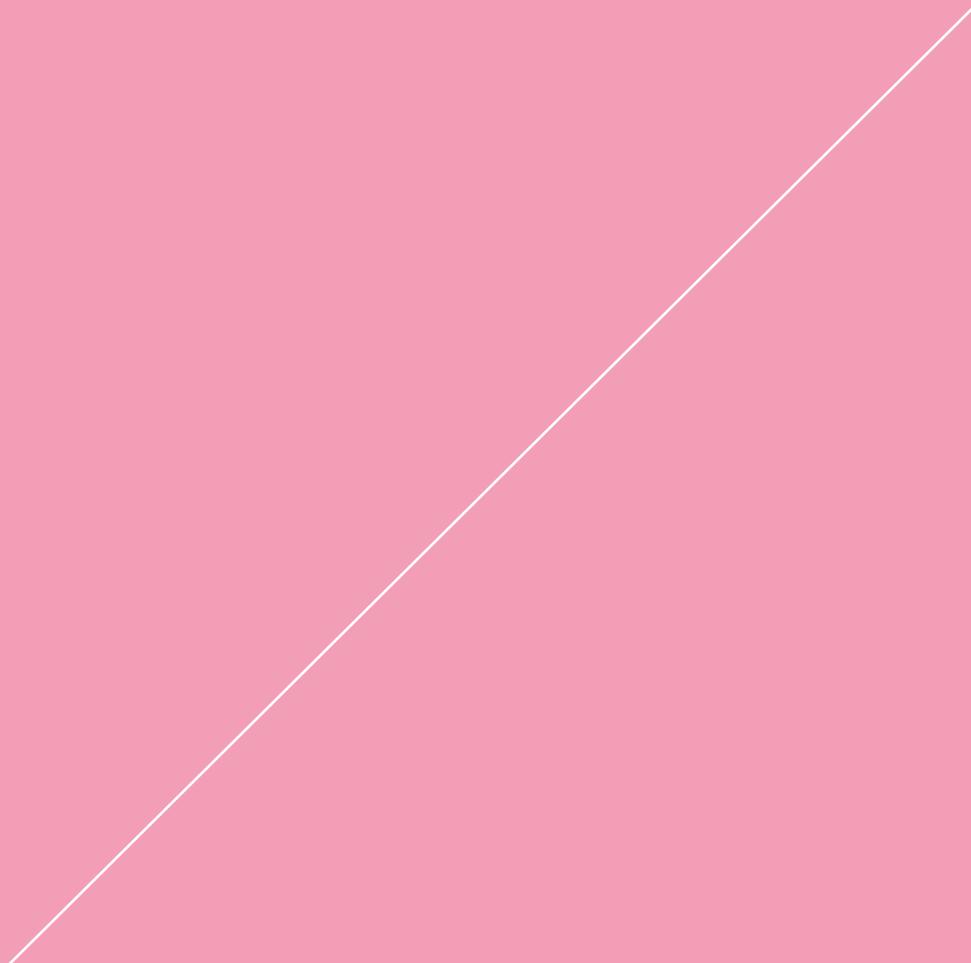


CHARETTE REPORT

September 2021



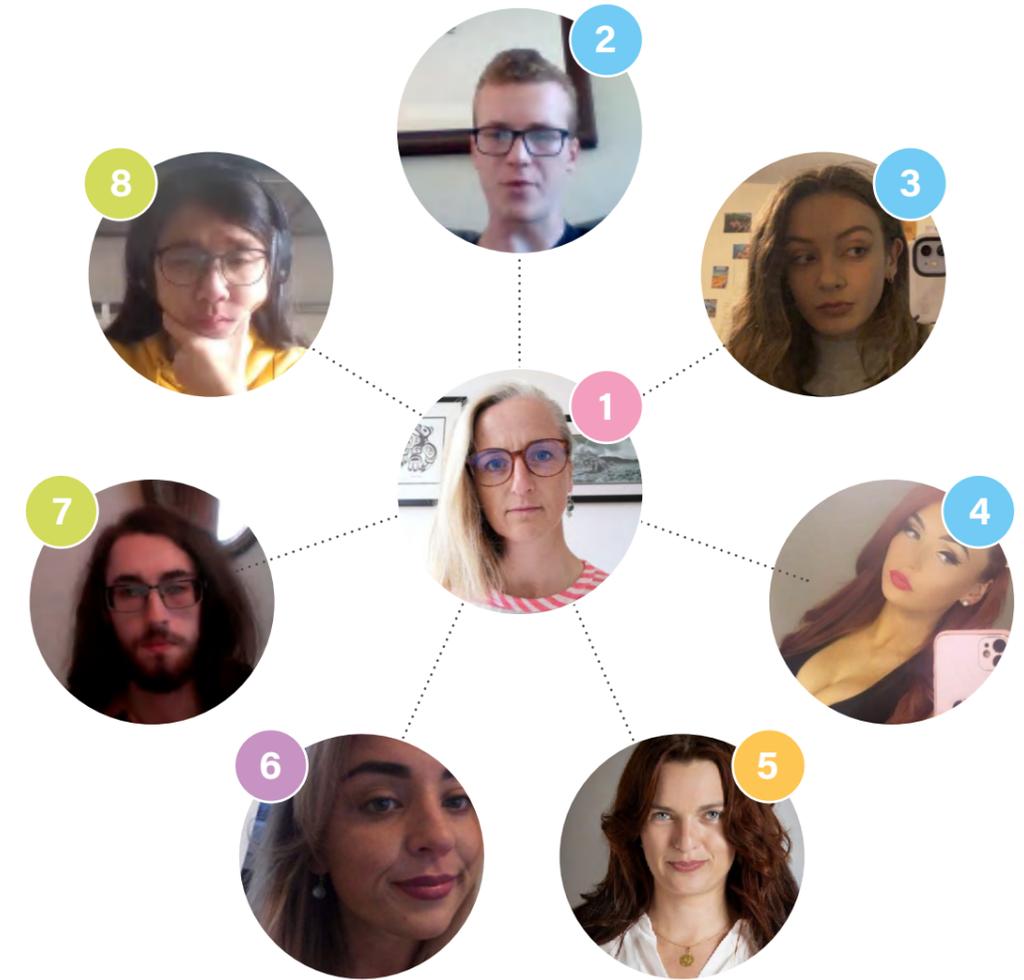
Kay McKeon

MA Design for Change, IADT

THE CONTENTS

THE TEAM	3
DAY 1 / INVESTIGATE	6
The Investigation	7
Task 1: Your Diagnosis	7
DAY 2 / OBSERVATIONS, GAPS, RANKINGS + QUESTIONS	8
Task 2: Observations + Gaps	9
Task 3: Competitive Benchmarking	9
Task 4: Information Sources	12
Task 5: 100 Questions	14
DAY 3 / PATHWAYS IDEATION + MAPPING	15
Task 6: Pathway Ideation	16
Task 7: 5W's + H	18
Task 8: Stakeholder Map	19
Task 9: Empathy Map	20
Task 10: Communication Timeline	23
INSIGHTS + CONCLUSION	24
GOING FORWARD	26

THE TEAM



Facilitator

1. Kay McKeon

New Media Studies

- 1. Oisín Keegan
- 2. Gemma Coleman
- 3. Holly O'Sullivan

MA Design for Change

4. Katarzyna Hasnik

Arts Management

5. Kate Grumley

Animation

- 6. Wolf Chung
- 7. Simon Love

DAY 1 / INVESTIGATE

The Investigation

Study Title

An investigation into the information deficits experienced by Irish Breast Cancer patients.

Research Focus

My research focuses on four sub-types of Breast Cancer - Triple Negative, Invasive Lobular Carcinoma, BRCA and Metastatic Stage Breast Cancer.

An Investigative charette

Focusing on the information that can be found online

- How does a patient find information on their disease?
- What gaps can we find?
- What other sources of information are there?
- How can media types, media categories and communication channels be used to connect with patients?

Task 1: Your Diagnosis

You have been diagnosed with a specific type of Breast Cancer.

- Triple Negative
- Metastatic
- Invasive Lobular Carcinoma
- BRCA

Go search websites to see what information you can find about your diagnosis, prognosis, treatment etc.

Tools Used

I wanted the students to have something to work with so I provided each of them with a spreadsheet of questions a patient might ask. I deliberately did not tell the students what websites to look at. I wanted to see where they would end up.

Like a newly diagnosed patient they would have to navigate the range of information available online to understand their diagnosis.

DAY 2 / OBSERVATIONS, GAPS, RANKINGS + QUESTIONS

Task 2 : Observations + Gaps

Based on what you researched yesterday write down what reflections and observations you have. How did you feel about the information you found? Did you find answers to your questions? Was the information helpful? What gaps did you notice? What other observations did you make?

“A lot of sites don’t have pictures or diagrams, that combined with lack of specific information, it’s like they expect you to know it yourself. You have just been diagnosed and been told about it and you’re automatically expected to know what to do and what you are going to go through?”

The overall observation was that the websites did not provide the students with the information they were looking for. Given that they had specific diagnosis to work with they found that most of the sites gave vague overviews. The level of content varied greatly, it was either surface information or dense and hard to digest. This was combined with poor navigation. They realised while *“navigating all the information”* it was *“hard to find information on what treatment involves, costs or the process”* and *“some sites are impossible to navigate.”*

A number noted that there was not enough guidance on emotional support, that it was hard to find personal stories to relate to and most sites didn’t cater to age.

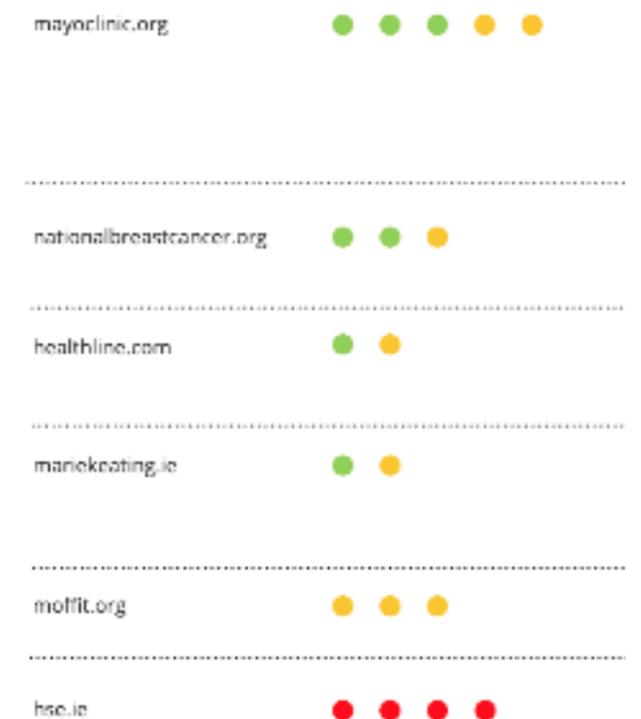
Key observations made by the students

- Lack of specific information
- Lack of images and diagrams
- Lack of after-care information

- Hard to find information on what treatment involves, costs or the process
- General timelines would be nice so that patients can go in with some basic expectations
- It’s top surface information or dense and hard to digest
- Not enough guidance on emotional support
- Most sites didn’t have much on how your experience might differ with age
- Most information could be more easily found on international sites.

Task 3: Competitive Benchmarking

Using a traffic light system, rank the sites you used for your research - Good (Green), Yellow (Average) and Poor (Red). Think about the observations and gaps you noted. Take screengrabs of what you liked and disliked.



Traffic Light Rankings

1. Mayo Clinic

- Pretty comprehensive. Had diagrams. The information was a lot easier to take in. Some places were still a bit dense, big chunks of text, a lot to take in.
- A good overview but I feel like it doesn't go into specifics as much as other websites.
- Good explanations not much detail when contrasted against other websites
- Most of the information was targeted at people who think they might have cancer, and don't know if they should go in to the doctor. Not much for diagnosed patients. Lacked much detail.

2. nationalbreastcancer.org

- Fairly nice website design. Generally same information that you would expect elsewhere. Broken down in a way that you can navigate. The information was organised so you could skip over what you don't need.
- Good diagrams links

3. healthline.org

- Big titles with the name of the cancer, then it would go into treatment, prognosis, diagnosis - easy to read.
- Easier to follow and well laid out compared to other websites about Breast Cancer and it is worded in a way that is not hard to follow. Goes in depth without being too wordy.
- The search tool wasn't very good 'Breast Cancer in children' came up as a popular search?

4. Marie Keating

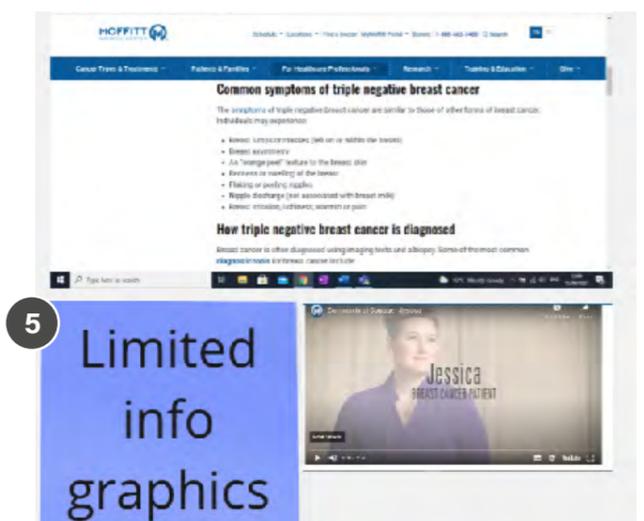
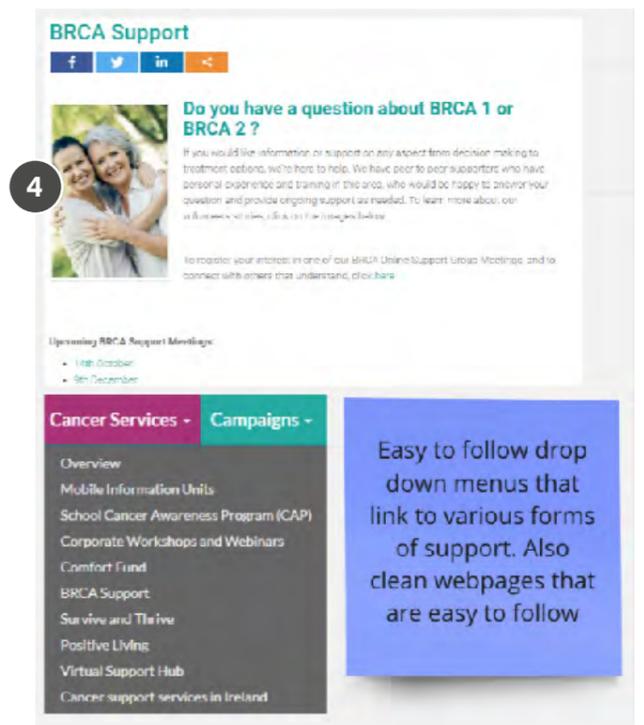
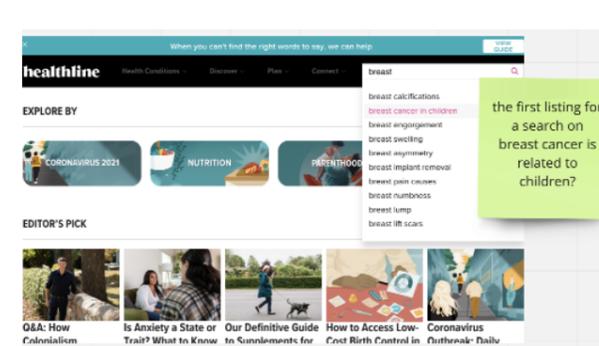
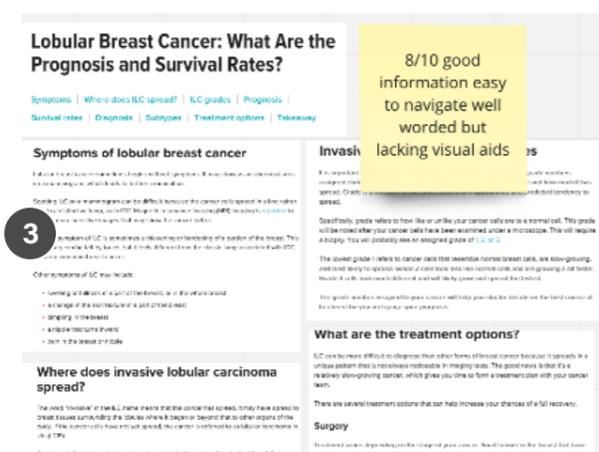
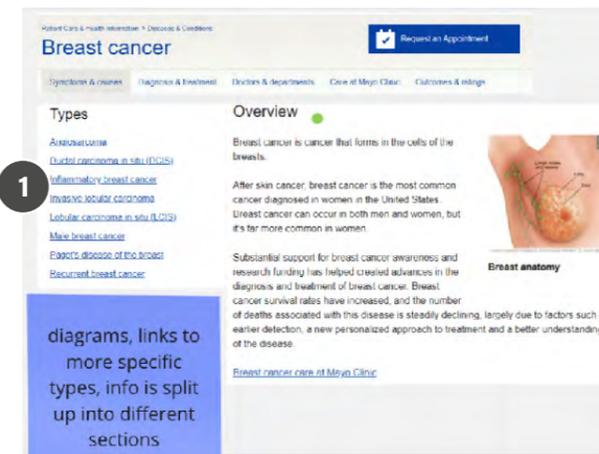
- Looked more useful for if you haven't been diagnosed yet or have just been and want to know more. Seemed to be aimed more towards support

5. moffit.org

- Well structured text, although not enough diagrams or visual representations

6. HSE

- It's a big wall of text, it's not very specific on things, it's based off the NHS one which I just looked at and it's all split up into different sections for symptoms and treatments. The HSE has all of them on one page, with less info and no links to other places for support. The NHS site has links to cancer charities. The HSE site is pretty unclear on what the treatments are and there are no diagrams. It's just very messy.
- Big wall of text with little specificity, harder to navigate, unclear on treatment roadmap, no diagrams. Very disappointing for a government health service
- They took out an ad so it was at the top of the page. It was mostly to tell people if they need to go to the doctor. It serves its purpose, but lacked information for diagnosed patients.
- The language is very vague, uses terms like 'might be' a lot, maybe this is because not everyone will be diagnosed with BRCA, but it still looks very vague.



DAY 3 / PATHWAYS IDEATION + MAPPING



Task 5: 100 Questions

Based on what you researched and observed what questions do you have? Fill out as many post-it notes as you can.

- 1) Compile 100 Questions.
- 2) Sort the questions into 5W's + H.
- 3) What questions mattered most to them? Through two rounds of voting they agreed on the most important question in each category.

This task produced a vast array of questions which I feel need further investigation. I would really like to use in them another workshop with participants who have experience and knowledge of the topic and could provide answers. Using a tool like an open card sort to organise the questions in a thematic way may provide more valuable insight.

How we learn + communicate

I gave a presentation on the different ways we learn – Visual, Auditory and Kinaesthetic – I wanted these to be forefront of the students minds as they worked through the tasks during the day.

Task 6: Pathway Ideation

I split the team into three groups of two and asked each team to research and list the common media types, categories and communication channels.

Group 1: Media Types

There are a number of different types of media, which are diverse and varied e.g.

- Art, Gaming or Radio

Group 2: Media Categories

Types of media can be classified into groups e.g.

- Broadcast media - newspapers
- Internet media - blogs
- Immersive experience - VR

Group 3: Communication Channels

A communication channel is a means of communication that is available to an organisation or individual e.g.

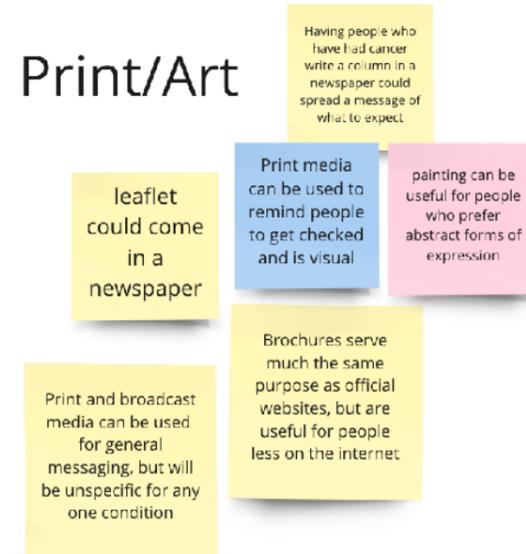
- Meetings - Video Conferencing
- Conversations - Telephone
- Events - public speaking

After completing the lists the teams used their findings to ideate ways to use media and communication channels to connect with patients, their ideas were then clustered and given titles. Pathways began to emerge with some ideas around cross channel connections. The clusters were very much in line with their list of sources from Task 4 with some expansion into Art and Events. Task 4 and 6 are both initial insights into how we use communication channels and are good points of referral for idea generation sessions during communication campaigns.

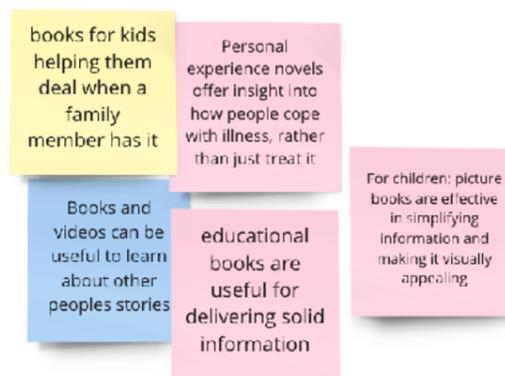
Human Interaction



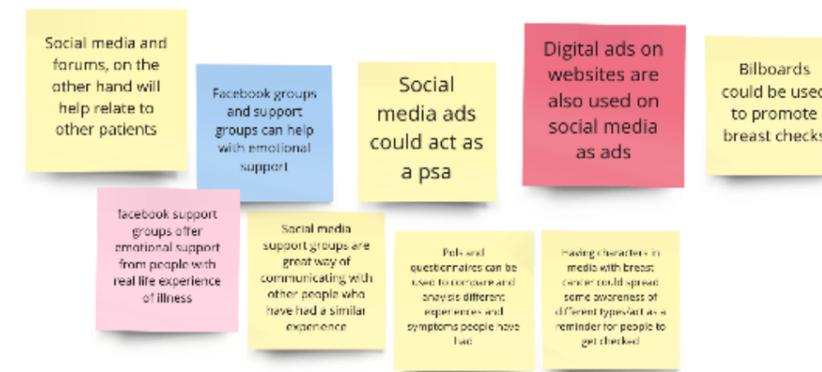
Print/Art



Books



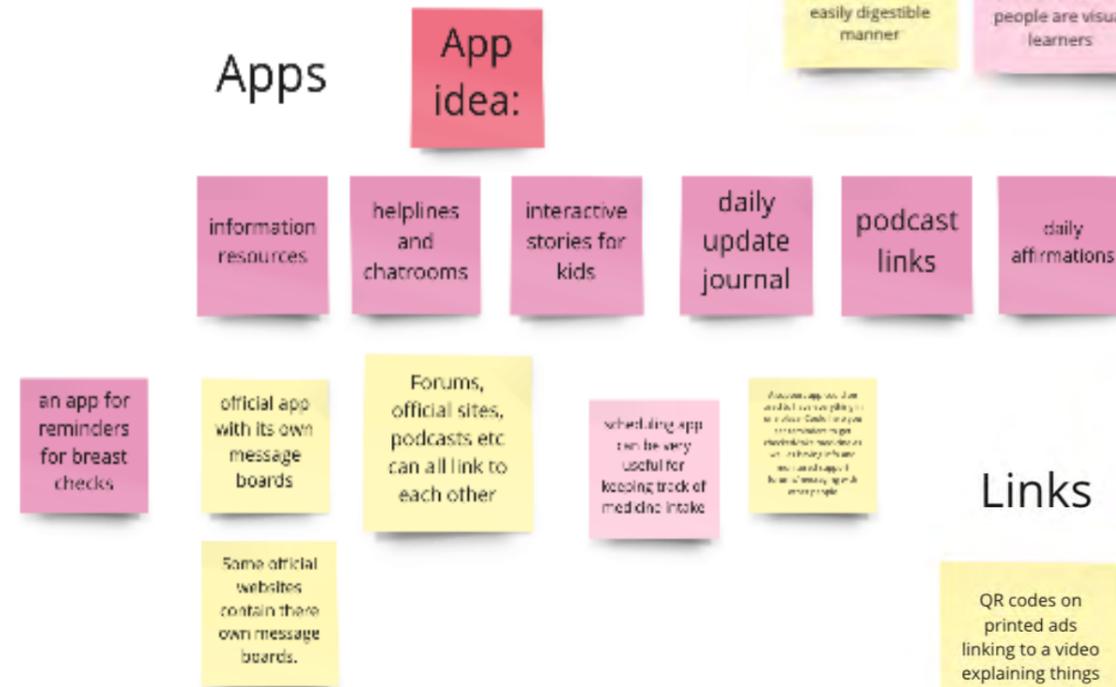
Social Media



Public Events



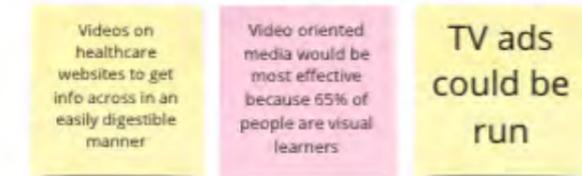
Apps



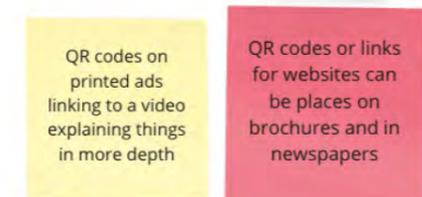
Audio/podcasts



Informative videos



Links



Task 7: 5W+H Questions

(A) Returning to the 5W+H Questions, based on your research and what you have learned so far see if you could answer the questions you picked yesterday.

In some cases the answers were vague (which reflects the level of information the group were able to access during their research) while other answers are more helpful and indicate the direction a person should take to find out more.

WHO

- Is breast cancer hereditary? which cancers are hereditary?
- yes, BRCA genes effect likelihood of breast cancer
- cervical and lung cancer are less likely to be hereditary
- The answer to this is kind of complicated, go ask your doctor

WHY

- Why isn't there more visual information rather than text?
- It is the difficult to explain something complex through images
- Scientific illustrations are expensive and the HSE doesn't get enough funding
- Some people aren't visual learners and learn more through text based information
- Majority of people remember more visual images, so visual images should also be widely available

WHAT

- What should you expect life to be like after being cured?
- Support groups and other survivors can help
- There is not clear message life will be after being cured each experience is individual
- it is not uncommon for cancer to redevelop
- When you are cured you should expect to have a normal life, but you should also expect to have some complications, so you should also expect to have some complications

WHERE

- Where can I access info about how much money is required to undergo long term treatment?
- HSE.ie
- Doctor
- Other Patients
- your insurance company
- Cancer.ie
- At Support Groups

WHEN

- When would I get treatment, how long would I wait if I don't have private insurance?
- varies depending on stage and grade of the cancer
- 25 public hospitals offer cancer treatment, depending on the location, it could vary depending on where you go?
- ask your doctor this, I go to cancer school

HOW

- How would experiences differ based on age/race etc?
- African American and Hispanics are more likely to develop TNBC
- TNBC is most common in under 50s
- less likely to be caused by hereditary genes the older you are

(B) Looking at media, communication examples and the Other Sources Board you created yesterday. Can you think of other creative ways to communicate answers to these questions to someone?

WHO: Is breast cancer hereditary? Which cancers are hereditary?

- Group discussion session between a number of patients and an equal number of doctors
- An online forum allowing patients to have discourse directly with one another for emotional support
- Infographics that teach people about genetics/what to look out for
- An easily accessible forum where you can have your questions answered by trained professionals
- App Idea: interactive kids game which requires player to answer related questions in order to progress
- Perhaps a one day workshop which seeks to answer a wide range of concerns of people effected by Breast Cancer

WHY: Why isn't there more visual information rather than text?

- There should be more videos to get ideas across quickly and concisely
- Having text be more broken up and simpler to understand would also be useful for people who would rather read/have to use a screen reader
- Have different colours for each section so its easy to find the information if images cannot be used
- Have different pages on the website for each section so the information isn't overwhelming
- Ask people what images and videos they would like to see and add them to websites, leaflets, etc.

WHAT: What should you expect life to be like after being cured?

- Reach out to people you follow and ask them about their experience and compare life after being cured
- Videos from previous patients, doctors could give the link or by QR codes and on websites

- A roadmap guide could be created by people who have been treated
- Supply links to articles/podcasts etc. from people who have been treated
- Group discussion between patients and those who are 1 year on from their diagnosis, mediated by a doctor

WHERE: Where can I access info about how much money is required to undergo long term treatment?

- Have QR codes on leaflets, leading to a website designed for all the information about the costs
- Have doctors and health professionals lay out a

payment plan for people on public health insurance

WHEN: When would I get treatment, how long would I wait if I do not have private insurance?

- Have a general treatment roadmap explaining this on healthcare websites with visuals and words
- Videos from other patients about how long they waited

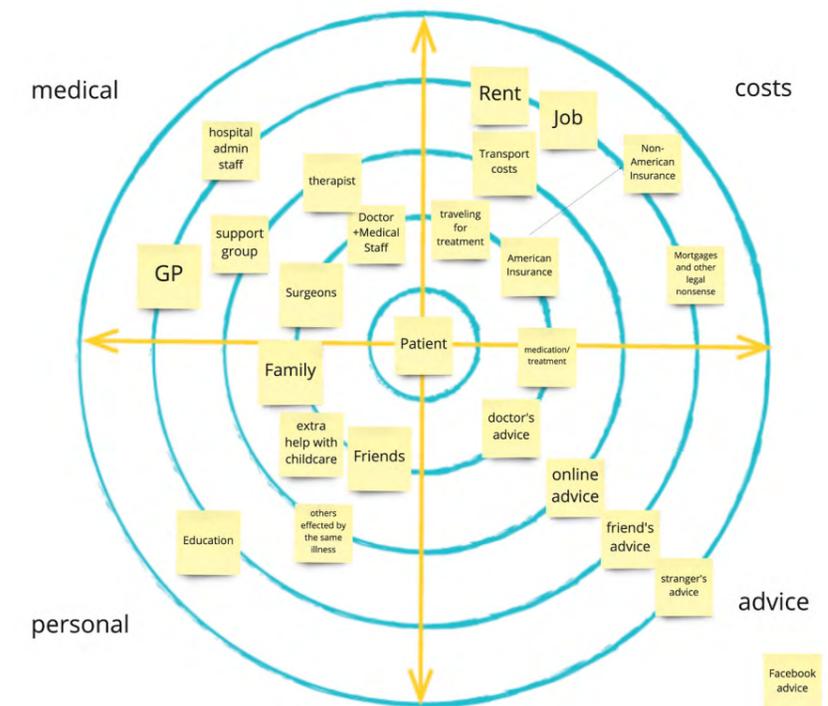
HOW: How would experiences differ based on age/race etc.?

- Let someone input this info about themselves on a website and bring them to a different page based on it
- Support forum could have different sections based on age/race etc.
- Put more focus on stories you hear less about in fictional media/a documentary

Task 8: Stakeholder Map

Based on the research and activities we have done catalogue the actors or stakeholders that are part of the ecosystem. Arrange them on a map according to prioritisation.

The stakeholder map produced was a general overview and some elements don't seem to be in the correct place, the students were unwilling to make changes, I feel they did not see the relevance in this exercise. In hindsight it would have been better to do this after working on the Empathy Map, the group could have been split in two both working on separate maps, a comparison would have been interesting.



Task 9: Empathy Map

Create an empathy map for a Breast Cancer Patient based on the research and what you have learned over the past few days.

I used the Empathy Map as an opportunity to see what level of understanding the students had for a patient. The students completed this task very quickly and I felt it was a much more successful exercise than the Stakeholder Map. It would be interesting to perform this task at the start of a workshop and then at the end, the comparison could show the development of participant knowledge.

Who
breast cancer patient

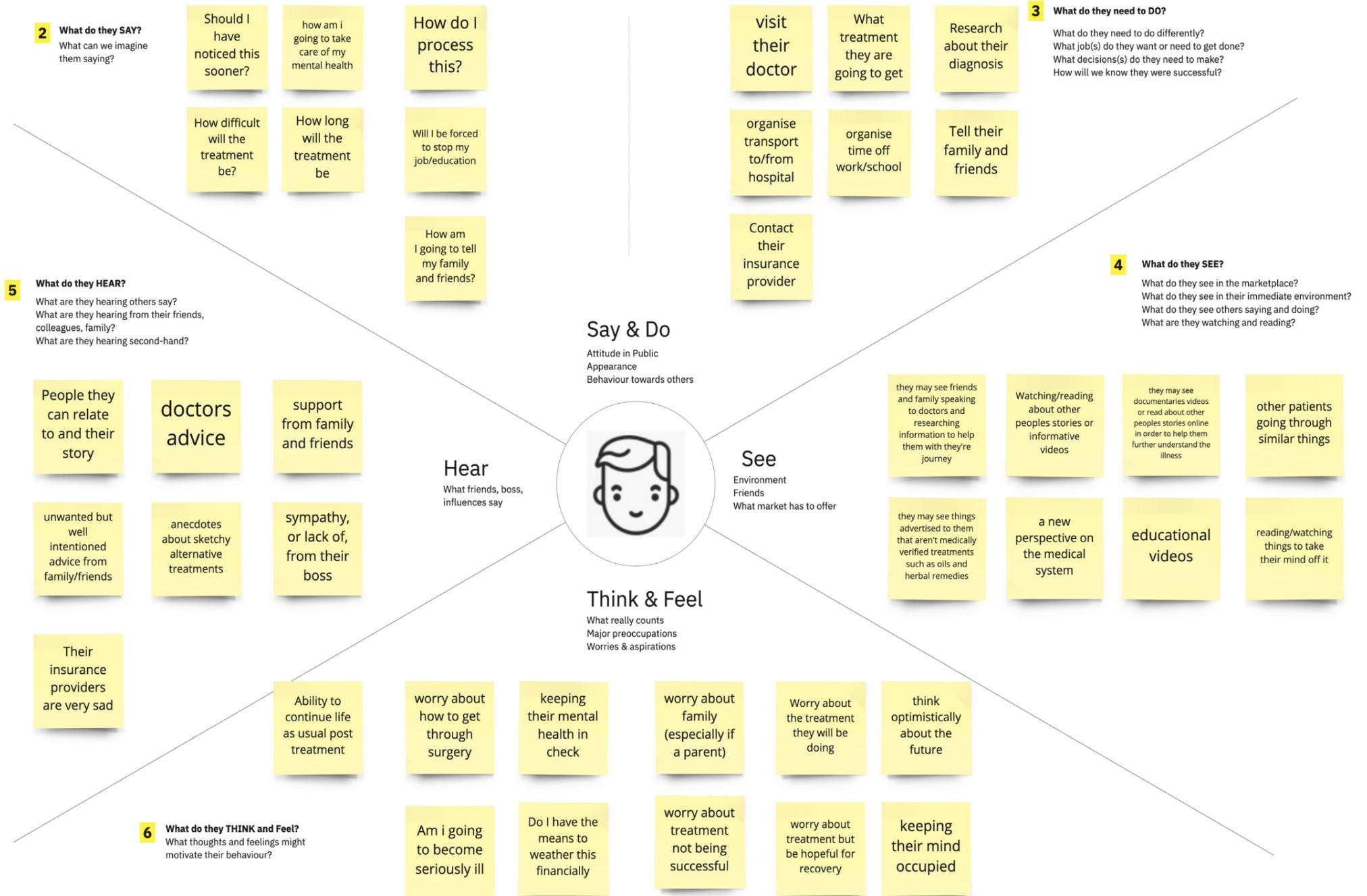
WHO are we empathising with?
Who is the person we want to understand?
What is the situation they are in?
What is their role in the situation?

Pains
What are their fears, frustrations and anxieties?

- fear of missing out on normal life
- fear of losing their hair
- Fear of the treatment and how weak you may become due to it

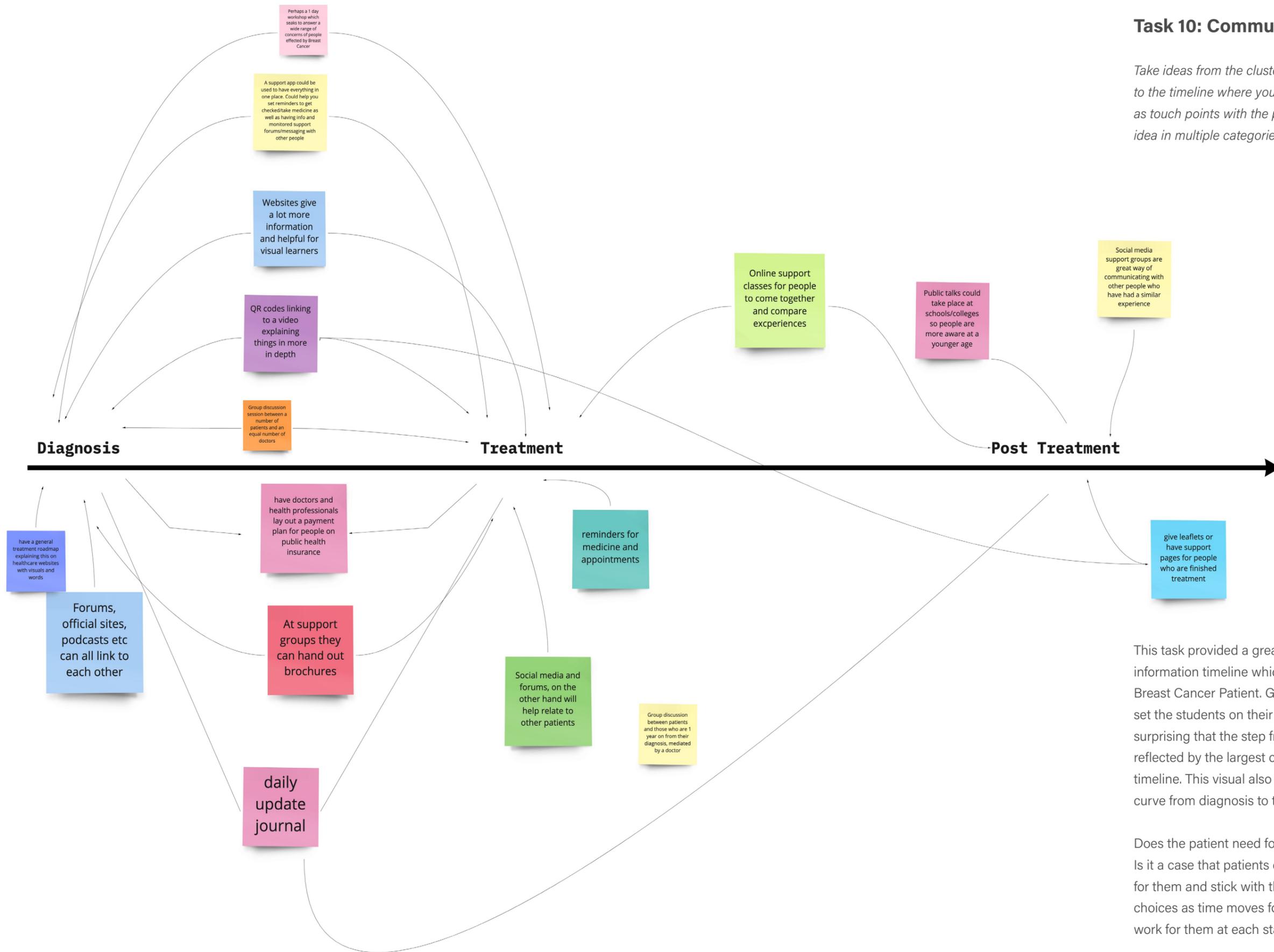
Gains
What are their fears, frustrations and anxieties?

- hope for recovery
- Gain a better understanding of their diagnosis
- Gain some new friends who have been in the same situation



Task 10: Communication Timeline

Take ideas from the cluster and the 5W+H and add them to the timeline where you think they would be best suited as touch points with the patient. You can have the same idea in multiple categories if you feel it is relevant



This task provided a great visualisation of the information timeline which would be experienced by a Breast Cancer Patient. Given that Task 1: Your Diagnosis set the students on their research journey it is not surprising that the step from diagnosis to treatment is reflected by the largest cluster of post-it notes on the timeline. This visual also reflects the steep learning curve from diagnosis to treatment.

Does the patient need for information lessen over time? Is it a case that patients choose the channels that work for them and stick with those? Do they change their choices as time moves forward? What works/does not work for them at each stage?

INSIGHTS + CONCLUSION

Insights from charette

- Searches on specific diagnosis showed that it was difficult to gather relevant content
- There needs to be a better understanding of what questions a breast cancer patient would have
- While using the internet the students searched on Google first and then navigated to sites they felt were relevant
- Searches produced either top level surface information or dense, hard to digest text
- General timelines would be nice so that patients have some basic expectations and understanding of the timings and process
- The right information at the right time brings ease. Timing is crucial.
- Visual aspects matters. There's a lack informative imagery to help people understand. Information delivery in form of videos, interviews, short animated films are better than long content, it is easier to absorb
- Community is important, it can provide support, guidance and information
- Online content is only trustworthy if its moderated
- Official sources need to be as clear and informative as possible
 - The HSE did appear on Google searches however the website had the lowest ranking in the competitive analysis. It was noted that it had a high ranking because of its Google Advert. The students noted that the content was "dense wall of text" which was poorly compiled and copied from another source.
- Content provided by Irish cancer support and resources is not being found by people when searching for answers on specific diagnosis, prognosis and treatments
 - Interestingly, Irish cancer organisations aimed at providing support and resources were not ranking on the students Google Searches. This shows that (a) these organisations are not reaching their potential users and (b) the information they are providing is limited.

Conclusion

The information gap becomes more apparent when a users search criteria is specific. It was hard for the students to find answers on their less common diagnosis – they struggled to find information on specifics e.g. prognosis, treatment and the process one would go through.

The **level of information for Irish Breast Cancer patients could be greatly improved.** One of the students stated "*Most information could be more easily found on international sites*".

Gathering information happens in a variety of ways, using online and offline methods. This charette highlighted the need for **a better understanding of how patients look for content.** The work the students produced in Task 4 gave insights into the numbers of ways one person could gather information on a topic. In Task 6 they examined how media channel combinations could reach an audience and in Task 7 explored possible solutions using communication channels.

This charette also highlighted the need for **a better understanding of what patients are looking for.** The students noted that there was an abundance of general overviews while more specific information was located in dense technical content, mostly scientific papers that the public could not understand.

GOING FORWARD

Where to next?

This charette and report have provided me with the opportunity to have a clear idea of how to gather insights and evidence to complete my deliverables:

Literature

I walked away from this charette really interested in investigating communication strategies. It is all well and good having a website, video channel or booklet with content but if users are not directed to that resource through some form of communication how will they know it exists? How do organisations cut through the noise and reach the people who need answers? I wish to look into communication strategies and collate information on successful health campaigns that utilised communication channels to maximum effect.

Workshop A - Communication Timeline

Participants: Patients + Carers

The aim of this workshop will be based how the students completed *Task 4: Your Sources* and *Task 10: Communication Timeline*, working with participants we will focus on creating a more detailed timeline of how and when they sourced information.

Workshop B - Mapping

Participants: Peer groups, support groups, allied health professionals and cancer researchers.

All the participants will have awareness, experience and connections within the Irish cancer arena. The aim will be to pool their collective knowledge to map out the current national services, support and resources that are available to Irish Breast Cancer patients.

Workshop C - Competitive Benchmarking

Participants: Developers, Web Designers, UX/UI

Using a traffic light system the participants will provide observations on Irish and international Breast Cancer websites. This initial benchmarking will aim to provide an overview of best practises by looking at information architecture and navigation, analysing pain points in user flow, and gathering insights on usability, literacy and accessibility practises

Online Anonymous Survey

This survey will be used to gather information from a large number of people to identify information gaps from diagnosis to post treatment.

Interviews

These will focus on gathering more in-depth insights into the information gaps experienced by patients.

