

[It may be helpful to look at problem definitions from previous years:

<https://www.healthhack.com.au/brisbane-problems-2019>

<https://www.healthhack.com.au/brisbane-problems2018>

<https://www.healthhack.com.au/brisbane2017problems>]

Problem owner name

Molly Lewis (Oscar)

Problem title

Oscar - Digital support system that explores empathetic ways that young adult sufferers can manage their experience of inflammatory bowel disease (Ulcerative Colitis and Crohn's disease).

What is the problem you want to solve?

More and more young people are being diagnosed with inflammatory bowel disease (IBD) and lack access to multi-disciplinary IBD care. Crohn's and Colitis Australia (CCA) have shared research findings from a national patient experience survey of IBD care. The 2018 research report demonstrates there is a high burden of Crohn's disease and ulcerative colitis in Australia. These patients are commonly young, unwell with chronic disease and have struggled with the condition for more than a decade. The reality is that this disease affects all aspects of a person's life, relationships, mental health, social interactions and employability. Currently the public healthcare system isn't meeting the social and emotional needs of these 18-25 year olds. Isolation from their peers, work and social environments when living with a chronic condition results in co-morbid health issues (Staricoff, 2004). IBD support groups acknowledge this, struggling to meet the needs of these young adults in their offered support groups.

We want to provide a digital support system for this group of people, so that they can find ways to communicate better with young people in similar positions, offering the potential tools to transform negative emotions that IBD brings.

Why do you want to solve this problem?

Australia has one of the highest rates of prevalence and incidence in the world and each year more and more young adults are diagnosed. Over 85000 Australians have Crohn's disease or Ulcerative Colitis and more than 5 million world wide have the disease. Crohn's disease is incurable and associated with a 47% increase in the mortality risk. Not much is known about IBD in the general public and sufferers are burdened with a hidden struggle that affects personal, social and work aspects of their life. This project centers around my own experience similar to the deeply unattractive topic of Inflammatory Bowel Disease and motivates me to shed light on this growing issue, demystify the stigma of discussing bowel habits and find ways young adults better manage their experience of IBD.

What do you envision as the ideal solution for this problem?

The ideal solution for this problem explores empathetic ways that young adult sufferers can manage their experience of IBD. Oscar communicates to young people, by offering the mindfulness tools to transform negative emotions that IBD brings. Being a device of choice to young people that acts to connect, support and demystify the experience of living with IBD. Oscar can help assist Crohn's and Colitis Australia to

drive improvements in quality of care and services for Australians living with IBD. From a back-end perspective we can collate data that better informs the Crohns and Colitis Australia board to better make decisions based on user needs to support patients. If we can look at the disease holistically we can identify all areas of improvement that are currently costing the healthcare systems financial burden. Oscar not only has the potential to save lives, but also the financial burden of a chronic illness. After the weekend, I hope that the MVP of our solution will be appropriately structured for us to do user-testing, understand potential of ML and tailored educational/motivational mindfulness messages depending on user engagement.

What sort of Open Source solution do you think can be created in 48 hours, by a small team of developers, designers and data analysts?

Build a model that supports young adults to connect and take part in their own daily mood quiz. Enable the model to generate recommendations for mindfulness activities for users. Test this model by adding a chat system or quiz into our current website for a live proof of concept. Present some interesting reportable insights and validation from users.

Are there datasets or people with domain knowledge that you will be bringing to work with? What/who are they?

It is estimated that the total cost of caring for Australians with IBD is estimated around \$3.1 billion each year, and that cost is expected to rise as the impact of the disease becomes more understood. I have conducted survey as well from a sample group of 12 participants for usability testing between ages of 18-25, I got useful responses that fed into the designs.

- 54% said the most common associated with IBD is frustration and 33% with anxiety
- 82% agreed that the mental side of IBD is just as important as looking at the physical symptoms
- 71% of people said personalised application that offers mindful activities to deal with common feelings associated with IBD would be most beneficial to use on a daily basis.

Could leverage painpal app please view here - <https://github.com/HealthHackAu2015/iCanPain>

What are the current solutions for handling this problem?

Currently I have created Oscar social media platforms such as Facebook chat to talk to people - very basic chat right now. I would love the ability to build deeper connections and offer recommendations to users, as well as connect them to other people that are in the exact same boat. People with this issue currently attend physical support groups, Facebook groups, discuss with IBD nurses and GPS's.

In terms of what else is out there for users, medication is their only alternative to managing their disease otherwise they are led to the critical decision of removing their colon. In terms of a holistic healthcare approach that focuses on their mental needs as well their physical, is slim to none. I have researched existing IBD apps and found that these apps only really dealt with the physical symptoms. From a user experience point of view, they aren't inviting to young people due to clinical style. Patients need long term management of their chronic illness, rather than a reactive model of treating acute flares. So that patients are equipped with the correct treatment and there is a long term understanding of their broader needs.

Summary for website (up to ~ 1 page)

PROBLEM

More and more young people are being diagnosed with inflammatory bowel disease (IBD) and lack access to multi-disciplinary IBD care. Crohn's and Colitis Australia (CCA) have shared research findings from a national patient experience survey of IBD care. The 2018 research report demonstrates there is a high burden of Crohn's disease and ulcerative colitis in Australia. Australia has one of the highest rates of prevalence and incidence in the world and each year more and more young adults are diagnosed. Over 85000 Australians have Crohn's disease or Ulcerative Colitis and more than 5 million world wide have the disease. Crohn's disease is incurable and associated with a 47% increase in the mortality risk.

Not much is known about IBD in the general public and sufferers are burdened with a hidden struggle that affects all aspects of their life. These patients are commonly young, unwell with chronic disease and have struggled with the condition for more than a decade. The reality is that this disease affects relationships, mental health, social interactions and employability.

SOLUTION

Oscar the mind-gut guru is a digitally based support system that looks at disease holistically exploring ways that young adult sufferers can manage their experience of IBD. Oscar communicates to young people, by offering mindfulness tools to transform negative emotions that IBD brings. Oscar (a web based application) will enable young people to connect, support and demystify the experience of living with IBD. With the help of Health Hack 2020, Oscar -can help assist CCA to drive improvements in quality of care and services for Australians living with IBD. If we can look at the disease holistically we can identify all areas of improvement that are currently costing the healthcare systems financial burden. It is estimated that the total cost of caring for Australians with IBD is estimated around \$3.1 billion each year, and that cost is expected to rise as the impact of the disease becomes more understood. Oscar not only has the potential to save lives, but also the financial burden of a chronic illness.

CURRENT SOLUTION (if there is one)

Although a current website (www.mind-gutguru.com) and social media accounts exists, this site doesn't allow users to connect with other sufferers of IBD, in particular, young people are missing out on this information. We want to create an app that is accessible to young people that incorporates the mindfulness exercises we know help with IBD. As well as a chat feature, that allows users to connect with others and don't have to suffer in isolation. This will be a hub where people use on a daily basis and find out more about Oscar, the mind-gut connection.