

Iteration, Iteration, Iteration

How Restructuring Data can Reveal Complex Relationships Between Chronic Illnesses and the Apps Intended to Support Them

This study intended to gain a broad understanding of how commercial apps may support people with chronic disease management, through the restructuring of data for analysis. The study formed an initial part of a larger PhD project looking into symptom tracking for people with chronic illnesses.

The study included apps designed for people with Rheumatoid Arthritis, Crohn's and Inflammatory Bowel Disease (IBD), Myalgic Encephalomyelitis (ME), and Anxiety conditions (aggregated and including Bi-Polar Disorder, Generalised Anxiety Disorder and Panic Disorder) to give an overview of how apps might engage with different types of chronic illness, all of which feature fatigue as a main symptom.

In this paper, we report on the process of creating and using an iterative process to rearrange the data collected in order to reveal more complex relationships between the chronic illnesses and the apps intended to support them.

1. Data Collection

The relevant NHS pages for each condition formed the foundation for data collection: ME (NHS. n.d.a), Rheumatoid Arthritis (NHS. n.d.b), Crohn's and IBD (NHS. n.d.c), and Anxiety (NHS. n.d.d). Further data was gathered using charitable websites dedicated to each disease: the *ME Association* (n.d.a) for ME, *NRAS* (n.da; n.d.b) and *Versus Arthritis* (n.da.) for Rheumatoid Arthritis, Crohn's and Colitis (2019) for Crohn's and *Anxiety UK* (n.d.a) for Anxiety. Combined, the websites provided a working list of symptoms, emotional impacts, lifestyle changes - both advised and inevitable - and treatments, including complimentary treatments as well as evidence-based interventions. Common comorbidities listed on these sites were also included.

An organic search was used to discover apps designed to support patients with each disease. This search replicated the method an ordinary patient might use and therefore took in pages recommending apps including Healthline (2019) and the NHS Library (NHS. n.d.e). While this is not an exhaustive list of relevant apps, the total of 38 apps selected covered a range of approaches, from games to help non-sufferers understand a condition and its implications better, to pain mapping and diary apps.

Method of Analysis

An iterative process was used to rearrange the data in order to produce different modes of analysis.

First Iteration - Linear Mapping

In the first iteration, Image 1, the information regarding each illness was clustered together. The different elements - symptoms, treatments, complementary treatments, lifestyle changes (inevitable), lifestyle changes (recommended), emotional responses - were each written on separate pieces of paper and were colour coded to make each element easier to identify. These clusters are arranged vertically on the left side (Column One) as shown in Image 2.

In this iteration, all the data is arranged in a single place and reads naturally from left to right. The data for each app was written on individual sheets of paper, lining up horizontally with the relevant illness. Post-it notes were added to the apps to add further details along with colour-coded stickers (green dots for a diary or tracking feature; blue dots for NHS approval or testing; yellow dots for social network element; red dots for pain mapping; whale stickers for a 4 star rating or higher¹). The apps are grouped roughly so that those with similar features appear close together. The apps that include tracking as a feature are on the left, with alternative and companion apps, which may not be designed to help manage the condition, on the right. For example, the toilet finder apps are furthest to the right as they don't deal with any symptoms but do offer a practical service. Broadly, the more features, the further to the left the app was arranged.



Image 1

¹ Please note that the type or colour of sticker is not offering any deeper metaphorical meaning. Especially the whales.

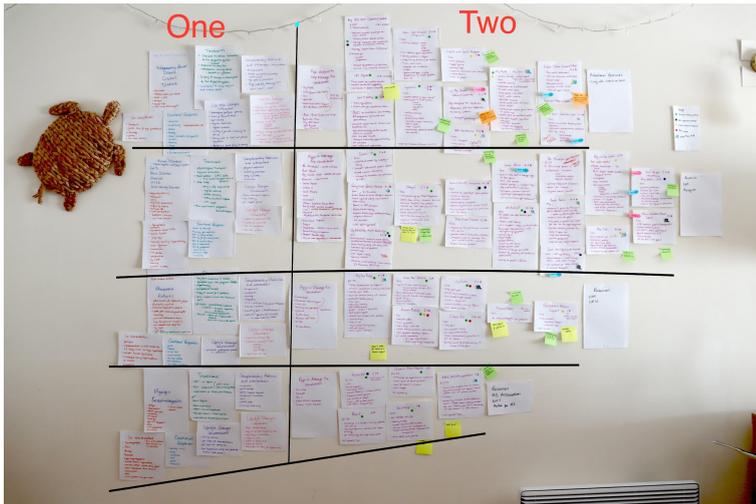


Image 2

Second Iteration - Stacked Discs

Chronic illnesses are not linear or static: symptoms may recede and relapse and there may be no particular logical progression. This means that while a patient may have a particular set of needs one day, they may have different requirements on another. To reflect this insight, the second iteration asked: *what would happen if the data was rearranged into a circular design that could be manipulated?*

A prototype for ME was made (Image 3), placing the disease elements onto a series of stacked discs that could be rotated. Rather than reading left to right, this model encouraged the researcher to move the layers in order to read them, naturally rearranging and reorganising as they did. This afforded a new kind of analysis that grouped different elements together to offer new perspectives. Rather than grouping apps to see how they compared to each other, now the various elements were being grouped to consider their relationships. This new grouping allowed further insight into how different elements of each disease might interact and how an app might be able to support that interaction.



Image 3

Third Iteration - Clocks

An immediate problem with the second model was the fixed arrangement of data on the discs: some elements would never appear together. To resolve this problem, the third iteration, inspired by the Weasley family clock in Harry Potter (Rowling, 1998) used rotating hands, effectively splitting up the elements and allowing freer movement (Image 4). Each 'hand' on the clock had a single element written on it which meant that any of the elements across the categories could be considered together in groups. Crucially, while grouping elements, there were never any elements that weren't visible, retaining the sense of exploring the whole disease, not just the most visible parts.

This third model afforded a more flexible way to rearrange the data but also offered an opportunity to measure how each app could be relevant to the various elements of each disease by placing the app description at the top of the clock and then moving the relevant hands to point toward it. This process was repeated for each app and every configuration of the clocks was photographed for comparison.

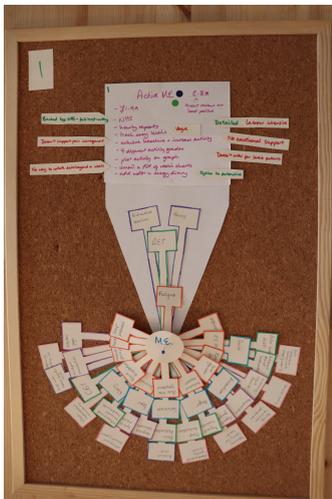


Image 4

Key Findings

Reiterating the data models encouraged different styles of analysis. The initial map was a commonplace, practical method of gathering a large amount of data but the stacked circles and the clocks challenged assumed linearity and offered a method for reimagining the data by physically moving it around and, in doing so, embraced the complexity of understanding the elements that make up the experience of each disease.

The clocks also showed which apps offered unique kinds of support, not centred around improving the condition per se but very much intended to help the patient manage their lifestyle. For example, *Flush - Toilet Finder and Map*, an app for people with Crohn's and IBD, isn't relevant to the medical management of most of the elements of the disease but offers a creative solution to needing to find a public toilet quickly, a necessity for many

people. This indicated that even while using a more holistic interpretation of the disease, the framework for analysis could still be refined.

Contribution

In the process of reimagining new models for displaying and analysing data, there is an opportunity to reconsider the relationships that may be found within complex data sets and a chance to challenge any preconceptions the researcher may have entered the study with. In this study, the process of reimagining models for analysing data about disease and its impact brought forward new insights and allowed for a more holistic analysis to take place.

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