"The Crowd Keeps Me in Shape": Psychology and the Past, Present and Future of Health Social Machines

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ABSTRACT

Health social machines ...

1. INTRODUCTION

Health and well-being are visible indicators of technological progress, as advances in healthcare and medicine are invariably reflected in increases in average lifespan, reduction of disease and suffering, and shortening of time needed to recover from illness and injury. As such, it is natural to ask how and whether the Internet and the Web, two of the most significant inventions in recent human history, have or may have an effect on health and wellbeing.

In this position paper, we examine a specific class of systems enabled by the Web and pervasive Internet-enabled systems, which we call health social machines. We define health social machines to encompass a broad class of systems that provide technologically-mediated interaction of large groups of individuals, typically via a website, app, and sensor-based online community. Individuals usually communicate and interact, directly or indirectly, through some mediated or moderation mechanisms, in order to collectively accomplish or address a health-related problem or need. Such problems, as we illustrate through examples we provide later, may be on the scale of an individual's disease or well-being management, to that of contributing evidence and insight to fundamental questions at the frontier of modern medicine.

We first describe the emerging landscape of health-related social machines, identifying sets of classes and characteristics such machines typically exhibit. We then focus on specific challenges faced by these classes in the longer term, and how emerging insights from behavioural economics and technological platforms may address some of these needs.

2. CURRENT HEALTH SOCIAL MACHINES: A BRIEF CLASSIFICATORY ANALYSIS

We first collected examples of popular health social ma-

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chines through a iterative process which started with filtering several popular blogs focused on health-technology, the "quantified-self" and "life hacking", for announcements related to apps and websites dedicated to addressing health issues. We then clustered the collected candidates using a Grounded Theory approach. This process yielded three, partially overlapping clusters of machines by the ways these machines sought to address health needs. Table 1 these clusters, comprising behavioural intervention, disease management, and collective sensemaking of symptoms, and associated machines falling in each category.

2.1 Behavioural Intervention

The first which we refer to as behavioural intervention machines are systems that seek to help individuals achieve certain health related-goals by altering their daily routine(s) and activities. The majority of systems we found in this category, which, itself is the largest of the three categories, aim to help individuals increase their general activity levels to increase fitness. Since these systems generally do not target any particular demographics or those conditions, we consider them general, preventative health machines with a focus on increasing fitness.

A large number, but not all, of such fitness machines either require, or are designed to complement, sensor devices that are intended to simplify regular measurement of various vital statistics of the individual. As such, they are designed to be quick and easy to use, and, even, in some cases, worn directly on the body, for the measurement of physiological signals or activity levels, at high temporal granularity. These on-body activity measurement devices range from simple accelerometer-based devices (such as the FitBit, Nike FuelBand), that can approximately estimate the number of steps/distance the wearer has travelled in a day, to slightly more complex on-body devices (such as the Body-Media CORE) that measure multiple physiological signals in tandem with activity level. Other, non-worn devices include iPhone-enabled blood pressure cuffs (e.g. Withings' Blood Pressure Monitor), internet-connectivity enabled weight/body mass index scales (e.g., Withings' WiFi Scale), and iPhoneenabled heart rate, blood oxygen level measuring devices (e.g., Zensorium Tinke).

2.2 Disease management

A second class of health social machines aim to help individuals cope with various kinds of conditions, including illness, disease, and mental health. While a few of such systems are general and designed to accommodate a wide variety of conditions, most of the machines available today are designed specific to a particular disease or class of diseases, such as diabetes, depression, Alzheimer's, autism, post-traumatic stress disorder (PTSD), Coeliac's disease, and so forth.

2.3 Collective sensemaking

The final class of social machines, of which we only found one extant example, PatientsLikeMe ¹, aim to crowd-source knowledge about disease, symptoms and treatments to individuals who have personally experienced them. To do this, PatientsLikeMe facilitates the independent report of symptoms that individuals are experiencing, connections between the symptoms and the particular disease(s)/conditions which they have bene diagnosed with, and the effects of particular treatments on their conditions. The result of this aggregation, at large scale, is a model relating symptoms to diseases to treatments and effects. This model can then be used by other individuals in a number of ways; first, those who are experiencing symptoms can diagnose themselves based on the symptom-disease associations, while those with already diagnosed with a condition can use the disease-treatmenteffects model to choose treatment(s) might the most favourable outcomes and experiences of others like them.

Preventative	wol	lnoce
1 reventative	wei	\mathbf{mess}

Device-based: Nike+, FitBit, Withings, BodyMedia, Zeo

App-based: RunKeeper

Site-based: Fitocracy, Traineo, Dailyburn, ExtraPounds, SparkPeople

Disease management

ALZConnected (Alzeheimer's patients),

Prevent (Prediabetics)

BigWhiteWall

Collective sensemaking

PatientsLikeMe

Table 1: Consolidated constructs of social machines.

CAPABILTIES AND METHODS OF SUP-**PORT**

In order to understand better how the social machines just described functioned to help individuals with their health related goals, we performed an analysis of each site/app's features and derived a set of observations pertaining to how they supported the goals each sought to achieve. We describe each, in turn, next

3.1 Supporting behaviour change

In order to support individuals to conform to their behaviour change interventions, we identified the following elements that these machines support.

1. Measurement and Tracking - As described earlier, in order to be able to provide feedback on progress, most of the machines provided support for some degree of data collection, ranging from facilitating manual data recording to automatically sensing activity and physiological signals through wearable sensors.

- 2. Salience and Feedback To remind individuals to comply with their intervention and reinforce encouragement for incremental progress, individuals' progress was made highly salient using a number of mechanisms. For wearable sensors, visible indicators (lights/displays) on the sensor often indicated progress, while for apps and services, visual prompts, messages and alerts delivered through social networks, e-mail, text messages, and asynchronous "push" notifications were common.
- 3. Gameification (Prizes) To futher motivate compliance, many of these systems incorporated a number of "gameification" features [?] meant to make progres seem like play. Such features typically involved rewarding participants with "points", "badges" and "prizes" for achieving milestones.
- 4. Social encouragement In addition to the individual gameification elements, social features were provided for most machines that encouraged indivdiuals to either compete to achieve their objectives either individually or in groups, or to support one another by "cheering them on" and supporting them in various ways. Competitive elements included "battles" and "challenges", supportive capabilities included "cheerleading", wagering, and donating "points" in support of another individual's cause.

3.2 Facilitating disease management

Disease management machines provide three kinds of support to individuals: first, like the behavioural intervention machines, to deliver actual interventions specific to individuals' conditions. One of the best examples of such intervention delivery is BigWhiteWall, which delivers mental health services through an online social network through a full-time staff of professional counselors who monitor the site 24 hours a day.

The second role these marhines serve is a place to exchange knowledge and insight, serving as both answer gardens [?] and serendipitous knowledge archives [?]. As answer gardens, these sites let individuals find and post answers to specific questions they have. As knowledge archives, individuals with similar circumstances can post and more easily stumble upon tips that are relevant to their particular situation(s) - which might help them improve their situation (even if they did not know to specifically ask or look for this information to begin with).

Third, these systems provide a mechanism of social emotional support, both in terms of empathy from people who have experienced similar situations in the past, or sympathy, from those who can relate and provide words of encouragement or advice.

Enabling crowd-based sensemaking

Health machines that seek to crowdsource information about disease and treatments at large scale require the ability to acquire information effectively and as accurately as possible from participants. Thus, effective elicitation of information becomes a primary challenge. Towards this capabillity, PatientsLikeMe supported a structured elicitation approach for the gathering of symptoms, relevant diagnosed diseases, treatments, and reports of experiences. Gathering structured data directly (in terms of ratings, diseases and

¹PatientsLikeMe - www.patientslikeme.com

summary of support provided by health social machines			
behavioural intervention (BI)	disease management (DM)	collective sensemaking (CS)	
* Measurement & Tracking * Salience through Feedback * Gameification * Social Elements: Competition, Peer Pressure & Support	* Intervention Delivery (in ways similar to BI) * Knowledge Exchange: Peer Q&A, Knowledge Garden * Social Emotional Support: Advice, Sympathy, Empathy	* Knowledge Elicitation * Aggregation & Summarisation of Knowledge	

Figure 1: Summary of the kinds of support offered by each of the classes of social machines described in Section 2.

treatments from a fixed lexicon) allowed these data can be compared and aggregated automatically across individuals.

Beyond elicitation, such sites require the ability to produce useful views of collected data so that participnats are not overwhelmed by the volumes of raw data produced by others. Towards this end, PatientsLikeMe used the structured data captured to synthesize raw simple aggregate visualisations and result summaries that could be easily interpreted.

4. CHALLENGES FROM A PSYCHOLOG-ICAL VIEWPOINT

- 4.1 Motivation
- 4.2 Salience
- 4.3 Explaining-away

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