CROWDSOURCING HEALTH INFORMATION: AN ETHNOGRAPHIC EXPLORATION OF PUBLIC AND PRIVATE HEALTH INFORMATION ON PATIENTSLIKEME.COM

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ABSTRACT

This is a study of the ways in which individual and community biosocial identities are produced and negotiated by members of PatientsLikeMe.com's Mood Disorder Community. In particular, I explore how the cultivation of presence and persona on a social networking site mediates the formation of identity, community, and patienthood. Over the course of five months, I engaged in participant-observations on the site and collected forum threads, blog posts, and policy documents. I argue that practices of reflexivity are built into the website's interface – particularly within profiles integrated with personal electronic health records (PEHRs). Members participate on the site to obtain informal social support and information in the form of personal experience. Members restrict their participation to protect their privacy and resist commodification of personal health information. User generated content on the site is intricately linked to practices of remembering and hope.

DEDICATION

I dedicate this thesis to my family with love – you are the most dedicated people in my life.

I also dedicate this thesis to the members of PatientsLikeMe's Mood Disorder Community. Thank you for your unending openness and sharing.

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Chapter One: Welcome To PLM – A Quick Introduction

> About PatientsLikeMe
>
> PatientsLikeMe was co-founded in 2004 by three MIT engineers: brothers Benjamin and James Heywood and longtime friend Jeff Cole. Five years earlier, their brother and friend Stephen Heywood was diagnosed with ALS (Lou Gehrig's disease) at the age of 29. The Heywood family soon began searching the world over for ideas that would extend and improve Stephen's life. Inspired by Stephen's experiences, the co-founders and team conceptualized and built a health data-sharing platform that we believe can transform the way patients manage their own conditions, change the way industry conducts research and improve patient care.
>
> Today, PatientsLikeMe is a for-profit company, but not one with a "just for profit" mission. We follow four core values: putting patients first, promoting transparency ("no surprises"), fostering openness and creating "wow." We're guided by these values as we continually enhance our platform, where patients can share and learn from real-world, outcome-based health data. We've also centered our business around these values by aligning patient and industry interests through data-sharing partnerships. We work with trusted nonprofit, research and industry Partners who use this health data to improve products, services and care for patients. (Read How We Make Money and our Privacy Policy for more.)
> ("About Us", Accessed September 15, 2010, http://www.patientslikeme.com/about/).

PatientsLikeMe.com (PLM) is a social networking platform created for medical patients and their care-givers. The website has a blue and white interface that is of a cool and sterile color pallet, reminiscent of nursing scrubs. The site has many features common to other popular social networking platforms, such as Facebook. Members can use the site to participate in many lively computer-mediated discussions with other members. Members generate their own content on the site as they share photos, links, and author testimonies based upon personal experience. Email-like private messages enable members to casually catch up with friends on the site and have intimate discussions. Members receive alerts from the site when their preferred content is updated and when PLM develops new features.

Like other social networking sites, members personalize their profiles to represent themselves publicly through expressions of current interests, desires, and feelings. Unlike other social networking sites, each profile on PLM has an integrated 'personal electronic health record' (PEHR) that allows patient-members and caregivers to keep track of, and share information about, changes in their health. Members track their health through a series of diagnostic scales that other members respond to regularly. Data disclosed by members is visualized in the form of graphs and charts within their PEHR on the site. Members also produce their own content in the form of journals, wiki-like discussion threads, and descriptions of personal experiences of illness and treatments. Members work together on the site to create a database of free patient-centered health information and testimony. Community in PLM is hinged upon groupings according to shared diagnoses, symptoms, and bodily experiences of patients. PLM provides members with a public space to reflect upon their personal experiences in illness, treatment, and sometimes, recovery, which can be collected by researchers and used as primary research material.

As a for-profit biotech company, social networking on PLM enables patients to participate in real biomedical research. Potential members who would like more information about PLM's business model simply need to turn to the site's FAQ (frequently asked questions):

> "**How does PatientsLikeMe Make Money?**
>
> We take the information patients like you share about your experience with the disease and sell it to our partners (i.e., companies that are developing or selling products to patients). These products may include drugs, devices, equipment, insurance, and medical services. Except for the restricted personal information you entered when registering for the site, you should expect that every piece of information you submit (even if it is not currently displayed) may be shared with our partners and any member of PatientsLikeMe, including other patients. We do not rent, sell or share personally identifiable information for marketing purposes or without explicit consent. Because we believe in transparency, we tell our members exactly what we do and do not do with their data.
>
> By selling this data and engaging our partners in conversations about patient needs, we're helping them better understand the real world medical value of their products so they can improve them. We are also helping companies accelerate the development of new solutions for patients.
>
> PatientsLikeMe is a for-profit company (with a not-just-for-profit attitude). Every partnership we develop must bring us closer to aligning patient and industry interests. Our end goal is improved patient care and quality of life.
>
> **Does PatientsLikeMe have Advertising?**
>
> No, we're not pursuing an ad-based business model right now. We want to preserve the sanctity of your experience on the site. Our business is based on aligning your interests as patients with industry interests. To do this, we share your data and experiences with industry to help them better understand the real world course of diseases."

("FAQ", Accessed September 15, 2010
"http://www.patientslikeme.com/help/faq/")

Social networking is re-envisioned by the site's creators as an ideal means through which patients participate in science with the aim of improving treatment outcomes, ultimately challenging general research practices within the United States of America. PLM collects 'real time[1] and outcome based' information from member PEHRs, profiles, and forum posts. This means that information is collected and published on the internet through a much faster process than with traditional clinical research.

Social networking is used to mobilize strangers who share common diagnoses into unified research participant pools *qua* patient communities. To produce data, the site harnesses the 'inherent productivity' of social networking – the human energy and labour expended by site users as they generate their own text and content. As members use the site to track their own health and provide and receive social support to peers, user-generated content is condensed and transformed into aggregated anonymized data reports by PLM's paid research staff. The data can then becomes a commodity in an economy of health

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[1] Real time refers to the experience of synchronous communication – in which the delay between production and consumption of media content feels instantaneous like a face-to-face conversation. The speed at which individuals can share information through the web is setting a new precedence for traditional paces of research and knowledge dissemination by professional researchers and media outlets that now have to compete with networks of amateurs with data-phones who can post photos, videos, and text from almost anywhere at any moment. For a more in depth discussion of time in text-based virtual words, see Marvin (1995).

information, with select 'partners' – nonprofits, research and academic institutions (including researching graduate students such as myself[2]), and the vast biomedical industry as participants.

On PLM, members act as 'data brokers' who own and control the flow of their personal information. Although PLM does not charge patient-members and caregivers to use the site (i.e. a subscription fee), engaging members in a novel research practice called *crowdsourcing* helps sustain the site's operations and enables staff researchers to participate in scientific discourses. The use of patient-data generated from PLM, when published in peer-reviewed journals, markets PLM's services to researchers and biomedical corporations, and ultimately emphasizes the power of social networking platforms, presenting PLM as a viable research tool and source of data. Studies published by PLM include an analysis of the vocabulary employed by PLM's members in comparison to medical professionals (Arnott Smith and Wicks 2008); off-label uses of prescription medication and the power of patient-centered and patient-controlled informatics to inspire novel approaches for biomedical research and treatment of

---

[2] At no point was I an employee or staff member of PLM. I did not pay for access to the site and was not paid to conduct this research. This ethnography would not be possible without PLM's commitment to advancing knowledge and attitude towards sharing and openness. As part of being accountable and reflexive as a researcher, I must admit that I did benefit professionally from my ability to observe members *in situ* on a high profile website such as PLM. Likewise, PLM may benefit from this thesis. PLM may experience increased publicity and peer-review as a result of this thesis' dissemination. My entanglement in a commercial mode of information exchange and research cannot be ignored.

amyotrophic lateral sclerosis (Frost, Massagli, Wicks and Heywood 2008); and the effects of PLM and social networking on medical decision-making by patients (Wicks et al 2010). These papers, produced using PLM's data, explore the effects of social networking using a variety of patient's experiences. PLM aims to develop a series of patented qualitative and quantitative methodologies for collecting and analyzing patient data from a social networking site supported by a body of empirical evidence. The uses a now familiar model of social networking to create a pool of dedicated research participants that has garnered attention from the media and social scientists.

According to the latest results of "The Social Life of Health Information" study by The Pew Internet and American Life Project, 74% of 3000 surveyed Americans use the internet. Of that 74%, four in five people (80%) have used the internet to search for health information and one in four (25%) people have consulted reviews of specific drugs and treatments (Fox 2011:2). Additionally, 68% of surveyed Americans participated in social networking of which nearly one in four people (23%) have followed the health experiences of others using a social networking site, one in seven (14%) used social networking for fundraising for a health related issue, and more than one in ten (11%) provided or received health advice on a social networking site in the form of a comment, query, or information (Ibid:3). For thousands of people who are members of social-networking sites like PatientsLikeMe, the internet is a place where they can collectively reflect on their experiences, as well as retrieve information about the state of their bodies, minds, and selves during times of illness. The internet provides a quick and relatively inexpensive way to participate in healthcare through self-education, by educating others, and being educated by other's personal experiences. Social-networking sites play an increasingly large role in the mediation of interpersonal communication and notions of community in everyday contexts, including health care.

Our time in social networks leaves e-footprints (Kleemann et al, 2008) of our presence and personas in the form of profiles, photos, videos, and text. These artifacts make our presence known in virtual worlds and represent our selves to others. What happens to discussions, profiles, and personal experiences once they find their way to the internet? How do individuals adequately safe-guard their identities online to avoid having colleagues and peers accessing personal health information that can be linked to their offline identity? Could someone be tracking the every move and utterance of another person as a result of participating in an online discussion group? My thesis explores the production of cultural artifacts used to assert identity and community within the patient social networking site PatientsLikeMe.com.

Thesis Statement and Research Questions

I am interested in how the social networking of patients with Mood Disorders impacts understandings of identity and community. Current research on the application of social media in healthcare delivery and research can be augmented by the perspectives of medical anthropologists and sociologists. Medical anthropologists and sociologists explore the ways in which information from the life sciences is used to construct understandings of the self, relatedness to others, and shapes how people behave and interact in an increasingly digitized world.

My thesis examines the language and practices of research participation in the Mood Disorder Community on the patient-centered social networking site PatientsLikeMe.com (PLM). In studying this specific demographics' social networking, I explore how member of PLM articulate notions of the biological self, a community of mental illness, and biosociality (Rabinow, 1996) as well as how an accumulation of experience-based knowledge intersects with for-profit medical research. In that process, I ask:

(1) How does patient social networking on the site PatientsLikeMe.com encourage the adoption of reflexive patient-consumer identities *via* profiles with integrated Personal Electronic Health Records (PEHRs)?

(2) How does community form on PatientsLikeMe.com around perceptions of shared medical conditions and experiences?

(3) What benefits do members attribute to their continued participation in PLM and what strategies do members employ to mitigate risks associated with the discloser of personal health information online?

To answer these questions; I draw upon six months of participant-observation of discussions within PLM's Mood Disorder Community as well as publications produced by PLM, including a content analysis of PLM's policy documents and peer-reviewed publications. I argue that a biosocial identity is produced on PatientsLikeMe when members engage in self-reflexive practices built into the site's interface. Members cultivate a public persona through their interaction with the site's interface in order to form social relationships. Members selectively engage and restrict their participation in order to regulate the e-footprints they produce on the site to preserve privacy when desired or required.

Key Concepts: Biosociality and Biocitizenship

The relationship between identity, health, and human societies receives a fair amount of attention within the disciplines of medical anthropology and sociology. In particular, Rabinow and Rose's (2006) expansion upon Foucault's concept of 'biopower' is particularly useful when trying to understand factors that contribute to the adoption of biomedical identities and truth discourses (cf. Foucault 1978) by lay-people. In an attempt to breathe some conceptual clarity into Foucault's original concept, Rabinow and Rose suggest biopower should not be thought of as simply the historical responsibility of sovereigns to preserve the vitality (or historical continuation/life) of the human species by exercising sovereign-right to take individual lives (196). Rather, they expand Foucault's notion of biopower to bring analytical attention to 1) the mobilization of science and other 'truth discourses' (even including medical anthropology) to make authoritative claims about how humans ought to live, 2) the strategies employed by various social actors to group-together others and justify collective intervention on their lifestyle in the name of health, and 3) instances in which individuals adopt group-designations by experts and individuals participate in interventions by acting upon the self and monitoring the actions of others (197). Rabinow and Rose extend biopower to analyze the ways in which individuals mobilize notions of biology and health to assert individual identity, define community, and define moral conduct in the name of individual, community, and species survival.

Contemporary inquiries regarding biopower must account for historical circumstances that necessitate or invite interventions upon lifestyle to preserve individual and collective health (199). We are challenged as social scientists to pay particular attention to the multitude of historical, political, economic, and moral factors that contribute to any situation and produce nuanced accounts of power that do not collapse its expressions into a single form originating from a sole source (i.e the state) (201). As a result, Rabinow and Rose provide a spectral analytical framework through which they study the mobilization of patient groups, feminists, racial minorities, and others who actively adopt or resist biological presuppositions that purport to know the 'truth' and 'facts' about their individual selves and communities. Rabinow and Rose's initial rereading of Foucault's biopower has been further developed by Rabinow, Rose and other scholars to explore material and cultural practices that produce biologically-oriented identities, communities, and economies.

Rose (2007) argues that since the 19th century, identity in the form of citizenship was understood, at least in part, through biological terms. Notions of flesh, blood, and recently genes are increasingly used to define or deny certain individuals full rights, freedoms, and obligations to the state (132). The emergence of global capitalism resulted in a transition from citizenship projects motivated by fears of degeneracy and racial purity to projects that objectify citizens as sources of biological commodities – organs, tissues, genes, and proteins – that can be used as living technologies in medical interventions (133). Embracing one's biology in a capitalist context can be a source of empowerment and a successful claim to citizenship when one's biological materials are seen as inherently valuable and commodifable; one has a 'biovalue' and is a 'biocommodity'.

Petryna (2002) illustrates how pain and suffering have become central to contemporary conceptions of citizenship in post-Chernobyl Ukraine (15). Cleanup workers and residents living in areas contaminated with radiation during the disaster continue to rely upon the available diagnostic technologies, knowledge of symptoms to gain recognition by the Ukrainians state, using the law to obtain access to welfare and medical care (15). In the context of post-Chernobyl Ukraine, claiming damage to one's biology and loss of productive capacities (including the ability to work) is not a source of prestige and empowerment, but an economic strategy for surviving in a circumstance of political and social uncertainty resulting from the collapse of the Soviet Union, the introduction of market capitalism, and decline of government welfare programs in Ukraine (ibid: 16).

Rabinow (1996) focused his work on the use of biological presuppositions to define group membership and community identities. Termed biosociality, new communities are formed around shared illness experiences and reliance upon medical devices and interventions. As new information and technologies become available, patients and other individuals can increasingly take healthcare into their own hands by engaging in informal social support networks and information sharing centers to preserve or improve their current health, emotional as well as physical.

As mobilized communities, individuals are increasingly able to participate in politics and biomedical economies to affect the direction of future research and technological development. Novas' (2006) work has looked at economies of hope in which

> "persons affected by genetic conditions have become significant authorities who are engaged in the promotion of the health and well-being of individuals and populations, who directly contribute to the production of biomedical knowledge and to its capitalization, and who elabourate novel norms relating to the conduct =of medical research" (290).

In a political economy of hope, patients' bodies and actions become a site of hope for the future. Hope, in Novas' concept, is not simply an imaginative process in which potential new cures and approaches to health care are envisioned. Hope is a moral act when overlapping worldviews of how the world, health care, and research ought to be are encapsulated into hopeful visions for the future. Hope is also a political act in which patient participation in practices of care and health promotion is a productive, and is an act that is capable of transforming the contexts in which health care research and delivery takes place (290). Thus, hope is both cultural and material; it is a process capable of producing change.

Other scholars have taken up the constructs of Rabinow, Rose, and Novas's work to explore interactions between identity, economies, and the production of knowledge in medicine. Gibbon (2008) studied the role of breast cancer research charity and health activism in the formulation of social relations among women in the UK who inherited BRCA genes. She finds that research fundraising becomes a cultural practice of remembering or memorialization of loved ones lost to breast cancer and generating hope for future generations who may also carry the gene (23). Silverman (2008) explores how parents of autistic children are categorized by geneticists as 'broad autistic phenotypes' despite no known biological markers for autism (39). In the case of autism, biological facts are socially constituted and experts in the field of genetics serve as 'pastoral keepers' who direct and shape assumptions of normal vs. abnormal human behavior, then place individuals within those categories. In the context of invitro-fertilization (IVF) in India, Bharadwaj (2008) argues that caste and gender relations in contemporary India do not afford biosociality as envisioned by Rabinow – that is, the formation of individual and group identities united by common biological hardship. She argues instead that women's bodies are "... seldom biosocial but rather always bioavailable for biocrossings" (111). The commercialization of IVF results in the increasing commoditization of some women's bodies and their biological materials, such as unfertilized ova (particularly those of the poor and most socially disadvantaged).

Anthropologists have yet to explore how emerging virtual worlds such as a social networking site can mediate or complicate the formation of biosocial identities, communities, and 'the facts' underpinning such identities and communities. Nor have anthropologists explored how the participation in such websites contributes to moral and political economies of hope, in which the promotion of well-being *via* the provision of informal social support and personal health information is seen as directly contributing to the production of knowledge and its capitalization. My thesis makes a contribution to literature on biosociality by addressing this gap.

Patient Social Networking as a Form of Health Communication and Consumerism

Within social media, individuals converse on a global scale about experiences of illness as well as share personal health information, including their evaluations of medical professionals, their diagnoses and treatments, and medical systems generally. The participatory and discursive context of information sharing has led some social scientists to suggest social networking may have therapeutic potential, including 1) empowerment when patients gain a sense of control over a condition, 2) communities that provide informal social and emotional support during illness, and 3) provision of safe-spaces for counter-discourse and questioning medical expertise (Fox, Ward and O'Rourke 2004, Broom 2005, Barker 2008).

For scholars interested in the communication of health information, the internet provides professionals with a new setting for the production of health information and new channels of information exchange (Neuhauser & Kreps, 2008). Information technology provides many medical professionals with low cost solutions for the delivery of health information and public health services across vast geographic distances in shorter times than traditional means of communication (Glueckauf & Lustaria, 2009). The mediated nature of health communication *via* information technologies provides some patients with an enhanced sense of privacy that reduces experiences of apprehension or stigma when communicating with others about health conditions (Wright et al, 2008). Others hope that information technologies can enhance patient agency in medical encounters by encouraging self-care and a sense of control where individuals exercise control over their own health as equal participants in the delivery and consumption of health care services. This is facilitated by an increased access to information and directives (Kreps 2008, Coile Jr 2008, Arntson 1989).

Since the mid 1980's, the scale of the circulation of print and electronic media in everyday life has increased due to global capitalism (Appadurai 1986). The movement of goods across traditional borders and economies led some social scientists to suggest human societies were entering an age of post-nationalism highlighted by the decreasing importance and presence of the political state and local economy in everyday life (Tambini 1997, Handler 1988). In theory, global circulation of media, peoples, commodities, and information presents opportunities for self-reflection through practices of self-representation materialized through mindful consumption of media and choice (De Certeau 1984, Giddens 1991). The emergence of modernity is marked by changes in the global organization of societies and changing relationships between societal institutions and individual citizens, which are enabled through the circulation of media and information technologies. The circulation of modern media results in opportunities for new reflexive practices and the construction of individual identities (Giddens 1991:1). Modernity charges individuals with the power to change the world by changing the self. Change is achieved at the individual level through lifestyle choices, self-monitoring, negotiating decisions with rational, selective consumption and the avoidance of risk factors that may negatively empact one's current or future health. Individualized-identities *qua* consumerism act as a source of empowerment and agency in modern societies when the self can "contribute to and directly promote social influences that are global in their consequences and implications" (ibid: 2).

Although literature by experts on health communication and consumerism point to both potential benefits and limitations regarding the adoption of IT and social media in the delivery of health information and services, this body of work contains implicit assumptions regarding the identity and role of patients in relation to medical experts and directives. Patienthood, in these accounts, goes hand in hand with consumerism. The experts who provide health information online aim to assist their audience with making ‘informed consumer decisions’. Informed consumer decisions incorporate the latest scientific findings and directives in the medical decision-making process. The early 1990’s bore the emergence of neoliberal capitalism, which created dramatic changes in the experience of ‘patienthood’ and medical expertise in the West. This change resulted in increased access to health information, coupled with disinvestment of social spending on health care. This ultimately resulted in the emergence of a ‘consumerist ethos’ in health care. The ‘informed patient-consumer’ is seen as a transition from notions of the traditional “good patient [as] compliant, trusting and complacent [with altruistic and paternal medical professionals]… to a ‘consumerist’ patient who is questioning, willing to make independent judgments on whether to accept a doctor’s advice, and capable of seeking out alternative sources of information” (Lupton, Donaldson and Lloyd 1991: 560). Changes observed in the relationship between patients and medical professionals are situated by these experts within overarching reorganization of day-to-day social life associated with ‘modernity’ and the emergence of global capitalism. These changes continue with emerging practices of crowdsourcing, in which the relationship between patients and medical researchers is also reorganized around the production of capital.

The Worth of Patient Social Networking: Defining Crowdsourcing

Online discussion groups, social networking sites, and other virtual worlds are increasingly recognized by individuals, researchers, and corporations as potential databases containing various forms of information, including personal health information. As such, researchers and corporations develop sophisticated technologies and techniques for collecting, storing, and using information generated in online contexts, such as data-mining and crowdsourcing.

Data-mining refers to “the extraction of implicit, previously unknown, and potentially useful information from data” (Witten, Frank 2005:xxiii) by computer algorithms designed to detect patterns in data sets and predict new data. In data-mining, (ro)’bots’ or computer programs are designed to enter and extract information from online worlds. Conner (1996) describes data-mining as a fast way to access and analyze “hundreds of millions of records” (p.3) and to map the relationships between variables in open-ended search queries in the context of marketing. Anthropologist Alvin W. Wolfe (2011) sees data-mining as a mapping technique for uncovering micro to macro networking and social relationships between various social actors (including individuals, communities, nation states, and supranational entities such as multinational corporations) and cultural practices. Data-mining results in the generation of new information in private databases produced from preexisting (and often public) sources of information – thus, data-mining can result in privatization of the public sphere.

Conversely, crowdsourcing refers to the outsourcing of various forms of intellectual and manual labour that "tap[s] the latent talent of the crowd" (Howe 2006a: 2). According to Howe,

> "Simply defined, crowdsourcing represents the act of a company or institution taking a function once performed by employees and outsourcing it to an undefined (and generally large) network of people in the form of an open call. This can take the form of peer-production (when the job is performed collabouratively), but is also often undertaken by sole individuals. The crucial prerequisite is the use of the open call format and the large network of potential labourers." (2006b:5)

The 'open call' format to problem solving described by Howe borrows from the computer science concept of open source. Open source refers to a philosophy towards software development that prioritizes collabourative improvement, transparency, and free distribution over régimes of intellectual property right (IP), exclusivity, and competition characteristic of capitalist production. (Parens, n.d., Albors et al, 2008). Open source projects represent a contemporary commons in which data exists as a collective resource for democratic and collective innovation available to all. Informed by the 'hacker ethic' (see Levy 1984, Himanen 2001), open-source challenges the monopoly of resources, production, and power used for the extraction of value from labour practices in global capitalism. Cove (2007) suggests that open source represents an alternative value system in which social capital – reputation, family, and other forms of group-based identity and allegiances – are used to challenge assumptions about the 'fundamental laws of reality' and dominance of capitalism as the organizing principle of Western societies (7). Open source represents an alternative discourse to self-interest that favors collabouration and creativity over hierarchy and privatization.

Crowdsourcing is heralded as a Web 2.0 low-cost solution to the high price and time consuming nature of sampling and data collection in product research and development (Kitter, Chi, Suh 2008). Such applications of crowdsourcing challenge traditional divisions between experts and amateurs by valuing local knowledge through an ethos of democratic public participation in the production of information (Brabham 2009). Crowdsourcing provides an alternative business model in which inspiration for future research direction and innovation emerge from the "collective wisdom of the crowd" (ibid) and ostensibly reflects the interests and inherent democracy of unstructured online communities.

Health care research and service delivery are not untouched by the emergence of Web 2.0 technologies including social networking sites and crowdsourcing. Through Web 2.0 technologies – internet protocols aimed at increasing the interactive and communicative potentials of the internet – people access and consume health information online but also challenge top-down models of knowledge production and dissemination when they create their own media content. In the form of blogs, videos, pictures, applications, and databases, User-Generated Content (UGC) embodies personal experiences, hopes, desires, and opinions, in the form of texts and graphics. The production of original content – such as blogs, images, videos, web pages, and computer programs has become a popular form recreation and creates many opportunities for employment, in which "individual knowledge [and experience] becomes shared information" (Kleemann et al, 2008:11). As everyday individuals take the production and consumption of media into their own hands, they are increasingly visible within constellating networks of voices[3] made accessible through the web on social networking sites and social media outlets. Information serves as focal points bringing diverse groups of individuals and corporations together in complicated networks of exchange. In this thesis, I argue that the same

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[3] Justin E. H. Smith (2011) argues the internet does not represent a resurgence of literary practices despite the dominance of text on the Internet. Instead he suggests discourse on the internet represents resurgence in *oral* practices of dialogue and monologue representations of subjective experiences and thought in the syntax and conventions of speech.

processes underpinning the production of identity on PLM also support the production of data collected by the site.

Although many benefits are attributed to medically-centered social media platforms, social scientists also express concerns regarding the futures such technologies signal and produce, such as practices of crowdsourcing and data-mining. Fule and Roddick (2004) suggest the automatic nature of data-mining can inadvertently violate norms of privacy because “knowledge discovery tools are commonly open ended and it is not possible to know what will be found until it is discovered” (160), particularly when mining non-anonymized data in medical or health research. Profit-oriented business models that rely upon the productive potentials and consumptive practices of crowds raise questions regarding appropriation and exploitation of UGC by private entities. Kleennmann et al (2008) suggest that crowdsourcing results in the creation of ‘working consumers’ who have the potential to be alienated from the ideas they produce with little or no remuneration despite increased worker autonomy and greater recognition of various forms of expertise (23-4). Barbham (2008) warns that ‘clouds’ – aggregated networks of crowdsourced individuals - cannot be mistaken for ‘communities’ but instead represent hybridized work/recreational spaces, in which “friendship and social networking are secondary to individual fulfillment and profit” (p. 30). Furthermore, Barbham suggests “we should keep a critical eye on the products produced by crowds and not assume that the meritocracy of crowdsourcing equates to a true democratic, accessible, co-creative process" (p. 31). For these scholars the alienating potential of crowdsourced research cannot be ignored. Howe (2006c) argues "it's only crowdsourcing once a company takes [a co-produced] design, fabricates in mass quantity and sell[s] it" (p. 1). Howe points to risks of appropriation of UGC and alienation of site users when information is collected and commoditized by the proprietors of social media platforms.

Social media contributes to the commoditization of health care services through product advertising, referral services for professionals and institutions, online shopping services for medical devices, pharmaceuticals, insurance, and medical advice (Walsh et al, 1993). In particular, personal electronic health records (PEHRs) constitute a new resource for researchers and market analysts who wish to mine databases for emerging market trends or uncover novel risk factors contributing to declines in public health (Coile Jr 2001:22). The professionalization of health care professionals is challenged when health information - "[r]ecipies or directives about practices for healthy living, as well as information about medical conditions and treatments, prescription drugs and alternative health products and therapies" (Wyatt, Harris and Wathen 2008:1), is easily incorporated on sites hosted by non-medical experts who promote or sell commercial health care services, medical devices, drugs, and information online (Coile Jr, 2008).

Further, the trustworthiness of online health information is questionable when governmental and professional organizations have limited ability to regulate the quality, security, and providers of online health information and record keeping services (Lundberg 2002:18). Studies purporting the cost-effectiveness of information technology in medicine are criticized for being too simplistic when considerations of cost are not translated into 'human factors' such as the impact of medicalized IT on survival rates in life years, quality of life, and psychosocial adjustment of patients (Glueckauf and Lustria 2008, Whitten & Love, 2005). Many in the field of health communication question the generalizability of using personal health obtained information and testimony as data, by pointing to disparities in access to the internet and participation in social media by ethnic minorities, known as the 'digital divide' (Glueckauf and Lustria 2008: 173). Therefore, due to the openness of social media, means though which research corporations obtains their research and capital (i.e. PLM's approach of generating data from patient testimony) may be interpreted as questionable and controversial science.

A Final Note on Privacy and Openness in Social Media

In a live interview with TechCrunch.com founder Michael Arrington on January 9th, 2010[4], the founder of Facebook, Mark Zuckerberg, suggested that new forms of visibility, enabled by Web 2.0 technologies, indicate that attitudes towards privacy were radically altered by the arrival and use of various types of social media. Zuckerberg recants,

> "When I got started [with Facebook] in my dorm room at Harvard, the question a lot of people asked was 'why would I want to put any information on the Internet at all? Why would I want to have a website?' And then in the last 5 or 6 years, blogging has taken off in a huge way and all these different services that have people sharing all this information. People have really gotten comfortable not only sharing more information and different kinds, but more openly and with more people. That social norm is just something that has evolved over time. We view it as our role in the system to constantly be innovating and be updating what our system is to reflect what the current social norms are. A lot of companies would be trapped by the conventions and their legacies of what they've built, doing a privacy change - doing a privacy change for 350 million users is not the kind of thing that a lot of companies would do. But we viewed that as a really important thing, to always keep a beginner's mind and what would we do if we were starting the company now and we decided that these would be the social norms now and we just went for it."

Zuckerberg suggests that social media creates new public spheres organized around new forms of sharing, an informatic altruism informed by a logic of 'openness'. As use of the internet becomes more integrated into everyday life in the West, the sheer 'publicness' of social media is starting to be recognized.

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[4] Copies of and reactions to the interview can be found on popular video sharing websites such as Youtube.com and Ustream.com. See "http://www.huffingtonpost.com/2010/01/11/facebooks-zuckerberg-the_n_417969.html" for an embedded copy of the video.

From nude self-portraits[5] to online utterances by educators about their students on social networking sites[6], the accessibility of personal information through social media can have real, sometimes negative, consequences when individuals are identified offline by their online content. In Zuckerberg's account of social media, Facebook and similar social media technologies passively reflect current expectations regarding openness and privacy already present in Western cultures. Zuckerberg sees his role, as the proprietor of Facebook, to update the platform to continuously *reflect* current social norms. As a world leader in social networking technologies, the active role Facebook takes in *producing* new cultural expectations and attitudes towards privacy through its business practices are strategically deemphasized. The increasing ubiquitousness of social media in our everyday lives and the consequences participation in social media provokes questions regarding the relationship between information online and identity offline.

Information generated by and about people online poses significant challenges to conventional expectations of privacy of personal information in offline locales because once something ends up on the web, in many cases it

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[5] "Viral" photo scandals involving bass player Pete Wentz and professional football athlete Chris Cooley accidently making their "private parts" public through photo sharing highlight how norms regarding internet conduct are still being determined, often by observing consequences on others.

[6] Fellow York University graduate student Bianca Baggiarini may forever be famous in Canada as the teaching assistant who publicly criticized her student's papers via Facebook, resulting in her own public humiliation. See http://www.excal.on.ca/news/ta-under-fire-after-facebook-blunder/

becomes defacto 'public,' which presents difficulties regarding the regulation of the reproduction and distribution of the content – a threat made more serious by the 'copy and paste' materiality of internet content. This issue is compounded when many user-agreements virtually relinquish service providers from regulations governing copyright and intellectual property (IP). Generally, site users retain ownership of their UGC but their ability to exercise that ownership, to control the use and distribution of their UGC, even by service providers, is limited. Non-negotiable conditions grant service providers with almost unlimited rights to store, reproduce, and sell user content without violating copyright or providing remuneration (i.e. Facebook). Increasingly, personal content from social media not intended for global distribution is permanently stored on servers and private databases owned by social media platforms. The information contained in such databases serves as an important revenue-generating resource for social media sites that sell UGC to advertisers and other private entities. In spite of this, internet users are selective about when and how they participate in order to mitigate risks associated with enhanced visibility and appropriation of personal information. This is also the case on PatientsLikeMe.com and, the focus of my thesis.

Structure of this Thesis

In chapter two, I discuss my methodological orientation and the techniques I used to collect and analyze data for this thesis. In particular, I reflect on Mauss' (1979) notion of body techniques to explore how my ethnographic techniques relied upon the tangibility of material documents and bodily interaction with those materials. I discuss the meaning of consent in ethnography of online environments and compare 'traditional' practices of informed consent with those of PatientsLikeMe. Lastly, I discuss the importance of lurking as a research method in virtual ethnography. I explore how my own experiences of transference on the site highlighted by how identity is a practice of representation through the restriction and cultivation of *presence* and *persona* in virtual worlds. In the remaining chapters, I demonstrate how the cultivation of presence and persona in virtual worlds enable the formation of biosociality on micro (individual - chapter three), mezzo (community – chapter four), and macro (research participation – chapter five) scales.

In chapter three, I provide readers with an expanded introduction to PLM's user interface and users. I explore how features in the site's interface – profiles with integrated PEHRs and forum threads – allow members to construct and represent individualized biosocial identities. I argue that a particular conception of patienthood and mental illness is built into the site's interface. To support my argument, I explore how PLM attempts to adapt its conception of patienthood by engaging with and acting upon feedback from members. Lastly, I argue that emerging practices of reflexivity are built-in to the site's interface. As members interact with profiles and PEHR tools on the site, they produce material accounts of patienthood that are 'countable' and therefore amendable to the logic of Western biocaptialism.

In chapter four, I turn from the micro to mezzo level of biosociality within PLM's Mood Disorder Community. In this chapter, I trace sweeping changes in the way patienthood is conceptualized by PLM's administrators – what I term the 'any patient' – and provide readers with a look at member reactions to the update. I explore the notion of 'community' in PLM's Mood Disorder Community and distinctions members make between the support they receive from members on the site versus 'normals' – family and friends without mental illness. Then, I turn to a forum thread on invisibility and loneliness on PLM to describe how social relations between members are formed within PLM's interface. I follow with an exploration of conflict between members within the Mood Disorder Community and the dissolution of community when members leave the site. Lastly, I briefly look at an instance when identity politics on the site intersects with national politics in the United States as an example of user empowerment. At the heart of all these process is the assertion of presence and persona on the site.

Chapter five describes how members conceive and reconceived their membership and participation on the site after a security breach. Issues of consent (discussed in chapter two) come to the fore in response to the security breach. This chapter explores members' notions of public and private information in virtual worlds. I look at who members see as ultimately responsible for the protection of their personal information. The protection of personal information is seen as the responsibility of members themselves, which is achieved through the regulation of presence and persona on the site. These issues are contrasted with members' perceptions of therapeutic benefits attributed to their participation and how privacy limits those benefits. The discussions invoked by a breach in security provide the basis for understanding the hope inspired by PLM and what benefits members attribute to biosocial identities, ultimately justifying a continued participation on the site.

Chapter Two: Methods and Ethics – Conducting Ethnography Online

This chapter explores methodological and ethical considerations made during the course of my fieldwork. Ethnography is, as Boellstroff (2008) states in his account of Second Life, "written in the language of 'is' not 'ought', concerned with description not prescription, [and] seeks to understand emergent aspects of culture" (26). In this project, I seek to describe and understand identity and community formations that emerge out of a digitization of human thoughts and emotions, in the form oparticular online environments like that of PatientsLikeMe.com. Insights garnered from my ethnographic study of patient social networking and research participation contributes to more recent discourses on contemporary experiences of patienthood within anthropology. My research also speaks to the increasing ubiquity of information technologies in many facets of everyday life and the ways in which social structures and cultural values shift to facilitate and sometimes resist these emergent changes. In this chapter, I describe the methods I used to collect and analyze data. Second, I discuss ethical considerations of entering, conducting participant-observations in, and eventually writing about biomedically-centered virtual worlds. In this discussion, I situate myself as a researcher and explain how I gained accessed to PLM's Mood Disorder Community. Lastly, I introduce the concept of 'presence' in online environments, which will serve as my foundation for considering biosociality in PLM's Mood Disorder Community.

Methods and Project Timeline

I conducted my participant observation without interviews over the period of September 2010 to February 2011 by focusing primarily on the perspectives of PLM's members and employees using the site. I started by reviewing the site's publicly accessible promotional materials, privacy policy, user agreement and academic papers published by the site. Despite not using interviews, I still participated within PLM's Mood Disorder Community and interacted with members. Ethnography without interviews does not intend to imply a form of covert observation nor passive observation without interaction or communication between site users and myself as a researcher. That is, ethnography without interviews privileges the utterances, actions, and interactions with participants in the field as I observed and participated with users online rather than privileging interviews as the primary context in which 'real data' is transmitted. The actions, commentaries, and day-to-day utterances of site participants (as well as my participation with them as an openly identified researcher on the site) *is* the data that makes up this ethnography. Sustained engagement was particularly important in the context of my research. Being present within the community over time was the main means by which members learned about me and my research. Being a participant was the main means through which I got to know members and identify trends on the site.

The design of PLM's platform allows members to comment openly on almost every area of the site, including newsletters and press-releases published by PLM, in addition to the profiles and forum posts of others. This provided an immense volume and diversity of analyzable field materials consisting of dialogue on what seemed like almost any topic imaginable. I restricted my observations to the Mood Disorder Community, which had over 20 000 members, and focused my efforts on forum discussions and comments left by members on PLM's publications. Posts made in these locations are unambiguously public within PLM. Although I did observe members profiles and PEHRs, their contents are not included in my analysis. PLM's administrators and I consider much of the information contained in them (such as names, locations, personal photos, and treatment histories) too sensitive and identifiable. To publish such information could compromise the anonymity of PLM's 100 000+ members and seriously damage the mutual trust between the site's membership, administrators, and researchers. I have omitted usernames, avatars, and any other identifiable features to uphold my ethical obligations to PLM's members and administrators. Additionally, in order to preserve the voice of members and contexts in which dialogue appears on the site, I left members comments largely unedited and complete when possible. Since PLM does not have an internal spellchecker, the grammar and spelling in many excerpts is raw and grammatically incorrect. Regardless of imperfections, the selected excerpts of member dialogue on the site are easily comprehensible and give readers a sense of how discourse actually occurs on the site.

In order to keep track of my navigation, interactions on the site, and identify new topic to follow up on, I printed a copy of all forum posts and publications I observed. During the initial phase of my fieldwork, I experimented with various digital forms of recordkeeping for the collection and analysis of field materials (e.g. html archives and PDFs). Each file format changed the appearance of the site and preserved different elements of it. I struggled with getting my 'transcripts' to appear visually as close as possible to the way the site appears on the computer screen without much success. Each format would omit elements of the site such as images, avatars, java scripts that expanded from small icons, or the ability to 'scroll' by limiting what I could print to the dimensions of the screen. I also struggled with developing a way of recording my own observations, thoughts, and questions in parallel with what I was observing virtually. At this point, I became aware of a research habitus and the ways in which my desires, expectations and my dependence on visuality impact my research practices. In Mauss' (1979) notion of body techniques, a habitus refers to the ways in which our bodily movements and embodiment are acquired through cultural practices and customs (101). My analysis techniques relied upon tangibility and the ability to mark up or otherwise manipulate paper documents by hand instilled during my schooling, which predates the Internet and hypertext. For this reason, I decided to print copies of field materials using the print command in my browser. Printed copies (opposed to digital copies) of field materials provided the most complete and tangible form of data that could be easily analyzed and organized.

A single 'digital page' of a forum thread contained 20 user posts, which equated to between 9 and 11 pages when printed out, depending on the lengths of user posts and whether or not they include pictures, videos, or copied and pasted various documents from other location on the web. Over the course of six months, I amassed over 3000 printed pages of forum threads, policy documents, newsletters, and press releases. Although the printed version also changed the way the site appeared, it offered many advantages over digital archiving. First, printing documents automated many of the organizational techniques I wanted to use. Each printed document has two time stamps, one marking when and where I observed the thread (the hyperlink address and printer time stamp) and the other marking the thread's author and when the thread was originally created. Printing also added page numbers and recorded the thread's title, creator, and location on the site. This provided a systematic way of keeping track of my movement on the site across the observation period. The materiality of printed documents enabled me to mark up, code, and record my thoughts or observations to follow up on alongside the primary materials, which kept them inherently intertwined. I would summarize my technique as primarily 'analog'.

My methodological approach draws from Latour's (2005) Actor Network Theory (ANT). ANT seeks to revitalize the field of sociology and related fields, such as anthropology, by attending to the ways in which "...new [forms of] association [are] being produced between elements which themselves are in no way [traditionally considered] 'social'" (8). Latour challenges social scientists to think beyond classical notions of 'the social' inherited from the discipline's founders (i.e. Durkheim), which presupposes 'society', 'community', or 'culture'. This can be achieved by refusing to rely on a "...convenient shorthand [otherwise known as 'the social'] to designate all the ingredients already accepted in the collective realm" (11)... or as Latour states:

> "The duties of the social scientist mutate accordingly: it is no longer enough to limit actors to the role of informers offering cases of some well-known types (11)... The task of defining and ordering the social should be left to the actors themselves, not taken up by the analyst (23)."

ANT demands that social scientists reconceptualize the advancement of epistemology as two interconnected but distinct activities: 'taking into account' before 'putting into order' (257). By this, Latour advises social scientists to explore how novel technologies and ideas serve as focal points for assemblages and politics that call into question previous collectives and politics. Such focal points make organization around previous focal points incongruent within the current context, which results in controversy and subsequent change. Attending to the influence of technologies and ideas – such as the internet or Einstein's theory of relativity – enables long held tenets in social theory to be challenged, and possibly refuted. As a result, the social scientists must expand the definitions of terminology when describing assemblages and social change before order can be proclaimed.

In *Reassembling the Social*, Latour argues the politicization and formation of collectives aggregated around illness is one such phenomenon where social scientists have expanded their definition of 'the social' to account for new ways of imagining community and the production of social change. Latour explains:

> "A reader, asking in what sense our theory of the social could be reconciled with 'conventional' sociology, offered as an objection the way AIDS patients mobilized as a group. Looking at traditional 'social movements', it was obvious to her that patients' organizations corresponded to 'conventional' definitions of the social because she had entirely forgotten how deeply innovative it was for patients to make politics out of retroviruses. For us on the other hand, AIDS activism, and more generally patient-based organizations, is just the type of innovation that requires completely new definitions of the social (23)".

Thus, my intention in this thesis is:

> "'to follow the actors themselves', that is try to catch up with their often wild innovations in order to learn from them what the collective existence has become in their hands, which methods they have elabourated to make it fit together, which accounts could best define the new associations that they have been forced to establish" (12).

The ideal result of ANT is a discrete and limited written account of the labour of collectivizing, which is undertaken in order to generate material and ideological change.

Latour warns maps cannot be mistaken for the territory which they describe (ibid:133) meaning research participants and the cultural practices anthropologists observe cannot be treated as synonymous with their theoretical abstractions. To do so continues a tendency in social theory to oversimplfy dynamic processes involving multiple intentional actors as a series of static and bounded variables that can be overcome through careful measure and control. Latour reminds social scientists to maintain distinctions between 'what is' – the actual – and 'the way we think it is' – an accumulation of ever-evolving working hypothesis and tested assumptions, grounded in repeated observations of the world. As the world changes, so should the theory and techniques we use to observe and analyze it.

Grounded theory (Charmez 2006, also see Strauss and Corbin 1987) was also an important methodological technique for analyzing my data. In grounded theory, data collection and analysis are concurrent activities that contribute to the collection and analysis of potential field materials. Instead of random sampling of forum threads, used in quantitative analyses of websites, I used a purposeful sampling strategy (Neuman 2006) that was split into two overlapping phases. Purposeful sampling enabled me to ensure that threads were produced by participants who were over 18 years of age and that a broad range of thread topics were examined. The first phase of sampling consisted of reviewing the 100 most recent forum threads the approximately four times I logged-on to the site per week, in addition to reading recent newsletters and personal emails I received from members of the site. After a couple months of observation, I continued to review the first 100 most recent threads but began using the site's integrated search engine to following up on themes and concepts discovered during the initial phase of observation and coding. Using the site's integrated search engine allowed me to follow up on specific events and issues in depth. I was able to make generalizations about those concepts through comparison of threads on the same topic. The excerpts selected for this thesis represent those generalizations and serve as 'best-fit' examples for the purpose of demonstration because they encompass (in a single thread) the widest range of views seen amongst threads.

At the end of the day, after I had spent some time participating on the site reading and responding to forum posts, I immediately coded print-outs post-by-post, forum-thread-by-forum-thread. I developed a set of organic key concepts based on reoccurring themes I observed in member comments and discussion. I consider this analysis a form of discourse analysis – observations regarding how social actors use language and text as tools to create and describe identities, actions, and relationships with others (Starke and Brown Trinidad, 2007:1373, also see van Dijk 1993 for a critical approach). Discourse analysis aims at producing a description of how relationships are forged between actors, objects, and actions through the use of language and how accounts of those relationships are communicated through language-in-use (Stark and Brown Trinidad 2007:1374). I chose to use discourse analysis due to the dominance of text as the mode of communication in PLM. Discourse is not limited to text but also entails what is communicated through the absence of speech or text, which can be rife with deeper meaning or easily misinterpreted as intentional. During the course of my time on PLM, the issue of silence arose in the context of loneliness (discussed in Chapter Four). For many members, a lack of response to their forum threads or comments on others threads was experienced as invisibility. At other times, some members choose to be silent in order to minimize their visibility on the site in an effort to preserve their privacy (discussed in Chapter Five). This was seen most often on member profiles, where members left sensitive questions blank, such as their age.

Ethical Considerations

Observation within the interior of the site commenced only after receiving ethical approval by the York University REB. Due to the personal nature of the information shared on the site and PLM's for-profit research motives, obtaining ethical approval from PLM's Director of Research and Development Paul Wicks was an essential step in gaining access and developing a research protocol that was ethical and tailored to the specificities of the site. Throughout my research period, Paul was extremely helpful in gaining the trust of PLM's members and ensured my transition into PLM's Mood Disorder community was smooth.

PatientsLikeMe.com specifically requested that I not monopolize online public spaces to conduct interviews, flood their users with research questions, or attempt to solicit participants with generic calls for interviews. Instead, PatientsLikeMe.com requested I take this research opportunity to immerse myself in the local culture of their site by joining any of their communities as an identified guest researcher. As a guest researcher, I was allowed to observe and participate in the forums as any other site user might – i.e. responding to posts with personal comments, experiences, and questions provoking to continue reflection and public discussion. My public profile identified me as a researching anthropologist, which contained a brief summary of my research interests and an informed consent statement explaining the scope of my research and how to withdraw from observation or express concerns should they arise. Receiving a guest researcher account was a professionalizing experience because it provided me with 'professional credentials' within PLM and distinguished my status and style of participation as different.

Fieldsite Boundaries: Is PLM Public or Private?

The first question any potential virtual ethnographers must ask themselves before entering and observing virtual worlds is what constitutes a public or private space online? This is an ethical question because websites that appear public at first glance (i.e. they are 'free' to join by anyone) might not be so clearly public on second glance (i.e. they might be clearly defined as a private space in the user agreement with specific protocols for researchers, as in the case of PLM). Patricia Lange (2007) has argued, following Gal (2002) that theoretical distinctions between the public and private are artificial. Public and private, she argues, can be thought of as relative to one another and dependent upon one's vantage point. Lange demonstrates this point with the following simple analogy:

> "For instance, a home is private when contrasted with the neighborhood. At the same time, public and private spaces exist within the home. At a higher level, community matters may appear private relative to affairs at the level of state government" (p. 12).

As a response, Lange has developed two fractionalized terms - the *privately-public* and the *publicly-private* to account for slippage between public and private domains online. Internet content is privately-public when the identity of producers and the context leading to the production of content (i.e. a Youtube video criticizing the government) is intentionally fabricated to protect the privacy of producers yet produces content for a general audience. Publicly-private refers to content that is generally accessible to a wide audience but is only meaningful to a select audience (i.e. inside jokes or symbolic references made between friends contained in Youtube videos).

I believe that Lange's insight must be taken a step farther. A person's vantage point is not simply ideological, that is – it is not simply a matter of how we *think* about a particular space or phenomenon. As Lange shows in her analysis of YouTube videos, ideological distinctions between public and private are *materialized*[7] in online worlds in a very particular way – the structure of internet content. As material expressions of cultural conventions governing the public and private, webpages constitute material objects amendable to empirical

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[7] Arguing digital content of websites is both digital and material might seem like an oxymoron. Boellstroff (2008) argues that a second artificial distinction exists in cyber anthropological literature – the real versus the virtual as artificial or not real. Boellstroff points out that although the avatars of players of the game Second Life might not be real in the sense that they have a the same physical materiality of the desk or computer the gamer uses to access the virtual world, relationships and interpersonal communications that occur in virtual worlds are *real* in the sense that do happen in space and time – albeit in a mediated form. As such, Boellstroff argues we should not think about online and offline worlds as distinct and disconnected spheres of human experience divided by reality and fantasy as unreal. Instead he proposes a new analytical distinction between the virtual as digital and "the actual", which signifies the material world.

collection and analysis aimed at uncovering underlying structure and cultural logics shaping the expression of online spaces.

In the case of PLM, ideas about what constitutes private and public is materialized through permeable site boundaries requiring a log-in credential and password in order to access the 'interior' of the site. This boundary is maintained to protect the privacy of site members' interactions and personal information. This boundary also demarcates relationships regarding property and ownership of material contained within the site. That is, this boundary marks the threshold between public and private space by marking the difference between public and private property (as defined in the site's user agreement). Understanding how online spaces are defined by their creators, through policy, users, and through practice, are important steps in ensuring our presence as researchers is consented to and that we do everything in our power to ensure that our research does not harm the safety, dignity, or privacy of the people with whom we work (AAA Code of Ethics).

Consent

Before contacting Paul Wicks, I reviewed PLM's user-agreement. Like contemporary research practices informed by the institutionalization of ethical review boards and informed consent, PLM provides its members and partners with a 'user agreement' that acts as a consent form. The agreement stipulates the terms of service between members and PLM. It provides a definition of a 'member' with guidelines regulating their conduct on the site. The user agreement is also a legal contract between PLM and its membership that outlines rights and obligations of members within PLM's environment. It starts with the following statement:

> "The following terms constitute an agreement between you and PatientsLikeMe, Inc. ("PatientsLikeMe"), the operator of www.patientslikeme.com (the "Site"). This agreement governs your use of the Site, both as a casual visitor and a registered member as described below.
>
> BY ACCESSING OR USING THE SITE, YOU AGREE TO BE BOUND BY THE TERMS OF THIS AGREEMENT. TO THE EXTENT YOU REGISTER ON THE SITE AS A MEMBER, THEN IN ADDITION TO THE TERMS THAT ARE APPLICABLE TO ALL USERS OF THE SITE, THE TERMS THAT APPLY ONLY TO MEMBERS SHALL APPLY TO YOU TOO." ("User Agreement", last updated November 18, 2009, http://www.patientslikeme.com/about/user_agreement).

The User Agreement stipulates that a member's use of the site must be strictly noncommercial and materials on the site are not meant to be taken off the site and shared with nonmembers despite the PLM's openness philosophy. That is, once user-generated content (UGC) is uploaded to the site commercial third parties must seek the permission of PLM in order to use and/or profit from it:

> "The Site content, including the Member Area and the content and information contained in the Member Area, is for the personal use of individual members only and may not be used in connection with any commercial endeavors. Organizations, companies, and/or businesses may not become members and should not use the Site without express consent from PatientsLikeMe. Members of PatientsLikeMe with individual commercial interests may not solicit or overtly promote their products or services within the Member Area. All content shared within the site is not for external use" ("User Agreement", last updated November 18, 2009, http://www.patientslikeme.com/about/user_agreement).

The agreement also clarifies the nature of ownership of user generated content on the site. User-generated content is defined as a 'submission' to the site's database and members retain copyright for content they produce using the site. But claims to ownership are limited due to the values associated with open-source informing PLM's openness policy and business model:

> "The Member Area includes community areas, such as forums and member areas, where members may post messages, images, and other content ("User Submissions"). If you are a member, you (or the author) owns the copyright in the messages, images, and other content you post in the Member Area, but by posting such content within User *Submissions to the Member Area you grant PatientsLikeMe and our affiliates the right to use, copy, display, perform, distribute, translate, edit, and create derivative works of your User Submissions, subject to the terms of the Privacy Policy*" ("User Agreement" emphasis added, last updated November 18, 2009,
> http://www.patientslikeme.com/about/user_agreement.

Although open-source does recognize authorship and ownership of digital materials, it does not recognize exclusivity of authorship and ownership. When members actively participate on the site, the ability to act as exclusive proprietors over their own private property is curtailed when PLM and its affiliates have almost unlimited right to use, copy, store, distribute, and sell member UGC.

The site explicitly prohibits commercial or anti-social non-human agents on the site:

> "You may not use any robot, spider, scraper, or other automated means to access the Site or content or services provided on the Site for any purposes. You may not post content on the Site that contains any viruses, Trojan horses, worms, time bombs, spiders, or other computer programming routines that are intended to damage, detrimentally interfere with, surreptitiously intercept or expropriate any system, data or personal information. You shall not attempt to make the Site unavailable through denial-of-service attacks or similar means. You shall not use contact information provided by members, or collect information about our members, to facilitate the sending of unsolicited bulk communications such as SPAM or SPIM or allow others use of your membership account to take such actions" ("User Agreement", last updated November 18, 2009, http://www.patientslikeme.com/about/user_agreement).

Any activities which compromise the security or commercial interests of PLM are not tolerated. In this context, PLM's environment is explicitly private. The information contained within it is reserved for immediate use by members and PLM's administrators who selectively make data available to business partners.

One area of divergence between conventional academic research and the research conducted by PLM is the notion of consent and withdrawal. In 'traditional' academic research, participants have the ability to withdraw consent from research *and* withdraw their data from analysis without penalty. Informed consent is a standard part of REB research protocols. Most often, consent must be administered to research participants before data is collected (with the exception of observations conducted in unambiguously public places).

Following the site's user agreement, consent was obtained from PLM's administrators *via* email prior to joining the site and starting research. Although I had permission from the site to observe and participate in the Mood Disorder Community, it was important for my own ethical commitments to announce my presence and inform members about the scope of my research and how to contact me should they want more information or wish not to participate. I introduced myself and my research by creating a thread in the site's forum. To introduce myself, my first step was to share information from my own biography – specifically, my childhood experiences of severe bullying while growing up as a gay male in an ethnic Italian-Canadian community, which resulted in years of low self-esteem, depression, anxiety, a diagnosis with irritable bowel syndrome at age 12 and a stress-induced ulcer at age 24[8]. The second step of introducing myself and my research interests to the Mood Disorder Community was to describe the aim of my research and how I would conduct myself as a researcher. I explained my aim was to capture the everyday realities of using Internet social-networking to obtain social support and how use of Internet technologies contributes to novel understandings and approaches to treating illnesses such as depression and anxiety. I explained to members that I wished to observe and participate in their discussions with their consent. I also explained what kinds of data I would not collect – their names, locations, conditions, avatars, doctors' names, or publish any screen captures of the site. Members welcomed me to the site and were extremely positive about my presence and research interests.

On PatientsLikeMe, the withdrawal of consent is not as clear as in conventional academic research. Paul Wicks warned me of this as we negotiated my access to the site. Since one of PLM's primary goals is the advancement of knowledge on several medical conditions through research, the withdrawal of consent including data is a contentious issue. PLM's user agreement does allow for the withdrawal of participation from research. Consent is withdrawn in the

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[8] The irony of this research experience was that upon conclusion, I experienced a radical shift in my perception of my own mental health – I felt mentally healthier than ever before despite my childhood experiences of anxiety, depression, and low self-esteem from years of severe bullying.

form of a 'self-initiated membership cancellation', which the following excerpt from PLM's user agreement shows:

> "You agree that PatientsLikeMe may, with or without cause, immediately terminate your PatientsLikeMe membership or limit or terminate your access to the Member Area or the Site without prior notice. Without limiting the foregoing, the following may lead to a termination by PatientsLikeMe of a member's membership and use of the Site: (a) breaches or violations of this Agreement or other incorporated agreements or guidelines, (b) requests by law enforcement or other government agencies, (c) a request by you (self-initiated membership cancellation), (d) unexpected technical issues or problems, and (e) extended periods of inactivity. PatientsLikeMe has no obligation to maintain, store, or transfer to you information or data that you have posted on or uploaded to the Site" ("User Agreement", last updated November 18, 2009, http://www.patientslikeme.com/about/user_agreement).

Members can have their accounts terminated by the site when they decide to withdraw consent but they must request termination by PLM. This situation is similar to traditional academic research, in which research participants can contact researchers to withdraw from a study. Unlike, traditional research in the social sciences, data on PLM cannot be easily withdrawn as the following exchange between a moderator and member shows:

> A: How does one delete a forum post? Possible?
>
> PLM Moderator: Hi, It is possible to delete content of a post, including the title if you are the creator of the thread. It isn't possible to remove the thread topic altogether.
>
> There is an option to edit your own post, once you have added it to the thread. Have a look at the bottom of your post and you should see the option to edit? Looks like you have found it as your post shows it has been edited.
>
> Pressing the edit button allows you to amend text and repost or to delete it, so that an empty post will remain. It is not possible to remove the post or thread completely.

> Hope that answers your question? Please let me know if you have further queries
>
> Thanks

A digital copy, whether visible or not to other members, may always exist within the site's servers and be accessible to those to PLM and its partners. Researchers have access to contributions by deactivated accounts up until the deactivation-date. That is, once user-generated content is submitted to the site, it has *permanence*. Permanence is achieved when user-generated content becomes *private property* as part of a database for research by private entities, such as research corporations. The permanence of data is a subtle difference between emerging research practices originating in the private sphere online and 'traditional research practices' conducted through 'traditional research institutions,' such as universities.

Members can terminate their membership at any time but their 'presence' and 'data' within the site do not disappear completely. When members choose to leave PLM, they become 'deactivated members'. When a member's account is deactivated, some of their 'data' (in this case, their profile and Mood Map) becomes inaccessible to other patient members but their forum posts and comments continue to be available to all members even after they leave the site. Although deactivated members may not be active participants on the site, they still retain a presence on the site within the memories of active members and on the medium itself. Their presence on the site leaves an "e-footprint" (Kleenmann, et al 2008:6) on the site through the content they produced while using the site. During my fieldwork, members often inquired whether others knew the whereabouts and status of members who left. I also encountered conversations between members no longer active on the site that occurred many years previous to my fieldwork period.

The permanence of data in virtual worlds also has implications for cyber-ethnographers. When research is mediated by virtual worlds, ethnographers must account for additional intermediaries who might access data during and *after* observation. The ease of locating online information using search engines means that the ability of ethnographers to fully protect the confidentiality of identities online is severely curtailed. I have done everything in my power to obscure identifying information in forum posts but my ability to protect members' identities ultimately depends on the strategies members already use themselves to protect their offline identities in virtual worlds. Members are highly aware that the information they post online can be viewed by a wide variety of audiences. Prior to my arrival, members were already adept to monitoring and controlling how much and to whom they disclose personal information on the site. Since forum threads are searchable using the site's internal search engine, readers might be able to link excerpts contained in this thesis to particular members on the site. This risk is present in every virtual world we choose to participate in and is thus not particular to PatientsLikeMe. My ability to protect members' identities also ultimately depends upon readers to recognize the personal nature of PLM's communities and resist the temptation to become virtual tourists. To infiltrate the site would undermine PLM's goal of providing a space where patients help patients. To be a virtual tourist transforms the suffering of PLM's members into an online spectacle – regardless of whether access to the site is inherently open to the public or not.

In order to protect the privacy of members on the site, I used capital letters to indicate the voices of different members. Each vignette from the forum indicates a single forum thread and I did not mix posts from different threads on the same topic. Although the same letters appear throughout my thesis, readers should not assume they represent the same speaker throughout the entirety of my thesis. The same letters were assigned for every example and indicate the sequence of voices rather than individual pseudonyms. If the same member responded more than once in the same thread, I coded their responses consistently with the same letter to avoid artificially inflating the number of speakers in a conversation.

Styles of Participation on PLM

In the above section, I describe the ability to withdraw consent on PLM as the ability to withdraw participation but not data. Before concluding my methods chapter, it is important to expand upon what participation means in the context of PLM because the style of participation of members affects their visibility within the site's forum. Scholars exploring identity in virtual worlds have noted how avatars – self-constructed representations of internet users – are "central to both immersion and the construction of community in virtual spaces" (Taylor 2002:110). Avatars constitute a form of *presence* "defined as the subjective experience of being in one place or environment, even when one is physically situated in another" (Witmer and Singer 1998:225, see also Steuer 1992). The materiality afforded by avatars enables us to 'be within' and 'experience' within virtual worlds. It is through presence that individuals on PLM cease to be 'lurkers' – invisible users who observe and consume content passively – and become active 'members' with identities or 'personae' on the site. Presence is moderated when members control their conduct in online spaces. The more members participate and disclose information about the self, the more the self and body becomes visible on PLM. Dumit (2003) refers to the act of identity construction using facts obtained through science and medicine as 'the objective self (39). Dumit argues:

> "The objective-self consists of our taken-for-granted notions, theories, and tendencies regarding human bodies, brains, and kinds considered as objective, referential, extrinsic, and objects of science and medicine. That we "know" we have a brain and that the brain is necessary for our self is one aspect of our objective-self. We can immediately see that each of our objective-selves is, in general, dependent upon how we came to know them. Furthermore, objective-selves are not finished but incomplete and in-process. With received-facts we fashion and refashion our objective-selves. (ibid: 39).

On PLM, materials imported onto the site by members serve as data that can be used to affirm or question one's diagnosis and assess the relative (internal) mental health of others in an online space. Furthermore, members on PLM not only receive the facts but also participate in the production and evaluation of facts over time through regular acts of disclosure on the site as research participation.

Anthropology's notion of personae comes from classical anthropologist Marcel Mauss' (1938) lecture on the historical and linguistic emergence of modern personhood (the reflexive-self later expanded upon by Anthony Giddens). I argue a new identity category is emerging because of Web 2.0 technologies: 'the profile'. The profile, made famous by social networking sites such as MySpace and Facebook, has become a standardized format for self-representation online within social media. Profiles have since moved offline as individuals increasingly include Facebook profiles and Twitter accounts to business cards and contact information. Increasingly, having a profile on a major social networking site is becoming as ubiquitous as having a phone number or social insurance number.

On PatientsLikeMe.com, I observed two overlapping styles of participations – passive and active. A passive style of participation refers to members who create a log-in in order to access the interior of the site but make little use of the site's tools or forum. Those who are passively present in online spaces are often referred to as 'lurkers'. Lurkers are people who watch but do not interact in online communities. In the context of PLM, there are members who join the site to access the forum and view member profiles without the desire to complete their own profile, update a 'Mood Map', or announce their presence in the forums by producing their own threads. Lurkers are known to exist in PLM amongst its members and administrators but their presence is difficult to detect and measure. During my observation period, some of these members emerged from lurking to become participants in particular forum threads. Frequently, these members would announce that they were present for long periods of time before making their presence known. Although the participation of lurkers is passive, they are still participants within the community. Lurking allows members to extract value from accounts of other people's experiences of illness and treatment without engaging in the production of new content.

An active style of participation refers to a high investment of time and level of self-disclosure on the site. Active participants have public personas in the forum and are often well-known among other members within the forum. The presence of members on PLM is directly related to how much they engage with the platform and how willing they are to disclose information about the self. Members create presence on the site by ‘importing’ personal information about themselves onto their Profile, Mood Map, and Forum posts using the site's ‘free-text fields’. A free text field refers to any element of PLM's interface that allows members to add text or images to the site and generate their own content by ‘filling in the blanks’. When members actively generating content, they become visible to others on the site – that is, they have a presence and a social persona within PLM's Mood Disorder Community. Presence is a form of representation in online environments through use and interaction with information technology.

Lurking as a Research Method

Based on my experiences as a researcher, being an active participant of the site requires a large investment of time, effort, and personal information. That is, cultivating a presence and persona online is a labourious practice – a particular kind of productive recreation. As an anthropologist, my role as a researcher switched between observer and participant depending on the context and phase of research. The only way members could assess my activities on the site was whether I chose to make my presence known through forum posts and private messages, which rendered my activity on the site visible. PLM's members expected me to have a particular kind of sustained engagement within the forum indicating my presence. I found that members inquired about my whereabouts when my participation was too passive and observational rending my presence invisible, meaning I was looking but not producing content. I would receive messages in my private mailbox asking how and where I was or whether I was still actively researching on the site. My passive participation in this instance was interpreted as a lack of presence despite being *on* PLM almost daily for observations.

Lurking is recognized as a unique methodological technique within the social sciences. Strickland and Shlesinger (1969) suggest:

> "The key difference between lurking and casual observation is that the lurker very self-consciously locates himself at the periphery of a social setting, pays strict attention to his degree of obtrusiveness in the situation and classified evidence thus obtained as specific to the anonymity of public or quasi-public behaviors" (248).

Lurking entails sensitivity to norms and expectations in cultural exchanges. Lurking also entails knowing when or when not to participate.

At many times, I felt unable to respond to the posts within the Mood Disorder Community. To do so would be to provide medical advice on living with mental illness that I do not have the professional authority to provide. To remain genuine, there were periods during my research that I felt lurking was the most appropriate and ethical way to participate on the site. As a lurker, I was still present and participating with PLM's members despite my occasional invisibility. Lurking allowed me to act a 'silent witness' to events unfolding in the lives of geographically distanced strangers. As a passive participant, I was still deeply affected by the accounts of members I read. As a result, I experienced something akin to what psychoanalysts refer to as transference (cf. Freud 1966). It is difficult, if not impossible, to be unaffected when reading testimonies of illness and stigma. I have tremendous respect for the people I encountered within PLM's Mood Disorder Community and the ingenious strategies they have developed to provide care for themselves and others, over the internet. Thus, even when acting as a passive participant, participation in PLM was still a 'felt' practice.

In the following chapter, I provide readers with an expanded introduction to PLM's interface and membership categories. I explore how members on the site cultivate presence and online personas as part of maintaining a member profile and personal electronic health record. I use profiles and PEHRs on PLM to reflect upon Rabinow's (1996) concept of biosociality.

Chapter Three: Reflexivity Built-In

The purpose of this chapter is to explore how biological identities are constructed through PLM's personal electronic health record system (PEHR) and profiles. In the Mood Disorder community, members are presented with opportunities to share information about themselves, their conditions, and their treatment experiences for the purpose of contributing to research advancing knowledge on various forms of mental illness. Through the maintenance of a member profile and PEHR, members make informational contributions to PLM's database as they use the site. The site's interface, particularly through profiles integrated with PEHRs, contains particular assumptions of patienthood and encourages members to think about their conditions as a series of quantified variables and scales that when aggregated constructs a visualized representation of their health and self over time. I argue that membership constitutes a form of biological citizenship on the site, that self-reflexivity is built into the site's interface and that the boundaries of biological citizenship are dynamic as the site continues to grow. In this chapter, I start with a discussion of avatars and how anthropologists conceptualize reflexivity and the representation of the self over the internet. I turn to a discussion regarding PLM's main features and categories of membership. I conclude with a reflection on how avatars representing each member's biological citizenship are produced on PLM.

Identity, the Internet and Avatars

On PLM, 'the profile' is a form of avatar that represents the persona and presence of individual internet users. As such, profiles are one of the primary ways that members can represent themselves and their experiences to others (along with forum posts) on the site. Since early theorization of the internet, scholars have explored self-representation and identity construction on the Internet. Howard Rheingold (1993) argues online environments such as Multi-User Dungeons (MUDs) – text-based fantasy games from the early internet – "are living labouratories for studying the first-level impacts of virtual communities... where magic is real and identity is fluid" (Chapter 5 p. 2). As such, anthropologists treat virtual worlds as field sites in which the transition from modernism to postmodernism and the effects of this shifting of identity can be studied (Poster 1990), including how flows of information are situated within historical, political, economic, and cultural contexts (Brown & Duguid 2000, Garfinkel 2000).

Sherry Turkle (1995) argues that "the anonymity of most MUDs ([in which] you are known only by the name you give your character) provides ample room for individuals to express unexplored parts of themselves" (185). That is, during the early 1990s, virtual worlds were sufficiently 'anonymous' and are able to provide more flexible adaptations of cultural norms, devoid of social stigmas, that inhibit the expression of particular aspects of the self in offline locales. Thus, identity could be constructed in online spaces through text, images, and hyperlinks that individuals choose for themselves without necessarily making reference to attributes deemed integral to offline identity (such as one's profession, birth name, appearance, etc). For Turkle, virtual worlds are "places where persona [the character one creates for themselves in online games] and self merge, places where the multiple personae join to comprise what the individual thinks of as his or her authentic self" (182). Turkle hypothesizes that identity is inherently fragmented within virtual worlds, and provide a social space where public and private perceptions of the self coexist and the 'true' self can be constructed reflexively. By this, Turkle is part of a tradition in the social sciences that sees online identity and sociality as experimental in nature, due to its relatively recent emergence.

Turkle's work builds upon Anthony Giddens' (1991) seminal work on self-identity in modernity. Giddens remarks that modernity and the self are marked by dynamism – "the self is not a passive entity, determined by external influences; in forgoing their self-identities, no matter how local their specific contexts of action, individuals contribute to and directly promote social influences beyond that are global in their consequences and implications" (2). For Giddens, the self in modernity is not contained to local expression and contexts. With the rapid rise of computer-mediated communications and global circulations of peoples, technologies, and ideas, individuals are increasingly visible and their actions can have effects beyond their local context. Thus for Giddens, the interconnectedness of humans in modernity renders thinking about the self impossible without considering a global sphere of 'others'.

Unlike Turkle, Giddens' account of the self is achieved not through existential modalities of self-actualization popularized by humanistic psychologists such as Abraham Maslow (1943) and Carl Rogers (1954, 1961). Instead, the self is achieved through the management of risk *via* self-control and repression, a reflexive monitoring aimed at avoiding risk factors that might impair the mind, body, or one's lifestyle (Giddens, 1991). Professional emphasis on risk factors has resulted in the emergence of preventative medicine (i.e cancer screening and free HIV testing) as individuals willfully take responsibility for keeping track of their health to avoid possible future impairment. Rabinow reaches a similar conclusion, albeit through the notion of the Care of the Self (cf. Foucault, 1978). Giddens argues that identity in modernity is subject to instrumentalization, in which surveillance and control of human populations can be achieved through "a sum of diverse factors amendable to analysis by specialists" (1992: 242). Surveillance and control are not exerted upon individuals in a 'top-down' fashion. Instead, Giddens hypothesizes that in modernity, the avoidance of risk is defused amongst individuals and power is decentralized and flows amongst networks of individuals.

Contemporary crowdsourcing and social networking continues this tradition of thinking of the internet as a living laboratory by treating social spaces on the web as databases and repositories of folk knowledge[9][10] or common sense[11] from which data can be extracted and used for the betterment of human societies. Betterment occurs when experts better understand how lay people use online health information to understand their world and make medical decisions. This assumption is central to the operation of PatientsLikeMe.com. PLM acts as a mediator between patients, their data, and researchers. The platform is itself a laboratory of identity in the metaphoric sense, as implied by Rhiengold, but also in a literal sense when participation in the site is monitored and quantified as empirical data. PLM's interface guides members through the process of representing and visualizing illness experiences and provides a space in which

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[9] See McCombie (1987) for a great analysis of differences between expert and lay persons use of common terms to distinguish between influenza and gastro-intestinal parasites colloquially called "the flu".

[10] See Smith et al (2008) for a review of folksonomies within PLM.

[11] Gramsci suggests "every social strata has its own 'common sense' and a 'good sense', which are basically the most widespread conception of life and man. Every philosophical current leaves behind a sentiment of 'common sense': this is the document of its historical effectiveness. Common sense in not something rigid and immobile, but is constantly transforming itself, enriching itself with scientific ideas and with philosophical opinions that have entered ordinary life. Common sense is the folklore of philosophy, and is halfway between folklore properly speaking and the philosophy, science, and economics of the specialists. Common sense creates the folklore of the future, that is as a relatively rigid phase of popular knowledge at a given time and place" (in Crehan 2002: 110).

members can think about their illness experiences in relation to those of others. The remainder of this chapter provides a close look at how identity is conceptualized within PLM's patient platform and how representations of the self are generated through careful self-monitoring using the site's Forum, Profiles and Personal Electronic Health Record system known as the Mood Map. I discuss membership categories on the site and conclude with a discussion of how biosocial reflexivity is built into the site's interface.

Introducing the Mood Disorder Community: Memberships and Identity Categories

The Mood Disorder community currently includes (but is not limited to) individuals suffering from several forms of depression, bipolar I and II, PSTD, anxiety, eating disorders, addiction, schizophrenia, schizoaffective disorder, and borderline personality disorder. At the time of writing, the Mood disorder community contained over 20,000 members, mostly from the United States, Canada, Australia and England. English was the only language I observed in use in the forums. Members can identify as either female or male. The community contained a number of members across age categories, including youths (15-18 years of age), adults (19-50), older adults (51-64) and as well as seniors (65+). PatientsLikeMe collects a number of statistics on its membership but I was unable to find a demographic breakdown of the community's members along traditional categories of age, sex, sexual orientation, gender, ethnicity, education, or socioeconomic status. Instead, the site provides a demographic breakdown of symptoms and treatments (i.e. pharmaceuticals, medical devices, and therapies) reported across the site's total 100,000+ members. In a sense, traditional identity categories – such as age, gender, or sexuality – are collected but deemphasized on PLM, while medically-oriented conditions and treatments are emphasized as the key attributes uniting and or differentiating members and communities on the site. The lack of demographic information available from the site makes it difficult to comment on the site's membership in regards to the digital divide (Milner 2001, Rogers 2006) using qualitative methods. Members did identify as both women and men ranging across age categories from teenagers and adults to seniors, but without systematic sampling and verification of the accuracy of self-reported ages and genders, this observation is only an impression. Although a number of members within the Mood Disorder Community disclose their professions and level of education, socio-economic status and ethnic diversity on the site was impossible to assess ethnographically without interviews.

In this thesis, I use the terms 'patients' and 'members' to describe the people I encountered using the site who are not (known) employees or clients of PLM. Official language used by PLM within its terms of agreement refers to site users as 'members' – community members belonging to a condition-based grouping within the site and members of an overarching PatientsLikeMe community by virtue of being actively registered site members. For many, to classify the people I encountered on the site as 'patients' may seem problematic if 'patient' implies a relationship of dependency and directed-care by an medical expert - for example by a physician, a nurse, or a therapist. Patienthood on PLM can be understood in two ways: as a status that is 'prescribed' by experts in the 'actual world[12]' and a 'self-ascribed' status that is reflexively-achieved through use of the site. By prescribed patienthood, I mean that site users come to the site with diagnoses already. In the Mood Disorder Community most of the members I encountered claim to be under the direct care of at least one expert before entering the site – most often already under the care of a psychiatrist (referred to within PLM's Mood Disorder community as a "pdoc"), a psychologist, a therapist

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[12] Boellstroff (2008) prefers the term "actual" to "real" in order to escape epistemic assumptions that virtual spaces and identities are inherently "unreal" due to the simulated nature of spaces and bodies online. Boellstroff reminds social scientists that distinctions between the online and offline is artificially created in theory when the internet has a materiality as a network of servers, fibreoptic cables, personal computers and users situated in the materiality of space and time on Earth. Although I agree with Boellstroff that distinctions between the online and offline is theoretically artificial, I believe social theory requires a better explanation of the materiality of online spaces necessitated by consequences arising from when user-generated content moves from online locales to offline places – such as the desks of insurance companies and employers – and has real material (i.e. financial) consequences for those who use the internet. What is important to note at this point is that digital materials circulate and move to and between public and private spaces. Online materials cannot move themselves, thus when individuals go online to obtain information, they extract it from one space and context into another. Consequences of online disclosure can be realized in online spaces such as social hostility, rejection, and ejection from online locales but these consequences are normally contained to particular spaces online. When online information leaks offline, the consequences are no longer contained online and affect multiple social spheres. For this reason, I believe that the demarcation of online and offline spaces, although minor, is still important for understanding how online spaces and practices are embedded in offline places and norms.

(referred to as a “t-doc”), or some other sort of medical professional who deals with issues of mental health, like a primary care physician (referred to as a “PCP”). PLM’s staff estimates that up to 94% of users joined the site with at least one diagnosis (Wicks et al 2010).

Patienthood on the site becomes a self-ascribed status when new members are asked to provide details of their diagnosis and previous medical history as part of maintaining their personal Electronic Health Record. Users make their own claims of having particular conditions without these claims necessarily being verified by the site’s administrators or an expert before access to the site is granted and participation begins. Members are already ‘patients’ who join the site to connect with others ‘patients’ and share their ‘patient experiences’ through self-reflection using the site’s tools and forum. PLM is far from a diagnosis ‘free-for-all’ and the site’s role in healthcare is seen by its users as supplementary to the medical care they receive in the actual world from experts.

Other Members on the Patient Platform: Caregivers and Guests

In addition to patients, membership to the patient platform is open to 'caregivers' and 'guests'. Caregivers are persons who join the forum on behalf of or in addition to a family member or friend. Caregivers have full functionality of the site's tools and can contribute their own health information or input health information on a Mood Map on behalf of a loved one. Caregivers provide a unique insight on illness because of their 'insider-outsider' status in the patient experience. Caregivers provide each other with support and community through the experience of caring for others, which many express as being physically and emotionally difficult. During my observation period, I encountered a number of caregivers who joined the site because they needed support from others individuals in similar situations of dependence and family illness. Many entered the site as caregivers and became 'patients' themselves once they started tracking changes in their own health using the site's tools. That is, caregivers sometimes transitioned from seeing illness as something outside of their individual body (affecting the body of another) to something also within their bodies.

Separately, guest accounts are open to researchers who are not employees or partners[13] of PLM. As a consequence of my presence in PLM, and in a data 'scraping' event that will be discussed in chapter five, guest accounts became 'Guest Researcher' accounts to clarify the purpose of our presence in PLM. Guests have accounts with limited functionality. Guest membership includes a profile, access to other members Mood Maps and access to the forums, symptoms, and treatment tabs on the patient platform. Guests cannot keep track of their own health and have no PEHR functions. As guest researchers, PLM defines us as outsiders to the communities we observe. The functionality of our accounts creates a boundary and visibly marks us on the platform.

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[13] In addition to patient-social networking, PLM is highly invested enabling patients to participate in the production of knowledge as a way to improve patient outcomes. The information PLM collects is shared with select "partners", who at the time my fieldwork included 1) an assortment of patient groups and voluntary health organizations (Accelerated Cure Project for Multiple Sclerosis, Myelin Repair Foundation, National Kidney Foundation serving New England, National MS Society, Central New England Chapter, and Parkinson's Unity Walk), 2) academic research groups and teaching hospitals (ALS Untangled, Forbes-Norris Pacific ALS Centre, NEALS Northeast Amyotrophic Lateral Sclerosis Consortium, Oxford University MND Care & Research Centre, Penn State Milton S. Hershey Medical Center, The Pew Internet & American Life Project, The Robert Packard Center for ALS Research at Johns Hopkins, The School of Library and Information Studies at the University of Wisconsin), as well as 3) makers of pharmaceuticals and medical devices (23andMe, Acorda Therapeutics, Avanir Pharmaceuticals, Novartis Pharmaceuticals Corporation, Sanofi-Aventis, and UCB)

Is PLM 'Medical Advice' or a 'Medical Service'?

It is important to make clear that PatientsLikeMe does not offer diagnosis of any sort and therefore, people who use the site are not patients *of* PatientsLikeMe.com, although they are referred to as 'our patients' in the site's policy documents. On the bottom of each page is a copyright statement which asserts that information on PatientsLikeMe.com does not constitute medical advice. This disclaimer is expanded within PLM's user-agreement:

> "ALL OF THE MATERIAL PROVIDED ON THE SITE, SUCH AS TEXT, TREATMENTS, DOSAGES, OUTCOMES, CHARTS, PATIENT PROFILES, GRAPHICS, PHOTOGRAPHS, IMAGES, ADVICE, MESSAGES, FORUM POSTINGS, AND ANY OTHER MATERIAL PROVIDED ON THE SITE ARE FOR INFORMATIONAL PURPOSES ONLY AND ARE NOT A SUBSTITUTE FOR PROFESSIONAL MEDICAL ADVICE OR TREATMENT. ALWAYS SEEK THE ADVICE OF YOUR PHYSICIAN OR OTHER QUALIFIED HEALTH PROVIDER WITH ANY QUESTIONS YOU MAY HAVE REGARDING YOUR HEALTH. NEVER DISREGARD PROFESSIONAL MEDICAL ADVICE OR DELAY IN SEEKING IT BECAUSE OF SOMETHING YOU HAVE READ ON THIS SITE.
>
> IF YOU THINK YOU MAY HAVE A MEDICAL EMERGENCY, CALL YOUR DOCTOR OR 911 IMMEDIATELY. PATIENTSLIKEME DOES NOT RECOMMEND OR ENDORSE ANY SPECIFIC TESTS, PHYSICIANS, PRODUCTS, PROCEDURES, OPINIONS, OR OTHER INFORMATION THAT MAY BE MENTIONED ON THE SITE. RELIANCE ON ANY INFORMATION PROVIDED BY PATIENTSLIKEME, BY PERSONS APPEARING ON THE SITE AT THE INVITATION OF PATIENTSLIKEME, OR BY OTHER MEMBERS IS SOLELY AT YOUR OWN RISK." ("User Agreement", last updated November 18, 2009, http://www.patientslikeme.com/about/user_agreement).

Participation on the website is not, in other words, to be conceptualized by its users as a replacement for directed care by experts. So, in this sense, PLM is not and does not represent itself as a service provider for medical care. The following exchange between a site user and a moderator (a paid employee of PLM responsible for improving customer experiences and site functionality by incorporating user suggestions into the site's design). This exchange shows one of the ways in which a boundary is drawn on the site between information exchange and the provision of care.

> A: This [list of important terms and common language used on PLM] is good, this is good! I had brought up the psychiatric/psychological acronyms problem on [moderator's username] thread about improving PLM. So I am happy to see alittle [sic] bit of an explaination [sic] of these abreviations [sic]. Although I would like something abit [sic] more thorough...ie: defining the different types of bipolar illness. I don't know....maybe I need to have a sit down with some psychology/psychiatry texts.....BIG SIGH. I am not much of a reader these days (except for PLM threads)....I don't have much of an attention span for reading technical stuff.
>
> Site Moderator: PatientsLikeMe doesn't really tread into providing definitions or explanations of diseases beyond our very basic glossary. But if you wanted to start a thread (or evolve this one) where everyone could contribute their more detailed definitions and resources, that would be a good way to use the forum to produce really useful collective information.

In this exchange, one can see that differences exists between what members can do on the site compared to what employees of the site can do. Employees cannot provide any sort of definitions or produce its own information about particular conditions beyond a general, common-sense way. To do so might cross the line of providing health information, diagnosis, or care in a way reserved for recognized medical experts. On the other hand, site users are not constrained in the same way that employees of the site are. As 'lay-persons' the site's users cannot be mistaken as 'providing a medical service' in the same fashion. This distinction enables site users to produce and share this sort of information and advice without the same consequences PLM might face if they employees acted as 'lay-persons', 'naively' sharing information and making recommendations.

Although PLM does not provide a 'medical service' to the people who become members to use the site's platform, PLM does provide informatic 'tools' that site members find therapeutic and medical in nature. Therefore PLM is a service provider, but not of 'medical' services. The site appears to provide its members with a series of 'services' or tools 'in service' to them. The site provides members with a 'membership' that entitles that member to a 'profile' and the ability to participate in 'forums' on the site and a personal Electronic Health Record as part of the site's 'tools' for members. Most importantly, the site provides its members with a means to come in contact with researchers and participate in the production and consumption of information through social networking and their use of the site's platform through a series of branded 'opt-in'[14] services for researchers.

During my observation period, I witnessed many uses of the forums from off-topic (i.e. the weather, reviews of new movies and popular music) to those which appeared educational (i.e. information cross-posted from journals and popular press articles, the review of government documents and insurance policies), and those which appeared very medical in nature (i.e. those which resembled group therapy and harm-reduction). In this respect, members 'medicalize' the site's interior through their use of the site's platform and provide services amongst themselves at the peer-level that PLM cannot provide as a service institutionally, due to offline regulation of health information and the medical industry at large.

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[14] As a corporate entity, PLM acts as a data-broker who mediates the boundary between biomedical corporations, researchers, and research participants. Mediation occurs through a series of branded PatientsLikeMe research tools that enable "direct-to-consumer research" by providing partners with tailored data reports aggregated by PLM's staff or by allowing partners to access members directly using the site's platform to collect data. During my fieldwork, these services included: "PatientsLikeMeInsights"; a data service that enables partners to access aggregated and anonymous standardized data "reports" securely and privately from the site, "PatientsLikeMeLeaders"; a service that allows researchers to organize and administer focus groups with PLM members within the site's environment, "PatientsLikeMeLens"; a survey service that allows partners to create and administer surveys among the site's members using the site's platform, and "PatientsLikeMeListens"; a keyword monitoring services for pharmaceutical corporations interested in member perspectives of their brands and products. During my observation period, I did not access or use these services.

PLM's Interface: the Forum, Profiles and PEHRs

The Forum

The 'forum' is the main public sphere on the site and area where visible social interactions occur. Forums are composed of 'threads', that is original topics of discussion made by users and the responses from other members to that topic indexed in a chronological order from oldest to newest response. Threads are organized by the time date they were created and the date they were last responded to. Threads that are most recently created or most recently responded to appear at the top of the forum and are most visible to members. The term 'forum', a colloquialism for synchronous bulletin-board message systems references the Greek polis. Forums are conceptualized by social scientists (i.e. Rheinhold) as inherently public spaces that cradle democratic discourse and civic participation. PLM's public messaging system is conceptualized as a free space for open expression and discussion amongst members. Each forum thread is tied to the identity of the author. Beside each forum post is an abbreviated version of the contributor's profile and PEHR that acts as a signature and identifies transitions between speakers.

Threads – topic-oriented discussions used to organize space within the forum (i.e. conversations following a single 'thread' or topic) – exist on a number of subjects and can be used in many different ways by different members. The majority of posts by members contain questions requesting feedback from users about particular symptoms, treatments, or experiences related to mental illness. Members respond to questions by sharing their own experiences and cross-posting resources and health information found on the web such as recent studies and excerpts from medical journal articles, and relevant headlines from the news. It is not uncommon to see members ‘copy and paste’ entire passages from other websites and documents augmented with their own interpretations and commentaries in their response to questions asked by others about particular conditions and treatments. Within the forum, members obtain individualized and personal responses from other members as a form of informational social support. Members are able to provide each other with advice and insight varying in scope from very generic and general to extremely detailed, referenced, and lengthy personal responses. Cumulatively, forums becomes a database of collected and collective ‘folk’ wisdom[15] about bodies, the mind, and health, from firsthand ‘knowledge’ garnered from experts and authoritative sources on the web, as well as self-produced by virtue of personal experience.

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[15] This topic was explored within PLM by Arnott Smith and Wicks (2008) who argue that lay use of medical terminology does not always coincide with the use of professionals. Frequently, members interchange symptoms with conditions (and vice-versa) or resort to colloquial names that differ from the language used by medical professionals. Arnott Smitth and Wicks argue that 43 percent of symptom and condition terms used by PLM’s members do coincide with use by experts, bolstering PLM’s claims as a useful resource for researchers.

Profiles as Avatars

Each person who joins the site becomes a 'member' and each member has a dedicated profile page, which publicly represents their self and their health in the forums. Profiles are attached to a unique set of log-in credentials that members create when they sign up for their free account in order to gain access to the site. A log-in consists of a unique username and password created by members in order to access and use the patient platform. Profile pages contain a variety of information about each user and users can remove, add or update the content to their profile at their whim.

In the context of PLM, creating a profile is a simple and standardized procedure. Members simply 'fill in the blanks' provided by PLM with their own content in the form of text and images. Information on user profiles includes things like their username, gender, age, location, condition history, photos and an 'about me' section for a personal message or biographical blurb from the user. Each profile contains a number of other site-specific demographics collected about the user, including the user's join date, the last date the user logged onto the system, last time the member updated their profile, the number of posts made by the user in the forum, and a 'thumbs up rating' indicating the number of times other members have found their participation and forum content helpful.

Mood Maps: Personal Electronic Health Records on PLM

In addition to profiles, PLM offers its members a type of personal Electronic Health Record known as the 'Mood Map' [16] within the Mood Disorder community. At the time of my fieldwork, each of PLM's communities had access to some form of charting software but the information collected within each community was different. The Mood Map allows users to record the symptoms they experience, treatments they engage in, and side effects they may encounter over time as well as an account of their diagnostic history. The site uses this tool to collect information from members through a series of structured questionnaires based upon standardized psychological measures employed by medical professionals in the mental health field. The tool is called a *map* because it *visualizes* each member's responses over time in the form of graphs and charts.

Users are encouraged to include diagnosis and treatment information retroactively in addition to after they join the site. Users can print out the information contained in their Mood Map for caregivers and medical professionals. The printed form of the Mood Map is called a 'Doctor Visit Sheet'. Many members highly value the Doctor Visit Sheet and Mood Map because of

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[16] For diagrams of what a PEHR or profile looks like, Polk's (2010) MA thesis on Boundaries-Making in PLM contains many wonderful examples. Due to the sensitive nature of these elements of the site and my ethical agreement with the site's administrators, I could not include images.

their ability to visualize and represent illness experiences over time as one member comments,

> "When I had my tdoc appointment today I brought in the doctor's chart that we can print out in PDF. I know I cycle and all, but it was really amazing to see my cycles. It blew my mind. My instant mood corresponded with my level of functioning and my destress [sic]. For me it is one thing to experience it but another to actually see it all match up."

The Doctor Visit Sheet allows users to integrate their record-keeping practices on the site into the care they receive from offline medical experts. Doctor Visit Sheets and PLM's Mood Map has the added effect of materializing illness or suspicions of illness through practices of visualization, that is – in their printed form, Doctor Visit Sheets provide members with a material record of internal processes such a stress, depression, and anxiety that patients can use to 'prove' their experiences to experts. Reflexively, when documented systematically and represented as a series of graphs and tables, illness becomes 'real' and 'realized' when a member sees and becomes cognizant of patterns in their moods and symptoms through the aid of visuals and a routine of self-disclosure. On a few occasions, I observed testimony of members who found that printing materials from the site, including their journal thread and Doctor Visit Sheets helpful when trying to obtain a diagnosis from a professional off the site. User-generated content in these contexts served as materials that could validate a member's suspicions that they did in fact have a mood disorder or that their previous diagnosis was inadequate.

During my observation period, the 'Mood Map' was a software tool specific to the Mood Disorder community. After my fieldwork, this tool was extended to all members on the site along with tools from other areas of the site that were popular (i.e. the Quality of Life scale from the Organ Transplant and Epilepsy communities). This extension of software tools between communities on the site was part of a series of changes in how patienthood is currently conceptualized by PLM's designers. The site's platform provides members with a structured and standardized template of patienthood that members can personalize by filling in with their own information. The collection of demographic information and medical histories through profiles and Mood Maps is standardized in the site's interface, which has the effect of boosting PLM's credibility as a source of data. Automation of identity and data collection helps researchers rule out possible confounds associated the individual differences and data collection techniques of human researchers. These standardized profiles and records also constitute the primary means through which bodies and identities are represented on the site to others and to researchers.

Member Input on Profiles

Over various points in the Mood Disorder Community's existence, PLM's staff has requested feedback from members regarding the content of member profiles. Members provide PLM's staff with suggestions on how to improve profile features and visual outputs, which PLM tries to incorporate when possible. Looking at the kinds of suggestions members provide about the way profiles are structured and displayed provides an interesting vantage point from which to view differences between how members conceptualize the experience and relevant variables in experiences of mental illness and the conceptions of the site's staff and programmers. A thread titled "Hey! help design the site: What would you want to add to your profile?", provides a clear example of such differences. The thread starts with a post by a former moderator (who left PLM before my fieldwork):

> Moderator: A lot of users have asked for new ways to record and talk about different events in their lives within their profile, when they are ill, or experience a loss, or go through a procedure, or get a new house, or have a child, all types of events and changes.
>
> We're trying to add better functionality for you to add these kinds of events into your profile so that the profile reflects your whole health and you can show other people what experiences affect how you are doing and feeling. SO [sic], I'm working on a list of events that could be added and annotated in the profile and would love to know what you think. What kinds of things would you like to record? How does the list (below) look to you? What am I missing?

Thank you! [Moderator's name]

Hospitalizations
-Surgical
-Non-surgical
-Psychiatric
-Rehabilitation

Other medical, surgical, or psychological events
-Injuries
-Accidents
-Illnesses
-Unexplained problems
-Procedures
-Tests
-Psychotherapy

Events in your personal life
-Change in relationship status
-Change in financial status
-Change in family situation
-Birth of a child
-Birth of a grandchild
-Happy events
-Major loss or adverse event
-Change in work situation
-Change in school status
-Major anniversaries

External events
-political events
-current affairs"

A: These all sound good. Maybe aquisition [sic] and death of a pet?

B: Other medical, surgical, or psychological events: Menstrual period.

C: This looks really promising and well thought out. Suggestions to add:
--move/relocation
--fight/argument with [blank]
--visit to/from [family]/[other]
--travel/vacation

B: [C] - I like the argument suggestion. Visit, too, as I could use that to make a note of when I spent long periods of time out of the house that exhaust me.

D: I would like to see a journal. Journaling has been very helpful in my therapy process. I would like to see what I'm thinking about when I'm depressed or anxious and then what I'm talking about when I've come out of that.

There is also a wealth of knowledge in books that can help people too. So how about a place to put books you have read that have helped, oooh [sic] you could put in websites too.

E: More indepth [sic] space to put your diagnosis would be good. Also if you where [sic] able to search for people who had the same sort of diagnoisis [sic] as you. (sorry if this is already about somewhere, only just finding my way around the site.)

F: I agree with [D], an online journal would really help me... I can't seem to write on paper so online is perfect!!

G: Journal, tick boxes for when an "as-needed" med has been taken.

Tic boxes for activities...yoga, walking, have kept house clean...

MENSTRUAL CYCLE, sub [sic] parts that would be helpful to me are: cramping, spotting. For others, particularly the women who will come to this board while going through menopause: flooding, vaginal dryness, hotflashes [sic]. Hormones play a big part in mood. This site is for mood. It is beyond silly to ignore the reality of a very good portion of users.

H: I don't think that "adding events" to my profile will do much considering those list of events really don't cover a lot and are very general. As others have said, I would rather blog or journal my events (or comment on my events) so that things are more specific. I would also like for a way that other members to comment on our events to express support.

I: [blank post – member is deactivated]

J: 1. menstrual and or female related problems

2. men related problems

3. natural disaster
4. death
5. divorce
6. marriage

i guess those 2 could go under change in relastionship [sic] status but u want to know what the old verus [sic] new status might be

7. a new dependant who is not a child
8. pregency [sic]
9. same day surgery

K: I can has age [sic] and sex please?

It would also be nice to be able to add what my relationship is to my patient(s). I think it would be really informative to know things about patient/caregiver relationships like whether it's father/son, son/mother, girlfriend/boyfriend, and 20/40, 35/16, 67/65.

L: Uh...we keep saying it...menstrual cycle. I use the 'Cycle Beads' (which crack me up because I also hand them out as an aid to planning conception and birth spacing...and I've got NO such plans myself) but another way to record that cycle would be great.

I agree with [K], it would be great if there was more info about the caregivers--I think it might help them get more useful information from other folks on the forums. They could definitely be optional, but it might be useful to have them.

I have recorded my hospitalizations as 'inpatient' treatment, but because they were so short (4 days, 5 days) they show up on my long term profile as thin red lines. On further reflection, I think these emergency hospitalizations / stabilizations are probably very different from planned inpatient treatment. (And I seriously wish I could get some of that planned inpatient treatment...like, I wish i could AFFORD it...I have a very funny story about my therapist referring me to McLean...me calling my insurance and McLean...and then me ending up in the ER hysterical because of that set of phone calls.

I started using blogger to keep a mood journal (as in 'started,' I mean like 'yesterday'). You can see it here...no "a" in black dog because that's a running club in the Twin Cities! I did ponder the irony there, people in the twin cities no doubt see a lot of the black dog.

Here's the problem...sometimes major events don't strike me as all that major. So, for instance, my aunt died in March and I had to spend a week with my family. It was awful--they drank a lot and were verbally abusive. I had just reached a point in therapy where I was talking about some heavy stuff from my childhood and it really was a bad time to have to go home. BUT, it wasn't like an immediate relative died, so I didn't think about it as a major event. I'm not sure I'd write about it without prompting.

Therefore, categories to tick might be good for me. On the other hand, having a journal option might encourage me to discover it on my own (or might encourage others to point it out to me.)

I think what I'm trying to say is that we need to find a balance of things that work for a wide range of people. (Well, duh, I guess.) So...maybe we need both categories to tick and a place to elabourate, or a place to write and then come back to the categories. Another way to generate categories might be to include an "other" and when the admin folks start seeing the same thing come up in "other" a lot, they could add it as a category. (So, if people keep writing "Other---mother-in-law-visit" we could include that...my "other stressors" would include baby showers...one of my least fav [sic] things. I like my friends' babies, but I can't stand baby showers because they make me feel like a bad person for not wanting kids.) [sic]

M: Whoa. Go slow on this one. The stressful events are much better as a generality. They are so subjective that there is absolutely nothing to be gained by adding specificity.

For example, if your brother dies and you were close, that's devastating [sic]. On the other hand, if your brother dies and you have never met him, that's another thing.

Don't muddy the water, please. This site does a couple things really well. It allows us to track our moods in a simple way and it collects the patients [sic] eye view of treatment and recovery. Things like political events and current affairs are just not relevant.

Specific treatments are good additions. Hospitalizations would be a useful addition. Child-hood sexual abuse might be helpful as well.

I would avoid drawing people to site whose depression isn't organic. If the etiology can be captured by a traumatic life event it doesn't help anyone. In other words, the people who feel bad because their dog died or because they got a serious disease are fundamentally different than those of us who have major mood issues that are independent of trauma. Of course, our illness can be re-activated by trauma, but it's still very different than normal sadness.

It's a different treatment course, different recovery timeline and requires different advice. It will reduce the salience of the "patients like me" philosophy.

Also, their [sic] is no need for such a service. There are plenty of support groups and traditional counselors that are far more beneficial. People in such a situation are also likely to get an appropriate referrel [sic] from their doctor or clergy.

This has nothing to do with bipolar disorder, major depression, bpd, ocd or any other DSM worthy pathology.

Stressful situations do trigger diathesis - but they are best labeled as "stressful situations."

Also, I understand that a major reason to record certain things on the profile is to facilitate data mining. The more bits and pieces you add to profiles the more difficult that will be. It will dilute meaning in aggregate - not enhance it.

If I was going to add a major feature it would be a method of presenting the accumulated wisdom of the forums.

Right now information sort of disappears into the void once it goes a few pages back on the forum pages. I can think of a couple solutions to this. One, you could use a "search cloud" feature as a header to each page. Traditionally these use a "heat map" approach - making the in-demand links larger.

The other is a Wikipedia like portal where we can edit and update sections using a community initiated information architecture. (yes that's wordy, but I swear it means something)

> What makes this site different that others are that we have topical, focused discussions that are grounded in personal experiences. We see treatment from the inside out, and that's valuable both to us and too the profession.
>
> Paul Wicks: Love the "cycle beads" concept!!!
>
> Please keep the ideas flowing; I can say that in any set of feedback ideas there will usually be three piles of ideas:
>
> 1.) Ideas we've thought of (or others have thought of) that we're in the process of implementing but which would still benefit from further input or refinement
>
> 2.) Ideas we'd love to do but either haven't assessed their priority or found a good solution and we're looking at weaving them into the plan
>
> 3.) Completely new ideas that make us slap our foreheads and say "Why didn't I think of that!?
>
> Please keep 'me coming, and we hope very soon to be able to turn some of these into reality.
>
> Paul

The above dialogue shows how PLM's staff actively solicits a patient perspective of mental illness and attempts to incorporate feedback into the site's interface. The suggestions made by members vary but a number of patterns emerge. Members ask to have gender and reproductive health recognized as a factor that impacts mental health. Members request the ability to track their offline relationships with others – such as with friends, family members, and dependents. Members also request the ability to track 'stressors' – everyday situations that affect members' moods – as a way of contextualizing changes in their everyday mental health. That is, some members treat their Mood Map as a practice of remembering through recordkeeping *qua* journaling, reading lists, and the recording of major life events such as deaths, marriages, and the dreaded 'mother-in-law visit'. The visualization of symptoms and corresponding major life events, as well as environmental stressors, provides members with a medium to reflect upon the self and their health both subjectively, as they experience life, and objectively, as they distance themselves from their immediate experiences by looking back in time *via* their record.

What is particularly interesting about this thread is the way some members differentiates what is considered 'useful information'. The usefulness of certain kinds of information over others contains implicit assumptions regarding the origin of mental illness. One member disputes whether environmental stressors should be included at all by invoking a notion of 'organic depression'. At the core of this invocation is a debate whether mental illness is a biological phenomenon – as chemical or physiological malfunctioning of the brain – or a response to environmental phenomena, such as unequal social structures and material conditions. Implicit in this debate is a distinction between the normal and abnormal, i.e. by proxy of sadness. One member argues that trauma and environmental stressors can exasperate the symptoms of depression but the sadness experienced by 'organically' depressed people is fundamentally different from 'normal' sadness experienced by those without physiological or chemical malfunction. The distinction is viewed by this member as potentially polluting the data collected by PLM and reducing its usefulness to researchers by adding extraneous variables.

Reflexivity-Built In

On PLM, members are asked to look into their own interiors and understand their conditions as a set of measurable variables. As such, identity formation online is an introspective self-referential practice, in which a reflexive image of the self and an individual's mental health can be revealed. Reflexive images of the self and health are constructed through oral articulations of experience in addition to use of sophisticated visualization tools, as the following comment to another member demonstrates,

> On recognizing triggers...I think being a member of PLM has vastly helped me identify my triggers and stressors. In particular, the instant mood function has been VERY helpful. I always step back and ask myself why I'm choosing a particular option, and that helps a lot in terms of figuring out stressors, such as the fact that bright fluorescent lights are causing my really bad tension headache and thus pissing me off, and that's why I chose "bad" then (true story, loll [laughs out loud]). Also, over time, looking at the mood maps can help you identify stressors/triggers as well. I know for me, when I look back over my mood maps, I'm able to say, "Weird, I was severely anxious for about 4 days in August but then it went away on X date...what was happening? Oh yeah, my (now ex-) boyfriend came to visit for exactly 4 days, and left that day my mood started to improve!" So then I knew that, for me, the ex was a trigger/stressor in my life.

PLM's platform provides members with the terminology and tools required to translate everyday experiences into a quantitative snapshot. Turkle (1995) sees identity construction online as tied to the 'modernist computational aesthetic'. The modernist computational ethic hypothesizes universal and knowable truths about bodies and personhood can be revealed through systematic investigation of the self using techniques of reason and logic characteristic of the scientific method and modernity (18-19). This resembles Rabinow's (1996) assertion that identity in modernity is deconstructed into a sum of overlapping variables. Similarly, programming languages encourage people to think about what they want the computer to do by breaking down tasks into a series of logical sequential steps. The effect is that any function of the computer can be broken down into its underlying hardware components and source codes, which provide the computer with an inherent rationality and logic. On PLM, members need not know sophisticated programming languages and web design or statistics in order to construct an image of their mental health as a series of variables. Quantified reflexivity of mental illness is 'built-in' the interface.

On PLM, the bodies of members are constructed through repeated acts of self-disclosure, or testimony, through the site's profile and PEHR system. Disclosure is automated and structured so that acts of disclosure can be compiled and compared across time and across members. An 'objective' image of the self can thus emerge by averaging a member's responses to questionnaires. The automation of data collection and standardization of representation through the use of rigid templates makes identity and the physical body accessible to the member as well as researchers in online spaces. Standardization allows the data within profiles and Mood Maps to be compared, aggregated and managed over time and space. The act of self-representation itself is automated on PLM to produce a standardized account of patienthood across profiles.

A notion of presence and representation through user-generated content is required for understanding identity in PLM. PLM's members must negotiate their presence and style of participation within the site on a daily basis. Although PLM's tools and platform are free to members to use, participation on the site and the research produced from it does have costs. These costs must be considered in terms of the time and energy members spend keeping their profiles and Mood Maps up to date. These costs must also be considered beyond the context of PLM. As the internet becomes more integrated into many aspects of everyday life – i.e. shopping, recreation, interpersonal communication, work, etc – profiles emerge as a new form of identification or social persona that are not strictly contained in virtual worlds. When we generate log-in credentials to any site, we must consent to user agreements in order to join our favorite social networking sites, forums, email servers, photo and video sharing websites. Consenting to a contract (i.e. the site's user-agreement) implies that the profile is more than a mere autobiographical representation. Profiles and log-in credentials are a form of legal personhood that makes us accountable and 'count-able'. For members of the Mood Disorders Community, to be identified with user-generated content on PLM can have consequences. In the United States where the majority of members reside, certain disorders and/or suicide attempts can be used to exclude individuals from private health insurance plans and social benefits. For this reason, members are careful about what they share and regularly remove content from the site by revising or completely removing content from forum posts.

Introspection and self-reference, as quantifiable variables are built into the interface of social media platforms. The aim of such environments is not to invent who you want to be (as in early MUDs) but to represent who you 'actually' are. In social media, the authentic self is achieved through the production of original media – user-generated content – in the form of personal photos, videos, and speech. As such, profiles on PLM are part of a 'truth discourse' (cf. Foucault) in which the self is constituted through a presentation of 'the facts' about one's self (i.e. variables measured by the Mood Map and phenomelogical-based testimony in the forum). The 'fill in the blanks' format used by social media to automate the production of user generated content without knowledge of computer programming and web design engages users in a directed and computational form of self-reflection. The level of reflexivity on PLM allows the facts to be made and remade through repeated self-measure and computation. Computation self-reflection on PLM challenges social scientists to think beyond notions of objective-self fashioning as simply the incorporation of 'taken-for-granted' facts into identity. Representations of the body and the self on PLM are actively disputed by members who find the variables chosen by PLM's administrators to be too narrow and unable to accurately capture their experiences.

In his essay "The Politics of Life Itself", medical sociologist Nikolas Rose (2001) argues the adoption of self-reflexive practices in heath promotion strategies is part of a historical change in techniques of governance and state management of health populations, termed biopolitics. Biopolitics refers to governance through a "politics [that] now addresses the vital processes of human existence: the size and quality of the population; reproduction and human sexuality; conjugal, parental, and familial relations; health and disease; birth and death" (53). A key strategy of governance in biopolitics is methodological record-keeping and computation of population statistics. The records produced through statistics have the effect of fixing subjects in time through the production of a material record. This material record serves as data from which new facts can be produced and possibly reincorporated into the objective selves of PLM's members.

The multiple and fluid forms of being online appear to contradict norms the fixed-computation aesthetic entailed by biopolitics and citizenship projects. Citizenship projects attempt to fix citizens in time and space by "individualizes human worth, essentializes variations in human capacities [as biological differences], reduces social phenomena to the aggregate of individual actions, and discriminates against, constrains or excludes those found to be biologically abnormal or defective" (Rose 2001:2, original emphasis). Records become a form of citizenship that gives individuals identities recognized by the state that can be verified and validated by linking personhood to data and records. In the context of post-Chernobyl Ukraine, indeterminancy and uncertainly regarding 'the facts' of damage caused by radiation (that is, a lack of records) limits the ability for some individuals to gain state recognition and support (Petryna, 2002: 11). In the context of PLM, members undertake the task of producing their own records, which can be used to validate their illness to others and well as themselves. I now turn to a discussion of community within PLM's Mood Disorder Community and how reflexive identity practices and the site's interface moderates social relations among members.

Chapter Four: Biosocial Community on PLM

In the seminal essay *Artificiality and Enlightenment: From Sociobiology to Biosociality*, Rabinow (1996) asks how emerging techniques for mapping the human genome might affect ethical and social practices in the West? He argues that scientists working to produce "a common language for physical mapping of the human genome" (96) might at the same time produce a common language for understanding the self, others, and society at large through the popularization of genetic discourses. New genetic practices, Rabinow argues,

> "...will cease to be a biological metaphor for modern society and will become instead a circulation network of identity terms and restriction loci, around which and through which a truly new type of autoproduction will emerge, which I call "biosociality." If sociobiology is culture constructed on the basis of a metaphor of nature, then in biosociality nature will be modeled on culture understood as practice. Nature will be known and remade through technique and will finally become artificial, just as culture becomes natural. Were such a project to be brought to fruition, it would stand as the basis for overcoming the nature/culture split" (99).

The genomic revolution continues historical trends of essentializing cultural practices as expressions of nature (i.e. eugenics, sociobiology). What marks the genomic revolution of the late 21st century is a tendency to view nature as increasingly amendable to 'the artificial' (i.e. once nature's underlying mechanisms are uncovered, their expression can be changed *via* technological intervention). What results is a new type of self-authored society and self; that exists as both biologically predetermined yet amendable to technological intervention and conquerable incrementally as new ways of seeing and speaking (cf. Hacking 1983) about the body, self, and society are developed through practices of science and engineering. Information produced by the biological sciences provides everyday individuals with a new set of cultural symbols and metaphors through which to reflect upon the self, community, and navigate everyday contexts. Biosociality becomes a way to incorporate 'the facts' into practices of everyday life (Savolainen 1995, de Certeau 1984), particularly Raymond William's (1958) notion that "culture is the whole way of life – the common meanings; to mean the arts and learning – the special process of discovery and creative effort" (32).

Although Rabinow argues new forms of assemblage will emerge from biosociality, it is not guaranteed that what anthropologists define as 'community' will emerge. Benedict Anderson (1991) defines communities as inherently imagined. By 'imagined', Anderson suggests that the likeness between members of a society is inherently invented or fabricated through ideology (6) meaning citizens and nations do not exist objectively in themselves. Community is *imagined*, Anderson argues, and social scientists are pressed to view assemblages (such as national citizenship or patient communities) as co-constructed socially alongside ideologies that underpin the relatedness between members. When "the members of even the smallest nation will never know most of their fellow-members, meet them, or even hear of them, yet in the minds of each lives the image of their communion" (6), community and citizenship are mentalities and ways of seeing relatedness and difference, which are materialized when adopted into citizenship projects that reflect culture back at citizenship (i.e. monuments). Hacking (2002) refers to the co-construction of individual and group as 'dynamic nominalism'. Dynamic nominalism hypothesizes "[c]ategories of people come into existence at the same time as kinds of people come to fit those categories, and there is a *two-way* interaction between these processes" (48, emphasis added). Thus for Rabinow and Hacking, both biosocial community and individuals are co-constructed. Dumit (2004) develops this point further by arguing the production of facts about the normal functioning of the brain are also part of the dynamic nominal relationship. Individuals must identify with suppositions about the normal function of brains – that is they must affirm the truth behind scientific facts (i.e. that depression is a neurochemical imbalance – while at the same time affirm that the facts describe themselves – (i.e. that they fit into the category of persons with a neurochemical imbalance and therefore must be depressed). Biocitizenship becomes a negotiated process of consent and adoption of 'the facts' rather than an imposition of evidence-based knowledge by scientific experts and political leaders in a top-down model.

As seen in the Chapter Three, distinctions between artificial and natural mental illness (i.e. 'organic depression') are actively disputed among some members of PLM's Mood Disorder Community. On PLM, members see themselves as alike because of their shared diagnoses and experiences of illness that are biological in nature. That is, membership to PLM is biosocial in design when members are aggregated or mobilized into special interest groups, united by perceptions of shared-somatic conditions or risks (Rabinow, 1996, Rabinow and Palsson 2001) involving the brain. At the same time, PLM's research platform allows members to actively engage with researchers and participate in the categorization of mental illness by participating in the production of facts. That is, members offer themselves as 'the kinds of people' that fill the category of mentally ill as well as the evidence to support such suppositions. Categories naturalize beliefs about the differences between types of people (i.e. normal and abnormal, ill or healthy) (Dumit, 2003) and PLM enables members to participate in defining those differences. Through biosociality, individuals embrace their biomedical designations and illness ceases to be simply a condition that someone has, but becomes part of who they are, thus framing how they experience and navigate communities.

In the case of PLM, the identities produced are biosocial in nature and members produce profiles that reflect the experience of being a patient. Rose

(2007) calls such identities a form of citizenship within medical communities, in which data and facts obtained through science come to define the self and community:

> "…collectives organized around specific biomedical classifications are increasingly significant. The forms of citizenship entailed here often involve quite specialized scientific and medical knowledge of one's condition: one might term this "informational biocitizenship." They involve the usual forms of activism such as campaigning for better treatment, ending stigma, gaining access to services, and the like: one might term this "rights citizenship." But they also involve new ways of making citizenship by incorporation into communities linked electronically by email lists and websites: one might terms this "digital biocitizenship." (135).

Rose coins the terms informational and digital biocitizenships to highlight the ways in which health information and information technology use is increasingly incorporated into practices of patient self-reflexivity and identity. As such, by exploring the ways in which patient-centric information technology is designed and used by everyday individuals – that is, adopted into practice – we can garner insight into the ways in which the engineering of information technology for biomedical research mediates how patients conceptualize their worlds as shared.

In the previous chapter, I argued that biosocial reflexivity is built into PLM's interface through the integration of social networking profiles with personal electronic health records. At the individual level, identity on social networking sites like PLM is produced *qua* repeated acts of self-disclosure and materialized *via* the site's mapping software. The articulations of identity and patienthood on

PLM are biosocial, in which the biological nature of mental illness is asserted *via* the use of validated scales produced by mental health experts and adopted by patients. The mapping of mental illness over time using the site's visualization tools, along with the production of user generated content on the site's forum provides members with materials they can use to assert, affirm, and dispute expert articulations of mental illness adopted by the site. The production of biosocial identities and biosocial avatars on the site is underpinned by a more general process of producing presence and a public persona on the site in order to be "there" and be visible to others.

In this chapter, I move beyond the micro-level of individual profiles and identity to explore how biosocial community and citizenship are mediated through participation in research on PatientsLikeMe.com. This chapter explores how a sample of a research population becomes a community on PLM. Strategic deployment of presence and persona on the site is channeled by members to produce and maintain relationships with others during and or despite mental illness. Members see their participation on the site as more than research. They use the site's platform to participate in other spheres of social life, such as caring for other and politics. First, I explore updates to PLM's platform and how likeness between individual members and communities is conceptualized by the site. I then explore how members articulate likeness within the Mood Disorder

Community by examining a user-generated thread on loneliness. I turn to an example of difference and how conflict between members is managed to explore the limits of likeness. Lastly, I explore an excerpt of a thread discussing recent healthcare reforms in the United States by a member who considered forming a PLM lobby group in order to participate in national politics. This provides a look and how biosocial identity on the site might one day move offline.

Updates to PLM's Structure: Introducing the 'Any Patient'

During my observation period, PLM was open to people suffering from several rare or chronic conditions including (but not limited to): ALS, MS, Parkinson's disease, HIV/AIDS, Organ Transplants, Cancer, Chronic Pain/Fibromyalgia (FM), and Mood Disorders. These conditions were the organizational backbone for the site's 'communities' and were used to divide online spaces within the site. Shortly after my fieldwork period, I received an email informing me that the structure of PLM's interface would change dramatically. The letter as follows states,

> "Dear PatientsLikeMe Member,
>
> We're excited to announce some big improvements to PatientsLikeMe that you will see starting tomorrow (2/22/11).
>
> These site upgrades are based on your suggestions and feedback so we want to highlight three major changes for you:

1) You can now share all of your conditions through a single profile

From the very beginning, you've told us you would like to share information about all the things you're experiencing as a patient, not just about a single condition. Now that's possible – through just one profile. This means there's no need for separate accounts if you have two different conditions (e.g., MS and Fibromyalgia). Plus, you can now add new conditions. Do you have arthritis, diabetes and TMJ? Share them all on your profile and find other members just like you.

2) You can see and learn from every member of PatientsLikeMe, and they can see and learn from you.

Since we launched our first community in 2006, almost 100,000 members have joined the site. Now you can all see each other's profiles and learn from the data you've been sharing.

You can also talk to one another in the forum. There are now specific forum "rooms" for your conditions, where you'll find the same people from your community, but there are also rooms where you can dialogue with and learn from everyone at PatientsLikeMe.

3) Any patient with any medical condition will soon be able to join PatientsLikeMe

Since opening our doors in 2006, we've had more than 25,000 requests to add more than 2,000 conditions on the site. Starting tomorrow, you'll see hundreds of new conditions available and we're adding more every day. By adding information on other conditions, more patients can benefit from you, and you can benefit from the experiences and data they share with us all.

For the next few weeks, we're closing the site to new members so you'll have a chance to test out these upgrades, try new features, and tell us what you think. Soon after that, you'll be able to invite the first of the new members to join. We also took this opportunity to update our FAQs and make our privacy policy easier to read. We try to do this once a year to make sure all of you, and any new members, know what we do with the data you share.

> We're excited about these improvements. We've already received a lot of great feedback from some of our members who tested out these upgrades last week. One thing was clear – every person had something new they could share and learn with each interaction.
>
> We look forward to hearing your feedback!
>
> Ben Heywood
>
> President and Co-Founder, PatientsLikeMe"
>
> ("Exciting Improvements to PatientsLikeMe!!!" Personal Communication, Februrary 22, 2011)

At the time of my fieldwork, the Mood Disorder Community was one of the newest groups on PLM ('live[17]' for about 4 years). The Mood Disorder Community was also one of the first areas of the site to aggregate people with a variety of conditions. Older communities on PLM were organized around a single condition – i.e. PLM's founding Amyotrophic Lateral Sclerosis Community. PLM's latest update would soon allow people with 'any condition' to join the forum. The update ushered in a generic form of patienthood (the 'any patient') to PatientsLikeMe.com and vastly expanded the number of conditions monitored by PLM. The latest update would also dramatically change the spatial distribution of the site, transforming formerly closed communities into a series of open 'rooms' in a single private PLM forum.

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[17] "Live" is a colloquial term used by social media to signify when a site transitions from its initial programming phase to its commercial phase. The term itself is interesting because it implies websites have their own vitality – they have a life-force of their own once they are "released" on the web.

The site's new design would aggregate members around 'families of disorders' connected by a 'molar' conception of the body (cf. Rose 2001) – the bodied viewed as series of overlapping biological systems and organs (such as the digestive tract or circulatory system). The newly formed assemblages would include a 'Digestive Disorders Room' (I.e. Irritable Bowel and Crone's Disease), 'Endocrine, Metabolism, and Nutrition Disorders Room' (i.e. eating disorders, obesity), a 'Heart, Blood and Circulatory Disorders Room' (i.e. heart attack and stroke), and 'Kidney and Urinary Disorders Room', in which new and current members could join based on their individual diagnoses. These new rooms would coexist with the community spaces that already existed on the site but those communities would also become rooms within an increasingly open and transparent PatientsLikeMe.

Member Responses to the 'Any Patient' Update

It appeared as if condition-based assumptions of patienthood and associations between particular conditions informing the architecture of the site suddenly appeared out of focus with the experiences of site members. That is, the imaginative qualities defining the *limits* of likeness – the boundaries and differences separating one group of patients from another (Anderson 1991:7) were collapsing upon themselves due to co-morbidity between conditions monitored by the site.

Two months before the introduction of the 'any patient', members within the Mood Disorder Community had already expressed concerns regarding how mental illness is diagnosed and then represented on the site. PLM's staff also participated in this debate by dedicating one of their monthly newsletters to the question "Can you have too many diagnoses?" The newsletter was inspired by a conversation in the Mood Disorder Community, in which one member asked:

> "I'm not a therapist nor a pdoc. I have seen individuals with 6, 7, 8, 9, different diagnoses. When do we say stop? How many is too many? When a pdoc states we have social anxiety AND phobia, are they not talking about the same thing? There are cross-over of symptoms. I'm just curious when one would draw the line and seek a second opinion. For me, 3 would be the limit. I may have some health issues (high blood pressure, acid reflux, etc., - which I do) but when it comes to the major Axis I disorders or even the Axis II disorders (BPDs), I would have to look closely at my life and what are the causes of it. Am I on too many medications that are conflicting and thus having a contradictory affect rather than a positive and helping affect [sic]. What are your thoughts?"

Among members within PLM Mood Disorder Community, concerns regarding the legitimacy of biomedical diagnosis began to surface on the site at this time. Did the condition-based categories used by the site accurately reflect the *true* experience of members? Instead of the rigid condition-based categories originally used to unite members into distinct patient communities, the site's new structure would allow members to provide PLM with flexible accounts of their experiences and medical histories unconstrained by assumptions of what kind of patients might join and participate in PLM.

Additionally, the clear boundaries that kept each community space in the forum separate and private posed ‘data problems’ unstated by PLM. For members in the Mood Disorder Community whose diagnoses overlapped group divisions on the site, participation on PLM was a fragmented experience requiring multiple log-in credentials/’usernames’ for each condition community they wished to participate in, artificially inflating the number of members present on the site. A single user might have more than one account in order to be present in both spaces at the same time (i.e. a person diagnosed with both Fibromyalgia (FM) and Major Depression would need two log in credentials, one for the FM community and one for the Mood Disorder community). Despite having different accounts, the members I encountered did not describe having different social identities within the differing communities. Their multiple accounts and corresponding PEHRs were linked by a single body and a single public persona that moved between communities and closed spaces on the site. Many members questioned their ability to control access to their data and personal information after the update. The update signaled the end of community-oriented privacy afforded by boundaries imposed by the site’s original design.

Member reactions to the update were mixed. Not surprisingly, some members liked the new open platform while others were concerned it might compromise their privacy, as the following excerpt from a thread discussing the recent update demonstrates:

> A: When we find an intriguing post, we can go back and read other posts by that person to learn more about them. Then we can subscribe to that member to keep up with their activity. I like that; I've made many new friends that way. As we discuss our common disorder we reveal details about our lives. Although we may try to be conscious of basic internet safety, we nonetheless build up often intimate pictures of ourselves as we share with other patients like us. With this new open platform, all our posts from all the forums show up in a search. This literally "fleshes out" our on-line identities - perhaps too much (?) I'd like to participate in several forums that relate to me, but hesitate to do so because I know each separate room will reveal a new set of facts about my life. Tying all those details from each separate, discrete forum together in one place is very --- unsettling. What do others think about this?

For this member, the site's forum is an important social space for meeting others on the site and forming social relationships. By subscribing to other members – that is, electing to have PLM's mail system send an automated message every time that member updates their profile, Mood Map or forum threads – she is able to manage her relationships on the site's platform and develop a sense of commonality through a shared disorder. The opening up of the site also results in the opening up of personal information and this member questions whether she can continue to manage her personal information on the site. Information that was once fragmented on the old platform has the possibility of generating a snapshot of the member's identity (in addition to a snapshot of their condition) that is *too* complete once aggregated.

> B: Hi. I'm in the ALS community and someone asked if everyone could see our posts, so I decided to check. And here I am, reading your post. The ALS community certainly shares your concerns about privacy.
>
> A: Hi, Thanks! You just highlighted the scope of the problem. Not only are all our posts available to any member who shares one of our rooms, but all rooms are now available to all members. I just entered the ALS community by clicking on a post in your history that was made in that forum. Yipes! I'm VERY uncomfortable about this. I know I can request to have my account closed, but does anyone know how to also remove the data I created and posts I made to the site? Do we just have to go in and manually delete it all?

The 'any patient' change to the site's platform raises issues of consent and ethics for this member. The original pretext in which personal health information can be collected, used, and shared by members on the site were negated with the update. This change provokes this member to reconsider her membership on the site and her withdrawal of consent includes the withdrawal of her user generated content. The ability to aggregate data enables others to 'flesh the body out' that is, construct identity by connecting the dots between self-disclosures about the body. Removing data enables members to resist this realization of their bodies and selves when consent is withdrawn.

> C: In all honesty - I think the only way to guard your privacy is to cease posting on any internet forum, e.g., maintain 'lurker' status. Granted, you would still learn quite a bit passively, but would lose out on the opportunity to post questions/comments, which could eliminate more learning opportunities.

Both the original member who created the thread [A] and the responder [C] see the protection of privacy as inherently the responsibility of site users, not site administrators. The protection of identity is achieved through the restriction of presence on any website. Choosing not to participate actively is seen by [C] as having consequences – such as the inability to obtain personalized feedback by making one's presence and persona known. Active participation and presence within the forum enables members to form relationships with others that may positively impact their health but active participation and presence on the site also produces data and enables forms of covert surveillance that members have little control over.

> D: The fact that we use names other than our real names helps, but really what's to worry? Most of it is friendly encouragment [sic] and socializing. In my recent situation I did worry some because of a pending medical case so I temporaily [sic] edited out my bio for awhile until that clears. Also If [sic] you have a post no matter how far back that you aren't too happy with you can go back and edit out a whole sentence or more if you want.
>
> E: Greetings all! 'Tis a beautiful Sunday here in sunny West Coast America; the nearby hills are covered in snow from the record-breaking storm that blew through yesterday . . . Today, not a cloud in the sky! My take on the privacy issue is twofold: First, PLM has always been pretty straightforward - if you post it in a forum, it is public information. Period. (PM's are reportedly 'private'). Our data is the life-blood of PLM. I understand and accept this simple fact. I also trust management in their claim to 'scrub' said data of personally identifying information. Second, we are all well into the information age. Purchases are tracked (whether made at supermarkets or online), mailing lists are sold and shared, and so forth. Did you know that if I contribute money to a political candidate, the candidate's name and my personal information are all available online to any inquiring member of the general public? There are businesses who do nothing but collect, sort and distribute data gathered from the ether . . . and few of us are aware that as we blissfully go through our daily routine, we spew data for others to collect. So. I am rather confident that PLM is not going to shoot themselves in their collective feet by carelessly using

> our data. We users are tasked with being aware that every word we say publicly will be read by people we do not know. Every once in a while, someone with a touch of malice sends off the equivalent of an obscene phone call in a PM (has happened in the Parkinson's Group). Bringing that offense to management's attention - and warning others in the group - seems to stop that activity pretty much in its tracks. Bottom line, I am more concerned about my personal information on Amazon.com than I am here. But then, I am male and somewhat circumspect in what I choose to share . . . Here's wishing you a great day!

The last two responders see their practices on the site as having little consequence. That is, the risks imposed by new levels of openness on the site do not significantly change the visibility of members' information on the site. The production and collection of data *via* user-generated content is seen by responder [E] as a rudimentary part of how the internet operates. Thus, surveillance is not seen as exceptional. Members can oscillate between passive and active styles participation depending on their information needs. Personalized and context sensitive data requires the deployment of presence and persona in order to make a member's individual context visible to others. Presence and persona are also restricted when needed, as when some members temporary edit out information for increased privacy.

Pondering Community on PLM: Is Community Imagined?

During my fieldwork, I came across a short thread within the Mood Disorder Community pondering specifically what constitutes 'community' and whether support groups on the internet (as PLM serves for many members) is 'enough' to be considered community:

> A: *I would never belong to a group that would accept someone like me as a member. - Groucho Marx*
>
> My psych[ologist] is certain that what I need in life, to fight off the loneliness, to get the support I need, is "community." So what is community? A conglomeration of individuals with something in common, say most textbook definitions. But there's also trust. And I don't know anyone who trusts anymore. I certainly don't. I see "HOPE" and I think "What are you selling?" I see "PEACE" and I think "Who do you work for?"
>
> Where do you find community? Do you have issues with trust? How do you move past them to become part of a community? How does the internet affect your idea of community, honesty, and trust? Do you think internet communities "count" in the sense my psych was referring to? Are they enough?
>
> B: Good questions.
>
> One word does it all: The Imagination.
>
> For me i [sic] would have to summarize that my community lives in my imagination... it's real alright. but [sic] it doesn't have an "address" and you can't drive there either. It's all the people in my life that I have come to trust and love in varying degrees. Some are family members, some are friends both near and far, some are here on PLM, some are people I have been acquainted with so long that when I run into them I am always happy to see them and vice versa. We talk for 10 minutes, 20 minutes or even an hour right where we are. We catch up, share info, update what's been happening since last we met. I have several very close friends but have never had them all in one room at the same time and have known three of them for 17-30 years. One I have only known three years. I also consider the friends of my children part of my community and in some cases their parents as well. When we gave a party for my son before he left for basic training two weeks ago we had several parts of our community converge and get to know one another more intimately than ever before. Community is elastic and creative and always moving and changing with your life.

> Thus, the conclusion that in reality, my community lives vibrantly and virtually in my imagination.
>
> A: That's a way I really hadn't thought about it before, [B]. Somehow, I always get these church potluck, Anne of Green Gablesish [sic], down on the farm type images in my head about what "community" is supposed to be. None of which is very easy to tap into for me anymore, especially since I don't do the whole church thing, but also because I've moved a bajillion [sic] times. From what you're saying, sounds like I can move all I want and still have "community."
>
> But . . . if I am sick and need a "community" to help me when the caregiving gets to be too much, guess that has to be the flesh and blood variety, right?

Like Benedict Anderson, [B] suggests community is virtual and imagined rather than solely situated materially in time and place. Community for [B] is dynamic in nature when [B] uses the terms elastic and creative. The thread's creator discloses that she is surprised by [B]'s ad hoc description of community as she contrasts it with her own assumption of community bound in religious and agricultural practices from turn of the century rural Canada popularized by Canadian author Lucy Maud Montgomery. [A] completes her response with an expression of doubt, asking whether there is a fundamental difference in the meaning of community when speaking of the body and illness – a category defined by shared biological materials of "blood and flesh".

> C: If you want community move here. You can't throw a rock and hit a Mormon church. And they have spies I swear! I bought my house and two weeks later I get their monthly newsletter with my name on it. I'm like how in the hell...the only place I would consider myself as part of a community would be here. My friends are my family not community. They're mostly all

> I have anymore to rely on for anything. One of them decided I need someone with me at my neurologist appointment next week so he's taking off from work to go with me. But I can't talk to them about my mental illness and my needs involved with that they don't understand so I come here. Or if I need support there are quite a few people here that will help as much as they can. And I've kinda [sic] grown on some of em [sic] even through the sarcasm and pigheadedness.

Another responder [C] argues that biological relatedness – i.e. flesh and blood – or commonality, like shared religion, and does not constitute community in his experience. Community for [C] is founded on shared understanding of needs and experiences, for which he turns to PLM despite the presence of offline relatives who accompany him to medical appointments. Although support and help are reasons why [C] turns to the Mood Disorder Community, he concludes with a subtle comment about the affective nature of community on PLM. Despite [C]'s self-perception of being sarcastic and stubborn, he has succeed in 'growing' on other members despite personality traits he sees and flaws. Simply sharing a medical condition is not community for [C], instead affective belonging is community.

> B: [A], the thing you need to imagine is wherever you are, if you need help because you are sick, you need to ask for that help and see who can and is willing to come and help. It may not be who you expect it to be. After I had my hip surgery which was a year after two suicide attempts, I felt like a big part of my husband's and my mutual social community just disappeared because it DID! The people we'd been hanging so much with were mostly parents of our kids friends. Good people, but when I kept ending up in the hospital for one thing or another... they weren't the part of my community that was really right for me. It took a while for me to understand this. In the end, it was my immediate family (dh [dear

> husband], sons), two of my sister in laws, two old friends here in town who had big problems of their own but they would just show up at my house whether even when I wouldn't answer my phone to come sit with me, be with me, whether I could talk or not. I also had a couple of friends who lived far away but they called, emailed or sent snail mail fairly regularly which also helped. I think I have just come to see that this patchwork of community is just as good as a homemade quilt made from scraps of old shirts, dresses and such as a brand new, straight from the mill to the store woolen blanket. so yes, you need real human hands to rely one as well as virtual ones but it doesn't have to land all on one shoulder.

The notion of presence for [B] is paramount in her clarification of community. [B] argues that in her context, it was her immediate family who she largely considers to be her community. Their inclusion in her definition is not contingent on their shared or imagined biological relatedness, but by the immediacy of their presence versus other individuals who disappeared during her experiences of illness.

> D: Hmmm, that is a great question. I think the word community certainly conjures up a particular image in one's mind, the one you mentioned that is all "churchy" and "homey" and all that. But I think that is just a product of our American society's conservative upbringing, and I don't really think it is appropriate in this context.
>
> I too suffer from anxiety and terrible loneliness... even when I'm physically with my family. I am still trying to figure out what and why. But my guess is your therapist means community in the sense of finding as many things to involve yourself in as you can, things that bring you happiness in one way or another. It probably also means finding as many like minded individuals as you can, people to share life and all of its joys and problems with, people that can help you meet your needs in one way or another. And all of those things can be a combination of real life and virtual life, I think.
>
> My two cents.

The last responder reinforces the notion that community is about finding like-minded individuals (commonality) either 'real' or virtual. [D] guesses that [A]'s therapist means 'involvement' by community, that is, *presence and active participation* within the lives of others as a way of finding happiness and joy and meeting daily health care needs. The above excerpt shows that presence during experiences of illness is more important to some members of PLM rather than actually sharing a diagnosable condition when defining community.

Presence and Invisibility: Difficulties Forming Social Relations on PLM

Invisibility and loneliness are some of the main obstacles new members encounter when they join PatientsLikeMe.com. The strategic deployment of presence and persona effects members' abilities to form relationships on the site and thus community. Since the feeling of invisibility is common amongst the 20,000+ members (at the time of writing) of the Mood Disorder Community's, one member created a community-oriented "Guide For Getting the Attention You Deserve" a year before my arrival. Threads such as the 'invisibility guide' demonstrates how social relationships on the site are mediated by the style of participation members adopt and how members attempt to reshape how other members participate as a way to facilitate community:

A: "**How do we prevent fellow members' posts from "slipping through the cracks?**

I am starting this thread because I'm trying to make the best out of my own circumstance and avoid seeing further situations where other members (usually those who don't post often) also feel they are "invisible and ignored on PLM." In fact, many of you who responded to my aforementioned thread voiced having that same feeling at times yourselves. While we as a community know that we would never intentionally ignore another member's requests for help, it's clear that PLM has grown so much that it is possible to accidentally miss these posts.

The intention of this thread is to provide guidelines, suggestions, and advice to other members on how to get the attention and the support they deserve from this community. I will include a few thoughts of my own below, but I hope fellow members will add more ideas.

1) **Make your thread titles as specific as possible.** For example, if you simply title it "help," it is hard to know exactly what type of help you need. Include more info in the title and you are likely to get more responses.

2) **Post during normal hours (if you can)**. A thread posted at 3 AM is much less likely to receive as many responses as one posted during daytime and evening hours. Evenings seem to be the most busy [sic], so more people will see your post.

3) **Fill out your profile as fully as you can.** When I see that a new person has posted a thread or a response, I will often go to look at their profile to find out more about them. It's difficult to get to know another member, much less help them, when there is very little filled out in their profile.

4) **If you feel comfortable, send a personal message to another member expressing your need for support.** While we are certainly a concerned and caring group of people on here, we still can't read each others' minds. It's hard to know that someone is having a hard time unless they reach out to you. Personal messages are much more effective ways to be heard than in the group format via the forum.

5) **Try to acquaint yourself with one or two other members who can be there for you.** It may not be the same as having someone there in real life, but sometimes just knowing one other person cares and is thinking

> about you can make all the difference. Get to know folks by visiting other people's profiles and commenting on them or replying to someone else's post. Give care and support to others (if you are able), and you will likely receive it in return.
>
> 6) **And finally: Be Patient and Persistent.** Our community is now composed of more than 16,000 members-- it's easy for someone to miss your post if the traffic in the forum is especially heavy. Posts get pushed to the back pages now quicker than ever before. If no one responds right away or your post gets pushed off the front page, "bump" it back to the front and wait until someone replies. Eventually someone will... c'mon, there's more than 16,000 of us! ;)
>
> ETA: If you send in more guidelines and suggestions, I will copy them and add them to this list here. Just let me know...

The above excerpt demonstrates how members decide to participate affects how others relate to those members. In order to be visible to others, members must tailor their participation to meet the informational needs of others, that is, they need to be present during geospatial times when others are online (i.e. North American time zones). Members must sufficiently represent their persona by being specific in profiles and forum posts in order to contextualize their needs and condition history. Members must also be willing to expend time and effort on the site by sending personal messages and replying to forum threads in order to be present in the lives of others. Reducing invisibility requires active participation and investment of one's time and energy into the site and its membership.

> B: Good idea! And good job!
>
> C: I've always enjoyed your positive threads [A], this is just another example.

> D: Thanks, [A]. This is helpful.
>
> E: This is a really important discussion - thank you for starting it, and the information you provided above is excellent.
>
> I think all of what you said above is important, but I think #5 is the one that stands out for me. I think finding and maintaining a few "deep" connections with other members is really important. It eased my transition onto the forum a lot to have people to ask questions and guide me. These people have eventually become critical components of my support system.
>
> I also think posting to other people's threads and providing support to others is also a good way to make connections that will prove useful when you need help.
>
> I'm glad we're discussing this and actively looking for ways to manage the growth of the community and the Forum traffic. Thanks again.

Responder [E] shows how some members incorporate PLM into their everyday practices of caring for the self. By being present in the lives of others *via* PLM's forum, members can depend on others to be there for them in times of crisis. Sharing and providing other members with social support creates domain specific social networks that members can turn to when they need support during illness.

> F: [A], glad to see you back on the forum...you are an asset to this community!
>
> G: Thank You [A],
>
> The information is very helpful and definitely [sic] helps to put things in perspective. Maybe PLM ought to use what you said as an opening to their New to this site thread. I know since I am new here, that It is overwhelming [sic] when you first get on the forum. Especially since I only found PLM because I was in crisis. I was reaching out to complete strangers. I didn't even post at first because I was afraid of being ignored. I did finally make a thread, "Feelings" it consists of poems cause that is the only way i [sic] know how to communicate how I feel when I'm that bad... Actually that is the best way i [sic] communicate my feelings at any

> given time. I also know that I was dissapointed [sic] that not many responded. I was greatful [sic] that a few did. When I went in the Chat however, many commented on them, which made me feel much better and much more welcome.
>
> I guess what I'm trying to say, is that I hope there is someway that PLM will Use Your post in a welcoming of somesort [sic] to new comers. It is definately [sic] needed. It puts things into perspective, and will help anyone new to understand how easy it is to be missed.
>
> PLM Moderator: Nice work, guys! I added a link to this topic in the New to PatientsLikeMe? Tips for using our forum thread.

Responder [E] see this thread as 'actively looking for ways to manage the growth of the community and the Forum traffic' despite the fact that neither [A] or [E] are employees of the site. Responder [G] makes the suggestion that PLM should use the thread to help new members adapt to the Mood Disorder Community's norms. Responses like this show the extent to which many members engage in recreational forms of labour for the benefit of the Mood Disorder Community. This thread was created in response to a previous thread created by the same author expressing her own personal feelings of loneliness and invisibility on the site. PLM's administrators readily adopt 'community-oriented threads' like this and integrate them into the site's platform as regular features (i.e. 'PLM's Picks' page - a list of forum user-generated threads deemed most educational and most popular amongst the Mood Disorder Community's members).

> A: Thanks all for the feedback so far-- just trying to address the need for greater site accessibility as our community grows larger and larger. Keep the suggestions coming! I know you guys probably have tons of ideas. :)

> H: thanks for the advice. i [sic] need support sometimes, and I realize that it is also important to provide support. I am not a frequent poster, but I have been helped and encouraged by this community. Peace. [H]
>
> I: Excellent idea [A] and thanks [PLM Moderator]. By the way I only caught this thread by it being featured at the top which kind of add more merit to needing this post.
>
> I'd like to add another one but, I'm not sure if it belongs here and it's rough.
>
> Participate. Either by posting or using the "helpful marks" feature and try to read beyond the first page when your situation and the time exists.
>
> J: I agree with [I]--to get the most out of PLM, you have to jump in and get your feet wet. It took me a while to start responding, and what I posted wasn't always acknowledged, but eventually people started recognizing me. It's hard to do, but if you put yourself out there, people will respond. It may take a while. Also, if you start a thread and it gets buried, "bump" it up to the top with a new post. That helps very much.
>
> This thread is a great idea, [A].
>
> K: Your suggestions are wise and I was thinking about this the other day. I'm relatively new. I definitiely [sic] am trying to put as much input as I can to help people out. But I'm not the most articulate person! And usually I think someone else has already given better advice than I ever could, but I add my beef in here or there anyway (like now). I think also that most of the people on this site are American. I'm in Australia, so when I'm on plm it's usually ungodly hours of the morning in the USA and it's kinda [sic] slow.. [sic]
>
> However, I often read posts, and even if I don't post myself, they can be helpful just reading what others have gone through, or other peoples [sic] advice to someone who might have a similar problem to me. I personally made a few posts and have recieved [sic] extremely helpful responses. Everyone here is really supportive. And it's a relief because it's hard to meet people in real life who can understand or relate to what I'm going through.

The responses by [H] and [K] show how participants of PLM must adapt the way they participate in virtual worlds in order to receive attention from others and then cultivate a known persona amongst PLM's members. Adaption may mean transitioning from lurking to becoming an occasionally active participant, as in the case of [H]. It might also mean accounting for differences in time-space between members in order to be present at the same time as others, as in the case of [K]. [K] alludes to a difference between her online and offline support networks. She finds that adjusting her participation is worth the effort because members on PLM better understand and relate to her condition than people she knows in 'real life'.

> L: Great topic! Thanks. I've subscribed to a number of depression forums over a period of quite a few years, and this is the first time I've found this topic on any of them. That makes PLM unique, at least in my experience. And gives me one more reason to be a frequent visitor and poster [sic].
>
> I think many member [sic] of PLM, if not all, have experienced deep and deeply disturbing feelings of being ignored, overlooked, diminished, etc., because people in our lives who are not depressed have such a difficult time understanding what it's all about. Many of us, in fact, suffer from the specific symptom of a heightened sensitivity to rejection, to being ignored, to being misunderstood, and so on. So I'm especially encouraged by all the posts and responses that encourage us to post more and respond more. I'm looking forward to feeling like I "belong" here, and to helping others feel that, too.

Respondent [L] also asserts that that there is a difference between the people who members meet on PLM versus those whom they know offline. This responder conceptualizes invisibility as both a social consequence of mental illness, as well as symptomatic of mental illness. This conveys the slippage between biological and social (and eventually artificial) described by Rabinow in terms of conceptions of mental illness. Invisibility is seen as a consequence of

Mood Disorders (i.e. depression) when non-depressed others cannot relate due to a lack of personal experience. Additionally, this member alludes to the idea that social consequences of mental illness can also be symptoms of Mood Disorders, which opens the door to technical solutions (i.e. medical interventions in the form of therapy or drugs) to social problems such as social stigma towards shyness or loneliness. Throughout this excerpt, members see their active participation on the site as positively contributing to their social support networks and well-being. Personal well-being is achieved through being present and active participants in the care of others mediated by the artificial; in this case, the site.

Conflicts and Leaving PLM: Side-effects of the Mood Disorder Community

During my fieldwork, I noted how many threads within the forum persisted spanning over two years. In many cases, the original authors and responders had long since deactivated their accounts. When a member decides to stop participating, the *vitality* of that individual's presence also diminishes on the site – that is, their presence is no longer dynamic and lively and their interactions with others through PLM as a medium of communication stops. The user-generated content leaves a trace of one's presence (an e-footprint) but their presence becomes disembodied and static – data without a body connected. Although bodies in PLM cannot be directly assessed or accessed by other members or researchers using the site, the traces members leave through their presence (in the form of user-generated content) is accessed by others when not removed manually (As discussed in chapter two). As an ethnographer, I found e-footprints left by deactivated members and the ways in which current members interact with them intriguing. Although members choose to leave, the bonds and conflicts between members on the site persist.

Content left on the site by past members continues to affect current members who use the site. Members must cope with the loss of the member and the data which remains (or is lost when removed manually). In a forum thread on leaving PLM, a member openly questions how PLM's Mood Disorder Community *should* conceptualize and cope with changes in the site's membership as individuals join and leave. Yet at the same time, members subtly address personal conflicts between particular members in the thread that are apparent even after those members deactivate their accounts.

> A: I just came across this, and I think it's a good thing to share.
>
> Membership life cycle for virtual communities [Hyperlink to a Wikipedia article on virtual community]
>
> Many of us have found after a while that the site is "not the same." Of course we understand that new people equal new dynamics, but why does the entire website seem to be different because of it? Can't people join into the already existing structure?
>
> It seems that in the past years, there has been a lot of research about online communities. The article I came across is just the tip of the iceberg, but I thought that it may be a good topic to discuss. Maybe we can find a way that people will have an easier time changing with the site,

> or maybe with the knowladge [sic] that it will change, it would be easier to accept and maybe even guide its change in the direction where we feel comfortable.
>
> After all, the members who have been here for a year need just as much support as those who have been here for a month.
>
> As usual, comments are welcome and encouraged.

[A] opens his thread with two perplexing questions: why does an entire website seem different when its users change and do new members simply join an already existing network on sites or is a site's social network fundamentally different when a portion of its membership changes? Change in the site's membership (or the site's interface through updates, which opened this chapter) is seen by [A] as a particular difficulty on PLM, which might be alleviated through better information and informing members of change or by providing additional support to particular members who find change particularly difficult.

> B: [A], maybe it gets just to [sic] damn frustrating to try and have a topic other than the usual stuff,the derpression [sic] side of all topics?just [sic] a thought.
>
> C: I've been here awhile. I left when I needed to. I returned when I needed to. I respect the fact that things change. Life changes. People change. So do web communities.

The first two respondents provide two interrelated suggestions. [B] suggests that just talking about depression itself might be depressing, thus making it difficult for members to discuss other topics. [C] asserts that changes are a rudimentary part of life and that PLM's membership changes with the needs of individual members. Members join when they need something from the site (i.e. support or information) and leave when they do not (i.e. participation on the site exasperates rather than ameliorates their conditions).

> D: @[A]: I can't say I agree nor do I disagree. I've actually been on this site since April and then my computer crashed and I just made up the same name basically. But this is how we learn; through evolution. Nothing can stay gold forever. The only thing is (now I'm still a newbie), to this site, but I've seen people come and go and it's like a revolving door. One minute they're there, and then all of a sudden they fall off the face of the earth. Now some people have a hard time with adaptation, especially when it's something new, also there's not enough encouragement (not blaming anyone at all), this site is great, to get new members to jump into the forums and find out their not the only one. I see a boundary between the older members and the younger members. Also maybe sponsoring people like how they do in N/A and A/A. Why don't we try to sponsor new members and show them the ropes. If there's a plan going on, I'd love to know. But it would be volunteer work and it feels good to make someone else feel good. Already the sites been changed a bit and it's confusing and frustrating to the new members. And some people are just against change. No matter how hard you try, wether [sic] it's developing a committee that assigns advanced/experienced PLM'ers to the newbies and we try to simplify everything as best as we can, we're still gonna[sic] have kinks in the system. Trial and Error is part of life, making mistakes is part of life, everyone not agreeing is part of life. It sux [sic]... I know. But I would look into the sponsorship thing. I think it'd be fantastic and at the same time you make new friends and you get more out of the PLM experience, 'Helping one another.'
>
> -[D]
>
> E [deactivated]: Well, [A], I have left and come back multiple times. You know this. I even made a thread about it a little over a month ago titled "I'm quiting [sic] PLM". I felt at that time I didn't belong. Like I wasn't accepted. I've learned that I have just as much stake in making my presence here accepted [sic] as any of the other members.

> I remember back when I first joined PLM. There were only like 2000 members, but now I look at the number of members we have and its [sic] over 10,000. In less than a year this site grew dramatically. I don't think anyone was prepared for the growth that this site has seen. That growth has caused a lot of problems and stress. We have all been witness to that, and some of us stayed and some of us left. Those of us that are still here need to remind everyone once in a while of this to disuade [sic] and discourage it from happening again.

For respondents [D] and [E], changes in the Mood Disorder Community's membership are embedded in the general growth and evolution of the website. As the site's interface and membership change, members must also change how they use the site. [D] suggests the ways in which members use the site to form relationships needs to change. She suggests adopting AA's infamous sponsor system enabling seasoned members to help new members assimilate into the community. [E] recants it was he who needed to change in order to deal with feelings of loneliness and rejection. Like [D], [E] also suggests the role of senior members on the site is to provide newer members with an 'institutional memory' of previous changes and how members coped in the past.

> F: Old or new.. Aren't we all good??? Just a thought...
>
> G [deactivated]: so is it ok if the "bad" people leave? Who determines "good" and "bad"?
>
> Some people leave because they can't stand all the bull shit drama. Sometimes staying on here is detrimental to a person's mental health. I think some people leave because they don't feel supported. Quite frankly if the story doesn't have a ton of drama then it often gets ignored and falls by the wayside. So why should those people stay around if they are not getting support? Why don't they get just as much support as those who

> can create that element of drama with their story. Just because people don't have or don't choose to include the drama doesn't mean that their feelings are any less and they don't need as much support. And yes, people leave over this. Most of the time we don't notice because they are not the ones posting "Why don't I get any responses" or "I'm leaving" threads.

Like [B], [E] argues that participation on PLM might have the opposite effect of helping patients. Instead, the politics of presence and personae on the site might induce stress and loneliness, thus negatively impacting the mental health of others. [E] concludes that those who leave usually feel invisible and the effects of invisibility goes unnoticed by others who make their presence known by other means, such as threads addressing loneliness or announcing their departure.

> F: Maybe we should be asking not why are "good" people leaving vs. "bad" people, but rather why are people leaving, period. Shouldn't we be giving such support that everyone wishes to stay?
>
> H: I agree with [G]....my own thoughts on this topic are this...I joined this site to have another avenue of support other than my friends. Sometimes it's hard on them to always hear about my depression. Of course if I am really struggling I can talk with them but for the most part I keep my feeling here or in therapy.If [sic] people find they're not getting [sic] the support they need here..they could make a thread about it. People would respond.
>
> I tend to be very sensitive to the pain of others..that save the world mentality...there is one person on here that seems to need help but isn't getting it. I got drawn into that but feel like now it's time to back off a little to preserve my own mental health.
>
> I have found many good supports here and am thankful for this site.

Both respondents [F] and [H] infer that members leave PLM when their needs are not being met by others in the community or the site itself. [F] questions implicit value judgments in the original author's use of ‘good’ in the thread title, pointing to the way it implies that the participation of some members is more desirable and valuable than others. [F] makes this comment twice, subtly at first, and more explicitly a second time as she attempts to defuse a personal conflict brewing between a few particular members. [H] discloses that she uses the site to expand her support network. Like [B] and [E], [H] implies that talking about depression can have side effects on those who listen, thus she is selective of whom she talks to about her condition as well as when she uses the site. [H] suggests that when the needs of individuals are not being met by the site, members are presented with an another opportunity to be active participants instead of leaving. [H]'s response of ‘there is one person on here that seems to need help but isn't getting it. I got drawn into that but feel like now it's time to back off a little to preserve my own mental health’ more explicitly addresses the personal conflict subtly addressed by [F]. [H] marks a boundary between herself and the other member she sees as acting out in search of help, reinforcing [B] and [E]'s perceptions that participation on the site can have negative side effects on one's own mental health *via* transference.

> H: I also think it's up to us to decide how much support we get here. I try to use the chat room when I can..or I post in my journal. I know that if I said in a post..hey! Need some help here! People would help for sure. I'm really quite amazed at all the help that is here. considering we all have our own issues and real lives to contend with outside of PLM.

> I: I have been going to AA for years. My wife is always asking what we do at the meetings and what do we get out of it. I tell her that it is comforting to find out that you are not alone and that you can discuss your illness with people that understand.
>
> I get the same benefits from this FORUM. It is great but you have to get involved to get all of the benefits.

Respondent [I] reiterates the notion that active participation in forums is necessary in order to benefit from the website and community. Community, for [I] is based on an emotional sense of belonging– a sense of knowing you are not alone and being able to share with people who understand because of their phenomological experiences of illness and treatment. [I] chooses to emphasize forum in capitals but what he means is not explicit from the text. [I]'s emphasis could be read as highlighting how the term 'forum' is in fact a homonym. Common sense definitions of forum may first refer to the Greek-Roman tradition of forums as spaces of discussion and debate in judicial and public affairs, and secondly refers to interactive web 2.0 bulletin board messaging systems (i.e. a medium) colloquially referred to as 'forums'.

> J: **Sometimes I wish I didn't need the same amount of support as I did when I first came (or as I needed before). Because if I still need support--does that mean I'm still sick? And why am I not "better"?** [Original emphasis]
>
> (afterthought: Below is whinging, um, maybe it belongs somewhere else I'm sorry.)
>
> Today I had to fill out a "justification of extension" form b/c I have been in grad school more than 7 years. My department average is 10. My total time will be 10.5.

What do I write? "Crazy"? That's what I want to write. But the issue has forced me to think about why I am taking so long...I am using the illness as a crutch? Part of me thinks that if I still want to deal with deadlines by killing myself, then I might still be in trouble...and the alternative? Some self-harm. Some very calm, logical self-harm that happens just like going to the grocery store and buying milk. I do it, and then I write.

Fucked. up.

But shouldn't I be better now?

K: [J] and [A], One of the things I know is that words like "shouldn't" are judgment words and most often they are harmful and used in a context that is painful for those it is directed at. It takes time to get better and there is no time line to predict how that will progress. Be kind to youself [sic] and remember [sic] it will take the time that is needed to be better. Don't be hurtful to yourself by expecting too much and then judging yourself for not living up to those expectations.

Take care of you,

[K].

L: People leave for lots of reasons... drama, feeling ignored or unsupported or devalued because their particular story lacks the OMG factor, or sometimes they simply outgrow the site. I keep a journal here, and there have been weeks at a stretch where the only thing I do here is fill out the charts and make a journal entry each day, because that's all the good I'm getting out of it. Other times, I spend several hours a day here, posting and doing my best to help.

A: Wow, I just came [back] to the site today and was surprised by the amount of imput [sic] it [this thread] received.

@[B] - There was a time, and I hate to bring up sour memories - where there was too much "unserious" [threads not dedicated to the discussion of mental illness] threads going around, and people were hurt because of it. I know that at times, I felt angry at the fact that five threads on the first page were games, and taking away space from people who were trying to ask important questions or getting needed support. It's all balance, and it depends who the clientele is.

@[C] - A very wise answer, and one that I wanted to bring up initially. Web communities are similar and different than real life communities. I remember in high school that every year we thought that the oldest grade were the coolest people in the school, and when they graduated, the school would be lame. It took me some time to realize that it is all based on perspective. When I was in the oldest grade, I thought the school was lame compared to my seniors, but to the freshmen, we were the coolest people and when we left the school would be lame. This is a similar trend.

@[D] - There was a program like that. I started it. For a period of two or three months, we had volunteers welcoming new members and offering help to any questions or issues that they had. I think it's still a great idea, but it died without any leadership. It was too much for me to handle at the time, and others took over, but over time it got left alone. One thing I will say, though, is that I don't think it changed how many people actually used the forum in the long run.

@[E] - Many people who are very depressed get the feeling of not belonging. I know many who have left the site when they were severely depressed for that exact reason. And when they get better, they come back on. Some people even create new identities for their change (you know who you are). I don't think that the growth has hurt the forum yet. I think that there will always be a certain amount or percentage of people who use it. This may be a very specific type of forum, but I'm sure there are statistics to membership vs. activity on online forums.

@[F] - All I meant was that people keep saying how this site has changed, and that it's not as good as it used to be. They reminisce about old members who have left and threads which are idle. Few people look back at the site and say "Remeber [sic] that member? Boy, that was trouble. Why can't we have more of that now?"

@[G] - For your first comment, see above. I'm sure you remember people on here that created drama that you felt your life would have been much better off never knowing. I don't mean to attack anyone, but some people are just not suitable to be a part of a community - especially one with people who are emotionally very sensitive. Your second point is true. I know people who have left because the threads just made them more depressed. I know I have considered leaving when I haven't gotten the support I needed, and I'm sure people who are less outspoken than I am have left because of this. I'd like to add that there are probably people

> who have left because they are doing alright, and they don't need the support they once used to.
>
> @[H] and [I] - When you are very depressed, it is so hard to ask for help. I know this personally, and I have made a "Need support" thread before, but recently could not bring myself to post on it. Remember that people who are depressed often have low self esteem, and feel that if no one notices they are not there, they deserve it. And they purposly [sic] test everyone to see if anyone notices their absence [sic]. It's counterintuitive and detrimental [sic], I know, but that's the way depression works.
>
> @[J] and [K] - Many people are on here for a long time, and some leave immediately. It doesn't mean that the ones who leave need less support. Maybe they need more and aren't getting it here (as was mentioned before), and they are hurt because of it.
>
> @[L] - I agree, and though I find it sad, that is the way life is. Teh [sic] more dramatic one's story is, the more attention it gets. That's why movies are so exhilerating [sic]. It's not a story about an ordinary person with an ordinary life. What kind of entertainment is that? We are drawn more to things which are not our norm.
>
> Thanks, all, for your comments, and please continue to contribute.

[A]'s reply to her own thread demonstrates the ways in which conversation online in a public context can be both publically private and privately pubic (Lange 2007) when responses produced for a general audience also contain private content not meaningful to all users. [A] addresses the forum in general but takes great care in responding to each member personally, suggesting that what appears as a single thread is in fact a number overlapping simultaneous conversations that are referenced subtly and brought into the thread by its respondents.

[A]'s reply shows how the Mood Disorder Community has implicit norms governing the conduct of members and the topics discussed within the forum. Members oscillate between active and passive styles of participation to maximize what they find helpful from the site and minimize side effects and social conflict that occurs when members disagree or violate the community's implicit norms. Many individuals aggregate on the site because many believe other members better understand their conditions and experiences than their relatives or friends without mental illness. Many members also find the site's tools and community, such as the Mood Map and journals in the forum - therapeutic. They withdraw from the site when conflict within the community and emotional transference produces negative 'side effects' for members.

Patients and Politics: PLM as Empowering

The act of recording changes in one's symptoms and treatments itself is often mentioned by members of the Mood Disorder Community as feeling therapeutic in nature. The above discussion on leaving and conflict in PLM shows multiple instances where members tailor their participation on the site to selectively receive social support or self-reflexively record changes in their health depending on their needs. During my fieldwork, the governance of health care and insurance in the United States was being debated nationally by the Obama

Administration[18]. In this brief instance I saw biosocial identification on the site can become bigger than the site itself, as a member aspires [half seriously] to extend PLM's reach and benefits beyond the local contexts of individual users on the site,

> "In the post about health insurance, I somewhat facetiously suggested that we turn PLM into a paramilitary organization and stage a coup. I spent most of the weekend mulling this over and have come to a conclusion: Why not?
>
> I'm not really suggesting that we take up arms aginst [sic] the U.S. government. Frankly, I think our system works pretty well as systems go. I believed in it enough to spend most of the past two years working on various campaigns on behalf candidates I believe in.
>
> That being said, we do have problem in our health care system it does require a revolution. Change will not come by voting for the "right" candidate. Change comes to those who organize, who pool their resources to make their case with one voice. We should form a Political Action Committee (PAC).
>
> Doctors have the AMA, Psychiatrists have the MHA, the drug companies have PHRMA, none of which represents our interests. PACS pool the resources and voices of its members to advance their collective interest. We have a collective interest. We should have a voice..."

Illness is transformed from an experience of impairment to an opportunity for empowerment and political participation that members are accustomed to in online locales, as the member continues,

> "...PLM is at its best when it gives us voice. We are not a support group nor are we a doctor substitute (Google, M.D.). PLM, through the wisdom of shared experience, enables each of us to be a participant in our own

---

[18] See www.healthreform.gov/ for the specifics of the 2001-11 health care reform debates and bill.

> care. Because of PLM, we are able to ask better questions. Because of PLM, we know when to seek a second opinion. Because of PLM, we are better able to recognize warning signs. We are better able to keep things in perspective. In short, PLM empowers us.
>
> Forming a PAC is in this respect the next logical step. A PAC can hire lobbyists (people with access to officeholders and the ability to communicate a message effectively), craft legislation and support candidates who share our agenda. A PAC can purchase targeted advertisments and mailings, organize conferences and get press in support of its cause.
>
> Please respond here with your thoughts. If you don't have anything to add but you think this is a good idea, please post that too. Consider it a signature on a petition.
>
> *I'll periodically revise this initial post in light of your comments and suggestions.*"
>
> (Original Italics and Emphasis)

Record-keeping and information-sharing in the social-support networks fostered by PLM are seen as empowering the site's members when members become active participants in their own care. This member sees political participation organized using social networking amongst patients as a natural extension that empowerment. Their presence and participation in online worlds is seen by this member as being capable of moving offline in order to assert the presence and participation of everyday individuals in national politics that affect their day-to-day lives. Although a political action committee never formed on PLM, the above excerpt shows how biosocial identity and community on a patient social networking site are not contained within the site. The possibility of patients using PLM's platform to recruit like-minded individuals and mobilize into a lobby group speaks to the extent to which online and offline worlds are interconnected. Presence and persona are not simply phenomena to be observed in virtual worlds, they are underlying components of day-to-day interactions (i.e. caring for the self and others) and essential to the formation of communities bound by shared phenomological experience and emotional bonds. Participation on the site, in this brief instance, truly becomes a form of national citizenship, in which one member sees himself and other members of as a category of persons in America that should have a voice in national politics.

In closing this discussion, I now turn from community formation within PLM's Mood Disorder Community to a discussion of how members conceptualize themselves as a research population. The scrapping incident, which I describe in the follow chapter, brings tensions about consent in online research and how information on PLM is considered both public and private to the fore. The following chapter demonstrates how the restriction of presence and persona serve as safety mechanisms for members to protect and regulate the dissemination of information they consider personal. Members overwhelmingly suggest that the responsibility of ensuring privacy belongs to members themselves but they question whether PLM's for-profit research practices are congruent with reciprocity traditionally found in community.

Chapter Five: Are We Research Participants or Community Members?

On October 12, 2010, Angwin and Stecklow of the Wall Street Journal (WSJ) published an exposé featuring PatientsLikeMe and an incident involving three member accounts. Rather than human members, PLM discovered the accounts were in fact 'scraping bots' - accounts operated by computer programs designed to infiltrate the password-protected areas of websites with the sole aim of copying forum threads and profiles. The bots were engaged in a data-mining practice referred to as scraping – the "harvest[ing of] online conversations and collect[ion of] personal details from social-networking sites, résumé sites and online forums where people might discuss their lives" (p. 5). The metaphor of scraping invokes imagery of the highly political practice of deep sea trawling, in which commercial fishing vessels use weighed nets in international waters to literally (and destructively) scrape the ocean floor in search of dwindling unexploited fish stocks.

In this chapter, The Wall Street Journal's report on data scraping serves as a case study in which we can explore patient perceptions regarding the benefits and limitations of their participation in a patient social networking community that is simultaneous a research participant pool and crowdsourcing platform. Contradictions between PLM's simultaneous goals of (1) providing a venue for patients to help patients through informal social support and information sharing, and (2) providing researchers with access to patients and their information in order to advance knowledge on a variety of conditions, began to surface for many members. The case provides a context for exploring privacy, openness, labour and appropriation of personal health information on PLM. That is, the site's reaction to the theft of PLM's private property forced many members to question their own claims to private property and the value of their participation in the Mood Disorder Community. This chapter explores how the personae and presence of members on the site is also mediated by practices of research participation and surveillance.

Openness and Personal Health Information as Open-Source

Openness is PatientsLikeMe's guiding principle. It posits that health information and user-generated content online is inherently 'open' – part of an information commons of collective experiences and knowledge:

> "You see, we believe sharing your healthcare experiences and outcomes is good. Why? Because when patients share real-world data, collaboration on a global scale becomes possible. New treatments become possible. Most importantly, change becomes possible. At PatientsLikeMe, we are passionate about bringing people together for a greater purpose: speeding up the pace of research and fixing a broken healthcare system." ("Openness Philosophy", Accessed September 2010, http://www.patientslikeme.com/about/openness)

Sharing and exchange among individual patients is seen as creating the potential for change through collaboration on larger geographical and chronological scales than normally feasible in clinical research. As a mediator, practices of social networking are seen as enhancing the ability of researchers to access data, in addition to prospective research participants than is currently possible in traditional offline research channels[19].

PLM's creators are extremely critical of privacy regulation and privatization of intellectual property, which PLM sees as a main reason why health information becomes inaccessible to those who need it most – patients. As such, PLM has developed an openness philosophy outlining its attitude towards privacy and private property,

> "Currently, most healthcare data is inaccessible due to privacy regulations or proprietary tactics. As a result, research is slowed, and the development of breakthrough treatments takes decades. Patients also can't get the information they need to make important treatment decisions. But it doesn't have to be that way. When you and thousands like you share your data, you open up the healthcare system. You learn what's working for others. You improve your dialogue with your doctors. Best of all, you help bring better treatments to market in record time." ("Openness Philosophy", Accessed September 2010, http://www.patientslikeme.com/about/openness)

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[19] Openness envisions biomedical research practices as collabourative and participatory like internet forums, social media, and peer-to-peer sharing. Openness draws upon the now famous alternative software development strategy "open-source" pioneered by Linux. Open-source "recognizes individual authorship but not exclusive intellectual rights" (Albours et al 2008:196), fostering transparency between independent programmers, software companies, and everyday users willing to experiment with custom-designed and collectively produced applications. Software is created through "voluntary participation and selection of tasks, programmers freely contribute their time and talent to write code that builds on shared software "kernels" that are open to anyone's innovation" (Rheindgold, 2006:8). The participatory context of open-source software development is seen as inherently democratic because of its implicit rejection of monopoly implied by copyright and patent.

To advance knowledge related to specific medical conditions and potential treatments, PLM's openness policy frames privacy and 'proprietary actions' as negatively impacting patient's experiences. The intentional protection of information from commercial exploitation by others, as in the case of patents, or legal conventions regarding the confidentiality between patients and doctors of others is portrayed as inhibiting patients from making informed health decisions through a lack access to information. Privacy, in effect, has negative side effects for patients according to PLM.

By sharing 'data' such as treatment outcomes, experiences with various medical professionals, drugs side effect and interactions, and subjective accounts of illness, PLM suggests the benefits of openness on PLM can have measurable effects on member's health through learning, which carry over into their relationships with medical professionals by opening up channels of communication within the healthcare system[20]. Openness becomes a tool for resisting economic and cultural norms of privacy that threaten the livelihoods of patients with measurable consequences on their wellbeing.

The language of PLM's openness philosophy cannot be divorced from the rhetoric of hope and change describe by Carlos Novas (2006), in which

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[20] In particular, PLM's research concerns "off-label uses" of prescription medication and the power of patient-centered and controlled informatics that inspire novel approaches for biomedical research and treatment of ALS (Frost, Massagli, Wicks and Heywood 2008), and the affects of PLM and social networking on medical decision-making by patients (Wicks et al 2010).

experiences of illness are transformed into a form of expertise that patients can exploit to directly contribute to the production and consumption of biomedical knowledge through research (290). On PLM, patients are morally charged with a duty to 'fix a broken healthcare system' by making individual contributions of data. Data, in its raw form, is a source of emergence and possibility as PLM's Openness philosophy states below:

> Most healthcare websites have a Privacy Policy [Hyperlink to Privacy Policy]. Naturally, we do too. But at PatientsLikeMe, we're more excited about our Openness Philosophy. It may sound counterintuitive, but it's what drives our groundbreaking concept.
>
> You see, we believe sharing your healthcare experiences and outcomes is good. Why? Because *when patients share real-world data, collabouration on a global scale becomes possible. New treatments become possible. Most importantly, change becomes possible.* At PatientsLikeMe, we are passionate about bringing people together for a greater purpose: speeding up the pace of research and *fixing a broken healthcare system*...PatientsLikeMe enables you to effect [sic] a sea change in the healthcare system. We believe that the Internet can democratize patient data and accelerate research like never before. Furthermore, we believe data belongs to you the patient to share with other patients, caregivers, physicians, researchers, pharmaceutical and medical device companies, and anyone else that can help make patients' lives better.
>
> Will you add to our collective knowledge... and help change the course of healthcare? ("Openness Philosophy", Accessed September 2010, http://www.patientslikeme.com/about/openness)

PLM's openness philosophy both dreams and attempts to create a new ways of 'doing healthcare' by changing the ways in which research is conducted. The values and practices associated with software and social media content are seen by PLM as enhancing medical research and progressive compared previous style of governance regulating information and property. The way time and collaboration are experienced on the internet are believed to augment the pace and transparency of scientific research. PLM is adamant that 'data' – or personal health information – rightfully 'belongs to you the patient' to share and contribute to databases of collective knowledge. Sharing is seen as a means of democratizing health care research and producing change in the way health care is delivered. The uneasiness resulting from the scraping incident would cause many members of the Mood Disorder Community to question whether openness could materialize the changes it promised. Members would also question whether PLM's openness philosophy was congruent with for-profit research, leading some members to question the nature of their participation and consent.

PLM's First Response to the Scraping

PatientsLikeMe's response to the scraping incident occurred in two phases – before and during my fieldwork period. The first response occurred on May 20th, 2010, immediately after the scraping bots were detected, in which PLM's founder Ben Heywood broke the news to members through his Blog (hosted on the site).

Transparency, Openness and Privacy

The following message was sent this morning to all members of PatientsLikeMe. Please read what we have to say about openness, sharing and its privacy implications and join the conversation.

****

Dear PatientsLikeMe Members,

What are the privacy implications of sharing in this open, online community? We talk a lot about this and, as a company, strive to be transparent about the risks and rewards to sharing here. Two recent events have prompted me to reach out to all the members of PatientsLikeMe to ensure we all understand openness, sharing and its privacy implications.

The first event happened last month when a patient asked us to remove all the data on his/her profile from the system. The member wrote:

"The reason I'm leaving is I feel I didn't fully understand the privacy impact of having all my health information for practically anyone in the world to see."

We rarely receive a request like this, but since receiving this one, I have thought about it every day. We do not want anyone to be surprised by the impact of sharing data on PatientsLikeMe. We believe in openness, but we also want people to *knowingly* make the choice to be open with their health information.

This brings me to the second event. Recently, we suspended a user who registered as a patient in the Mood community. This user was not a patient, but rather a computer program that scrapes (i.e. reads and stores) forum information. Our system, which alerts us when an account has looked at too many posts or too many patient profiles within a specified time interval, detected the user. We have verified the account was linked to a major media monitoring company, and we have since sent a cease and desist letter to its executives.

While this was not a security breach, it was a clear violation of our User Agreement (which expressly forbids this type of activity) and, more significantly, a violation of the community's trust. Your Account Information (e.g. your names and emails) was **NOT** in danger of being stolen. It is likely that the forum information that was "scraped" would be sold as part of that company's Internet monitoring product. In fact, we sell a similar service, PatientsLikeMeListen^{TM}, to our clients so they better understand the voice of the patient.

What does this all mean to you? What can you do?

1. We recognize that people write very personal things in the forum and often use real names. In any growing network of tens of thousands of members, there is no way to ensure that information you share in the forum or on your profiles will not be read by others. Know that the information you enter in our system is shared (unless we tell you it is private, like full name and email in your Account Information). It can and will be read by other patients, the PatientsLikeMe team, researchers, and others that use PatientsLikeMe, including our partners with whom we share de-identified data.
2. Please weigh the benefits of sharing and the amazing value you all create in helping each other versus the risks of people, unknown to you, reading your posts. Your input helps PatientsLikeMe and our partners learn about your disease and make better products to meet your needs.
3. Learn and understand why we value openness. If you haven't, please read the Read This! FAQ. If you want to know how we make money, you can take a look at this FAQ or go to our Partners Page and know that we sell your data and insights (but not your identity) to our customers.
4. Consider the value of being part of the PatientsLikeMe community and make the right risk decisions for yourself. Together, we can really change the way diseases are treated and managed by putting you, the

> patients, in the center of healthcare. We can hold companies accountable for the strengths and weaknesses of their products and also help make those products better - but that requires openness and that is your choice.
>
> We welcome your comments and questions and we love feedback. This has been posted on our blog, which is a good place to dialogue, as is the forum.
>
> On behalf of the entire PatientsLikeMe team, I want to thank you for being part of our communities and sharing your experiences.
>
> Sincerely,
> Ben Heywood
> President and Co-founder, PatientsLikeMe
> (http://blog.patientslikeme.com/2010/05/20/bentransparencymessage/
> Accessed October 2010)

Although Ben Heywood assures members that the discovery of data-mining bots does not constitute a security breach – that is, *restricted* data such a member's real names and passwords were not obtained by the bots – the detected presence did highlight some of the risks associated with the cultivation of presence through information sharing in virtual worlds. Ben Heywood's blog post on openness aims to ensure members participate 'knowingly' – that is, that their participation is *informed* and *consented to.*

Media Reporting and Member Responses to the Scraping

Five months after Ben Heywood's first post on openness and the scraping incident, The Wall Street Journal published its article featuring PLM's scraping incident. The article was accompanied by a second blog post by Ben on October 11th 2010 and contained a direct link to the article for PLM's members. Ben writes:

> "Julia's piece includes details regarding how this incident happened, how we (and you) responded and more. We are very excited about this article. Having a rigorous debate about transparency, openness and privacy is critical to us achieving the trust we want to have with you, our patients.
>
> What Nielsen did was clearly a violation of our User Agreement. However, we believe this incident (and this article) have spurred an important ongoing discussion about what is right, just and appropriate regarding how companies operate in this new networked world. As I said to Julia, this is a new frontier. We also believe there's a lot for everyone to learn from this experience, especially around how to put patients first." ("PatientsLikeMe in Wall Street Journal: Transparency, Openness and Privacy (cont'd)", last updated November 18, 2009, http:// http://blog.patientslikeme.com/2010/10/11/patientslikeme-in-wall-street-journal-transparency-openness-and-privacy-contd/).

Ben Heywood was right. There were many discussions within the Mood Disorder Community in response to the Wall Street Journal's article. In these discussions, members collaboratively define current social norms and attitudes towards privacy and participation in social media. The remainder of this chapter examines member reactions to the scraping incident and how members negotiate participation in the site's community *via* social support despite the commercial context of crowdsourcing research.

Case 1: Responses to Ben Heywood's Blog

In order to foster rigorous debate, all of PLM's grey literature has a space for open commentary by PLM's members. Some readers of Ben's blog left publicly viewable comments in response to Ben's update on the scraping situation. As one can see from reading the dialogue below, members are highly aware that their activities on the site, although private in nature, are extremely public[21].

1. Ben and Jamie,

   Thanks for helping make this story public. It is a necessary wake up call about how each one of us must understand our complete loss of privacy.

   As we state in the ACOR privacy policy:

   "Please be careful not to disclose on the mailing lists any personal or other information that you do not wish other people to have access to or that you would later want to remove. Except as set forth elsewhere in this Privacy Policy or in the Terms and Conditions, ACOR cannot and will not remove content from any mailing list or from the archives of the mailing lists. Accordingly, each subscriber should weigh the potential benefits and risks participating on the lists. **The only sure way to protect one's privacy is to never write to the lists**. Moreover, although we strive to deter abuse of our resources, it is possible that unknown persons or entities could access and archive the lists without our permission."

   The WSJ article is a MUST read for anyone doubting that privacy in this network age is dead. A lot of scary information about what is done to

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[21] These comments appear on Ben's blog, which is accessible without log-in credentials. I chose to leave the names of members who responded to Ben's post because these names are already within the public domain.

maximize profits based on the mosaic effect. We are all in for a wild ride.

Comment by Gilles Frydman — October 12, 2010 @ 6:58 am

2. Although I am angry about people responsible for “scraping” ,Bilal Ahmed should take responsibility for his own carelessness,he [sic] himself made his own identity public by adding the link to his profile.If [sic] he didn’t want to be identified then he should never have added the link to his blog or he should have used a Pseudonym for his blog too.

   However considering the sensitivity of the “moods” community meaning the subject matter that it covers,I [sic] do think that there should be some “extra” security to prevent anyone other than members or those who have direct permission having access to that information.But [sic] again members should take precautions themselves if they are concerned about the information they are revealing.

   We are responsible for the information we give away on the internet.I [sic]personally have nothing to hide,but [sic] still don’t like the idea of someone using my information without my permission and think there should be laws to protect people from “scraping”.I [sic] am not naive enough to think that anyone would stop doing it but then at least “we” would have something to be able to go after those companies,individuals with, that abuse the laws.

   If you don’t want anyone to know who you are then it stands to reason not to reveal any personal information to people you don’t know or don’t trust.Names,age, home-town,jobs,school,business,doctor,car, etc.,

   I question the morals of a company or individuals who make a business out of STEALING peoples intimate details and shared feelings and thoughts to invade their privacy and manipulate their spending habits.

   I have always had great faith in the transparency and openness policies of PLM and am comfortable using the website.

   Comment by Leddy — October 12, 2010 @ 12:04 pm

3. Although the onus is on the user not to reveal personal information they don’t want to be made public (something everyone in this internet age

needs to unfortunately understand), the real issue here is that this site did take steps to ensure privacy by forcing registration. Did they go far enough, arguably not, but now they've learned and will likely correct this with stronger authentication.

But, that's not the issue.

The company in question maliciously STOLE private content by impersonating a user and invading the site. This was a conscious act proven by the fact that they had three (fictitious) users activated and when first caught, called in representing themselves as this "user" to get reactivated. THIS IS NOT WEB SCRAPING! This was an intentional act targeted at this specific site. Please do not place blame on anyone but the perpetrator.

Comment by Phil — October 13, 2010 @ 10:50 am

4. I totally agree with Gilles Frydman. How anyone could use the words "private" and "internet" in the same sentence shows a severe lack of internet understanding... You should not have to be an IT specialist to understands the flaws in OPEN DISCUSSIONS... scraping or not...

   Comment by Vinny — October 17, 2010 @ 6:11 pm

5. Thanks to everyone for your comments. Regarding the call for stronger authentication, we've always had email confirmation as part of our registration process. We have considered "CAPTCHAs" in the past, which may allow for better human authentication. However, CAPTCHAs can prove challenging for people who suffer from visual or cognitive impairment (as some of our members do). While there are alternatives that claim to be accessible, many are still a challenge for our patients.

   We have other techniques in place to detect automatically created accounts and most of the incidents, so far, have been with manually created accounts. So CAPTCHAs would be difficult for our real users without stopping abusive ones. We are constantly improving our tools to stay ahead in this game.

   Comment by Benjamin Heywood — October 18, 2010 @ 7:31 am

6. plainly and bluntly, I am not happy tp [sic] find out that a site known as patients like me are selling information about its users to major corparations [sic] and drug companies.
   It is disgusting to have an outlet like PLM to make profits from us users. People like me that are using the site to learn and compare illnesses with others that suffer the same is what I was told the site was for and I find out that PLM is SELLING my privacy without my consent is awefull [sic]. The information that I share is meant for other patents that have the same illness as me, not for big companies to exploit. Patients Like me and other data site need to ask permission from its user before being sold. Remember, Patients Like me may be owned by a specific indavidual [sic], but it is its users that contibute [sic] who make is successful, with out users, PLM would no longer exisit [sic] and therefore before selling us out, ask us if we want to be sold. I think i [sic]will delete my account at PLM because of them selling my personal life.

   Comment by Krisztina — October 20, 2010 @ 1:35 pm

7. Hi Krisztina,

   Thanks for your comments. We certainly want you to feel comfortable on our site. That's why we try to be as upfront as possible about how we make money. It's one of the links right on the front page of the site. It's also part of our User Agreement, which you agreed to before joining. To clarify, we do not sell your personally identifiable information (name, email, address, etc.). We de-identify the data shared by all of our members before we sell it to companies that want to learn more about your experiences. Please let us know if you have any additional questions. We hope you'll continue to share on PatientsLikeMe.

   Ben
   Co-Founder, PatientsLikeMe

   Comment by Benjamin Heywood — October 21, 2010 @ 11:23 am

Within the above discourse, the majority of responders do not see presence and utterances on the internet as inherently private. Many people on PLM agree that severe restriction of one's presence in online spaces is the only way to ensure the security of one's privacy. Members provide a number of suggestions to PLM on how to improve PLM's interface and the scraping incident was no different. In the above dialogue, responders provide Ben with a number of suggestions on how security and authenticity on the site might be improved. Gilles' response highlights how internet users are inherently responsible for their own data and conduct in online spaces. Tactful participation in virtual worlds requires members to cultivate a form of media literacy that enables them to maximize the benefits of participation while at the same time mitigating the inherent risks associated with participation. They must know how privacy is regulated online and offline and make informed decisions about when and how to participate. They must be aware that 'non-human entities' as well as human users exist in online spaces, some of which have malicious intentions. These non-human entities can exist in the form of software [ro]bots as in this case, or in the form of 'cookies' which hide in our browser's caches and track our conduct online discretely. Members' responses above suggest that members must also assess the profit-generating motives underpinning the creation and sustenance of online spaces. The internet is inherently public but it is also inherently capitalist – full of entities looking to make a quick buck by offering internet users something or by extracting something from them.

The above dialogue shows how some members work out responsibility and accountability for ensuring privacy in virtual worlds. Immediately after Neilsen's – a New York based marketing firm – bots were discovered, the accounts were deactivated by PLM's administrators. In response, PLM received an email from Neilsen posing as a member asking why their account was terminated in an attempt to regain access to the site. Members provided assessment regarding who is accountable and responsible for privacy online. Members do see the proprietors of virtual worlds as also having some ethical responsibility to members, mainly to be open and transparent about their data collection practices and ensure consent is obtained when making money. That is, members see Neilsen's data-mining actions as inherently different from those of PLM. The way Neilsen entered the site and responded to discovery was seen by members as dishonest and invasive due to the multiple levels of deception involved. As one responder suggests, what Neilsen did was not crowdsourcing but was clearly theft because it violated the contract between PLM and its members and attempted to continue after it was caught.

The value of trust in PLM is reciprocal - trust is invested in PLM and its mission, and that trust must be returned by the company through advancement in knowledge in service of PLM's members and transparency regarding PLM's uses of member's data. PLM's members are seen by PLM to invest trust in the cooperation through their willingness to share information about the self through disclosure. PLM members' information is collected and held 'in trust' – a repository database that accumulates interest through its sale to researchers and corporations. PLM pools the information invested in it in order to produce capital to sustain itself and participate in knowledge production in a digital economy. Trust in the context of PLM can be conceptualized as analogous to shares in a publically traded corporation and its operations conform to models of corporate ethics (i.e. transparency and returns to 'share' holders). As a corporate entity, PLM is obligated to provide its members with returns on their 'investments' in the site by providing members with updates on the site and scientific publications showing their faith in PLM is well placed.

I find the last response most interesting because it highlights the ways in which members are required to negotiate PLM's identities. First, PLM represents itself as a space built for patients by caregivers and patients[22]. In this space, PLM

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[22] James Heywood has commented on how at the time of his brother Stephen's diagnosis, ALS was considered an "orphan disease" (CBS 2000). Orphan diseases refer to extremely rare conditions that affect less than 1 in 1500 people in the US. James expressed frustration that the rarity of such conditions means there is little incentive for biomedical corporations to invest large amounts of time and resources towards finding new treatment options. He suggests this is so because it is hard for these corporations to recuperate the funds they invest in the research and development of treatments, since treatments will not be sold on large scales. As a response, the brothers became advocates of a new ethics for biomedical research that puts patients before profits. They expressed their extreme dissatisfaction with the attention ALS received in biomedical research community by creating a non-profit research foundation and then later PatientsLikeMe. The context of Stephan's tragic diagnosis led Ben and James to become "active" caregivers in Stephen's condition and public advocates for ALS suffers. As active caregivers, Ben and James were highly involved in Stephen's day to day routine, helped him raise his newborn

demands altruistic donations of the self – the sharing of personal health information in the form of user generated content. Submissions are framed as able to change the ways in which healthcare and research are practiced in the US. Practices of openness are framed as inherently democratic and resistive to regimes of private property and copyright PLM sees as slowing down research and limiting the chances of patients. However, this responder's comments highlight a disjuncture between PLM's rhetoric for patients and its proprietary practices as a business. PLM's profit generating motives are seen as incongruent with openness when PLM asserts content on the site is in fact *its* private property (instead of belonging to members). Consent in this respondent's comment is not unlimited. She consents to patients using her information for personal use, not PLM using her information for private motives. This response highlights how participation on PLM ceases to be recreational and therapeutic and becomes an uncompensated form of work for some users. That line becomes the limit of consent and forces many members to withdraw from the site.

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son, and custom-designed a wheelchair that integrated a personal computer and respirator. As public advocates, Ben, James, and Stephen took to the spotlight of the national media, participated in a documentary and founded a non-profit research foundation dedicated to sharing Stephen's struggle with the world. This work received a lot of media attention during the early 2000.Their Brother Stephen's story was featured in The New Yorker (2000), an episode of CBS's "60 Minutes" (2000), the book "My Brother's Keeper" by Jonathon Weiner (2004), and a Sun Dance film festival award winning documentary "So Much So Fast" (2006).

Case 2: Reactions within the Mood Disorder Community

Within the Mood Disorder community, similar sentiments regarding the disjuncture between compensated and uncompensated work, privacy and openness arose in response to the scraping incident. The incident resulted in a number of members eventually terminating their accounts due to the lack of compensation for time and content. As one member writes as he starts a forum thread in response to Ben's blog post:

> "I gather you've all seen the message from Ben Heywood about Openness and Transparency in PLM.
>
> I sort of knew that PLM collated patient data and used it for research, or shared it with certain companies (eg., pharmaceutical and mental health care industries) but surprised to hear they sell it.
>
> In this day and age, it's not so uncommon and probably not so surprising, but when I take part in Market Research myself I get paid a small amount. Why shouldn't that happen here? We are providing the information that generates the income ....it is in fact our own intellectual property (unless they've said not in the fine print)
>
> I'm thinking I might leave unless we get offered some $ .... I'm on a disability pension, life is hard enough ... I can do without knowing that I'm making money for someone without seeing a cent."

This member's post questions whether participation on PLM is truly reciprocal. This member highlights that when people share information online, they become alienated from their property. Although this member is correct that user-generated content does remain the intellectual property of members, the logic of open-source informing the site negates their ability to make any claim to it.

Submissions become digital copies of intellectual property that PLM is able to use without royalty or compensation. Participation in PLM's mission becomes unpaid work for this member, and he consequently considers withdrawing his consent.

Reactions to this member's post were mixed. Although some expressed discomfort regarding the selling of their information and questioned PLM's profit-generating motives, many did not see PLM's actions as out of the ordinary for the medical industry nor did they view the sale of information as directly harmful to members as replies from four separate members show:

> A: repeat [from elsewhere on the forum]. If anything I say or post helps to find a cure for bipolar tomorrow or 10 years from now I am happy to contribute to this community. My son is 27 and bipolar. Maybe my drug data and behavioral information will help some PhD find answers from our monologues that will help yeild [sic] answers for my son, you, your friend. Maybe we'll help find a cure.
>
> I personally don't have time to cruise the internet looking for mentally ill persons on other forums. I find myself happy to have landed here with all these great people to hold my hand. That is payment enough.
>
> It's a free country. You can do as you choose. I believe in capitalism.
>
> B: Agreed. If I can help find a cure, good.
>
> But I have to wonder... if the revenue from selling data is that much more than the revenue that advertising would raise, then whoever is buying this data must think it's really valuable. Why do they consider our data so valuable? They wouldn't pay so much for it if they didn't expect a greater return from it. I had no idea there was such big bucks going on here...

C: Personally, I am okay with my health data being shared (in aggregate) for the purpose of research rather than targeted advertising by the drug companies. And before you start freaking out, please keep in mind that before PLM shares your health information, it is stripped of any information that could personally identify you:

> 'In addition to serving the individual needs of our members, PatientsLikeMe provides information to Partners and other third parties, including for use in scientific research and market research. PatientsLikeMe **removes pieces of personally identifiable information** that can reasonably be used to identify you (i.e. "de-identifies" your data) prior to sharing information with third parties. PatientsLikeMe shares such de-identified data that relates to you, in some cases as part of individual records and in other cases in aggregate form, with third parties. **For example, we may look at scientific questions such as, "Do certain treatments work better for some types of people versus others?"** - PLM privacy policy' [Original emphasis]

I've been with the PLM mood community pretty much since its inception, tracking my mood every single day. It's the only mood tracking site or software I've found that lets me effectively input my 10+ years of health data, so I can see the overall trends. I've known from day one that my health information was going to be shared, and I know there are a lot of people out there who wouldn't be comfortable with that, especially since we have such a strong tradition of privacy surrounding health information, and mental illness still carries a stigma in many places. I don't want to discount those people's concerns, but my perspective is that I'm tired of my experiences being ignored by people who are making life-or-death decisions about my health. It's about time for the way we diagnose and treat mental illness to reflect the reality experienced by those of us who actually have to deal with these illnesses every day. Let's give them the data they need to understand who we are and what we need to be well."

D: "And might I add, that even if one didn't know until now that PLM sells (shares) our data with companies they choose to sell to I would hope they could see now what an enormous gift we are giving without spending a dollar of our own. I consider my participation in PLM's site, all of it, a donation of sorts.

> Like giving blood, or time and energy to a political campaign I support, PLM is an organization I believe in and want to give my time, energy and yes, data to. I have spent a fair amount of time making sure I keep my data as detailed as possible for their use.
>
> Again, like Ben Heywood said, PLM has to pay for a well trained staff to run this site. I hope they are getting paid a decent salary, too. Just as I would for anyone else doing such kind of work. We can see the glass as half empty or half full. It's up to us as individuals to decide this for ourselves."

The continued participation of PLM's members is attached to beliefs that their presence and data might one day lead to the development of novel treatments or even cures for mental illness. That is, their continued participation is tied to moral and political economies of hope. Morally, members hope that their informational contributions might one day challenge the stigma associated with mental illness that renders their experiences 'private' and invisible. The giving of information is compared to the donation of actual bodily materials, such as blood or organs. Through the metaphor of donating blood and expressing a desire that their content might have future value to their future selves, their children and to researchers, PLM's members actively reference cultural attitudes associated with gift-giving and altruism.

The above also shows members express faith in capitalism and the ability of the free market to self-regulate and produce innovation. The ability to generate capital is seen as the cost of freedom and democracy. What is sold, according to one member, is not their identities, *per se*, but testimonies of their personal experiences. Participation on PLM is seen as 'economical' in the sense that it saves members time and money. Access to a community of patients like them and free use of the PEHR's visualization tools is seen by many as enough of a benefit to warrant the sharing of information. As one of the above responses show, many members do feel that their participation is reciprocated through access and uninhibited use of the site.

Other members are much more skeptical about PLM's motives and the validity of PLM's research due to its for-profit motives. For-profit research and self-interest in capitalism appears ethically contrary to the rhetoric of reciprocal sharing, which leads members to question whether their participation constitutes real research or whether PLM's user agreement is legal if members join the site when ill.

> E: "first of all .. I don't buy the research crap .. PLM doesn't seem to be associated with a hospital or a psychiatric facility for it to be able to be doing research .. and I mean ACTUAL research ..
>
> collecting statistics .. contacting vendors for various drugs/meds .. and selling them patient information .. is not research .. it's just collecting stats ..
>
> I'm not saying PLM hasn't be useful .. it sure has .. and it will continue to be .. I just feel there should be an option where you're allowed to opt-in for the "we're going to sell every piece of personal information we have on you and make us some money!" bit .. how do we know where the information goes? .. do people bid for it? .. I mean what is it used for? .. don't you have be like an actual doctor to really figure out side-effects and report that back to pharma firms? .. I may be complaining of an headache,

but PLM doesn't know if it's because of my meds or the fact that I bashed my head against the wall or whatever ..

I can't believe I've been here for two-three years .. and I didn't know the information was being SOLD! .. this web-site is monetizing on my misery .. research/development is one thing .. but all of their data is up for sale, it seems .. PLM's beginning to sound like one of those "oh take a survey and we'll paypal you 2 cents" sort of emails .. I'm sure they make a lot more .."

F: *"By creating and sharing your health profile with the community, you can learn more about how your condition affects you and help others learn from your experience."* [Italics added]

That was the understanding that I had... and we were helping each other through our experiences... then, plm [sic]decided that they were not getting enough "data" so they began blocking threads... pushing their true agenda... money. Forgive me for having assumed that this was somehow a non-profit supported by research grants and such. I simply never occured [sic] to me to ask... i [sic]was too ill to even think.

G: I figured from the get go, that we were lab rats, I just didn't care because I felt like I was getting what I needed from this place. Love and support and it was real. The members here. Truly strong amazing people. I mean that. I have been so touched by you all. Amazing folks who survive and thrive throughout your pain and suffering. Your compassion despite your own afflictions is beyond beautiful to me. I felt close, and now this place no longer feels close. In fact, I am upset with the fact that this place is being dictated and stamping and selling our personal shit. IT's okay to study it. By all means, study it, but to try and stuff your pockets with green over others misery. Shame on you. Shame in the game. Fuck that!

H: I'm sorry you guys... but, i'm [sic] still trying to wrap my head around this whole idea that my life for last two years has been up for sale... I feel I have a right to know who your customers are, PLM... in the name of "transparency, honesty and (my) privacy.

There was NO MEETING OF THE MINDS WHEN I SIGNED MY (CONTRACT) AGREEMENT. Therefore, there is no contract/agreement. I was mentally ill at the time (as you were aware). And therefore, was unable to fully understand the "risk."

For these members, the experience of having one's information sold is objectifying and alienating. They see community practices on the site as separate from the economic activities on the site, in which they have limited information or say. For this group of members, the moral and political economies embedded in the site's design are incongruent, when the need for accurate and updated data takes precedence over community and the provision of social support. To produce capital from information shared freely undercuts reciprocity in sharing and transforms the relationship between PLM's administrators and members from one of patients helping patients, as stressed in the site's mission statement and family origins, to an unequal relationship between a proletariat work force and MIT-trained capitalists who own the means of production.

Some members also question the validity and legality of health research that uses crowdsourcing. PLM's lack of direct connection with traditional gatekeepers of medical services and information (i.e. universities and hospitals) forces some members to question whether the information the site collects is 'real' research. This question of validity also draws a related question regarding the legality of PLM's research and practices of consent. At this point, some members fully adopt biosocial identities to question whether they can even legally consent. Mental illness changes in this instance from impairment and exclusionary category of personhood (that is, they cannot sign contracts legally) to a protective and empowering resource. Adopting an identity as ill allows members to potentially renegotiate the legality of their agreement with PLM and make claims to property and potential royalties. The withdrawal of consent allows these members to put a value to their participation and expertise as patients.

In her mediations on the commoditization of human organs, Nancy Scheper-Hughes (2000) notes "the problem [of erosion of social values through capitalism] is that markets are by nature indiscriminate and inclined to reduce everything—including human beings, their labour, and their reproductive capacity—to the status of commodities" (193). Human beings and their reproductive and labour capacities, i.e. human energy, become commodities when they are assigned a monetary value, such as a price tag or a wage. In the case of PLM, some members see the sale of their personal health information as the reduction of their experiences to commodities. Members point to differences between rhetoric and actions, while other members see the actions of PLM as perfectly ethical.

Melinda Cooper (2008) argues social scientists should attend to how capitalism is constantly expanding beyond its limits by entering new objects and new forms of labour into process of production. In order to sustain ever-expansive growth required for capitalist accumulation, "…the periodic recreation of the capitalist world is always required and necessarily accompanied by the recomposition of capitalist limits" (Cooper, 2008: 20). That is, capitalism requires new objects to enter into the status of commodities and/or the creation of new consumer bases to which these new found commodities can be sold in order to continuously produce profit – capital. In this case, social support and discourse on a social networking site enters into the flow of capital producing new bioinformatic commodities, new recreational labour practices, and a new market that is simultaneously a research population.

Personal health information contained in medical records and the memories of individuals is increasingly entering the realm of the free market. Traditionally, personal health information is treated as confidential or private. As private, personal health information is considered 'priceless' and its circulation is highly regulated to protect the privacy of individuals. Unregulated circulation of personal health information can have severe consequences on individuals when it is attached to their legal identities, such as citizenship and/or employment. Personal health information can be used to discriminate against individuals as defective or citizens and undesirable labourers, which can have real material consequences when they are excluded from work or benefits from the state. The rhetoric of open source software development in internet for-profit research allows slippage between private as personal and private as public rending the personal ‘privatizable.’ Personal health information thus becomes capable of becoming private property of others governed by the logic of capitalism.

User agreements and privacy policies in crowdsourcing (as discussed in Chapter Two) allows personal health information to enter the data economy. Space on PLM, although accessible by virtually anyone is technically private – meaning the space and any materials generated within in the site through submissions are owned by PLM despite the site’s rhetoric of openness. Content produced on the site and the energy required to be present and visible within its boundaries is harnessed by PLM to produce a bioinformatic commodity that can be sold on the open market without direct compensation to PLM’s members. Once personal health information resides on the site’s privately-owned ‘public sphere’, it easily becomes private through strategic deployment of contract – the site’s user agreement – and the ethical practice of anonymity. Anonymity, although designed to encourage openness between researchers and research participants by protecting participants from consequences attributable to their participation, has the converse effect of alienating users from their content by detaching the producer’s identity from its material embodiment. The experiences of research participants become objectified and are narrowly translated to as data, which can then be disassociated from participants, who ultimately receive little direct compensation for their time and energy.

Ownership of user-generated content is not completely negated by anonymity, as PLM's user-agreement showed (in Chapter Two). Members retain ownership of their content but grant PLM almost unlimited right to copy and use user-generated content without royalty and few restrictions. The infinite reproducibility of digital materials, what I term 'the copy and paste mentality of the internet' combined with ambiguities regarding the publicness of online spaces, allows researchers who crowdsource to bypass issues of compensation and reciprocity. That is, ownership is *virtually* negated when PLM can copy, reproduce, and sell a member's data without technically violating copyright. PLM's members are seen as consenting to their own objectification and alienation by subscribing to the site and its philosophies in exchange for access to the site and materials.

In Kate Crehan's (1997) analysis of Gramsci's concept of hegemony, Crehan argues that consent is a significant a tool as coercion in the naturalization of state power (102). That is, through common sense – or the adoption of scientific, philosophical, and political assumptions about how the world works into one's worldview – a folklore about the self and society are produced, adopted, and then reproduced uncritically (110). By adopting rather than questioning authoritative presumptions of what is reality and how it should be governed, individuals consent to their domination by allowing intellectual elites to maintain the authority to define reality despite their experiences as 'lay-persons'. Participation on PLM is both coercive and consented when members cannot change the terms of service nor control the use of their content on the site. At the same time, many members see benefits to their participation and willfully adopt the site's policies, meaning they consent to the terms of service. Members find agency on the site despite possibilities of coercion through alienation by monitoring their participation and deploying their presence strategically. Strategic deployment of presence allows members to extract their own value from participation and control the extent to which value can be extracted from them, in particular when members leave fields blank or falsify their information.

Conclusions and Future Directions

Throughout my thesis, I have tried to show how identity and community are mediated not only by information technologies, such as a social networking site for patients, but also by the ways in which these technologies are envisioned and materialized through use. Interfaces contain implicit assumptions of who their users are and how the technology will be used. Although assumptions of identity and practice are contained within interfaces, designers and users must also anticipate unintended uses and consequences of emerging technologies, such as the appropriation of personal health information originally shared with the aim of helping others at individual, community, and institutional levels. The aim of this thesis was to expand upon Rose's (2007) under-theorized notions of informational and digital biocitizenships by exploring the ways in which individuals on PLM form community and identity through social networking and online research participation. Members come to see themselves as related to others through biological categories through their interactions with an information technology.

In Chapter Two, I explored particular ethical and methodological considerations made in order to study biosociality within PLM's Mood Disorder Community. In this chapter, I argued further research on the nature of consent in online spaces is required. I illustrated that consent on PLM does not completely mirror the consent practices in academic research. Instead, the private context of PLM as a for-profit research corporation entails different notions of public and private space materialized through a distinction between public and private property. This distinction has measurable effects on members of the site, particularly in their ability to withdraw personal health information despite members legally owning their user-generated content. I also introduced the concepts of presence and personae in online spaces, which serve multiple functions for members. As members monitor the presence of their personae on PLM, they are able to be visible and knowable to other members on the site as well as accountable as data.

In Chapter Three, I explored how reflexivity is built into the site's interface. Reflexivity on PLM was biosocial in nature because identity is conceptualized as a series of biological measurable variables that software on the site can visualize and 'remember' for patients. Patienthood on the site was both self-ascribed and prescribed, meaning members do not conceptualize the site as a means for making direct challenges to the epistemological claims of health experts regarding the biological nature of mental illness. Members used the site in supplementary fashion to offline care in order to be increasing participants in their own healthcare and the healthcare of others. The way patienthood was conceptualized on the site is not strictly a top-down power relation when members' suggestions and requests are integrated into the interface. At the same time, traditional identity categories corresponding to the digital divide (i.e. age, gender, sexuality, education, socioeconomic status, and race) were deemphasized by the site's design. Consumerist categories of brand name prescriptions, medical devises, and therapies were emphasized as categories that count in the statistics collected by PLM.

In Chapter Four, I showed how likeness between members in conceptualized within the site's interface and amongst members of the Mood Disorder Community. During my fieldwork period, PLM's notion of patienthood shifted from closed biosocial communities centered on single medical conditions to a generic and aggregated very of patienthood – which I termed the 'any patient'. Introduction of the any-patient forced members to reconsider their participation on the site and whether health information is considered public or private through increased visibility on the site. Conversely, unintentional invisibility was a big issue for members on the site, especially those who prefer lurking – a passive style of participation on the site. Invisibility was seen by many members as an ideal opportunity to transition from passive to active participation on the site, which many members perceive as having measurable therapeutic effects. Many members also experienced negative side effects from their participation on the site, forcing many members to reduce how active they participate. Many members, including myself, experienced emotional transference when reading testimonies of ill health by others that some members see as negatively impacting their mental health. Lastly, an attempt to form a PLM lobby group by a member within the Mood Disorder Community indicates social scientists cannot artificially distinguish between online and offline identity. Participation and empowerment on the site were seen as capable of moving off the site by one member. Patienthood ceased to be an online identity and is transformed into an offline political identity, what Rose (2007) refers to as biocitizenship.

Lastly, in Chapter Five, I explored how members conceptualize their research participation on the site. I explored an incident involving the site's infiltration by a data-mining bot, which PLM's found Ben Heywood later denied was a breach of security. The security breach forced many members to reconceptualize their participation and the security of their data. Issues of consent in online environments and ownership of user generated content come to the fore. Members questioned whether the moral and political economies of hope on the site – that members can fix a broken health care system and challenge conventions regarding the privacy of health information seem incongruent with the site's motto of patients helping patients. Some members saw the actions of PLM as not exceptional while others see for-profit research as undercutting the site's rhetoric of sharing when information flows from the bottom up but monetary profits do not trickle from the top-down.

Emerging Futures: The Provision of Public Services through Private Interests

PatientsLikeMe has become increasingly popular because of media attention garnered by the scraping incident and the Heywood's personal family struggle with ALS. In particular, PLM's platform has become an interest of the US Food and Drug Administration, which has adopted the site's platform for reporting pharmaceutical adverse events and side effects. Since PLM's platform tracks the dosages of medications and quality of treatments members engage in over their time on the site, the platform presents regulators with a novel and cost-effective means for ensuring the continued safety of new medical products and devices by government regulatory bodies. What I believe is important about the FDA's adoption of PLM's platform is that in the US, self interest and for-profit biotech can simultaneously provide a public regulatory service. That is, the widespread adoption of social media means that offline institutions must also increasingly adopt social media platforms as a service to be delivered and regulated. The adoption of PLM by the FDA shows a blending between public and private economic spheres when private spaces are used to provide public services.

Personal health information on PLM straddles traditional divides between public and private in a similar way. Personal health information on PLM is produced simultaneously for PLM's membership – but not for a general audience due to the necessity of log-in credentials in order to access the site. That is, space on PLM is both public and private depending on whether we talk about space versus property. Identity on PLM is also publicly private when members cultivate avatars to represent themselves yet guard their 'true' identities from undesirable audiences. Personae enable members to walk the line between public and private on PLM, selectively emphasizing certain elements of members' identities and experiences while intentionally deemphasizing other facets.

What Lange's fractualization of the public private dichotomy does not address is a slippage between the public, the private (in terms of privacy) and the private (in terms of property). My time within PLM's Mood Disorder Community has shown that the public and private information about identity is concurrently being worked out at the same time as the public and privacy of digital property. What complicates this matter on PLM is that user-generated content, in the form of testimony of one's experiences, is also an account of identity, body, and personhood offered up to the scrutinizing eye of researchers and science.

Online health-based consumerism is increasingly mediated by notions of participation, privacy, and transparency/openness from social media. That is, PLM's founders are able to participate with biomedical experts in the production of biomedical 'facts', health information and a 'data economy' by relying upon notions of the internet as a democratic public sphere for self-representation and ambiguities surrounding the fair use of other people's intellectual property in social media. PLM mobilizes these presuppositions about the democratic and creative nature of 'open-source' social media in order to gain access to and privatize the personal health information of its members. Conversely, PLM strategically deploys its own patenting of intellectual property to protect member UGC from appropriation by unauthorized commercial third parties. This act grants PLM with almost unlimited right to collect, reproduce, and sell coveted personal health information that virtually negates claims of ownership and private property by members who contribute to PLM's information commons.

Despite risks of appropriation and objectification, many members continue to participate in PLM and see real personal and collective benefits to their continued participation. Many of the individuals I encountered who participate in PatientsLikeMe perceive medical benefits to record-keeping and the chance of participating in biomedical knowledge production is worth more than individual privacy. That is, they 'medicalize' the site's social networking platform and incorporate it into their everyday care. Members accept designations as patients and research participants with the hope that their contributions might one day change régimes of privacy and intellectual property that slows down or inhibits scientific innovation. Hope is an integral part of PLM's mission statement and member's willingness to participate. Hope becomes a way to both *imagine* and *materialize* change through everyday practice.

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